The Relationship of Primary Caregiver Perceptions of Language and Behavioral Levels of Children with Autism to Primary Caregiver Stress and Ratings of Family Climate

By

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Abstract

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Advisor: Georgiana Shick Tryon, Ph.D.

The present study explored language and behavioral levels in a sample of 85 children on the Autism Spectrum between the ages of 6 to 12 years. It also studied the relationship of these levels to Primary Caregivers' ratings of parental stress and family environment. Participants were Primary Caregivers of children diagnosed on the Autism Spectrum who attended therapeutic schools specifically designed for children on the Spectrum and through support group newsletters and blogs. Language levels were measured by Primary Caregivers' ratings of non-verbal, pre verbal, phrase speech and verbal as defined by the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore & Risi, 2002). Primary Caregivers of verbal children also completed the Children's Communication Checklist-2 (CCC-2; Bishop, 2006). Behavioral levels were measured as Externalizing and Internalizing by the Children's Behavior Checklist (CBCL; Achenbach & Rescorla, 2001) completed by the Primary Caregivers and 71 of the children's teachers. Primary Caregivers also completed the Parenting Stress Index-

Short Form (PSI-SF; Abidin, 1995) and the Family Environment Scale (FES; Moos & Moos, 2002) to measure Primary Caregiver stress and family environment respectively. Results found a wide range of language functioning. Both Primary Caregiver and teacher behavior ratings did not reach Borderline Range. Externalizing and Internalizing behaviors were highly correlated among Primary Caregiver scores, but not for teacher scores. When correlating language and behavior scores, CCC-2 General Communication Composite (GCC) scores yielded moderate correlations with both Externalizing and Internalizing Primary Caregiver ratings. Teacher Externalizing scores yielded a mild negative relationship with maternal rated language levels and Teacher Internalizing scores were negatively associated with the CCC-2 Social Interaction Difference Index (SIDI) scores.

In terms of Primary Caregiver stress, CCC-2 language scores of the verbal children suggested a differential effect of language functioning on Primary Caregiver stress. GCC scores produced moderate negative correlations with 3 of the 4 stress measures: Parent-Child Dysfunction, Difficult Child, and Total Stress. CCC-2 SIDI score produced a negative moderate correlation with the fourth stress measure: Parental Distress. Primary Caregiver behavior scores yielded moderate correlations across parental stress measures. Teacher behavior scores paralleled the pattern of the language scores: Externalizing scores correlated with 3 of 4 stress measures while Internalizing scores were associated with Parental Distress.

Language functioning did not seem to play a significant part in family climate. However, behavioral ratings suggested there was some link between the children's behavior ratings and family communication among its members. Primary Caregiver Externalizing and Internalizing scores yielded moderate negative correlations with the FES Expressiveness and Relationship Domain. Moderate positive relationships were found with the Conflict scale. Overall, this study elucidated the differential effects of varying language and behavior levels on Primary Caregiver stress and ratings of family functioning in a sample of children on the Autism Spectrum.

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CHAPTER I

Introduction

Although it is rewarding, parenting is stressful (Crnic & Greenberg, 1990). There is evidence that raising a child with a disability is even more difficult than parenting a typically developing child (Clayton, Glidden, & Kiphart, 1993 Dyson, 1993). This seems particularly true when the child has a Pervasive Developmental Disorder (PDD), a disorder that the text revision of the *Diagnostic and Statistical Manual* (DSM IV-TR; American Psychiatric Association, 2000) lists as covering Autism and Asperger's Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). PDD is marked by severe and pervasive impairment in three areas of functioning including language, communication and stereotyped behavior, and interests and activities. Any or all of these impairments may prove stressful to parents.

Mental retardation often accompanies Autism (DSM IV-TR, APA, 2000). Research shows, however, that parenting a child with Autism is more stressful than parenting a child with Down Syndrome, which is also accompanied by mental retardation (Hoppes & Harris, 1990; Rodrigue, Morgan, & Geffen, 1990). As most children with Autism, but not all, have IQs in the Mentally Retarded range (DSM IV-TR, APA, 2000) there must be other symptoms of Autism that add to parental stress in addition to mental retardation.

One factor that may be confounding the effects of IQ in children with Autism is language functioning. Language skills can affect the functioning and the long-term adjustment of children with Autism (Kjelgaard & Tager-Flusberg, 2001; Venter, Lord, &

Schopler, 1992) as well as affect parental stress (Bebko, Kostantareas, & Springer, 1987). There are several types of language functioning, one of which is pragmatic language, or the language used to communicate in a social manner. Pragmatic language includes turn taking in a conversation, following the ebb and flow of a conversation, and understanding the subtle language used to convey meaning rather than the comprehension of the spoken words themselves, such as in sarcasm (Attwood, 1998). It is easy to understand how one can confuse pragmatic language functioning with more formal language and cognitive performance (Twactman-Cullen, 2000). Thus, a child may be quite high functioning in formal language (i.e., have a superior IQ and an excellent vocabulary) but still have severe difficulties in social interaction because of pragmatic language impairments (Sacks, 1995). It follows, then, that having a child with Autism who has pragmatic language difficulties could relate to the stress level of his/her parents. Indeed, some authors (Bristol, 1984; Garfin & Lord, 1986) believe that the severity of communicative impairment of a child with Autism may be one of the greatest sources of family stress.

The behavior of a child with Autism could also influence a parent's level of stress particularly when the child has a diagnosis that has externalizing behavior as a comorbidity. When investigating comorbid psychiatric disorders within the population of children with Autism, Lefer, Folstein, Bachman, Davis, et al. (2006) found that the median number of comorbid diagnoses per child was three, and the mode was also three. The comorbidities found, in descending order of frequency were Specific Phobia, Obsessive Compulsive Disorder, Attention Deficit Disorder, Separation Anxiety, Social Phobia, and Oppositional Defiant Disorder. Additionally, Summers, Houlding, and Reitel (2004) found that families identified externalizing disorders (e.g., attention problems, aggressive behavior) as a primary concern. Although, I did not find any research concerning parental stress connected with children with Autism's internalizing behavior (e.g., emotional reactivity; anxiety/depression), the high prevalence of these symptoms in children with Autism begs investigation in terms of its possible relationship to parental stress (Bristol, 1984; Summers, Houlding, & Hawkins, 2004; Tamanik, Harris, & Reitzel, 2004).

There is a recent trend in therapeutic approaches to Autism for clinicians to train parents as therapists (National Research Council, 2001). This training allows parents to address the language and behavioral needs of their children with Autism and aids in the generalization of therapeutic gains to the everyday environment. Investigators (Brookman-Frazee, 2004; Williams & Wishart, 2003) generally have found that not only does the functioning of the children with Autism improve using this approach, but training parents to address their children's needs also reduces parental stress. Yet, results of studies are mixed with some studies using parents as therapists showing reduced parental stress and others indicating no changes in parenting stress. These equivocal results may have, in part, been due to the lack of investigators' differentiation among children's language levels and behavioral symptoms. These different areas of language and behavioral functioning, as well as the varying levels within them, may be associated with different stress profiles in parents (Blackledge & Hayes, 2006; Brookman-Frazee, 2004;Hastings & Johnson, 2001; McConahie & Diggle, 2007; Olley, 1999; Smith, Donahoe & Davie, 2000; Williams & Wishart, 2003).

Another possibility for the equivocal results of studies of using parents as therapists is that the focus of the therapy was the child's needs rather than the parents. It may be that by identifying the symptoms that relate to stress in parents, psychologists would facilitate development of programs specific to the needs of parents of children with Autism that yield better results.

In terms of parental stress, Moes, Koegel, Schriebman, and Loos (1992) compared stress levels of mothers and fathers of children with Autism. They found that mothers showed significantly more stress than fathers on each inventory they used. Their results suggested that stress may relate to the differing responsibility assigned to child-rearing for each parent. Indeed, Hastings (2003), Hastings et al. (2005), and Herring et al. (2006) found similar results. Because mothers of children with Autism appear to experience more stress than do fathers, this study focused on primary caregiver stress. Thus, by using primary caregiver reports in this study, I focused on the needs of the person who reports more stress - the mother or primary caregiver. A primary caregiver focus is also important because it is the primary caregiver who usually delivers home-based therapy. To this investigator's knowledge, there has been no study addressing the relationship between a child with Autism's language functioning and his/her externalizing behavior. Additionally, there is little, if any, research regarding primary caregiver stress in relation to their children's internalizing behavior.

The symptoms of a child with Autism may not only affect his/her caregiver's stress level. Research has shown that family functioning could also be affected. For example, Donnenberg and Baker (1993) measured stress of parents with children with externalizing behavior disorders or Autism. They then directly asked parents about their perception of the influence of their child who had either externalizing behaviors or Autism on family functioning. They found the parents believed that both types of children influenced their families' stress in much the same way despite having different disorders.

In terms of family functioning, Rodrigue, Morgan and Geffen (1990) found that mothers of children with Autism reported less family adaptation than mothers of children with Downs Syndrome. Donnenberg and Baker (1993) found that families of children with externalizing disorders and children with Autism were more similar to each other than to typically developing peers. They found that lower family functioning was primarily child-related. When interviewing families of children with Autism, Hutton and Caron (2005) found that families of children with Autism reported that there was little to no time for family fun or vacations, which they reported as stressful. As mentioned earlier, Bristol (1984) and Garfin and Lord (1986) point out that the severity of communication impairment in children with Autism may be the greatest source of family stress.

As one can see, Autism's collection of symptoms overlap with many other diagnoses. Past research has compared and contrasted Autism with many other syndromes, which include Downs Syndrome and AD/HD. When studying varying levels of language in children with Autism, Tager-Flusberg (2004) noted that classic studies about children with Autism compared them to other groups of children with and without disabilities. She noted several methodological problems with this approach. They included: (a) the heterogeneity of the symptoms of Autism, (b) different levels of cognitive functioning within the population of individuals with Autism, and (c) the effect of developmental change on symptoms of Autism. Concomitantly, when studying the behavioral difficulties in this population, LeCavalier (2006) found the same difficulties.

In order to address these issues, Tager-Flusberg (2004) and LeCavalier (2006) suggested that studying the range of functioning levels of these symptoms of Autism *within* this population would aid in identifying important aspect of this mystifying syndrome.

Although one may infer the relationship of the range of language and behavioral symptoms to primary caregiver stress separately from past research, it is important to explore how the symptoms (e.g., language and behavioral levels) that are specific to Autism relate to primary caregiver stress and family functioning. Thus, the purpose of this study was to examine the range of language and behavioral symptoms in a sample of children with Autism as well as the relationship of pragmatic language levels and externalizing and internalizing behaviors in a sample of school-aged children within the Autistic spectrum to self reported primary caregiver stress and to primary caregivers' ratings of family environment.

This study sought answer the following questions: What are the language levels of this sample of children with Autism? Do they differ from the general population and if so, how do they differ? Similarly, what are the externalizing and internalizing behavior levels of this sample of children with Autism? Do they differ from the general population and if so, how do they differ? Is there a negative relationship between language levels of children with Autism and primary caregivers' self-reported stress levels? And is there a negative relationship between externalizing and internalizing behavior of children with Autism and their primary caregivers' self-reported stress? And how do the different symptoms of Autism relate to aspects of family functioning as reported by the primary caregiver?

By answering these questions, the relationship of these symptoms specific to the autistic population upon primary caregiver stress may be better understood. Baker, Landen, and Kashima (1991) and Maddux, Eyberg, and Funderburk (1989) found that high parental stress can interfere with carrying out a behavior management program. Concomitantly, Dadds, Schwartz, and Sanders (1987) found that when parent training programs are broadened in order to include emphasis on parents' stress and coping, family well-being may be increased. Therefore, the results of this study may facilitate the development of effective programs by understanding the relationship between language levels and behaviors of children with Autism and their primary caregiver's stress and ratings of family functioning.

CHAPTER II

Literature Review

This chapter provides a review of the literature covering Autism and parental stress beginning with a discussion of Pervasive Developmental Disorders (PDD), its symptoms, and subcategories (i.e., Autistic Disorder, Asperger Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified) that are pertinent to this dissertation. A discussion of the history of how the PDD diagnosis evolved elucidates the issues surrounding past and present research on Autism. The next two sections describe intellectual and language functioning within these diagnoses and the interrelationship between them. A discussion of the emotional and behavioral correlates of these diagnoses, including externalizing and internalizing behaviors follows, as well as a discussion of the relationship between language and behavioral problems.

The chapter then defines and discusses parental stress and family functioning in relation to having a child with Autism. What follows is a description of programs that address parental involvement in the education of children with Autism as well as the drawbacks of these programs. Because this dissertation explored the relationship between language and behaviors of children with Autism and primary caregiver stress, the clarification of this relationship may aid the development of better programs involving caregivers/parents, and so will provide social validity for this study. Finally, the chapter concludes with the rationale for this study along with the hypotheses tested.

Autism

As defined by DSM IV-TR (American Psychiatric Association (APA), 2000), Pervasive Developmental Disorders (PDD) is the umbrella category that covers five disorders (i.e., Autistic Disorder (a.k.a., Autism), Asperger Syndrome (a.k.a., Asperger's Disorder, Asperger's, AS), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Rett's Disorder, and Childhood Disintegrative Disorder. Severe and pervasive impairments in several areas of functioning characterize the PDDs. It is important to note that individuals with PDDs exhibit *deviant* development across the areas of reciprocal interaction skills, communication skills, and in stereotyped behavior, interests, and activities (APA, 2000). According to the National Institute of Mental Health (NIMH, 2008), because "all of these disorders are characterized by varying degrees of impairment in communication skills, social interactions, and restricted, repetitive and stereotyped patterns of behavior" (p. 1), they are often called Autism Spectrum Disorders (ASDs). ASDs/PDDs have multiple causes that Satzmari (2003) portrayed as "a cascade of structural and biochemical events that culminate in the disorder(s)" (p. 173).

Research attempting to differentiate Autism, Asperger Syndrome, and PDD-NOS suggests that these subgroups differ only in symptom severity and IQ (Miller & Ozonoff, 2000; Myhr, 1998; Ozonoff et al., 2000); therefore, these groups fall along a single spectrum representing the same disorder. In contrast, Rett's Disorder and Childhood Disintegrative Disorder are unique and rare disorders that should not be considered among the Autism Spectrum subtypes (Myhr, 1998). This dissertation has participants from three of the five PDD/ASD diagnoses (i.e., those disorders on the spectrum): Autistic Disorder, Asperger Disorder, and PDD-NOS.

Autistic Disorder is also known as Autism. According to the DSM-IV-TR (APA, 2000), Autism occurs in a 4 to 1 ratio of boys to girls, has an onset prior to the age of 3, and is often, but not always, accompanied by mental retardation. Impairment in social interaction is "gross and sustained" (APA, 2000, p. 70), with symptoms including lack of eye contact, facial expression, and gestures. Communication skills are also severely delayed, with manifestations such as echolalia or lack of language altogether (APA, 2000, p. 70). Individuals with Autistic Disorder may have encompassing preoccupation or stereotyped or restricted interests that are abnormal in intensity and/or focus (APA, 2000, p.71).

Another PDD category that some of the participants in this dissertation manifest is Asperger Syndrome, the newest addition to the PDDs (APA, 2000, p. 830). The core similarities between Autistic Disorder and Asperger Syndrome are severe and sustained impairment in social interactions and the existence of restricted, repetitive patterns of behavior, interests, and activities. However, according to the DSM-IV-TR (APA, 2000), children with Autistic Disorder, or Autism, have a more severe lack of interest in people than do those with Asperger Syndrome. Obsessive interests are symptoms of both disorders, but with Autism, these interests are more entrenched and more deleterious to social development (APA, 2000). Both disorders manifest an inflexible adherence to routines, but mental health practitioners or special educators can more easily and successfully prepare individuals with Asperger Syndrome for transitions (National Research Council, 2001). Unlike Autistic Disorder, Asperger Syndrome usually has a later onset and is rarely accompanied by mental retardation. In fact, DSM-IV-TR (APA, 2000) states that there is no significant delay in cognitive development or in the development of age-appropriate adaptive behavior for these individuals. With Asperger Syndrome, by definition (APA, 2000), there are no clinically significant delays in early language and the literature views any difficulties with language associated with this disorder as socially-based (APA, 2000, p. 82).

The third PDD category that some participants in this dissertation display is PDD-Not Otherwise Specified (PDD-NOS). DSM-IV-TR (APA, 2000) stipulates that one should use this category when there is an impairment of social interaction due to either impairments of verbal/nonverbal communication skills or the presence of stereotyped behaviors, interests, or activities. However, one should only use PDD-NOS when the criteria are not met for a specific PDD (such as Autistic Disorder or Asperger Syndrome), schizophrenia, Schizotypal Personality Disorder, or Aviodant Personality Disorder. Thus, individuals with PDD-NOS may approach, but not meet, criteria for other PDDs. DSM-IV-TR excludes the diagnosis of ADD or AD/HD when the symptoms occur exclusively during the course of PDD. Perry (1998), Kennedy (2002), and Kutscher (2005) indicated that children with PDD-NOS are frequently misdiagnosed as having AH/HD. Appendix A presents the full diagnostic criteria for Autistic Disorder, Asperger Syndrome, and PDD-NOS.

According to Rutter and Schopler (1987), "of all the psychiatric syndromes arising in childhood, Autism is much the best validated by empirical research *(sic)*" (p. 180). The diagnostic agreement for the presence versus absence of ASD or PDD is far higher than agreement for the specific DSM-IV-TR PDD subtypes (Mahoney et al., 1998;

Stone et al., 1999; Volkmar et al., 1994). That diagnostic validity among subtypes is compromised is an unfortunate state. In order to understand how this came to be, the following section discusses the history of the diagnosis of Autism.

History of the diagnosis of Autism. PDD and its subcategories arose from two separate traditions (i.e., American and European) within the history of child psychiatry and have different historical routes (Szatmari, 2000). This dichotomy of definitions between Americans and Europeans has had a powerful influence on the development of the criteria for Autism and its subtypes. It is important to understand the histories of these disorders in order to interpret past and present studies that attempt to define the PDD subtypes.

Autism was originally considered a type of childhood schizophrenia or infantile psychosis (Bishop, 1998; Rutter & Schopler, 1992). Leo Kanner, from Johns Hopkins University, first introduced the notion of infantile autism and thought of it as an early form of childhood schizophrenia (Kanner, 1943). In 1943, he reported on 11 children who manifested an apparently congenital disturbance of affective contact. His descriptions were precise enough to be useful in classifying a large number of children who had been previously hard to understand. These included the "idiot savants" who were described earlier than Kanner's work. His work became extremely well-known soon after he published his paper.

Instant notoriety, however, was not the case for Austrian Hans Asperger. He published a paper one year after Kanner that described a similar condition to infantile autism, but his population seemed more intelligent and exhibited more developed social skills (Asperger, 1944). The term he used to describe his group was "autistic psychopathy" (Asperger, 1944, p. 76). Asperger's original intent was to differentiate his population from Kanner's Autism. However, Asperger's work was relatively unknown to English-speaking clinicians, although it had some recognition in Europe. It was not until 1981, when Lorna Wing published a series of papers describing Asperger Syndrome that most American clinicians became aware of Asperger Syndrome. Neither Wing nor Asperger, however, provided explicit guidelines for the diagnosis of Asperger Syndrome. In fact, Wing did not attempt to make a clear distinction between Autism and AS. It is understandable, then, that her work spawned several definitions for the AS diagnosis (Klin, Volkmar, & Sparrow, 2000). Given the history of Autism and Asperger Syndrome, it is also understandable how the different definitions can run along continental lines.

By 1980, a year before Wing's (1981) paper, Autism was first included in the DSM-III (APA, 1980) with Autism and related disorders grouped within the PDDs (Volkmar, Ciccetti, Bregman, & Cohen, 1992). But the DSM-III only included Autism, Rhett's Disorder, and Childhood Disintegrative Disorder. As PDD research continued to inform diagnosis, the autistic diagnostic criteria changed in 1987 with the publication of DSM- III-R (APA, 1987). The criteria for Autistic Disorder were broadened to encompass the entire spectrum of the syndrome over developmental levels and across the lifespan (Volkmar et al., 1992).

So as readers can see, there were different definitions for PDD and its subcategories over the years. When surveying the literature comparing Autism with Asperger Syndrome, it seemed that research on these disorders has evolved parallel to that of their diagnostic criteria. The early studies were plagued with problems such as differing criteria to separate individuals with Autism from those with Asperger

Syndrome. Thus, prior to the publication of DSM-IV (APA, 1994), it was not unusual for a research study to assign individuals to groups using DSM-III (APA, 1980) to diagnose those with high-functioning Autism (i.e., individuals with Autism with normal to high intelligence) (Howlin, 2003) and the ICD-10 (World Health Organization, 1993), or any other diagnostic system, to diagnose Asperger's Syndrome (Rutter & Schopler, 1992). This procedure could have obscured group differences and so influenced study outcomes. Not only did these diagnostic difficulties interfere with comparing the subtypes within studies, but they also interfered with comparing the results of studies against each other (Szatmari, 2000).

Tager-Flusberg (2004) summarized past research on the language difficulties that children with Autism have. She did this in order to identify which aspects of language are uniquely impaired in Autism. She pointed out that the classic studies about children with Autism compared them to other groups of children matched on age, IQ, and mental age. She noted several methodological problems with this approach. They included: (a) the heterogeneity of the population of individuals with Autism, (b) different levels of cognitive functioning within the population of individuals with Autism (i.e., those with Mental Retardation and those with Superior IQs), (c) the effect of developmental change on autistic symptoms, and (d) sample size and acquisition. She suggested an alternative strategy to study children with Autism using a within-group design to focus on identifying the complex expressions of the language phenotype across the full range of the syndrome.

Lecavalier (2006) also reviewed classic studies concerning the emotional and behavioral difficulties exhibited by children with Autism. He found that the wide range of behavioral manifestations of difficulties in this population is a major barrier to the study of this diagnosis. Lecavalier (2006) suggested using cluster analysis to study emotional and behavioral symptoms in children with ASD. The goal of cluster analysis is to derive clusters of symptoms with minimal within-group variance and to increase between-group differences (Lecavalier, 2006). Cluster analysis makes the subject (rather than the symptoms) the basic unit of analysis. It enables the study of all cases on the behavioral dimensions.

By understanding the past and present state of research on the diagnosis of Autism, one can see how the subclassification boundaries between Autism, Asperger Syndrome, and PDD-NOS can be blurred. It is with this in mind that this dissertation focused on children on the autism spectrum that have the three diagnoses of Autism, Asperger Syndrome, and PDD-NOS. Studying the language and behavioral functioning of these children instead of their specific diagnoses ensured that no child on the Autistic Spectrum was excluded and that the participants displayed the similar symptoms of deficits in language and behavior that are common in individuals with ASDs.

Yet even with the expansion of DSM criteria for Autism, remnants of past criteria still haunt present clinical diagnoses. The National Research Council (2001) stated that there is a strong association of Autism with Mental Retardation. Epidemiological studies typically estimate that about 70% of children with Autism score within the range of Mental Retardation, although there is some suggestion that the proportion of children with Autism with Mentally Retardation has decreased (Fombonne, 1997). Indeed, Wing (2000) noted that she believed there was an increased used of the diagnosis of Asperger Syndrome (which is generally not associated with Mental Retardation) in the United

Kingdom since the publication of her paper. This change may be a function of more complete identification of children with Autism who are not Mentally Retarded: a broader definition of Autism that includes less cognitively impaired children, such as those diagnosed with Asperger Syndrome, as well as greater educational opportunities for children with Autism in the past 2 decades (National Research Council, 2001). In an attempt to investigate the relationship between symptoms of Autism and intelligence, researchers developed several classifications outside those of the DSM to better understand ASD characteristics.

Different classification systems of the ASDs. Satzmari (1992) reviewed 20 papers that he believed adequately investigated the internal or external validity of the various types of ASDs. From this review, he suggested reorganizing the classifications of Autism. Satzmari found that there were three main groups that one can distinguish within the autism spectrum: Asperger Syndrome and two atypical subtypes of Autism. Satzmari most noted Asperger Syndrome for its less deviant language development, although it was marked by pedantic, repetitive, and one-sided conversation. The other two groups divided the Autistic Spectrum disorders by IQ scores: Low Functioning Autism that is characterized by a low IQ, and High Functioning Autism marked by a high IQ. Satzmari seemed to think that dividing the ASD groups in this manner would add clarity to outcome and treatment research.

The subtyping of Autism by IQ scores remains a controversial issue. In their study, Volkmar, Cohen, Bregman, Hooks, and Stevenson (1989) explored the Wing subtypes of Autism as an alternative. This system includes three subtypes based on the quality of social interaction: *aloof* (those who actively avoid social interaction); *passive* (those who passively accept interaction but do not seek it); and *active-but-odd* (those who seek interaction but interact in an odd or eccentric fashion) (Attwood, 1998). This system has several advantages: it makes use of an essential diagnostic feature (i.e., quality of social interaction) that practitioners and researchers can observe directly; it is intended to cover the range of syndrome expression; it is atheoretical; and it has practical implications for management of individuals with autism (Volkmar et al., 1989).

Volkmar and colleagues' (1989) study drew their sample from several sources: a treatment center for children and adults with Autism, a developmental disabilities clinic, and a facility for the retarded. A total of 149 children and adults comprised the sample. Seventy-eight of the participants were persons with Autism who had a mean chronological age of 15.10 years, a mean mental age of 4.78 years, and a mean IQ of 37.05. All met the DSM-II (APA, 1968) criteria for Autism. Thirty-four persons had atypical PDD with a mean chronological age of 12.80 years, a mean mental age of 6.04 years, and a mean IQ of 61.88. These participants had some, but not all features of Autism. There were 37 developmentally disordered individuals without PDD who had a primary diagnosis of Mental Retardation, developmental language disorder, or schizophrenia with childhood onset. This non-PDD group had a mean chronological age of 11.86, mean mental age of 3.13 years, and a mean IQ of 49.70.

All participants in Volkmar et al.'s (1989) study had recent comprehensive evaluations performed by one of more of the authors that included measures of intellectual, communicative, and adaptive functioning. The authors employed two sets of measures to address reliability and validity of the Wing subtyping approach. The first measure was clinical ratings by four child psychiatrists to classify each participant in a

Wing subtype (i.e., aloof, passive, and active-but-odd) on the basis of detailed records of each case. At least two of the four raters were blind to the Wing group assignments made by other raters, but not blind to the diagnosis that was specific to ASD. The second measure was a 23-item questionnaire that the teacher/caregiver completed. The authors drew these items from the description of the subtypes. Results found that the Wing subtypes differed significantly by chronological age, mental age, IQ, and adaptive functioning. Interestingly, a discriminate analysis using only IQ as a predictor of Wing type assigned only 53% of all cases correctly. The authors concluded that, while IQ was a powerful predictor of subtype assignment, it clearly did not fully account for it.

As readers will note, the average IQ's of the participants in this older study were in the Mentally Retarded range. Although this is a good example of early research struggling with the issue of intelligence in Autism, it still took some time to come to a fuller understanding of the symptoms of Autism

The recent addition of Asperger Syndrome to the DSM-IV-TR (APA, 2000) led to the exploration of the expansion of the range of the Autism Spectrum to include children with IQ's in the normal or near-normal range of intelligence. Mayes and Calhoun (2004) focused on one aspect of the DSM-IV-TR (APA, 2000) criteria for Asperger Syndrome that was the absence of cognitive delay. They attempted to differentiate children with clinical diagnoses of Autism versus Asperger's Syndrome on the basis of normal versus below normal cognitive functioning. They postulated that if IQ and age could account for the differences between the two groups (i.e., Autism and Asperger's), then cognitive delay as a diagnostic distinction between high functioning Autism and Asperger Syndrome in the DSM-IV-TR may not be satisfied.

This was a retrospective study (Mayes & Calhoun, 2004) with 157 children with a mean age of 5.10 years, mean mental age of 42 months, and a mean IQ of 65. Males outnumbered females 122 to 35. All the children had a diagnosis of Autism or Asperger Syndrome or both diagnoses. The authors formed two groups: children with below normal IQ (less than 80) and those with normal IQ (above 80). They used the following tests, depending upon age and current version: Bayley Mental Scale (I or II) (Bayley, 1993); Stanford Binet Intelligence Scale (L-M or IV) (Thorndike, 1972) or the Weschler Intelligence Scale (Weschler, 1991). Clinicians completed the Checklist for Autism in Young Children (Mayes & Calhoun, 1999). This instrument contains 30 symptoms of Autism.

Results showed that children with below normal IQs had a significantly greater total frequency of autistic symptoms than did children with normal IQs (Mayes & Calhoun, 2004). However, when the authors removed the effects of IQ, chronological age, and mental age, these differences were no longer significant. In other words, differences that were found could be accounted for by preexisting differences in IQ, chronological age, and mental age. They compared the presence or absence of 30 symptoms related to Autism for children with normal and children with below normal intelligence and did not find significant differences in frequencies between the two groups for any of the symptoms. The authors stated that it seems illogical to subdivide a psychiatric disorder (i.e., PDD) on the basis of intelligence. The DSM-IV-TR (APA, 2000) does not do this for any other disorder that occurs in childhood. According to the DSM-IV-TR's multiaxial assessment system,

> Axis I is for clinical disorders and other conditions that may be a focus of clinical attention….Axis II is for reporting Personality Disorders and Mental Retardation. Using Axis II ensures that consideration will be given to the possible presence of these conditions that may otherwise be overlooked (APA, 2000, p. 27).

The ASDs are marked by deficits in three areas: communication, socialization, and stereotyped behaviors. But the ASD subtypes are in dispute (Szatmari, 2000). Indeed, Lorna Wing herself "argue(d) strongly against [Asperger Syndrome]'s existence as a separate entity" (Wing, 2000, p. 430). Alternately, Szatmari (2000) gave reasons that the PDD's should not be considered as a "continuum" (p. 410). Yet he went on to say that a classification system must be *useful*. His response to the question of the validity of the PDD subcategories is, "valid for what?" (Szatmari, 1992, p. 600). In order to conduct genetic studies, Szatmari suggested combining the autistic disorders (Szatmari, 1992).

Indeed, the American Psychiatric Association seems to agree with Szatmari. Asperger's Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified will be folded into a single broad diagnosis, Autism Spectrum Disorder, when the new DSM V is published in 2012. This category will encompass the entire range of Autism, from high-functioning to profoundly disabling. Apparently, this approach is in line with a new approach to mental illness. Instead of viewing disabilities as "you have it or you do not", this approach views disabilities as a continuum, or spectrum. This allows clinicians to recognize other, comorbid conditions and so treat the whole person. Thus, a child with ASD could also be treated for AD/HD or the other prevalent comorbidities that often occur with Autism (2009, November 2, NYTimes).

In this vein, this study attempted to explore some of the different symptoms of the Autistic Spectrum and their effects on maternal stress. Thus, this dissertation combined the different subtypes and so used children diagnosed with Autism, Asperger Syndrome, and PDD-NOS as participants. Instead of dividing children by ASD subcategories, it examined the children by language and behavioral symptoms common to the ASDs and looked at the relationship of these symptoms to primary caregiver stress and family functioning.

Language and Autism Spectrum Disorders

The previous section illustrated how cognitive functioning can confound the understanding of autistic symptoms. The following section discusses the role of various aspects of language in the ASDs. By clarifying the different types of language functioning, the understanding of this symptom of the ASDs will be clearer.

Venter et al. (1992) evaluated the role of various cognitive and behavioral measures in childhood to predict social-adaptive and academic attainment in high-functioning adolescents and adults with Autism in a retrospective study. Originally, the participants were 58 high-functioning children with Autism (23 females and 35 males) who initially received assessment during their preschool and early school years. The authors performed a follow up assessment 8 years later. The participants were a part of a collaborative study on sex differences and familial aggregation.

Venter et al. (1992) administered the following at the beginning and at the end of the study: Weschler tests (Weschler, 1974, 1991), Vineland Adaptive Behavior Scales (Sparrow, Balla & Chiccehetti, 1984), Peabody Picture Vocabulary Test-R (Dunn & Dunn, 1981), Raven's IQ test (Raven, 1960), Neale Analysis of Reading (Neale, 1958), and Schonell Graded Spelling Test (Schonell & Schonell, 1960). Each participant completed a battery of psychometric tests using a standardized protocol compatible with each participant's IQ and language level. At follow up, one examiner administered all tests over the course of 1 to 2 1/2 days. Results found that, overall, verbal skills emerged as by far the strongest predictor of both adaptive and academic outcomes. Although Verbal IQ was the most consistent current predictor of both outcome measures, the other language measures (i.e., receptive vocabulary, global judgments of the presence of communicative speech before 5 years, parental descriptions of language deviance, and a test of comprehension of oral language) served as independent predictors of outcome measures.

In 2001, Kjelgaard and Tager-Flusberg re-examined the language profiles of a large well-defined sample of children with Autism. Participants were 89 children diagnosed with Autism using the Autism Diagnostic Interview-R (Lord, Rutter, & LeCouteur, 1994) and the Autism Diagnostic Observation Schedule-Generic (DiLavore, Lord, & Rutter, 1995). The authors recruited participants from a multi-project investigation. Mean chronological age was 88.07 months, mean Full Scale IQ was 68.49, mean Verbal IQ was 76.29, and mean Non-Verbal IQ was 82.95 as measured by the Differential Abilities Scales (Elliot, 1990).

Kjelgaard and Tager-Flusberg (2001) administered to the children a standard battery of language tests measuring their phonological, lexical, and higher-order semantic and grammatical language abilities. They included the following: Goldman-Fristoe Test of Articulation (Goldman & Fristoe, 1986), Peabody Picture Vocabulary Test III (Dunn & Dunn, 1997), Expressive Vocabulary Test (Williams, 1997), Clinical Evaluation of

Language Fundamentals (Wiig, Secord, & Semel, 1992), and Repetition of Nonsense Words from the NEPSY (Korkman, Kirk, & Kemp, 1998). There were no differences between receptive and expressive levels of performance by these children. This suggests that verbal children with Autism do not show a major discrepancy between their receptive and expressive language skills**.**

The scores on each of the language tests, however, showed wide variability among the children in this study. To explore this variability further, Kjelgaard and Tager-Flusberg (2001) formed three groups of participants based on their Peabody Picture Vocabulary Scores: those who scored in the normal range (SS = > 85), those who scored in the borderline range (SS = 84-70), and those whose scores were more than two standard deviations below the mean (SS = < 70). The authors compared language test scores of these groups with their IQs. They found that IQ itself accounted for only *some* of the heterogeneity found in language among children with Autism. When comparing the scores of the above three groups with the intelligence measures, the authors came to the same conclusion as Venter et al. (1992), "Language skills can be independent of IQ in Autism and may, in fact, be more important in understanding both the current functioning and the long-term prognoses of children with this disorder" (p. 301).

The results of the studies by Kjelgaard and Tager-Flusberg (2001) and Venter et al. (1992) point out the subtle relationships between language and cognition as well as between language and social functioning. Attwood (1998) explained that there are several levels of language functioning. Among them are formal language and pragmatic language. Formal language refers to the skills used that social context does not influence. An example of this would be expressive vocabulary (e.g., defining words) or abstract verbal reasoning. Pragmatic language refers to the use of language to communicate in a social manner, such as turn taking in a conversation, following the ebb and flow of a conversation, and understanding of subtle language cues to convey meaning rather than the comprehension of the spoken words themselves, as in sarcasm. To illustrate, Attwood (1998) uses the sentence "I didn't say she stole the money". A person can say this sentence in several different ways to convey many different messages:

> *I* didn't say she stole the money [but someone else did].
>
> I *didn't* say she stole the money [I definitely didn't say it].
>
> I didn't *say* she stole the money [but I implied it]. (p. 80)

Pragmatic language is quite difficult to measure because it is embedded within language skills themselves. Indeed, there are few, if any, single language tests to measure it, although some language tests have a subtest for pragmatics (Wetherby & Prizant, 2000). Thus, one can easily understand how pragmatic language functioning can be confounded with the results of more formal language and cognitive measures (Twactman-Cullen, 2000). A child may be quite high functioning in formal language, but still have severe difficulties in social interaction as a result of pragmatic language difficulties. It follows then that children with pragmatic language difficulties could have an impact upon family functioning. Indeed, some authors believe that the severity of communicative impairment of a child with Autism may be one of the greatest sources of family stress (Bristol, 1984; Garfin & Lord, 1986).

Tager-Flusberg (2004) reviewed classic studies about children with Autism that compared them to other groups of children who were matched with them on chronological age, IQ, and mental age. The author did this to identify which aspects of language are uniquely impaired in Autism. Consistently, results found pragmatic language functioning to be impaired in children with Autism.

In order to fully appreciate the role of pragmatic language in social functioning, one must turn to how pragmatic language develops and how this development affects the child's relationship to his/her mother. The rudiments of conversation are seen in early infancy. Normal infants engage in reciprocal gaze and affective exchanges (Stern, 1974) that set the stage for conversational turn-taking. As early as 3 months, infants take a vocal turn after being spoken to by their caregivers (Bloom, Russell, & Wassenberg, 1987). Early forms of topic maintenance are found when infants and their caregivers attend to the same thing at the same time. This is called joint attention. Between 6 and 8 months, infants begin to follow their caregiver's line of visual regard (Scaife & Bruner, 1975). This is called referential looking. Caregivers help to develop these skills by building a kind of scaffolding around what the child says (Bruner, 1978).

However, children with ASD have exhibited deficits in these early fundamental skills. For example, children with Autism do not orient to certain speech sounds - their mother's voice (Klin, 1991) or to their own name (Dawson, Multzoff, & Osterling, 1995; Osterling & Dawson, 1994) as readily as typically developing children do. Thus, they may miss many opportunities to learn new language, because they may not attend to much of the speech directed at them (Carpenter & Tomasello, 2000).

Similarly, children with Autism do not tune into other people in the more active ways that typical children do. Many studies (see Carpenter & Tomasello (2000) for a summary) have found that children with Autism do not share interest and attention with others, or respond to others' requests to share interests or attention with them along with deficits in joint attention and visual regard.

These skill deficits are evident very early in development-even before the diagnosis of Autism is made (Baron-Cohen et al., 1996; Osterling & Dawson, 1994) and persist throughout childhood (Baron-Cohen, 1989; Landry & Loveland, 1988). Deficits in joint attention reliably differentiate children with Autism from children with various other developmental delays (Mundy et al., 1986; Mundy et al., 1990; Wetherby et al., 1998). It is unclear whether the cause of this is a primary deficit in Autism or a result of more basic deficits such as difficulties with interpersonal relatedness, affective sharing (Hobson, 1993), or shifting attention between two stimuli (Courchesne, 1994).

Whatever the underlying reason, these deficits affect children with Autism's relationship with their mother. Both mother and child misunderstand each other's social and communication cues, which leads to frustration, withdrawal, and tantrums. As mentioned earlier, the child with Autism misses the opportunity to learn social language which affects his/her interactions with others. Concomitantly, the mother also has difficulty dealing with society at large in explaining her child's dysfunction (Claiborne-Park, 1995). For more on maternal stress in connection with her child's Autism, please see the section "Parental Stress and Autism".

Emotional and Behavioral Correlates of Autism

Relative to their typically-developing peers, children and adolescents with ASD have been found to have a higher prevalence of depression, bipolar disorder, anxiety, psychotic disorders, and aggression (Pearson et al., 2006). Obviously, comorbid emotional and behavioral difficulties of a son or daughter with ASD can be stressful to a parent. This high comorbidity rate adds to the heterogeneity of the ASD population and is a barrier to fully understanding this diagnosis (Lecavalier, 2006).

Gadow, DeVincent, Pomeroy, and Azizian (2004) were the first to examine DSM-IV (APA, 1994) psychiatric symptoms in a relatively large sample of 172 pre-school aged children with ASD. They compared these children to 135 children without ASD from a psychiatric clinic and two community-based samples of children in regular and special education (*n* = 64). The children ranged from 3 to 5 years old. Parents and teachers completed the Early Child Symptom Inventory, a DSM-IV-referenced rating scale (Gadow & Sprafkin, 2000). Gadow et al. (2004) found that the preschoolers with ASD presented with more severe DSM-IV psychiatric symptoms than those in regular and special education who did not have ASD. The most prevalent diagnoses were Generalized Anxiety Disorder (GAD), Oppositional Defiant Disorder (ODD), and Attention Deficit/ Hyperactivity Disorder (AD/HD). Interestingly, they also found that the children with the most severe ASD symptoms had fewer psychiatric symptoms. The same authors conducted a similar study for elementary school aged children in 2005 and found similar results (Gadow et al., 2005).

Some researchers have begun to explore the diagnosis of comorbid psychiatric syndromes in children on the Autistic Spectrum in relation to intellectual functioning. Bradley and Isaacs (2006) studied levels of inattentive, hyperactive, and impulsive (IHI) behavior in teenagers with intellectual disabilities, with and without Autism. They identified 36 teenagers with an IQ of 75 or lower who met the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter & Lecouteur, 1994) criteria for Autism. They were matched for age, gender, and non-verbal IQ with the same number of children with an intellectual disability only. Bradley and Isaacs (2006) further subdivided the group with Autism into those with IHI behavior and those without. Results showed that those with Autism and an intellectual disability had more IHI behaviors than those with an intellectual disability alone. Additionally, more children with Autism met the criteria for AD/HD and hyperkinetic disorder regardless of their IHI levels. About one in two teenagers in the intellectual disability/Autism group displayed clinically significant inattentive, hyperactive, and/or impulsive behaviors as compared to one in seven of those with an intellectual disability alone.

Indeed, when investigating comorbid psychiatric disorders *within* the population of children with Autism, Leyfer, Folstein, Bacalman, Davis et al. (2006) found that the median number of comorbid diagnosis per child was three and the mode was also three. Participants in this research study were 109 children with Autism, ranging in age from 5 to 17 years, all of whom met ADI-R (Lord, Rutter, & LeCouteur, 1994), and the Autistic Diagnostic Observation Schedule (ADOS; Lord et al., 2000), and DSM-IV-TR (APA., 2000) criteria for Autism. Parents completed the Autism Comorbidity Interview-Present and Lifetime Version (Leyfer et al., 2006) that was a modification of the Kiddie Schedule of Affective Disorders and Schizophrenia (KSADS; Ambrosini, 2000; Chambers et al., 1985; Kaufman et al., 1997) for Autism. Results showed that 72% of the children with Autism had at least one DSM-IV Axis I disorder in addition to Autism. Over 30% had two diagnoses. Specific Phobia was the most common DSM-IV mood disorder in children with Autism with 44% of the sample meeting the criteria for this disorder. Thirty-seven percent of the participants met criteria for Obsessive Compulsive Disorder; 12% of the children with Autism met the criteria for separation anxiety; 7.4% of the sample met the criteria for Social Phobia. In terms of disruptive disorders, 31% of the children with Autism met the AD/HD criteria and 7% met ODD criteria. Additionally, Summers, Houlding, and Reitzel (2004) found that families of children with Autism identified externalizing disorders as their primary concern.

Tonge, Brereton, Gray, and Einfeld (1999) explored the potential differences in psychopathology between children and adolescents with Asperger Syndrome and those with high functioning Autism. The sample consisted of 75 participants with Asperger Syndrome and 52 participants with high functioning Autism. They administered caregivers the Developmental Behavior Checklist (Einfeld & Tonge, 1994,1995). An analysis of covariance (ANCOVA) was used to control for the effects of age and cognitive level and to determine whether the groups differed in their levels of psychopathology. The authors found that children and adolescents with both Asperger Syndrome and high functioning Autism presented with high levels of clinically significant behavioral and emotional disturbance. Results indicated that 85% of the Asperger group and 65% of the high functioning Autistic group exhibited clinically significant levels of behavioral and emotional disturbance. Tonge et al. (1999) stated that this is higher than the 40.70% found in a general epidemiological population of young people with an intellectual disability (Einfeld & Tonge, 1999) and much greater than the 10%-15% in general childhood populations (Rutter, 1989).

Autism and AD/HD Symptoms. Recent research has begun to explore the comorbidity of AD/HD and anxiety within the population of individuals on the Autistic Spectrum. As readers will see below, it is often difficult to tease externalizing and internalizing behaviors apart from each other as well as from symptoms of Autism itself.

As the studies reviewed above (i.e., Leyfer et al., 2006; Summers et al., 2004; Tonge et al., 1999) suggest comorbidity rates can be very high within this population calling into question the DSM-IV's exclusionary criteria for AD/HD. The studies' results further suggest that the treatment of both the autistic symptoms and the comorbid conditions could lead to better treatment outcomes (Chalfant, Rupee, & Carroll, 2007; DeBruin et al., 2007; Holtman, Bolte, & Poustka, 2007; Lutejin et al., 2000; Reisersen, Constantino, Volk, & Todd, 2007).

Reisersen et al. (2007) assessed whether children with AD/HD have elevated levels of autistic traits. Using 946 twins identified from Missouri birth records, the authors contacted the parents by phone and administered a brief screening interview that measured present or past inattentive symptoms. The authors included twin pairs in the study if at least one twin of the pair exhibited three or more AD/HD symptoms. The parents then completed the Child Behavior Checklist (CBCL; Achenbach, 1991), and the authors assigned each child to a DSM-IV AD/HD subtype based on the CBCL score. Parents completed the Social Responsiveness Scale (Constantino & Gruber, 2005) to quantify their children's autistic traits. Reisersen et al. (2007) found clinically significant elevations of autistic traits in children meeting diagnostic criteria for AD/HD.

Holtman, Bolte, and Poustka (2007) examined the impact of inattention, hyperactivity, and impulsivity on the children and adolescents with PDD. A total of 182 participants (41 females and 141 males) were diagnosed as having PDD. Holtman et al. (2007) divided the youth into a high-PDD group and low-PDD group in terms of AD/HD symptoms as measured by the CBCL (Achenback & Rescoria, 2001). Holtman et al.

(2007) found that the PDD group with higher numbers of AD/HD symptoms exhibited a significantly higher degree of both internalizing and externalizing symptoms.

Autism and Anxiety symptoms. Gillot, Fumiss, and Walter (2001) explored the extent and nature of anxiety experienced by children with high functioning Autism. They compared a group of 15 children with high functioning Autism with 15 children with specific language impairment, and 15 typically developing children between the ages of 8 to 12 years. Each group consisted of 13 boys and 2 girls matched for chronological age and gender. The authors administered the children the Spence Children's Anxiety Scale (Spence, 1997) and the Spence Social Worries Questionnaire (Spence, 1995). Children with Autism were found to have considerably higher levels of anxiety than both the children with language impairments and the typically developing controls. The highest subscale scores for children with Autism were in separation anxiety and obsessive compulsive disorder.

Kim, Szatmari, Streiner, and Wilson (2000) reported the prevalence and correlates of anxiety and mood disorders among 9- to 14-year old children with Asperger Syndrome and high functioning Autism. When these children were 4 to 6 years old, they had been diagnosed with either Asperger Syndrome (n = 19) or Autism (n = 40) by a series of diagnostic cognitive and behavioral measures that the authors reviewed. Kim et al. (2000) contacted the families 6 years later to assess the children for evidence of psychiatric problems. Compared with a sample of 1,751 community children, the children with Asperger Syndrome and high functioning Autism demonstrated a greater rate of anxiety and depressive symptoms that substantially impacted their daily lives. Kim et al. (2000) found no differences in these symptoms between these ASD groups.

Hurtig et al. (2009) reported that by using cross-informant reports, psychologists are able to view the whole picture of presenting symptoms. This could aid in discussions between the child, parent, and teacher. As some symptoms may be misinterpreted by some of the people involved and may not be detected at all by others.

Hertig et al. (2009) conducted a study to examine psychiatric symptoms in adolescents with high functioning Autism Spectrum Disorders using multiple informants. Forty-three 11 to 17 year old adolescents with high functioning Autism or Asperger Syndrome were recruited from a epidemiological study in 2000-2003 in Finland. The 1991 versions of the Achenbach questionnaires were used: the CBCL Youth Self Report and CBCL-Teacher Report form (Achenbach & Rescoria, 1991) using American norms. Results found that adolescents' with AS/HFA reports of problems on the anxious/depressed scale were significantly related to reports by their parents, yielding a Spearman correlation of 0.29 ($p < .05$). Similar results were found for parent-child identification of withdrawn and attention problems, both with a correlation of .29 ($p < .05$). Parent and adolescent ratings of the adolescents' thought problems were not significantly related, having a correlation of .06. Externalizing behavior scores yielded a parents-adolescent ratings correlation of .46 ($p < .01$), and internalizing behavior scores resulted in a correlation of .27 ($p < .05$) between parents' and adolescents' ratings of these problems.

When comparing the adolescents' and teachers' ratings of the adolescents' behavior, Hertig et al. (2009) found a strong positive correlation for the withdrawal scale with a correlation of .66 ($p < .01$) and significant, positive correlations between teachers and adolescents anxious/depressed (.34; $p < .01$) ratings, social problems (.44; $p < .01$)

ratings, thought problems (.36; p < 01) ratings, and attention problems (.20; $p < .01$) ratings. Adolescent-teacher ratings correlated of .43 ($p < .01$) for externalizing problems and .56 ($p < .05$) for internalizing problems.

Parents' and teachers' ratings of the adolescents' behavior were also significantly related with a strong correlation of parent-teacher ratings of adolescents' social and externalizing problems of .59 ($p < .05$). Parent and teacher ratings of adolescent aggressive behavior ($r = .44$) and total problems ($r = .34$) were also significantly related at the $p < .05$ level. Thus, although parents and teachers see adolescents in the different environments of home and school, they tend to observe similar adolescent problems behaviors. This dissertation also examined the relationship between primary caregiver and teacher ratings of the externalizing and internalizing problems of children with Autism.

Although the above study involved a different population (higher functioning autistic adolescents with Autism in general education) than the population in this study that used the full range of Autism of school aged children in mostly therapeutic schools, this information adds essential information to the description of a population that is somewhat similar to the dissertation sample.

Diagnostic issues arising from comorbidities of Autism. The relationship among externalizing and internalizing comorbidities within the Autistic Spectrum is still quite unclear. Bradley et al. (2006) pointed out that often a criterion for a comorbidity may be due to different sources depending upon the individual being diagnosed. For example, one may better understand the DSM- IV item for impulsivity "often interrupts or intrudes on others" (APA, 2000, p. 92) as more indicative of pragmatic language difficulties than as an AD/HD symptom. Sukhodolsky et al. (2008) pointed out that the DSM-IV criterion for Autism "insistence on sameness" (APA, 2000, p. 71) could be a reflection of anxiety, or that repetitive behavior of children with Autism could be either a coping mechanism for anxiety, or a symptom of sensory integration deficits.

Comorbidities of Autism may also be developmentally related. Ghaziuddin, Weidmer-Mikhail, and Ghaziuddin (1998) found that, in a group of individuals diagnosed with Asperger Syndrome, children were more likely to suffer from AD/HD, while adults more frequently had depression. Although a review of treatments for comorbidities of Autism is beyond the scope of this paper, many researchers have suggested that treatments of the wide range of comorbid conditions, from medication for AD/HD symptoms (DeBruin et al., 2007; Lutejin et al., 2000; Santosh, Bairol, Pityaratstian, Tavare, & Gringas, 2006) to cognitive behavioral therapy for anxiety symptoms (DeBruin et al., 2007; Chalfant, Rupee, & Carroll, 2007), are quite effective in reducing comorbid symptoms.

The Relationship between Language and Behavior

As Lindsay, Dockrell, and Strand (2007) pointed out, two main lines of research have examined the connection between language and behavioral difficulties in children in general. One of these approaches studied the increase of behavior problems in children with language disorders (Beitchman, Brownlie, Inglis et al., 1996). The second approach studied the greater prevalence rates of language problems in children with behavior difficulties (Ripley & Yuill, 2005). Redmond and Rice (1998) estimated the co-occurrence of language and behavioral difficulties in children with ASD to be between 50% and 70%.

McCabe (2005) conducted a study to investigate the relationship between speech and language impairments and concomitant social competence and behavioral adjustment in preschoolers without ASDs. Participants included parents and teachers of 131 children with speech and language impairments and 39 children without disabilities. Adults who had contact with these children completed several rating scales measuring behavioral and social competency. McCabe (2005) found that children with greater language impairment had significantly more behavior problems and poorer social competence than those with articulation-only disorders and controls.

It is generally accepted that a great proportion of challenging behavior is "socially mediated" or a compensatory factor for language difficulties (Carr & Durand, 1985; Damico & Nelson, 2005; Kevan, 2003; McCabe, 2005). Carr and Durand (1985) were pioneers in this area of investigation. They posited that one could view severe externalizing behavior problems as a means of non-verbal communication (Carr & Durand, 1985; Durand, 1990). Thus, externalizing behaviors such as tantruming, hand-biting, or rocking serve a function of communication for the child. Durand (1990) developed the Motivation Assessment Scale that identifies the possible function these behaviors serve in expressing the child's wants and/or needs. One function of challenging behavior may relate to sensory integration needs. Thus rocking or hand-flapping may alleviate the discomfort of sensory integration deficits. Another function posed is escape from a demanding task. For example, when the child tantrums, the caretaker often terminates the task. Another function that externalizing behavior may serve is to elicit adult attention. Thus, adult attention may reinforce the tantruming. The last function of challenging behavior may be to acquire tangible rewards. For example, when a child cries for a toy, the adult may eventually give the child the toy. Durand's Functional Communication Training (Durand, 1990) was designed to ameliorate these externalizing behaviors. Although treatment of externalizing behavior is not the focus of this dissertation, the theory of Carr and Durand (1985) illustrates the concept underlying the connection between language and externalizing behavior.

Researchers have also found language difficulties to be correlated with social withdrawal/internalizing behavior. Stanton-Chapman, Justic, Skibbe, and Grant (2007) examined the social and behavioral characteristics of 45 preschoolers with Specific Language Impairment compared with 53 children with typically developing language skills. Mothers of these children completed the Social Skills Rating System (Gresham & Elliot, 1990) and the Child Behavior Checklist (CBCL; Achenbach, 2001). Stanton-Chapman et al. (2007) found large and significant differences in cooperation, assertion, responsibility taking, and self-control between the preschoolers with language impairments and typically developing children. Interestingly, both impaired and control children had similar scores on the CBCL Externalizing subscale but the preschoolers with language impairments exhibited a significantly greater amount of internalizing behavior, especially in withdrawal behaviors.

Stanton-Chapman et al. (2007) found smaller, but still significant, between group differences between children with language disorders and typically developing children for Anxiety/Depression, Somatic Complaints, and Sleep Problems with no differences between groups in Emotional Reactivity. They concluded that, in their sample, children with language difficulties exhibited more difficulties in Social Withdrawal Problems. The authors speculated that language difficulties may lead to externalizing behavior problems later in development or among children with more severe behavior problems as mentioned above. Indeed, McCabe (2005) and Damico and Nelson (2005) speculated that withdrawal behavior may be a behavioral accommodation rather than a behavioral deviance. Withdrawing from social situations may be adaptive. For example, when the child withdraws in a classroom situation, the teacher may not call on him/her.

Kevan (2003) pointed out that much of the research concerning language and behavioral functioning focuses upon expressive language and lamented the lack of research exploring the relationship between receptive language and behavior problems. Specifically, the field of language impairment lacks studies examining the separate contributions of receptive and expressive language difficulties to problem behavior. Indeed, Damico and Nelson (2005) agreed with Kevan because receptive language is essential to making sense of one's world. Without receptive language, environmental stimuli, especially social stimuli, would have little or no meaning to the child and therefore, could make the world a confusing and overwhelming place.

Kevan (2003) also noted that receptive language is inherent in task difficulty. That is, no matter how easy a task is, if you do not understand what to do, it will be difficult to perform. Thus, a child's difficulty with receptive language in understanding a task could explain the externalizing behavior involved in tantruming to escape a difficult task rather than verbally expressing the need to escape the task altogether. McCabe (2005) pointed out that receptive language could contribute to withdrawal/internalizing behavior because when a child fails to understand the verbal cues of a peer, she could withdraw from social interaction altogether.

Even though studies show that language and behavioral problems are highly correlated, Damico and Nelson (2005), Lindsay et al. (2007), and McCabe (2005) were quick to point out that correlation does not necessarily mean causation. They all suggested that there may be other contextual and within-child factors that bring about this association. Within-child factors would be especially salient in the population of children with ASD. As there is even less known about the relationships between language and behavioral functioning within the population of children with Autism than there is about other populations of children, this dissertation study compared the separate levels of formal and pragmatic language to the externalizing and internalizing behaviors in a sample of children with ASD. A more complete understanding of these relationships may shed light on the understanding of these four factors (i.e., formal language, pragmatic language, externalizing behavior, and internalizing behavior) in relation to primary caregiver stress and the family environment.

Parental Stress and Family Functioning

In her review of the social action research, Webster-Stratton (1990) speculated that researchers have avoided defining stress, because it is so complex, and so difficult to measure. She cited the conclusion of the steering Committee for Research on Stress and Health and Disease: "after 30 years no one had formulated a definition of stress that has satisfied even a majority of stress researchers" (p. 302). She went on to indicate that stress often goes undefined in the literature and the approach that authors have often taken to specify stress is "I know it when I see it" (p. 302).

Crnic and Greenberg (1990) documented "daily hassles" as the "irritating, frustrating, annoying, and distressing demands that to some degree characterize everyday transactions with the environment" (p. 1629). In parenting terms, daily hassles are the challenging childrearing and care-giving demands such as being nagged or whined at, cleaning messes, or settling arguments. Daily hassles contrast with major life stresses such as poverty or a major child illness. In their study, Crnic and Greenberg used 74 mother-child pairs. At the time of the study, the children were typically developing 5 year olds. The authors video-recorded interactions of each mother-child dyad during free play and when involved in a task requiring joint problem solving. Mothers also completed the following questionnaires: Parenting Daily Hassles (PHD; Crnic et al., 1983), Satisfaction with Parenting Scale (SWPS; Crnic et al., 1983), General Life Satisfaction (GLS; Crnic et al., 1983), Life Experiences Survey (LES; Sarason et al., 1978), Family Environment Scale (FES; Moos & Moos, 1989), Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983), and Brief Symptom Index (BSI; Derogates & Spencer, 1982).

Crnic and Greenberg (1990) coded mother-child interactions from videotape. They made global 5-point ratings of the quality of mothers' and children's behavior along seven dimensions: gratification, affect, sensitivity, control, involvement, activity, and behavioral organization. Results found that although life stresses and daily hassles significantly predicted behavioral aspects of the child, hassles proved to be a more powerful source of maternal stress than life stresses. Their findings indicated that parenting hassles are related to less satisfaction in parenting and lowered functional family status. Crnic and Greenberg (1990) suggested that these relationships are both circular and dynamic. Thus, less satisfied parenting leads to negative parenting that leads to negative child behavior. This, in turn, may lead to more hassles. Crnic and Greenberg

(1990) stated that to fully understand parental stress, investigators must consider more factors inside as well as outside the family.

As readers can conclude from the last sentence, parental stress and family functioning are often interdependent. The systems approach in research encourages the exploration of various factors of family life that include the investigation of each member's role as well as the family's functioning as a whole (Hastings, 2003; Hastings et al., 2005; Patterson & Fleishman, 1979; Seligman & Darling, 1997). Indeed, when researching parental stress and family functioning for this study, the author of this dissertation found that most of the studies included both parental stress and family functioning measures. And so, too, did this dissertation study.

What follows is a review of the literature examining stress levels of parents (generally mothers) of children with disabilities including children with Autism, followed by a review of the literature on family functioning in these families. As parental stress and family functioning are often included in the same study, the latter section cites many of the studies covered in the earlier section, but for clarity's sake, the latter section focuses exclusively on the results concerning the functioning of families with a child with Autism.

Parental stress and child disability. Studies point to specific stressors of parenting a child with disabilities. Clayton, Glidden, and Kiphart (1993) showed that there are multiple influences of a child's level of functioning and parental life satisfaction that create difficulties in interpreting the data reflecting stresses of a parent of a child with a disability. For example, Clayton et al. (1993) cited that a parent can obtain a high stress score simply because the child's disability places high demands on the parents and family rather than because the demands of the child's disability negatively impact family functioning. The authors also pointed out that parent stress measurements can confound the high number of disability demands with the negative impact of disability demands.

In a longitudinal study, Dyson (1993) compared parental stress and family functioning in families with and without children with disabilities. Participants included 38 families with a child with a disability and 36 families with a child without a disability. Dyson matched the groups by age range, family SES, and parental marital status. All parents completed the following questionnaires throughout their children's infancy to preschool years: Questionnaire on Resources-Short Form (Friedrich, Greenberg, & Crnic, 1983) and the Family Environment Scale (Moos & Moos, 1981). Dyson found that parents and families of children with disabilities exhibited significantly higher parental stress throughout the four years of the study.

Richdale, Francis, Gavidia-Payne, and Cotton (2000) suggested that investigators should consider what it is about a particular disability that makes it more or less stressful to parents. Participants in their study were 52 children, ages 2-19 years, with an intellectual disability and their families including: 9 children diagnosed with Down Syndrome, 7 diagnosed with Autism, 13 diagnosed with Fragile X Syndrome, and 11 diagnosed with other disorders. The sample also included 25 children, aged 2-17 years, who were typically developing and their families. Parents (in most all cases, mothers) completed the following questionnaires: demographic information, Sleep Problems Questionnaire (Richdale, Cotton, & Hibbit, 1999), Epworth Sleepiness Scale (Johns, 1991), Apnea and Narcolepsy Scales (Douglas, Bronstein, Nino-Murcia, Keenan et al., 1994), Development Behavior Checklist (Einfeld & Tonge, 1994), and the Parenting Hassles Scale (Stoneman & Gavidia-Payne, 1994).

Richdale et al. (2000) found a significant association between the presence of sleep problems and both the intensity and frequency of daily hassles (i.e., settling arguments) as well as the presence of child behavior problems (i.e., disruptive behaviors). Although this study focused on sleep problems and their relationship to parental stress, the authors pointed out that the results have implications for the development of specific supports for parents of children with disabilities. However, they could not point out whether these supports should be for direct support for the specific symptoms or psychological support for the stress associated with the symptoms.

In her review of the literature concerning the stress of parenting a child with AD/HD, Mariellen Fischer (1990) summarized several lines of research. She found that studies showed that parents of children with AD/HD reported more stress than parents of children without AD/HD. Studies also showed that parental discord was associated with having children with AD/HD. More importantly, research regarding parent-child interaction suggested a child-to-adult direction of effect more than the reverse. In other words, research suggests that child factors (i.e., the child's pathology) seem to be the source of parental stress rather than parental factors (i.e., parental pathology) (Fisher, 1990).

In sum, it appears that the child's disability can be a source of stress to parents. Richdale et al. (2000) were not sure if support for parents with a child with a disability should be a direct support for the child's specific symptoms or psychological support for the stress associated with the symptoms. It follows that by fully investigating a specific disability and the relationship between its symptoms and the parental stress associated with the disability, one could identify parent support needs that are specific to that disability. In turn, parent interventions geared to those specific needs would be more effective in reducing parental stress.

Parental stress associated with Autism relative to stress associated with other disabilities. In general, studies show that parenting a child with Autism is more stressful than parenting a child with Down Syndrome (Hoppes & Harris, 1990; Rodrigue, Morgan, & Geffen, 1990). However, the studies did not specify which subtypes of Autism their participants had nor did they assess participants' intellectual functioning. Nonetheless, the studies' results provided important information.

Rodrigue et al. (1990) found disorder-specific impacts upon 20 families with children with Downs Syndrome and 20 families of children with Autism who were matched with 20 families of typically developing children on the Vineland Adaptive Behavior Scale (Sparrow et al., 1984). Rodrigue et al. (1990) made and videotaped a home visit to each family that lasted 2 to 2 1/2 hours where the children and their mothers engaged in interactive play. The authors rated the videotapes for verbal interaction, nature of verbal interaction, parent's mood, degree of interaction, and parent responsiveness. In addition, parents completed the Parenting Sense of Competence Scale (Gibaud-Wallston & Wandersman, 1978), the Ways of Coping Scale (Lazarus & Folkman, 1984), the Marital Adjustment Scale (Locke & Wallace, 1959), the Family Adaptability and Cohesion Evaluation Scales III (Olson, Portner, & Lavee, 1985), and the Impact on Family Scale (Stein & Jessop, 1985).

Mothers of children with Autism reported less parenting competence, less marital satisfaction, more family cohesion, and less family adaptation than mothers of children in the other two groups (Rodrigue et al., 1990). Mothers of both groups of children with disabilities reported more disrupted planning, caretaker burden, family burden, and frequent use of self-blame than mothers of typically developing children.

Hoppes and Harris (1990) compared maternal perceptions of child attachment and maternal gratification in mothers of 21 children with Autism and 17 children with Down Syndrome. The children were between the ages of 4 and 10 years. Hoppes and Harris (1990) took a brief developmental history. Also, they conducted an open-ended interview that focused on the mother's adaptation to her child's disability, her perceptions of the child's attachment to her, and her experience of gratification in her relationship with the child. The authors also administered the Parent Report of Child Behavior Inventory (Schafer & Finkelstein, 1975) and the Maternal Gratification Scale, which was derived from "Child Reinforces Mother" subscale of the Parenting Stress Index (Abidin, 1979). This study found a significant correlation between perceived attachment and gratification for mothers from both groups. Mothers of children with Autism, however, reported significantly lower perceived attachment with and gratification from their children than did the mothers of children with Down Syndrome. Open-ended interview data suggested that the child with Autism's lack of interpersonal responsiveness was a source of maternal stress.

Donnenberg and Baker (1993) compared the stress levels of parents of 22 children with externalizing behaviors, 20 children with Autism, and 22 children with no behavior problems as diagnosed using parental responses to the Child Behavior Checklist (CBCL;

Achenbach & Edelbrock, 1983) who were between the ages of 3 1/2 to 6 years. The authors matched the groups on several variables including parental age, child age, race, birth order, SES, and CBCL internalizing/externalizing scores. Donnenberg and Baker (1993) also interviewed teachers of the children with Autism. The primary caretaker (in all cases but two, it was the mother) filled out a demographic questionnaire, the Family Impact Questionnaire (Donnenberg & Baker, 1993), the Parenting Events Questionnaire (Crnic & Greenberg, 1990), the Parenting Stress Index (Abidin, 1990), the Parenting Sense of Competence Scale (Gibaud-Wallston & Wandersman, 1978), the Beck Depression Inventory (Beck, Ward, Mock, & Erbaugh, 1961), and the Didactic Adjustment Scale (Spanier, 1976).

Donnenberg and Baker (1993) found that parents of children with externalizing behavior problems (i.e., hyperactive/aggressive) reported greater negative impact of children's symptoms and less positive feelings toward parenting than did parents of typically developing children. Parents of children with Autism reported comparable levels of stress and its impact to parents of children with externalizing behavior problems. The three groups of parents did not differ on broader measures of parental and marital well-being. These findings suggested that various disabilities may affect parents in a similar way. The children with Autism in this study were within the Mentally Retarded range of intelligence. Results of this study may have differed if Donnenberg and Baker (1993) had employed participants who were diagnosed with high functioning Autism or Asperger's Syndrome.

Parental stress and Autism. Most studies of parental stress associated with having a child with Autism have not had a comparison group of parents of children with another type of disability. Instead, these studies focused on parental stress associated with their children's symptoms of Autism. Bebko, Konstantareas, and Springer (1987) assessed the impact of various individual symptoms of 40 children with Autism on mothers' and fathers' self-reported stress and professionals' accuracy in estimating parents' perceived stress levels. Both parents moved into their children's summer program residence for the final three days of the program to join in the treatment and assessment process.

The children's primary caseworker/therapist who had generally worked with the family during the preceding 3 to 12 months also participated. Parents and caseworkers filled out a 14-item questionnaire adapted from the Childhood Autism Rating Scale (CARS; Schopler, Reichler, DeVellis, & Daly, 1980) that asks for ratings of the degrees of severity of the autistic symptoms of their child. They also made another rating for how stressful they found each symptom on a 4-point scale. All raters, both clinicians and parents, judged the children with Autism's language and cognitive impairment as the most severe and stressful symptoms. Both parents agreed on both symptom severity and degrees of stress. Parents of older children judged symptom severity to be lower than did parents of younger children. Professionals judged parents as more stressed than the parents judged themselves. Readers should note that the children with Autism were not classified into subtypes. The CARS (Schopler et al., 1980) was developed prior to the DSM-IV-TR (American Psychiatric Association, 2000) and so was intended for use in measuring more severe forms of Autism.

Koegel et al. (1992) studied stress profiles across mothers of children with Autism who ranged in age (from 3.1 years to 23.1 years) and intellectual functioning (from severely retarded and untestable to near normal on standardized tests) who were from various parts of the United States (California area; Appalachian area) and from Munich, Germany. Koegel et al. (1992) grouped functioning levels as High IQ (above 50) and Low IQ (below 50). Each mother filled out the Questionnaire on Resources and Stress (Holroyd, 1987). Data showed that the stress profiles of mothers of children from the High- and Low-IQ subpopulations of Autism were all very similar, and all were consistently different from the norms provided by the questionnaire. Results suggested that there is a common stress profile for mothers of children with Autism. Major differences between the mothers of a child with Autism and the mothers of normative families were on the dimensions of dependency and management, cognitive impairment, limits of family opportunity, and life span care. The authors suggested that these results show the importance of developing treatment programs aimed at reducing stress specific to parents of children with Autism.

Several studies have found differences in the stress levels between mothers and fathers of children with Autism. For example, Moes, Koegel, Schreibman, and Loos (1992) ran a study to compare stress levels of 18 mothers and 12 fathers of children with Autism who ranged in age from 3 to 14 years with a mean age of 6 years. The parents filled out the Questionnaire on Resources and Stress-Revised (Holroyd, 1974), the Coping Health Inventory for Parents-Form D (McCubbin, McCubbin, & Cauble, 1979), and the Beck Depression Inventory (Beck et al., 1961). Mothers showed significantly more stress (i.e., had higher scores) than fathers on each inventory**.** This response pattern suggested that stress may be related to the differing responsibility assigned to child-rearing for each parent.

Additionally, Herring et al. (2006) compared maternal and paternal stress levels in parents of 123 children, ages 20-51 months assigned to a PDD-NOS group or non-PDD-NOS group based on their diagnoses. Parent pairs completed a checklist on child behavioral and emotional problems, family functioning, their own mental health, and the stress they experienced in relation to parenting their child. Interestingly, Herring et al. (2006) found that child emotional and behavioral problems contributed significantly more to mother stress, parent mental health problems, and perceived family dysfunction than did child diagnosis, developmental delay, or child gender. Compared with mothers, all fathers reported significantly less stress in relation to parenting their child.

There is further research suggesting that mothers' stress levels are influenced by different family factors than fathers' stress levels. Hastings (2003) explored how mothers experience stress differently from fathers. Participants were 18 couples who were biological parents of children with Autism, ages ranging from 8-17 years. Parents filled out the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) to measure mental health and the Parent and Family Problems subscale of the Questionnaire on Resources and Stress (Fredreich et al., 1983) to measure parental stress. The children's teachers completed the Teacher Report version of the Development Behavior Checklist (Einfeld & Tonge, 1995). Results found that mothers and fathers did not differ in their levels of stress and depression, but mothers reported more anxiety. In contrast to fathers, mothers' stress levels were associated with child behavior problems and fathers' mental health, but these relationships were not obtained for fathers.

Hastings et al. (2005) followed up on these results in a similar study with preschoolers using 48 parents of children with Autism, ages ranging from 28-45 months.

Hastings et al. (2005) used the same measures as did the previous study except for one additional measure: the Kansas Inventory of Parental Perceptions Positive Contributions Scale (Behr, Murphy, & Summers, 1992). They found that their children's behavior problems and their husbands' depression predicted maternal stress. Interestingly, mothers reported more depression but more positive perceptions about their children and the children's impact on themselves and family members than did fathers.

Although a systems approach to research on families of children with disabilities encourages the study of family members other than mothers (Hastings, 2003; Hastings et al., 2005; Patterson & Fleishman, 1979; Seligman & Darling, 1997), results from the above research point out that mothers are both more positively and more negatively affected by their children with Autism than are fathers. This may be because mothers are usually the primary caregivers. Because of this, mothers' ratings seemed to have a wider range and so this dissertation study focused on primary caregiver/maternal stress. These results may contribute to the development of more effective programs for primary caregivers of children with Autism by indicating the unique needs and perspectives of primary caregivers with children with Autism.

Family functioning relative to having a child with a disability. Several studies have compared the family functioning of children with and without disabilities. Margalit, Ravin, and Antonia (1992) investigated coping, sense of coherence, and family climate among 78 families of children with disabilities and 83 families of typically developing children in the Tel Aviv area. The 78 children with disabilities consisted of the following: 40 were learning disabled, 26 were mentally retarded, and 12 children had emotional disturbances/behavioral problems. The children in the disabled and control groups did not differ significantly in terms of age, education level, or number of siblings. Students from the Special Education Department of Tel Aviv University administered the following questionnaires to the mothers and fathers in their homes: Coping Scale (Moos et al., 1987), Family Environment Scale (Moos & Moos, 1983), Child Behavior Checklist (Achenbach & Edelbrock, 1983), and Sense of Coherence Scale (Antonovsky, 1987). Results found that parents of children with disabilities reported a lower sense of family coherence and increased use of avoidant coping relative to parents of typically developing children. Within the families of disabled children, there was less emphasis on family relations and fewer opportunities for personal growth than reported by families of typically developing children.

Dyson (1993) examined family functioning in families with and without children with disabilities in a longitudinal study of 38 families with a child with a disability and 36 families with a child without a disability. Dyson matched the groups by children's age range, family SES, and parental marital status. Throughout their children's infancy to preschool years, all families completed the Questionnaire on Resources-Short Form (Friedrich, Greenberg, & Crnic, 1983) and the Family Environment Scale (Moos & Moos, 1981). Dyson found that the children's disabilities did not necessarily result in deviant family functioning.

These studies included children with several disabilities, which may not relate to family functioning in the same manner. Studies comparing family functioning in families of children with Autism with the functioning of families of typically developing children or families of children with other disabilities provide information on how Autism impacts families.

Autism and family functioning. Hutton and Caron (2005) qualitatively explored how a diagnosis of Autism in a child alters life for a family, through one-hour phone interviews with 21 parents of children with Autism. They structured the interview around three areas of interest: four questions on recognition and diagnosis, five questions on the services that the family used, and six questions on how the family coped with having a child with Autism.

Their results (Hutton & Caron, 2005) showed that parental reactions to the diagnosis included relief, shock, grief, and self-blame. The most common services that the child with Autism needed (in descending order) were: speech therapy, occupational therapy, in-home behavior specialist support, developmental therapy, applied behavioral analysis, physical therapy, respite, and one-to-one classroom support. In terms of family coping, the families used the adjective "stressful" more than other adjectives to describe what it had been like to be a parent of a child with Autism. The families often cited that there was little or no time for fun and/or family vacations; they also reported the need to plan ahead for any activities.

Previously, this literature review cited other studies concerning family functioning. These studies also addressed issues other than family functioning, such as parental stress and intervention effectiveness. One conclusion of the study by Clayton et al. (1993) (reviewed earlier in this document) was that family problems are at least partially influenced by the child with Autism's level of functioning rather than by parental life satisfaction. Also cited previously, Bristol (1984) and Garfin and Lord (1986) concluded that the severity of communicative impairment in the child with Autism may be one of the greatest sources of family stress.

Parents involvement in the education of their child with Autism. With the evolution of the understanding of Autism Spectrum Disorders came the parallel phenomenon of the evolution of the education of children with Autism. Originally, the answer to educating children with Autism was to institutionalize them (Claribrone-Park, 2005; Grandin & Scariano, 1996). However, the past 2 decades have led to an explosion of literature regarding the treatment of Autism (National Research Council, 2000). Presently, education of individuals with Autism has its own spectrum in terms of integration with the general population. Treatments range from home-based programs to center-based programs where the individuals are in segregated environments to settings in which the child with Autism is taught with typically-developing children (Handleman & Harris, 2001; National Research Council, 2000). However, research in this area has not identified any approach that is universally effective (National Research Council, 2000; Olley, 1999). Perhaps the reason that authors have yet to identify a universally effective treatment approach is because there is none. This may be due to the heterogeneity of child functioning within the Autism Spectrum, and thus, there may be several different effective therapies relative to the symptoms displayed by individuals with Autism. For example, Belinger and Smith (2005) found that an intensive behavioral in-home treatment was less effective for children classified as "aloof" by the Wing (1981) subtypes than those classified as either "passive" or "active-but-odd" as per Wing (1981).

Along with the expansion of treatment options and education for children with Autism came approaches emphasizing the inclusion of the parents in the therapeutic treatment. Hastings and Johnson (2001) explored the predictors of stress in parents of children with Autism who were in a home-base programs using Applied Behavioral

Analysis. This approach organizes subskills that are required for specific tasks and teaches them by reinforcing closer approximations until the child fully acquires the skill (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993). Another approach was studied by Williams and Wishart (2003) who explored the effects on the family as a whole when parents implemented the Son Rise Program. This approach requires that a room in the house be specifically designed to reduce distractions. Both of these independent studies came to the same conclusion that positive family outcome is more likely when the family perceives the intervention is running well (Hastings & Johnson, 2001; Williams & Wishart, 2003). From these results, it appears that parent/family perceptions of the treatment is key to reducing stress whether the treatment is a behavioral intervention or a family systems approach.

Blackledge and Hayes (2006) took this conclusion one step further. They pointed out that these recent studies focused on the needs of the child and ignored the psychological needs of the parents. Although a child focus may lead to some reduced parental stress due to improved child functioning, studies measuring the reduction of parental stress were methodologically weak. Indeed, McConachie and Diggle (2007) concurred. In reviewing the literature, they found few studies that involved a concurrent element of experimental control. Of those that did, there were no significant findings using a well-validated measure of stress such as the Parenting Stress Index (Abidin, 1979).

In order to explore the possibility that focusing on the parents' needs, rather than those of the child with Autism, would provide greater reductions in parental stress, Blackledge and Hayes (2006) designed a study using the Acceptance and Commitment

Training (ACT) technique to reduce stress in 20 (15 female and 5 male) parents of children with Autism. ACT training focuses on parental distress and is used to treat a variety of specific psychological problems and anxiety, not just for parents of children with Autism but for parents of children with other disabilities as well. Blackledge and Hayes (2006) found no significant differences for clients during a waiting period before treatment, but found pre- and post-treatment improvements on the Beck Depression Inventory II (BDI II; Beck et al., 1996) and the Global Severity Index of the Brief Symptoms Index (GSI: Derogatis & Melsaratos, 1983). This study had its drawbacks as well. The authors reported that several parents dropped out of the study when they discovered ACT was not specifically geared for use with parents of children with Autism. This seems to support the conclusion of Hastings and Johnson (2001) and Williams and Wishart (2003) that parent perception of a treatment for Autism can affect levels of parent/family stress.

From the above discussion, the reader can concur with McConahie and Diggle (2007) that there is a need for improved research in the area of stress reduction in parents of children with Autism. The literature has explored the effectiveness of programs that focus exclusively on the child's needs and of programs that focus exclusively on the parents' needs with the same equivocal results. Yet, there may be another approach to this conundrum.

Because Fisher (1990) found a child-to-adult direction in parental stress (i.e., the child's behavior causes parental stress), what seems to be missing in research concerning stress in parents or families of children with Autism is the clarification of the relationship between the symptoms of Autism and parental stress and family functioning. Indeed, in the sleep study, cited earlier in this review, Richdale et al. (2000) suggested that investigators should consider what it is about a specific disability that makes it more or less stressful for parents.

This dissertation study attempted to measure the relationship between language and behavioral symptoms of children on the Autistic Spectrum and primary caregiver stress and primary caregivers' assessment of family functioning. Thus by identifying different symptoms' relationships (e.g., pragmatic language functioning, externalizing behavior versus internalizing behavior) with primary caregiver stress or with family functioning, interventions could be tailored to target specific primary caregiver/family needs.

Rationale

With the increase in rates of Autism in the general population, there is a concomitant burgeoning of research in the area (Klin, Volkmar & Sparrow, 2000). Initially, studies compared children with Autism to other populations in terms of intellectual, language, and emotional/behavioral functioning (Lecavalier, 2006; Pearson et al., 2006; Tager-Flusberg, 2004). These studies provided evidence that Autism displays heterogeneity of symptoms and functioning levels. Tager-Flusberg (2004) pointed out that this heterogeneity of language functioning is one of many methodological problems that interferes with the study of language functioning in children with Autism and suggested a within-group design to cover the complex language functioning across the spectrum. Similarly, Lecavalier (2006) pointed out that the wide range of emotional/behavioral functioning in this population is also a barrier to the study of Autism. He suggested using cluster analysis in order to decrease within-group differences and increase between-group differences. With these concepts in mind, this study examined children with ASD with diverse language skills (non verbal, pre verbal, phrase speech, and verbal) and broad emotional/behavioral difficulties (externalizing and internalizing) in order to study the association of these symptoms with primary caregiver stress and primary caregiver assessment of family functioning. The study also examined the association of primary caregiver ratings of children's behavior with similar ratings by teachers to determine the relationship of behavioral concerns in school to those at home.

Venter et al. (1992) found that parental description of language deviance is one of the factors that can serve as an independent predictor of social-adaptive and academic attainment outcomes of children with Autism. Sukholdost, Seahill, and Gadow et al. (2008) suggested that parent ratings could be a useful source of information about anxiety problems in the population of children with ASD. Indeed, many researchers use parent/family ratings to measure social/psychiatric functioning of their children. Ten studies cited in this literature review (i.e., Bradley & Isaac, 2006; Donnenberry & Baker, 1993; Gadow et al., 2004; Holtman et al., 2007; Kim et al., 2000; Lefeyer et al, 2006; Reisersen et al, 2007; Stanton-Chapman et al., 2007; Tonge et al., 1999; Venter et al., 1992) used parent/family ratings as an indication of the functioning of their child with Autism to measure outcomes other than parent/family stress.

The reader may have noted in this literature review on parental stress that most studies used mothers exclusively as participants or that mothers were often overrepresented in the participant pool. As mentioned earlier, Moes et al. (1992) studied parental stress in Autism. They found that mothers reported significantly more stress than fathers. Herring et al. (2006) found that child emotional and behavioral problems contributed more to maternal stress than to paternal stress. Hastings (2003) found that mothers of school-aged children with ASD reported more anxiety than fathers and that stress levels were associated with child behavior problems. When replicating this study with preschoolers on the autistic spectrum, not only did mothers report more depression than fathers, they also reported more positive perceptions about their child than fathers (Hastings et al., 2005). With this in mind, this dissertation used primary caregivers (who were almost exclusively mothers) of children on the autistic spectrum as participants.

Ironically, research concerning stress of parents of disabled children found that parental stress is disorder-specific. In her literature review of parents with children with ADHD, Fischer (1990) found a child-to-parent direction of effect in parental stress. Hastings (2003) also performed a literature review of studies of parents of children with various disabilities and also found a child-to-parent direction of effect in parental stress. What seems to be missing in research that investigates stress in primary caregivers of children with Autism is the investigation of the effect that particular symptoms of Autism (i.e., language and behavioral difficulties), as well as the functioning levels of these symptoms, have on primary caregiver stress and family functioning. This study endeavored to fill this gap.

Purpose

One purpose of this study was to describe the language levels of a sample of school aged children attending therapeutic schools specifically designed for children with Autism as reported by their primary caregivers. To assess these language levels, primary caregivers rated their child with Autism as non verbal, pre verbal, phrase speech or verbal. Those with a verbal child then completed the Children's Communication

Checklist-2 (Bishop, 2006) that measures formal and pragmatic language as communication. The study also described the emotional/behavioral functioning of these children by their primary caregivers in the home in terms of externalizing and internalizing behavior as measured by the Child Behavior Checklist (CBCL; Achenbach & Rescoria, 2001) as well as in the classroom as measured by the Child Behavior Checklist-Teacher Report Form (Achenbach & Rescoria, 2001). It also explored the possible relationships within and between these language and behavioral symptoms in a sample of children with Autism.

The study measured caregivers' stress using the Parental Stress Index (PSI; Abidin, 1995). The Revised Family Environment Scale (FES: Moos and Moos, 1989) measured family functioning.

In order to determine if a link exists between the child's language and behavioral functioning and primary caregiver stress and family functioning as reported by the primary caregivers, this study examined the relationships among the language and emotional/behavioral functioning measures and the primary caregivers' reported stress levels, and family functioning.

Hypotheses

When investigating the range of behaviors of children on the Autism Spectrum, Holtman et al. (2007) found that a group of children with PDD and high ADHD symptoms exhibited a significantly higher degree of externalizing and internalizing symptoms. Therefore this investigator hypothesized the following:

HO1: Externalizing and Internalizing scores on the Child Behavior Checklist (CBCL: Achenbach & Rescoria, 2001) will be significantly correlated.

Redmond and Rice (1998) estimate the co-occurance of language and behavioral difficulties to be between 50%-70%. Additionally, McCabe (2005) conducted a study which found that children with greater language difficulties had significantly more behavior problems and poorer social competence than those with articulation-only disorders and controls. In order to understand the effect of language and behavioral functioning of children with Autism relative to primary caregiver stress, it is important to understand the relationship of language and behavioral symptoms within the population with Autism.

> HO2: Primary caregiver language ratings and CCC-2 (Bishop, 2006) scores will correlate significantly and inversely with Externalizing and Internalizing CBCL scores (Achenbach & Resoria, 2001).

To this writer's knowledge, there is no research linking the children with Autism's language and behavioral functioning to their primary caregivers' stress. Since Fisher (1990) found a child-to-adult direction of effect on stress in parents of children with ADHD, it seems reasonable the symptoms demonstrated by children with Autism would also affect primary caregiver stress. Therefore the author presents the following hypothesis:

> HO3: Primary caregiver language ratings and primary caregiver rated CCC-2 (Bishop, 2006) scores will be inversely correlated with primary caregiver scores on the PSI-SF (Abidin, 1995)
>
> HO4: Externalizing and Internalizing scores on the CBCL (Achenbach & Rescoria, 2001) will be positively correlated with primary caregiver scores on the PSI-SF (Abidin, 1995).

HO5: Primary caregiver language ratings and primary caregiver rated CCC-2 (Bishop, 2006) scores will be positively correlated with primary caregiver scores on the FES (Moos & Moos, 1983).

HO6: Externalizing and Internalizing scores on the CBCL (Achenbach & Rescoria, 2001) will be inversely correlated with primary caregiver scores on the FES (Moos & Moos, 1983).

CHAPTER III

Method

This chapter explains the methodology used in this study that investigated caregiver-rated language and behavioral functioning in children with Autism and their relationship to caregiver stress, as well as family functioning. This chapter describes the participants and their selection and details the measures and data analysis.

Participants

Selection Procedure. I contacted mothers, or primary caregivers (who will be referred to as "caregivers" for the sake of economy), of children on the Autism Spectrum in two ways: through schools designed specifically for the children on the Spectrum, and through newsletters/blogs of parent support groups for children on the Autism Spectrum.

After receiving approval for this study from the Institutional Review Board of the City University of New York Graduate Center (see Appendix B), I contacted 71 principals and directors of programs specifically designed for children on the Autism Spectrum via email and apprised them of the purpose and goals of this study. I contacted them by sending them cover letter (see Appendix C) with an attached introductory letter (see Appendix D). Twenty-five principals (35% of those contacted) and directors agreed to have their programs participate and applied for approval of their schools' Institutional Review Boards. The principals/directors then generated their own cover letters to accompany the consent packet and apprised me of the number of caregivers from their schools whose children fell into the age range (see below) of this study. I then mailed the schools the number of consent packets via post. The schools then mailed the consent packages to caregivers from their sites in order to ensure confidentiality. The consent packets contained the school's cover letter, a letter of introduction (see Appendix E), instructions (see Appendix F,) a consent form (see Appendix G), a request of summary of results (see Appendix H), and a self-addressed stamped envelope for the mothers to return the consent forms.

The 25 participating programs require evaluations of their entering students in order to determine their diagnosis on the Autism Spectrum as well as to determine if their programs could meet the children's educational, emotional, and behavioral needs. Generally, the programs had a low student-to-teacher ratio, usually 6 to 12 students in a class with one teacher and at least one aide. The programs also provided additional services such as Speech, Occupational, and Physical Therapy as needed by the individual student. Most of the teachers in these programs hold Masters degrees and state licenses in their respective fields. I did not collect teacher demographic data.

In addition to the 25 programs, I contacted five support groups via email and four of these put a call for participants in their newsletters or blog (see Appendix I). Because of the newsletter postings, caregivers contacted me via email and I sent them each a consent packet containing the letter of introduction, consent letter, and a request for a summary of results as well as a self addressed stamped envelope for the caregivers to return the consent form.

When I received the signed consent forms, I sent questionnaire packages to the caregivers to complete. The packet also included a questionnaire for the child's teacher. All questionnaires were accompanied by a self addressed stamped envelope for easy return to me.

I sent out 399 consent packets to the therapeutic schools. Newsletters/blogs generated 22 requests for consent packets. A total of 421 consent packets were sent out to potential participants, and a total of 103 potential participants (24.74%) of those contacted) requested questionnaire packages that were sent out to consenting caregivers. The caregivers returned 85 of the 103 questionnaire packages (82.52% of those who requested packages) with questionnaires completed. Thus, 20.19% (85 out of 421) of caregivers solicited participated in the study. Of the 85 participating caregivers, 66 were recruited from the therapeutic schools and 19 were recruited from the newsletters/blogs. Seventy-one teachers returned completed questionnaires concerning the children's behavior in school, which yields an 83.5% return rate for this measure.

Child participants. The children involved in this study were required to be diagnosed on the Autism Spectrum (i.e., Autism, Asperger's Syndrome or PDD-NOS) by at least one of the following: medical doctor, neurologist, psychiatrist, or licensed psychologist. They were also were required to be between the ages of 6 to 12 years. I chose this age range for several reasons. This range covers the usual ages of elementary school children and therefore the participants were usually be located in the same building of the program and thus more accessible. Also, the 6-12 year age range is consistent with the age ranges covered by the measures used in this study. Last, and most important, this age range was chosen in light of child development. Bebko et al. (1987) found that parents of older children with Autism judged symptom severity of their children to be lower than that of younger children. Thus, the age range of 6 to 12 years allowed for the examination of symptoms of Autism at a period in development when they are prevalent as reported by parents. Additionally, one of the measures assessed caregiver stress. If the study included younger children, it was possible that some caregiver stresses that usually accompanies early childhood would be confounded with stresses that were in fact associated with Autism.

Seventy (82.4%) of the children in the study were male and 15 (17.6%) were female. This gender breakdown is similar to the national ratio for Autism (4 boys to 1 girl) cited in the DSM IV-TR (APA, 2000). The mean age of this sample was 111.67 months (9.3 years) (*SD* = 25.94 months, 2.16 years). Most of the children were diagnosed with Autism. Table 1 illustrates the breakdown of the children's diagnoses.

Table 1

Children's Autism Spectrum Diagnoses

Diagnosis	Frequency	Percent
Autism	53	62.4
Asperger's	8	9.4
PDD-NOS	24	28.2
Total	85	100

The mean age at diagnosis was 39.4 months (3.28 years). The range was 18 months (1.5 years) to 120 months (10 years) with a standard deviation of 18.26 months (1.52 years). The DSM IV-TR (APA, 2000) states

> By definition, the onset of Autistic Disorder is prior to age 3 years…Manifestations of the disorder in infancy are more subtle and difficult to define that those seen after 2 years. In a minority of cases, the child may be

reported to have developed normally for the first (or even 2 years) of life(p. 73). Thus, this sample is consistent with the DSM IV-TR (APA, 2000) age criterion.

Thirty-three (38.8%) of the children were diagnosed by more than one doctor. The data for this category were then entered for each diagnostician and so the percents do not add up to 100. Please see Table 2 for a breakdown of diagnostician.

Table 2

Diagnosticians for Sample Children

Diagnostician	Frequency	Percent
Medical Doctor	33	38.4
Neurologist	44	51.8
Psychiatrist	16	18.8
Psychologist	21	24.4
Other	6	7.0

According to caregivers, most children in this sample displayed consistent eye contact. This may be because in recent years, eye contact has been one of the goals of therapy. Thus, the category of limited eye contact usually means that the child can make eye contact upon demand. Please see Table 3 for the breakdown of the frequency of eye contact.

Table 3

Children's Eye Contact

Amount of Eye Contact	Frequency	Percent
Consistent Eye Contact	52	61.2
Limited Eye Contact	25	29.4
No Eye Contact	8	9.4
Total	85	100

Most of the children in this sample were reported to have no comorbidities. Please see Table 4 for the number of comorbidities.

Table 4

Number of Children's Comorbidities

Amount	Frequency	Percent
None	55	64.7
One	23	27.1
Two	3	3.5
More than two	4	4.7

ADHD was the most frequent comorbidity reported. Mentally Retarded was the next most frequent comorbidity. Please see Table 5 for a list of comorbidities and their percentages. Please remember that seven children had more than one comorbidity so that the percentages do not total 100. Comorbidities that were reported singly were color blindness, hydrocephalus, hypotonia, premature birth, immune deficiency, sensory processing disorder, and Tourette's Disorder.

Table 5

Description of Children's Comorbidities

Comorbidity	Frequency	Percent (Total)	Percent (of comorbid cases)
None	55		0
ADHD	10	27.1	33.3
Mentally Retarded	8	9.4	26.7
Anxiety Disorder	3	3.5	10.0
Cerebral Palsy	2	2.3	6.7
Epilepsy	2	2.3	6.7
Obsessive Compulsive Disorder	2	2.3	6.7
(Other)Those reported singly	7	8.2	23.3

Fifty-six (65.9%) children were reported to have no medical issues and 29 (34.1%) were reported to have medical issues. Physical problems consisted of orthopedic problems and cleft palate. Among the medical issues that needed medication were ADHD, mood disorder, allergies, seizures, and asthma.

Most (88.2%) of the children attended therapeutic schools. Please see Table 6 for the breakdown of type of educational program attended by the children.

Table 6

Educational Programs Attended by Children

Type	Frequency	Percent
General Education	9	10.6
Small Class in Gen Ed	1	1.8
Therapeutic School	75	88.2
Total	85	100

Within the classroom itself, the mean child:teacher ratio was 4.85 (*SD* = 3.6) to 1. The mean child:aide ratio was 4.68 (*SD* = 2.99) to 1. Please refer to Table 7 for a summary of additional educational services the children received. Please remember that some most children received more than one service so that the percents do not add up to 100.

Table 7

Children's Additional Educational Services

Type	Frequency	Percent
Resource Room	3	3.5
Speech/Language Therapy	76	89.4
ABA	33	38.8
Occupational Therapy	70	82.4
Physical Therapy	35	41.2
Counseling/Social Skills	18	21.7
Home Services	19	22.6

Forty-four caregivers were involved in direct services for their child. This usually means the caregiver would engage in extra practice with the child at home in order to generalize therapeutic gains to the natural environment. Of those 44 involved in their children's therapy, 25 (56.8%) reported that they werer involved in daily therapy; and 18 (40.9%) reported that they werer involved on a weekly basis. Twenty-nine (65.9%) were trained by the therapists to administer this therapy and 11 (25%) were supervised by the therapists. Of those being supervised, 4 (36.4%) were supervised on a daily basis and 5 (45.5%) were supervised on a weekly basis.

Primary Caregivers. Participants included 82 mothers, 2 fathers, and 1 grandmother, totaling 85 primary caregivers. Their mean age was 45.08 years (*SD* = 7.54 years). Most primary caregivers were married as shown in Table 8.

Table 8

Primary Caregivers' Marital Status

Status	Frequency	Percent
Married	62	72.9
Divorced	15	17.6
Single	3	3.5
Separated	2	2.4
Other	3	3.5
Total	85	100

In terms of employment, there was almost an even distribution between full-time, part-time, and unemployed primary caregivers.

Table 9

Primary Caregivers' Employment Status

Status	Frequency	Percent
Full-time	31	36.5
Part-time	24	28.2
Not employed	28	32.9
Student	2	2.4
Total	85	100

Most primary caregivers were employed as minor professionals (31.8%) with administrators being the second most common profession in this sample. Almost a third of the primary caregivers did not report their occupation. Please refer to Table 10 for a breakdown of employment status of caregivers.

Table 10

Primary Caregivers' Occupations

Occupation	Frequency	Percent
Menial Labor	1	1.2
Unskilled	4	4.7
Machine Operator	1	1.2
Small Business	1	1.2
Clerical/Sales	5	5.9
Semi-professional	3	3.5
Minor Professional	27	31.8
Administrator	11	12.9
High Executive	4	4.7
Student	2	2.4
No Response	26	30.6
Total	85	100

A high percentage of primary caregivers in this sample held an undergraduate degree (45.9%) with another quarter of the sample holding a graduate degree. One person did not report her educational status. Indeed, this sample of primary caregivers is quite educated. This may be because it requires some sophistication to navigate the health care and legal systems in order to place a disabled child into the appropriate therapeutic school.

Table 11

Primary Caregivers' Education

Level	Frequency	Percent
Less than 7th grade	1	1.2
Some High School	3	3.5
High School Graduate	3	3.5
Some College	17	20.0
Undergraduate Degree	39	45.9
Graduate Degree	21	24.7
No response	1	1.2
Total	85	100

Sixty-nine of the 85 primary caregivers (81.2%) were natives to the U.S. while 16 (18.8%) were born in other countries. Most were Caucasian (71.8%). Please refer to Table 12 for their ethnic breakdown.

Table 12

Primary Caregivers' Ethnicity

Ethnicity	Frequency	Percent
Caucasian	61	71.8
African American	4	4.7
Asian	8	9.4
Hispanic	7	8.2
Other	4	4.7
Not Reported	1	1.2
Total	85	100

Most of the primary caregivers came from the New York Metropolitan area. Please see Table 13 for a summary of the home locations of the primary caregivers.

Table 13

Primary Caregivers' Home Locations

State	Frequency	Percent
NY	41	48.2
NJ	13	15.3
IL	8	9.4
CA	5	5.9
CO	4	4.7
MA	3	3.5
AZ	1	1.2
IA	1	1.2
IN	1	1.2
ME	1	1.2
NC	1	1.2
NH	1	1.2
Not Reported	5	5.9
Total	85	100

Secondary Caregivers. Caregivers reported that 76 (89.4%) of the children had a secondary caregiver living in the household who was male; 9 (10.6%) did not have a secondary caregiver living with them. Mean age of the secondary caregivers was 43.69 years (*SD* = 8.59).

Of the 76 secondary caregivers reported, most were married. Please see Table 14 for secondary caregiver's marital status.

Table 14

Secondary Caregivers' Marital Status

Status	Frequency	Percent
Married	59	77.6
Divorced	10	13.2
Single	2	2.6
Separated	3	3.9
Other	2	2.6
Total	76	100

Most of the secondary caregivers were employed full-time. In terms of occupation, about a quarter of them were minor professionals, administrators, and high executives. Please see Tables 15 and 16 for employment status and summary of occupations respectively.

Table 15

Secondary Caregivers' Employment Status

Status	Frequency	Percent
Full-time	63	87.5
Part-time	3	4.2
Not Employed	6	8.3
No response	4	5.26
Total	76	100

Table 16

Secondary Caregivers' Occupation

Occupation	Frequency	Percent
Menial Labor	1	1.3
Unskilled	3	4.2
Machine Operator	6	8.3
Small Business	3	4.2
Clerical/Sales	1	1.4
Semi-Professional	1	1.4
Minor Professional	17	23.6
Administrator	16	22.2
High Executive	18	25.0
No Response	6	8.3
Total	76	100

About a third of the secondary caregivers held a graduate degree with a little more than a quarter holding an undergraduate degree. Table 17 gives the breakdown of the secondary caregivers' educational status.

Table 17

Secondary Caregivers' Education

Level	Frequency	Percent
Less than 7th grade	1	1.3
Some High School	3	3.9
High School Graduate	6	7.9
Some College	12	15.8
Undergraduate Degree	24	31.6
Graduate Degree	30	39.5
Total	76	100

The ethnicity of 7 secondary caregivers' was not reported. Fifty-five (79.7%) of the remaining 69 secondary caregivers were reported to be natives to the U.S. Fourteen (20.3%) were not born in the U.S. About half of the secondary caregivers were reported to be Caucasian, and the ethnicity of 11 of the secondary caregivers was not reported. Please see Table 18, which describes the ethnic breakdown of the secondary caregivers.

Table 18

Secondary Caregivers' Ethnicity

Ethnicity	Frequency	Percent
Caucasian	42	64.6
African American	3	4.6
Asian	6	9.2
Hispanic	8	12.3
Other	6	9.2
Not Reported	11	14.0
Total	76	100

Family. Because there are many factors that may influence parental stress, I asked the caregivers about their families as well. Most (66.7%) mothers reported that there were two adults living in the household. As the term "Adult" was defined as a person over the age of 18 years, the caregiver was included in this number. Table 19 describes the distribution of adults in the household.

Table 19

Number of Adults per Household (Including the Caregiver)

Number	Frequency	Percent
1	14	16.7
2	56	66.7
3	10	11.9
4	4	4.8

Most (51.8%) caregivers reported two children in the household. Table 20 describes the number of children per household. One of the children in this sample attended a residential school and was not counted as living in the household.

Table 20

Number of Children per Household

Number	Frequency	Percent
0	1	1.2
1	25	29.4
2	44	51.8
3	12	14.1
4	2	2.4
5	1	1.2

About one third of the children had either a brother or sister. Please refer to Table 21 for the sibling breakdown.

Table 21

Number of Siblings

	Brothers		Sisters	
Number	Frequency	Percent	Frequency	Percent
0	51	60.0	52	61.2
1	26	30.6	28	32.9
2	5	5.9	5	5.8
3	3	3.5	0	0

Nine (10.6%) children in the sample were reported to have one sibling with a disability and 4 (4.7%) were reported to have two siblings with a diagnosis. Please refer to Table 22 for number of siblings with disability and Table 23 for the list and frequency of reported siblings' disabilities. Some caregivers did not report this information and so the frequencies do not add to 100 percent.

Table 22

Number of Siblings with a Disability

Number	Frequency	Percent
NA-no sib	25	29.4
0	47	55.3
1	9	10.6
2	4	4.7
Total	85	100

Table 23

Diagnosis and Frequency of Sibling Disability

Diagnosis	Frequency	Percent
NA-no sib	27	32.1
None	42	50.0
Autism	7	8.1
Aspergers	3	3.6
PDD-NOS	1	1.2

Family Environment. Nineteen (26.0%) of the families qualified for free lunch. Seventy-nine (92.9%) caregivers reported contact with extended family not living at home. Twenty-eight (32.9%) caregivers reported extended family involvement for more than 25% of the child's daily life. Please see Table 24 for frequency of contact with extended family.

Table 24

Frequency of Contact with Extended Family

Time	Frequency	Percent
None	6	7.1
Daily	10	11.8
Weekly	18	21.2
Monthly	17	20.0
Holidays/Birthdays	20	23.5
Other	14	16.5
More than 25%	28	32

English was the only language spoken in 70 (82.4%) of the households. Please see Table 25 for a list and frequency of those who reported another language spoken in the home.

Table 25

Second Language Spoken in the Household

Language	Frequency	Percent
None	70	82.4
Chinese	3	3.5
Spanish	3	3.5
Russian	2	2.3
Albanian	2	2.3
Italian	1	1.2
Portuguese	1	1.2
Japanese	1	1.2
Not Reported	2	2.3
Total	85	100

Of the children exposed to a second language, most (14.3%) were exposed to it on a daily basis. Please refer to Table 26 for second language exposure time. No child was reported to be fluent in the second language, but 5 (6.0%) were reported to have receptive skills in the second language and 4 (4.8%) were reported to respond to the second language using one- to two-word phrases. Independent *t*-tests compared the CCC-2 (Bishop, 2006) measures (see below for description of measure) of the 43 verbal monolingual and bilingual children. There were no significant between-group differences. Please refer to Table 27 for the results of *t*-tests comparing the CCC-2 scores of the verbal monolingual and bilingual children.

Table 26

Second Language Exposure

Interval	Frequency	Percent
NA	70	82.4
Daily	12	14.1
Weekly	2	2.3
Not Reported	1	1.2
Total	85	100

Table 27

T-tests Comparing GCC scores of Monolingual and Bilingual Sample Children

GCC	*F*[a]	Sig[a].	*t*	*df*	Sig. (2-tailed)	Δ*M*	Std. Error Difference	CI
Equal variances assumed	.01	.91	-.42	42	.52	-5.65	8.80	-23.40-12.10
Equal variances not assumed			-.74	42	.48	-5.65	7.60	-23.35-12.05

Note. N = 43.

[a] Leven's Test for Equality of Variances.

Professional emotional support may also affect parental stress. Please see Table 28 for caregivers' rates of participation in organized support systems. Please bear in mind that some of the primary caregivers participated in more than one form of support.

Table 28

Participation in Organized Support Systems

Form of support	Frequency	Percent
Individual Therapy	16	18.6
Group Therapy	6	7.1
Support Group	14	16.5
Sibling Support Group	4	4.7

Instruments

Consenting caregivers completed the following questionnaires:

Demographic Questionnaire (Connolly, 2009) (Appendix J). This 5-page questionnaire was designed to obtain demographic information and information about other factors that may contribute to the caregiver's stress. Home information included information about both parents such as education, employment, siblings, other languages that may have been spoken in the home and the child's fluency of the second language. The mothers/primary caregivers were also asked about other support systems outside the home.

The Demographic Questionnaire (Connolly, 2009) also contains a section that gleans information about the child including age, gender, and eye contact. The caregiver rated the child's language level according to levels set by the Autism Diagnostic Observation Scale (Lord, Rutter, DiLavore, & Risi, 2001): (a) non-verbal, described as "*does not speak with words*", (b) pre-verbal, described as "*uses gestures/one word utterances*", (c) phrase speech, described as "*two to three word utterances*" and (d) verbal, described as "*at lease able to put words into simple sentences*". Information obtained about the child also included the specific diagnosis (i.e., Autism, Asperger's, and PDD-NOS) and which professional (i.e., medical doctor, neurologist, psychiatrist, or licensed psychologist) diagnosed the child, possible comorbid conditions, and medications. The questionnaire also asks for information pertaining to the child's school included child-to-teacher ratio and other possible Special Education services the child may have received.

Children's Communication Checklist - U.S. Edition (CCC-2; Bishop, 2006).The 43 caregivers with children who were verbal completed this because the CCC-2 (Bishop, 2006) measures the communication skills of verbal children only. The CCC-2 (Bishop, 2006) was developed in the United Kingdom, but also has American norms that this study used. The CCC-2 (Bishop, 2006) is a measure designed to assess children's communication skills in the areas of pragmatics, syntax, morphology, semantics, and speech. It has an age range of 4.0 to 16.11 years. A caregiver rates the frequency of the communication behavior described in each item. Ratings are from 0 = *less than once a week* to 3 = *several times a day.* The CCC-2 (Bishop, 2006) consists of 70 items that are divided into 10 scales: Speech, Syntax, Semantics, Coherence, Initiation, Scripted Language, Context, Non-verbal Communication, Social Relations, and Interests. Each scale consists of seven items: five items address difficulties in communication skills that the child may have and two items focus on the strengths the child may have in each area. The CCC-2 yields a norm-referenced overall score, the General Communication

Composite (GCC), formed by summing the scaled scores of the subtests. The GCC is an overall measure of communication skills and is a normalized standard scale that has a mean of 100 and a standard deviation of 15. The CCC-2 also has a consistency check. This score indicates that the scores derived from the caregiver are valid.

Another score from the CCC-2 (Bishop, 2006) that this study reports is the Social Interaction Difference Index (SIDI). This is a special index derived by subtracting the sum of the scaled scores of the Speech Syntax, Semantics, and Coherence subscales (aspects of formal language) from the sum of the scaled scores from the Initiation, Non-Verbal Communication, Social Relations, and Interests subscales (the aspects of social/pragmatic language). The SIDI was designed to be helpful in identifying children with a communication profile that might be characteristic of language impairment or ASD. SIDI scores ranging from -10 to +10 were typical, and obtained by about 90% of the normative sample. Scores outside this range are more common for clinical groups. SIDI scores of 11 or greater are more similar to scores obtained by children with a diagnosis of Specific Language Impairment (SLI). SIDI scores of -11 or less are more similar to scores obtained by children with the diagnosis of ASD.

The CCC-2 manual (Bishop, 2006) reported that data collection for standardization research on 950 children (100 children for each year in the age ranges from 4.0 to 13.11 years and 150 for each year in the 14.0 to 16.11 age range) occurred from January 2005 to May 2005. Based on data from the U.S. Census Bureau, *Current Population Survey* (October, 2002), the sample was stratified by age, race/ethnicity, geographic region, and parent education level (*parent* includes natural parent, guardian, or primary caregiver). Half the sample of children (n = 475) was female and half (n =

475) was male. Approximately 27% of the children in the sample were reported to receive special services. Of the general sample, 10% received Speech Language therapy, 4.5% received resource services for reading, 7% were in gifted and talented programs, 2.3% received Occupational and/or Physical therapy, 2% received counseling services, and 1% received other services.

The CCC-2 (Bishop, 2006) test-retest reliability was calculated by using the data collected on 98 children from the standardization study. The sample of 98 children was separated into 3 age groups (ages 4.00 to 6.11 years, 7.00 to 9.11 years, and 10.00 to 16.11 years) with each age group including 30 to 34 children. The sample included 52 males and 46 females. Test-retest reliability coefficients ranged from .86 to .96. In terms of internal consistency, alpha coefficients ranged from.71 to .83 in the 10 scaled scores. The reliabilities for the GCC ranged from .94 to .96 for the various age groups.

The validity data on the CCC-2 U.S. Edition (Bishop, 2006) were gathered from three clinical samples: children with Specific Language Impairment (SLI), children with Pragmatic Language Impairment (PLI), and children with ASD. All of the children were ages 4.00 to 16.11 years. A matched control sample was selected so that a child from the standardization sample was matched to each child in the clinical sample on age, sex, race/ethnicity, and parent education level. For a GCC level below 1 standard deviation, 70% of the children who had SLI were identified as such by the CCC-2, and 85% who did not have SLI were identified as such. Eighty-nine of the children with ASD were correctly identified, and 97% of children without ASD were correctly identified.

In 2004, Norbury, Baird, and Bishop conducted two validation studies of the CCC-2 British edition (Bishop, 2003). In the first study, the questionnaire was given to families of 87 children attending full-time special education in England for SLI, PLI, and ASD. In addition, the teachers of half the sample completed the CCC-2 forms for the same children providing evidence for interrater agreement. In the second study, the student sample was increased to include 24 children with similar diagnoses in Scotland and 27 more children referred for clinical evaluation at a neurodevelopment center. It was found that the CCC-2 distinguished children with communication impairments from non-impaired peers. This measure was also found to have an interrater agreement of .79. Please see Table 29 for the internal consistency (alpha coefficients) for the scales and GCC of the CCC-2 from this study. Alpha coefficients could not be calculated for the SIDI scores as they were not standard scores.

Table 29

Sample Reliabilities of CCC-2 Scores

Scale/Composite	N	Number of items	Alpha
Speech	43	7	.286
Syntax	43	7	.430
Semantics	43	7	.588
Coherence	43	7	.474
Initiation	43	7	.586
Scripted Language	43	7	.329
Context	43	7	.219
Nonverbal Communication	43	7	.352
Social Relations	43	7	.338
Interests	43	7	.408
GCC	43	70	.874

Achenbach System of Empirically Based Assessment Child Behavior Checklist-Caregiver Report Form (CBCL-CRF; Achenbach & Rescorla, 2001). Achenbach and Rescorla designed the CBCL-CRF to obtain information on children's academic performance, adaptive functioning and behavioral/attention problems as reported by the mother/caregiver. It is considered one of the premier measures of child psychopathology (Aschengrand, Angelosante, & Kindall, 2005; Biederman et al, 2001; Krol, DeBruyen, Coolen, & vanAarle, 2006). The mother/caregiver rates 113 behaviors as 0 = *not true of the child,* 1 = *somewhat/sometimes true,* and 2 = *very true of the child* based on the preceding two months. Scores are reported as *T*-scores (*M* = 50; *SD* = 10).

The behaviors are grouped into 6 Syndrome Scales that are then further grouped into Internalizing (Anxious/Depressed, Withdrawn/Depressed, and Somatic Complaints) and Externalizing Behaviors (Rule-Breaking Behavior and Aggressive Behavior) and a Total Score (composed of all of the above mentioned Syndrome Scales and the following Syndrome Scales: Social Problems, Thought Problems, Attention Problems, and Other Problems). The Externalizing scores are especially salient to this study as externalizing disorders are speculated to be another source of parental stress along with (lack of) language functioning (Donnenberg & Baker, 1993; Fisher, 1990; Garfin & Lord, 1986) for caregivers of children with autism. The CBCL (Achenbach & Rescorla, 2001) also has other subscales that aid in DSM IV diagnosis, but were not used in this dissertation study.

The manual (Achenbach & Rescorla, 2001) indicates that the CBCL scale derivations are composed of factor-analyzed responses of parents of 1,753 children from ethnically and SES diverse groups. This group fits a National Survey of Children, Youth, and Adults that investigators from Temple University conducted from February 1999 through January 2000. For the school aged version, reported test-retest reliabilities (8 day) were .92 for Externalizing Scale and .01 for the Internalizing scale and .94 for Total Problems. The school aged version reported that the percent of variance accounted for by referral status was .33 for the Externalizing scale, .26 for the Internalizing scale, and .36 for Total Problems.

There is consistent evidence that the CBCL (Achenbach, 1991) is effective in distinguishing between referred and non-referred populations (Achenbach, 1009; Chen, Faraone, Biderman, & Tsuang, 1994; Drotar, Stein, & Perrin, 1995). The CBCL is particularly useful in assessing overall levels of internalizing, externalizing, and total problems (Mcmann, Barnett, & Lopez, 1993). Indeed, it seems that these broad measurements may better capture the heterogeneity of the behavioral problems displayed by children with Autism than the individual subscales because children with Autism display a wide range of behavioral difficulties.

Biederman et al. (2001) evaluated the long-term stability of the CBCL (Achenbach & Rescorla, 2001) in a longitudinal clinical sample of youth with AD/HD. Participants were 105 Caucasian, non-Hispanic boys with AD/HD between the ages of 6 to 17 years at baseline. Mothers completed the CBCL at baseline and at a 4-year follow-up. There were no statistically significant relationships between these longitudinal measures of the Internalizing, Externalizing, and Total scores as well as the Syndrome Scale scores. The researchers concluded that the CBCL is a useful measurement of longitudinal development in clinical samples of youth with AD/HD.

Aschengrand, Angelosante, and Kendall (2005) investigated the utility of several scales of the CBCL (Achenbach & Rescorla, 2001) when diagnosing anxiety disorders in youth. Participants were the mothers and fathers of 130 children (ages 7 to 14 years; 69 boys and 61 girls) who were evaluated at a specialty health clinic. One hundred children were referred for treatment and 30 children were non-anxious volunteers. The parents completed the CBCL. Aschengrand et al. (2005) found that mothers' ratings on the CBCL served as a useful screening for the presence of broad-spectrum anxiety. They also found a significant correlation between ratings of Internalizing Problems and the diagnoses of Generalized Anxiety Disorder and Social Problems.

Duarte, Bordin, deOliveria, and Bird (2003) conducted a pilot study of the older version of the CBCL/4-18 (Achenbach, 1991). This study compared and contrasted three groups of Brazilian children: 36 children with Autism and related conditions, 31 with other psychiatric disorders and 34 controls matched by age and gender. The overall age range was 4 to 11 years. Most of the children in the three groups were males (83%, 74%, and 94% respectively). Trained interviewers administered the CBCL to the parents. Duarte et al. (2003) found that the CBCL (Achenbach, 1991) Externalizing and Internalizing scores were not useful for identifying children with Autism. In fact, the global scores of the CBCL (Achenbach, 1991) (i.e. Total, Externalizing. and Internalizing) were similar to controls. However, two groups of items showed good predictive properties for identifying children with Autism: Thought Problems and Autistic/Bizarre factors. They concluded that the CBCL/4-18 (Achenbach, 1991) could identify children with Autism in clinical and school settings in Brazil.

Sikora, Hall, Hartley, Gerrard-Morric, and Cagle (2008) followed this study up by comparing the present version of the CBCL (CBCL/6-18; Achenbach & Rescorla, 2001) that will be used in this dissertation, with the Gilliam Autism Rating Scale (GARS; Gilliam, 1995). The GARS (Gilliam, 1995) is a behavior checklist developed for use in individuals ages 3 - 22 years. The questionnaire consists of 56 items, each describing a different behavior often observed in individuals with Autism. Those filling out the questionnaire rate the frequency of the behavior on a 4-point scale (0 = *Never Observed* to 3 = *Frequently Observed*). Participants were caregivers of 109 children classified with Autism, 32 children classified with ASD, and 51 classified as Non-Spectrum as measured by the Autism Diagnostic Observation Scale-G (ADOS-G; Lord et al., 2000). Mothers completed both checklists. The researchers found that the GARS (Gilliam, 1995) did not distinguish children with ASDs from those without. The Withdrawn subscale scores of the CBCL (Achenbach & Rescorla, 2001), however, were higher among children with autism than children without ASD. Sikora et al. (2008) also found that the CBCL subscales had better sensitivity and specificity in identifying children with Autism than the GARS (Gilliam, 1995).

I must point out that the identification of the children on the Autism Spectrum was not the focus of this study. Indeed, the children in this study have already been diagnosed with ASD by a medical doctor or licensed psychologist. It is the *behavior* of the child with ASD that was studied and the relationship of the behavior to maternal stress. Because children with Autism display a wide variety of behavioral difficulties, the Externalizing and Internalizing scores were used in this dissertation. Indeed, after discussing Duarte et al.'s (2003) study, these scores are especially salient because they found that these scores did not identify children with Autism. Thus the Externalizing and Internalizing measure the participating child's behavior and not the symptoms of Autism. Please see Table 30 for internal consistency coefficients of this sample's CBCL-CRF scores.

Table 30

Sample Reliabilities of CBCL-CRF Scores

Scales	*N*	Number of Items	Alpha
Anxious/Depressed	82	13	.736
Withdrawn/Depressed	82	8	.565
Somatic Complaints	83	5	.623
Social Problems	81	11	.767
Thought Problems	81	15	.801
Attention Problems	81	10	.810
Rule Breaking Behavior	80	17	.599
Aggressive Behavior	83	18	.905
Other Problems	83	16	.664
Externalizing	85	2[a]	.770
Internalizing	85	3[b]	.648
Total	85	9[c]	.866

[a] Externalizing included Rule Breaking Behavior and Aggressive Behavior scales.

[b] Internalizing included Anxious/Depressed, Withdrawn Depressed and Somatic Complaints scales.

[c] Total included all scales.

Achenbach System of Empirically Based Assessment Child Behavior Checklist-Teacher Report form (CBCL-TRF; Achenbach & Rescorla, 2001). The caregiver participant gave this measure to the child's teacher to complete. The CBCL-TRF (Achenbach & Rescorla, 2001) is a complementary version of the CBCL-CRF (Achenbach & Rescorla, 2001). Similar to the CBCL-CRF (Achenbach & Rescorla, 2001), it is designed to use for children between the ages of 6-18 years to measure problem behaviors in the school setting. Similarly, the CBCL-TRF (Achenbach & Rescorla, 2001) contains 113 questions that are rated on a 3-point scale. Scores are reported as *T*-scores (*M* = 50; *SD* = 10). It yields the same 6 Syndrome Scales that are then further grouped into Externalizing behaviors (Rule-Breaking Behavior, and Aggressive Behavior) and Internalizing behaviors (Anxious/Depressed, Withdrawn/Depressed, and Somatic Complaints) and a Total Score (all of the above mentioned Syndrome scales and the following Syndrome scales: Social Problems, Attention Problems, and Other Problems).

The manual (Achenbach & Rescorla, 2001) indicates that the TRF scale derivations are composed of factor-analyzed responses of teachers of 4,437 children. It must be noted that the authors used the samples from their 1989 and 1999 National Survey Sample. For the TRF, the reported test-retest reliabilities (8 day) were .89 for Externalizing, .86 for Internalizing, and .95 for Total Problems. The TRF version reported that the percent of variance accounted for by referral status was 19 for Externalizing, 14 for Internalizing, and 26 for Total Problems.

Although these ratings may be good indicators of behavioral levels by themselves, much research has shown that those informing on the same child in different settings (i.e., parents *vs.* teachers) can be quite disparate. Achenbach, McConaughy, and Howell (1989) conducted a large meta analysis of 269 data samples that revealed an average correlation of .60 between ratings of child behavior by pairs of parents and an average correlation of .28 between teachers and parents.

Interestingly, Konold et al. (2004) examined whether the manner in which behavioral constructs are measured differs across informants, across time, and across child gender for the CBCL-CRF (Achenbach & Rescorla, 2001) and the CBCL-TRF (Achenbach & Rescorla, 2001). This study involved 700 children from prospective longitudinal database of the NICHD Study of Early Child Care and Youth Development. Behavior ratings were taken from both parents and teachers for the same typical developing child at 54 months and first grade. They found that the Internalizing/Externalizing structure of children's behavior problems withstood a multitude of stringent invariance tests. They also found that different informant raters of the children's behavior in the same setting were consistent over time and gender. They concluded that differences between parent and teacher ratings of behavior problems seem more likely to result from differences in situation-specific behavior of the child rather than from measurement error.

This finding is quite relevant to the population of children with ASD, especially to those in therapeutic schools that are set up to meet the individual needs of the child. Comparing the CBCL-CRF (Achenbach & Rescorla, 2001) caregivers' ratings and the CBCL-TRF's (Achenbach & Rescorla, 2001) ratings provides more insight to the children's functioning across settings as well as provide information as to the possible source of the caregivers' stress from the children's behavior. Please see Table 31 for this sample's reliabilities of the CBCL-TRF.

Table 31

Sample Reliabilities of the CBCL-TRF Scores

Scale	*N*	Number of Items	Alpha
Anxious/Depressed	68	16	.678
Withdrawn/Depressed	67	8	.738
Somatic Complaints	71	3	.237
Social Problems	64	11	.511
Thought Problems	65	10	.558
Attention Problems	63	26	.893
Rule Breaking Behavior	67	12	.341
Aggressive Behavior	65	20	.820
Other Problems	3	7	.333
Externalizing	71	2[a]	.719
Internalizing	71	3[b]	.551
Total	71	9[c]	.791

[a] Externalizing included Rule Breaking Behavior and Aggressive Behavior scales.

[b] Internalizing included Anxious/Depressed, Withdrawn/Depressed and Somatic Complaints scales.

[c] Total included all scales

The Parenting Stress Index-Short Form 3rd Edition (PSI-SF; Abidin, 1995). Abidin (1995) created the 36-item PSI-SF to sample a diverse range of stressful influences on parenting practices. The theoretical model of the determinants of dysfunctional parenting guided construction of the PSI (Abidin, 1995). This theory posits that the total stress a parent experiences is a function of certain salient child characteristics, parental characteristics, and situational characteristics that directly relate to the role of being a parent. The PSI-SF (Abidin, 1995) is a direct derivative of the PSI and was developed as a psychometrically sound, but brief, screening measure of parenting stress (Abidin, 1995).

The PSI-SF (Abidin, 1995) consists of 36 items that the caregiver answers in a Likert-type scale. The choices are as follows: SA - *strongly agree*, A - *agree*, NS - *not sure*, D – *disagree,* and SD - *strongly disagree*. The PSI-SF (Abidin, 1995) is comprised of 4 scores: Total Stress, Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. It also includes a scale for Defensive Responding that indicates the individual may be responding in a defensive manner and caution should be used in the interpretation of that protocol.

The Total Stress score is designed to provide an indication of the overall level of stress an individual is experiencing. It consists of all 36 items with a range of raw scores from 36 - 180. The Parental Distress subscale determines the distress a parent is experiencing in her role as a parent is a function of personal factors that are directly related to parenting. Parent - Child Dysfunction Interaction focuses on the mother's perception that the child does not meet her expectations to determine if these interactions are reinforcing to the mother as a parent. The Difficult Child subscale focuses on some of the basic behavioral characteristics of children that make them easy or difficult to manage. The three subscales have 12 items each and have a range of possible raw scores of 12 - 60. Raw scores can be transformed into percentiles for easy interpretation.

The gender ratio of the normed population of the PSI-SF (Abidin, 1995) was 54% male and 46% female. The ethnic composition of the normed population was 96% White, 3% African American, and 1% Other. In order to explore the applicability of the PSI-SF (Abidin, 1995) to other cultural populations, Reitman, Currier, and Stickle (2002) administered the PSI-SF (Abidin, 1995) to 196 parents of pre-school children. The mean age of the mothers was 27.15 years and the median family income was $7,242 per year. The ethnicity of the group was 85% African American and 15% Caucasian. These mothers completed the PSI-SF (Abidin, 1995), the Conners' Parent Rating scale-Revised: Long Form (CPRS-R:L, Conners, 1997), and the Brief Symptoms Inventory (BSI: Derogatis & Melisaratos, 1983). Reitman et al. (2002) found that the PSI-SF (Abidin, 1995) was highly internally consistent. The means were also comparable to those found in the manual. Regression analysis supported the construct validity of the PSI-SF (Abidin, 1995). The CPRS-R:L (Conners, 1997) Oppositional subscale accounted for the greatest variance in the PSI-SF (Abidin, 1995) Difficult Child subscale. BSI (Derogatis & Melisaratos, 1983) scores were associated with the Parent-Child Dysfunctional Interaction and Parental Distress subscales, Reitman et al.'s (2002) results appeared to support the use of the PSI-SF (Abidin, 1995) with lower socioeconomic, primarily African American mothers. Additionally, Reitman et al. (2002) found that the data provided indirect support for the generalizibility of the 3-factor model of parenting stress.

Abidin (1995) reported test-retest reliabilities for the PSI-SF as follows: Total Stress was .84; Parental Distress was .85; Parent-Child Dysfunctional Interaction was .68; and Difficult Child was .78. He also reported the following correlations between the PSI-SF and the longer version of the PSI (Abidin, 1995): Total Stress was .94; Parent Domain was .83; and Child Domain was .86. In terms of validity, the manual of the PSI (Abidin, 1995) cited 89 studies validating the use of the PSI in studying parenting of children with various disabilities, including developmental issues, behavior problems, disabilities (including Autism-see Donnenberg & Baker, 1993), and illness as well as in studies of at-risk families, parental characteristics, family transitions, and marital relations.

This dissertation used the Total Stress score as a gross measure of how language and behavior levels affect caregiver stress. Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child scores glean a more precise picture of the possible sources of stress of mothers of children with Autism. Studies cited in this paper that used the PSI (Abidin, 1995) in conjunction with the aforementioned CBCL (Achenbach & Rescorla, 2001) include Donnenberg and Baker (1993), Mash and Johnston (1983), and Webster-Stratton (1990). Please see Table 32 for this sample's reliability scores for the PSI-SF.

Table 32

Sample Reliabilities for the PSI-SF Scores

Scales	N	Number of Items	Alpha
Defensive Responding	82	7	.866
Parental Distress	80	12	.907
Parent/Child Dysfunction	78	12	.864
Difficult Child	78	12	.992
Total Stress	69	36	.951

The Family Environment Scale-Third Edition (FES; Moos & Moos, 2002). The FES (Moos & Moos, 2002) is one of the most widely used family environment measures in clinical and family research (Chipuer, 2002). The FES (Moos & Moos, 2002) has three forms. The Real Form (Form R) measures people's perceptions of their current family environment. The Ideal Form (Form I) measures people's preferences about what an ideal family is. The Expectation Form (Form E) measures people's expectations about family settings.

This study used Form R because it reflects the caregiver's perception of the current functioning of the family at the time of this study. The FES Form R reflects the parents' perception of their family climate. It is composed of 90 true-false items that comprise 10 subscales that have 9 items each. These are divided into 3 Dimensions. The Relationship Dimension is comprised of the Cohesion, Expressiveness, and Conflict subscales. The Cohesion subscale measures the degree of commitment, help, and support that family members provide for one another. The Expressiveness subscale measures the extent to which family members are encouraged to express their feelings directly. The Conflict subscale measures the amount of openly expressed anger and conflict among family members. The System Maintenance Dimension is comprised of the Organization and Control subscales The Organization subscale measures the degree of importance clear organization and structure in planning family activities and responsibilities. The Control subscale measures how much set rules and procedures are used to run family life. The Relationship and System Maintenance Dimensions reflect the internal functioning of the family.

In contrast, the third Dimension is Personal Growth. This Dimension taps into the linkages between the family and the broader social context outside the family, and for this reason, it will not be used in this study. However, the scales that make it up will be reported and used for analysis. This Dimension is comprised of the five following scales: The Independence subscale measures the extent to which family members are assertive and self-sufficient; the Achievement Orientation subscale measures how much activities are cast into an achievement orientation framework; the Intellectual-Cultural Orientation subscale measures the level of interest in political, intellectual, and cultural activities; the Active-Recreational Orientation subscale measures the amount of participation in social and recreational activities, and the Moral-Religious Emphasis scale measures the emphasis on ethical and religious issues and values.

There is no Total Score for the FES (Moos & Moos, 2002), nor are there scores for the three Dimensions. Thus, I used the subscale scores in this dissertation and combining them to obtain raw scores for the Dimensions. In order to obtain the Relationship Domain, I reverse-scored the Conflict scale in order to make it consistent with the other two scales, because Conflict is a negative attribute while Cohesion and Expressiveness are positive attributes. Then the scores were averaged to produce the Relationship Domain. The System Maintenance Domain was an average of the Organization and Control scales.

Moos and Moos (2002) reported internal consistency and 2-month test-retest stability as follows (respectively): Cohesion was .78 and .86; Expressiveness was .69 and .73; Conflict was .75 and .85; Organization was .76 and .76; Control was .67 and .77; Independence was .61 and .68; Achievement Orientation was .64 and .74; Intellectual-

Cultural Orientation was .78 and .82; Active-Recreational Orientation was .67 and .77; Moral-Religious Emphasis was .78 and .80. Please see Table 33 for reliabilities of this sample's FES scores.

Table 33

Sample Reliabilities of the FES Scores

Scale/Domain	*N*	Number of Items	Alpha
Cohesion	84	9	.751
Expressiveness	81	9	.522
Conflict	83	9	.711
Independence	82	9	.153
Achievement Orientation	83	9	.425
Intellectual/Cultural	83	9	.689
Active/Recreational	83	9	.753
Moral/Religious	83	9	.669
Organization	82	9	.671
Control	82	9	.266
Relationship Domain	85	3[a]	.593
System Maintenance Domain	85	2[b]	.350

[a] Relationship Domain included Cohesion, Expressiveness and Conflict scales.

[b] System Maintenance Domain included Organization and Control scales.

Munet-Vilaro and Egan (1990) stated that the psychometric test construction criteria that Moos and Moos (2002) used to select items to be included in the final Form R were met. These were as follows: that the overall item split should be as close to 50:50 as possible to avoid items characteristic only of extreme families; items should correlate more highly with their own subscale total than with any other; each of the subscales should have an approximately equal number of items score true and scored false to control for acquiescence response set; the final subscales should show only low to moderate Pearson's intercorrelations; and each item (and each subscale) had to maximally discriminate among families. The validity of the FES has been corroborated through 200 studies where it has been used to differentiate between normal and dysfunctional families, family types, and to relate to treatment outcomes in predictable ways (Moos & Spinrad, 1984).

Procedure.

I prepared a key sheet (Appendix K) that included spaces for each caregiver's identification code, age, gender, and diagnosis of the child as well as the scores of the questionnaires. It did not contain any identifying information, but allowed me to summarize questionnaire and demographic data without identifying information. When each caregiver returned the signed consent form, I wrote a code number on the consent form and placed it in a separate file in a locked file cabinet. I copied each caregiver's consent form and returned it to her for her records in a packet containing the questionnaires that had the same corresponding code number as the consent form. The packet included a self-addressed stamped envelope in order for the caregiver and teacher to return-mail the completed questionnaires to me as well as a request for the summary of the findings that did not have the code on it.

When the coded packet was returned, I removed the uncoded request for the summary of findings and placed it in a separate file in a locked file cabinet. I accessed this file at the end of the study and sent study results to caregivers who requested them. I scored the questionnaires and transferred each score to the corresponding coded key sheet. I then put the coded questionnaires in a separate file in a locked file cabinet. Thus, I worked from the coded key sheet with the questionnaire scores and demographic information without other identifying information.

I sent summaries of findings to all primary caregivers who requested them. I shredded each of these requests after the summary was sent. I will keep the rest of the data and consent forms for 5 years as per APA guidelines and will shred them at that time.

Data Analysis.

The following statistical analyses were conducted: descriptive statistics (frequencies, means, standard deviations) to summarize caregivers' and secondary caregivers' (if available) demographic information. Descriptive statistics also include the children's ages, gender, diagnosis, caregiver-rated language levels, and CCC-2 (Bishop, 2006) scores (when applicable) as well as externalizing, internalizing, and total CBCL-CRF (Achenbach & Rescorla, 2001) and CBCL-TRF (Achenbach & Rescorla, 2001) scores.

To determine the relationship between language and behavior in this sample of children with Autism, caregiver-rated language and CCC-2 (Bishop, 2006) score were correlated with both CBCL-CRF (Achenbach & Rescorla, 2001) and CBCL-TRF (Achenbach & Rescorla, 2001) scores using Pearson Product Moment correlations.

To determine how the autistic child's language functioning related to maternal stress, Pearson Product Moment correlations were conducted between the caregiver-rated language levels and CCC-2 (Bishop, 2006) scores and the scores from the PSI-SF (Abidin, 1995). To determine how the child's language functioning was related to the family environment, caregiver-rated language levels and CCC-2 (Bishop, 2006) scores were correlated with scores from the FES (Moos & Moos, 2002).

To discover how the child with Autism's behavior related to maternal stress, Pearson Product Moment correlations were conducted between separate Externalizing and Internalizing CBCL-CRF (Achenbach & Rescorla, 2001) and CBCL-TRF (Achenbach & Rescorla, 2001) scores and all of the subscales of the PSI-SF (Abidin, 1995). In order to determine how behavioral functioning affected family environment, separate Externalizing and Internalizing CBCL-CRF (Achenbach & Rescorla, 2001) and CBCL-TRF (Achenbach & Rescorla, 2001) scores were correlated with subscale scores of the FES (Moos & Moos, 2002).

After the above statistical analyses were conducted, a further *post hoc* analysis was conducted in order to determine factors that predicted the PSI-SF Total Stress scores as suggested by correlations that resulted from the hypothesis testing.

CHAPTER IV

Results

This chapter summarizes the results of this study in terms of language and behavioral levels of children with Autism Spectrum Disorder in relation to caregiver stress and family functioning.

Descriptions of Children's Language Levels

Caregiver-rated language levels. In the Demographic Questionnaire, the caregivers rated their children's language levels according to the levels set by the Autism Diagnostic Observation Scale (ADOS; Lord et al., 2001): (a) non-verbal, described as "*does not speak with words*", (b) pre-verbal, described as "*uses gestures/one word utterances*", (c) phrase speech, described as "*two to three word utterances*", or (d) verbal, described as "*at least able to put words into simple sentences*". As rated by the primary caregiver, 35 (41.2%) of the 85 children were verbal. The smallest language group was 8 (9.4%) pre-verbal children. The mean of this sample was 1.80 and the *SD* was 1.23. Please see Table 34 for the breakdown of caregiver-rated language levels.

Table 34

Caregiver-Rated Children's Language Levels

Level	Frequency	Percent
Non verbal	22	25.9
Pre-verbal	8	9.4
Phrase Speech	20	23.5
Verbal	35	41.2

Note. N = 85.

CCC-2 scores for verbal children. The Children's Communication Checklist-2 (CCC-2; Bishop, 2006) measures the communication skills of verbal children. It is designed to measure functioning in the areas of the formal language areas of Speech, Syntax, Semantics, and Coherence as well as the pragmatic language areas of Initiation, Non-Verbal Communication, Social Relations, and Interests. There were 43 (50.59% of the sample) children whose CCC-2 (Bishop, 2006) scores were valid based on the measure's consistency check. (Please note that there were eight children whom caregivers rated as phrase speech but whose protocols passed the CCC-2 consistency check). The CCC-2 (Bishop, 2006) General Communication Composite (GCC) is a norm-referenced composite score formed by summing the scaled scores of the 10 subtests. (Sample subtest means for the readers' perusal are in Appendix L)**.** The GCC is reported as a standard score with a mean of 100 and a Standard Deviation of 15. The CCC-2 (Bishop, 2006) manual reported a GCC mean of 72.4 (*SD* = 11.7, *n* = 62) in a sample of children with ASD. A typically-developing matched sample yielded a mean GCC of 106.2 (*SD* = 13.1, *n* = 62). The 33.81 scaled score point difference between these normed samples yielded a *t*-value of 14.40 (*SD* = 2.72, *p* < .001).

This study's sample of 43 verbal children with ASD had a mean GCC of 80.37 (*SD* = 15.95). Thus, the mean GCC of this study's sample is higher than that of the normed sample of ASD children reported by the CCC-2 (Bishop, 2006). This study's sample also has a larger standard deviation than the normed ASD sample, which may be a reflection of the wider range of language levels in the sample of children with Autism in this study. This sample's GCC mean was 25.86 points, almost two standard deviations, below the mean for typically developing children. This suggested that the verbal children in this sample had much lower communication skills than typically-developing children.

The Social Interaction Difference Index (SIDI) is derived by subtracting the CCC-2 subscales that measure formal communication skills (i.e., Speech, Syntax, Semantics, and Coherence) from those that measure social communication skills (i.e., Initiation, Non-Verbal Communication, Social Relations, and Interests). For the SIDI scores, 89.95% of the normed sample's scores reported in the CCC-2 (Bishop, 2006) manual (*n* = 876) fell between -10 and +10. SIDI scores of +11 and above are similar to those children diagnosed with a Specific Language Impairment and SIDI scores of -11 or below are similar to those children diagnosed with ASD. Of the norming sample, 4.77% of the SIDI scores fell at 11 or above, and 5.94% of the SIDI scores were -11 or less. The CCC-2 manual (Bishop, 2006) reported SIDI scores of a sample of children with ASD (*n* = 62): 64.52% fell within the -10 to 10 range; 8.06% fell at or above 11; and 27.42% fell at or below -11.

Of the SIDI scores for the current sample of 43 verbal children on the Spectrum, 65.11% (*n* = 28) fell between -10 and 10; 9.30% (n = 4) fell at or above 11; and 25.58% (*n* = 11) fell at or below -11. The characteristics of this sample of children on the Spectrum are very close to the sample of children with ASD in the CCC-2 (Bishop, 2006) normed sample. Scores of children in the current sample averaged -3.14 (*SD* = 10.82). Although the mean SIDI sample score fell within the average range, participants exhibited a wide range of scores that extended from over +11, which is comparable to scores of children with Specific Language Impairment, to -27, which is similar to scores of children with ASD. Tager-Flusberg (2004) reported similar results for a sample of children with ASD.

Table 35 shows that there was no significant relationship between GCC and SIDI scores, suggesting that communicative language was a different measure than social language. The table also shows that children's ages were not significantly related to either GCC or SIDI scores. This is not surprising, because language difficulties are a prime symptom of Autism that are present at any age.

However, there was a strong significant relationship between caregiver-rated language levels and SIDI scores. Because the SIDI scores are a reflection of the difference between communicative and social language, this suggests that higher caregiver ratings of their children's overall language (i.e., verbal, pre-verbal, phrase speech, verbal), were associated with smaller differences between their children's communicative and social language.

Table 35

Mean, Standard Deviation and Correlations Among Age, Maternal Rated Language Measures

	n	M	SD	GCC	SIDI	Maternal-Rated Language Levels	Age
GCC	43	80.37	15.95	1.00	-.253	.146	-.214
SIDI	43	-3.14	10.82	-.253	1.00	-.424**	.050
Caregiver-Rated Language Levels	85	1.80	1.23	.146	-.424**	1.00	.035
Age (months)	85	111.67	25.94	-.214	.050	.035	1.00

Note. GCC = General Communication Composite; SIDI = Social Interaction Difference Index

$^{**}p<.01$ level (2-tailed)

Descriptions of Behavior

CBCL-Caregiver Report Form scores. All 85 caregivers completed the Child Behavior Checklist -Caregiver Report Form (CBCL-CRF; Achenbach & Rescorla, 2001). The subscale scores are reported for the readers' perusal in Appendix M**.** Table 36 presents the CBCL-CRF Externalizing, Internalizing, and Total scores. The scores are reported as *T*-scores that have a mean of 50 (*SD* = 10). According to the manual (Achenbach & Rescorla, 2001), Borderline Range *T*-scores are from 60-63 (84th -90th percentiles), whereas Clinical Range *T*-scores are above 63 (90th percentile). Readers should note that the average Externalizing and Internalizing scores for the sample fell just below the Borderline Range. The average Total Scale score, however, fell within the Borderline Range. These scores are comparable to those found by Duarte et al. (2003) for a sample of youth with Autism.

Table 36

Means, Standard Deviations, and Ranges of CBCL-Caregiver Report Form Scores

Scale	*M*	*SD*	Range
Externalizing	58.56	10.46	32 - 80
Internalizing	59.28	9.53	33 - 70
Total Score	63.67	9.95	29 - 84

Note. N = 85.

CBCL-Teacher Report Form scores. Seventy-one (83.53%) of the teachers of the 85 children completed the teacher form of the CBCL (CBCL-TRF; Achenbach & Rescorla, 2001) to assess the children's behavior in school. Table 37 shows the CBCL-TRF scores. These scores are very similar to the scores from the CBCL-CRF. Both the Externalizng and Internalizing mean scores fell within the Average Range. The mean of the Total score was also within the Average Range, but missed Borderline Range by 4 points suggesting that the Total problem score in this sample was elevated in comparison to the normed sample, but yet, did not reach Borderline Range. Sample subscale scores are available in Appendix N for the reader's perusal.

Table 37

Means, Standard Deviations and Ranges of CBCL-Teacher Report Form Scores

Scale	*M*	*SD*	Range
Externalizing	58.92	7.22	41 - 74
Internalizing	56.51	8.43	38 - 75
Total	61.20	6.58	48 - 78

Note. *N* = 71.

Hypothesis Testing

Tests of hypothesis 1, relationship between externalizing and internalizing behavior. Hypothesis 1 stated that there would be significant positive correlations between caregivers' ratings of children's externalizing and internalizing behaviors. Table 38 shows that the Externalizing, Internalizing, and Total scores were significantly, positively related to each other, but not to children's ages. Thus, regardless of their age, children in the sample who showed elevations of one type of behavior also showed elevations of another type of behavior. Thus, Hypothesis 1 was supported for primary caregiver ratings of externalizing and internalizing behavior.

Table 38

Correlations among CBCL-CRF Scores and Age

	Externalizing	Internalizing	Total	Age
Externalizing	1.00	.724**	.882**	-.017
Internalizing	.724**	1.00	.834**	-.109
Total	.882**	.834**	1.00	-.028
Age	-.017	-.109	-.28	1.00

Note. $N = 85$.

**$p<$ 0.01 level (2-tailed)

Table 39 presents the intercorrelations among CBCL-TRF scores and children's ages. In contrast to the CBCL-CRF, there were no significant relationships among ratings of externalizing and internalizing behavior by the children's teachers. Similar to the caregivers' CBCL-CRF scores, the teachers' Externalizing, Internalizing, and Total scores did not relate significantly to children's ages. CBCL-TRF Total scores, however, produced significant positive correlations with Externalizing and Internalizing behavior. In terms of Hypothesis 1, externalizing and internalizing behavior in the classroom as reported by the teacher did not exhibit significant relationships. Thus, teacher and caregiver ratings together yielded only partial support for Hypothesis 1.

Table 39

Correlations between CBCL-TRF Scores and Age

	Externalizing	Internalizing	Total	Age (months)
Externalizing	1.00	.156	.793**	-.067
Internalizing	.156	1.00	.559**	-.172
Total	.793**	.559**	1.00	-.126

Note. *N* = 71.

**p < .01 level (2-tailed)

Comparison between caregiver and teacher CBCL scores. Table 40 presents the intercorrelations of caregiver and teacher CBCL scores. Caregivers’ CBCL ratings correlated positively and significantly with the comparable CBCL teacher ratings. Teachers' Externalizing ratings were also significantly related to caregivers' CBCL Total ratings. The correlations are in the low to medium range and are comparable to those between parent and teacher (e.g., $r = .28$) cited in the manual (Achenbach & Rescorla, 2001). These correlations are also comparable to those found by Hetig et al. (2009) who suggested that they may reflect the different demands and/or structure of the home and school environments.

Table 40

Correlations between Caregiver and Teacher CBCL Scores

	Caregiver Externalizing	Caregiver Internalizing	Caregiver Total
Teacher Externalizing	.308*	.121	.333**
Teacher Internalizing	.038	.235*	.123
Teacher Total	.189	.183	.292*

Note. $N = 71$.

*$p < .05$ level (2-tailed) **$p < .01$ level (2-tailed)

Tests of hypothesis 2, relationship between caregiver-rated children's language and their home and school behavior. Table 41 presents the results of correlations among caregivers' ratings of children's language and children's behavior at both home (caregiver-rated) and school (teacher-rated). Hypothesis 2 stated that all three language ratings would have significant inverse relationships with children's externalizing and internalizing behaviors. The table shows that this prediction held true for only 4 of 12 of the correlations.

Results suggest that home versus classroom behavior is differentially associated with different aspects of language as rated by caregivers. As measured in this study, caregiver Externalizing and Internalizing behavior ratings yielded significant negative relationships with the GCC scores of the verbal children in this sample. Thus, the lower the general communication skills that a verbal child exhibited, the more Externalizing and /or Internalizing behavior (s)he displayed at home. Although it is not part of this study's hypothesis, it should be noted that the caregiver Total CBCL score yielded a significant negative correlation with the GCC language score, which was similar to the correlation between caregiver Externalizing CBCL score and the GCC score. This is interesting, because the Total CBCL score contains measures that are sensitive to symptoms of ASD (Duarte et al., 2003; Sikora et al., 2008) that include the Thought Problems and Attention Problems subscales in addition to the subscales included in both the Externalizing and Internalizing scores.

In contrast, classroom behavior, as reported by the teachers in this sample, did not yield any significant correlations with the GCC score ratings by caregivers. However, the caregiver-rated language levels, which included ratings of the non-verbal children as well as ratings of verbal children, produced a significant negative relationship with teacher-rated Externalizing behavior scores. Thus, the lower overall language level (i.e., the non-verbal to verbal range), the more Externalizing behavior in the classroom. In contrast, classroom Internalizing behavior was significantly negatively associated with the verbal children's SIDI score. This results indicates that the less relative social language a verbal child has, the more withdrawn behavior (s)he exhibits. In sum, Hypothesis 2 had only minimal support.

Table 41

Correlations among CBCL Caregiver's and Teacher's CBCL Ratings and Language Measures

Behavior	Caregiver-rated Language Levels[a]	GCC[b]	SIDI[b]
CBCL-Caregiver Externalizing[a]	.001	-.489**	-.039
CBCL-Caregiver Internalizing[a]	.167	-.388*	-.143
CBCL-Caregiver Total[a]	-.018	-.484**	-.025
CBCL-Teacher Externalizing[a]	-.235*	-.271	.025
CBCL-Teacher Internalizing[a]	.150	.126	-.353*
CBCL-Teacher Total[a]	.154	-.154	-.126

Note. GCC = General Communication Composite; SIDI = Social Interaction Difference.

[a] *N* = 85. [b]*N* = 43.

**p* < .05 (two-tailed) ***p* < .01(two-tailed)

Tests of hypotheses 3 and 4, parental distress. Table 42 presents means, standard deviations, and percentiles for caregivers' ratings on the Parenting Stress Index-Short Form (PSI-SF; Abidin, 1995). Relative to the normative sample, these primary caregivers were experiencing much stress indeed. Relative to the manual norms, the mean Total Stress raw score fell at the 98th percentile. In fact, the lowest raw score was Parental Distress, which fell at the 75th percentile of the manual norms (Abidin, 1995)

Table 42

Means, Standard Deviations, and Percentiles for Caregivers' PSI-SF scores

Scale	*M* (Raw Score)	*SD*	Manual Percentile
Parental Distress	33.28	11.82	75
Parent-Child Dysfunction	30.19	9.68	95
Difficult Child	40.11	11.56	98
Total Stress	103.89	28.67	99

Note. *N* = 85.

Children's language and caregiver stress. Hypothesis 3 stated that children's language would be significantly, negatively correlated with caregivers' ratings of stress. Table 43 presents the results of the correlations among scores for language measures and the PSI-SF scores. While all but one of the relationships among the three language measures (i.e., caregiver-rated language level, GCC, and SIDI scores) and PSI-SF scores were in the predicted direction, only 4 of 12 were significant. Three of these significant results involved the verbal children's general communication skills (assessed by the GCC). Specifically, higher levels of caregiver Total Stress, Parent-Child Dysfunction, and ratings of Difficult Child were associated with less communicative skills in the verbal children of the sample. This suggests that the lack of communication skills relates to poorer interactions between parent and child. In contrast, lower levels of relative social language (assessed by the SIDI score) among the verbal children were associated with caregiver distress in the parental role. Thus, there is some support for Hypothesis 3, particularly in regard to children's general communication skills.

Table 43

Correlations Among Scores for Language Measures and PSI-SF Scores

	Parental Distress	Parent-Child Dysfunction	Difficult Child	Total Stress
Caregiver-Rated Language Level[a]	-.115	-.105	.001	-.096
GCC[b]	-.262	-.374*	-.439**	-.432**
SIDI[b]	-.303*	-.006	-.139	-.192

Note. GCC = General Communication Composite; SIDI = Social Interaction Difference Index.

[a]N = 85. [b]N = 43.

* $p < .05$ (2-tailed) **$p < .001$ (2-tailed)

Children's home and school behavior and caregiver stress. Hypothesis 4 stated that both caregiver and teacher ratings of children's Internalizing and Externalizing behaviors on the CBCL would be positively related to caregiver stress as measured by caregiver ratings on the PSI-SF. Table 44 presents the correlations among caregivers' ratings of their children's behavior on the CBCL and their ratings of the parenting stress they experienced (PSI-SF scores). Correlations for every comparison between caregiver CBCL scores and PSI-SF scores were positive and significant (at the $p < .01$ level). The magnitude of these effects ranged from a low of .33 (medium effect; Cohen, 1992) between Total CBCL score and Parental Distress to highs of .68 (large effect; Cohen, 1992) between Externalizing behavior and Difficult Child. The sizable correlations between both CBCL Externalizing and Internalizing scores and the PSI-SF Difficult Child and Total Stress scores appear to indicate that both types of behavior were very stressful for caregivers in this study.

Table 44

Correlations between Caregiver CBCL Scores and PSI-SF Scores

	Parental Distress	Parent-Child Dysfunction	Difficult Child	Total Stress
Caregiver CBCL Externalizing	.355**	.459**	.680**	.575**
Caregiver CBCL Internalizing	.325**	.339**	.605**	.498**
Caregiver CBCL Total	.330**	.397**	.662**	.540**

Note. N = 85.
***p* < .01 (two-tailed)

Table 44 shows the results of teacher ratings of children's Externalizing and Internalizing behaviors on the CBCL and caregiver stress as measured by the PSI-SF. The correlations in Table 45 indicate the children's externalizing behaviors at school related significantly to total caregiver stress, parent-child dysfunction, and stress from having a difficult child. Internalizing behaviors at school was only significantly correlated with caregiver stress as she sees herself in the role of a parent. These correlations were in the medium range. Taken together, they provide partial support for Hypothesis 4.

Table 45

Correlations between Teacher CBCL and Caregivers' PSI-SF scores

	Parental Distress	Parent-Child Dysfunction	Difficult Child	Total Stress
Teacher CBCL Externalizing	.227	.257*	.340**	.327**
Teacher CBCL Internalizing	.251*	-.045	.106	.129
Teacher CBCL Total	.313**	.212	.296*	.326**

Note. $N = 71$.

*$p < .05$ (2-tailed) **$p < .01$ (2-tailed)

Tests of hypothesis 5 and 6, family environment. According to the Family Environment Scales (FES; Moos & Moos, 2001) manual, the FES scores are reported in *T*-scores with a mean of 50 and a standard deviation of 10. Despite the enormous stress these primary caregivers were under, their family functioning was very close to the manual norms. Independence and Active/Recreational sample means are about .5

standard deviations below the manual mean. Independence reflects the extent to which family members are self sufficient and make their own decisions. Active/Recreational measures the families' participation in social and recreational activities. Given that these families had at least one child on the Autism Spectrum, it is understandable why these scores tended to be lower. Please see Table 46 for FES scores.

According to the FES manual (Moos & Moos, 2001), the scores can be grouped into two Domains that reflect internal family functioning. The first domain is the Relationship Domain that is a summary of how family members relate to each other. It consists of the Cohesion, Expressiveness, and Conflict scales. The Relationship Domain was computed first by reverse scoring the Conflict scale in order to make it consistent with the other scales because the higher conflict is a negative attribute while Cohesion and Expressiveness are positive attributes. Then the scores were averaged to produce the Relationship Domain scores. The second Domain score was System Maintenance that reflects how well the family is internally structured in order to conduct day-to-day activities and chores. This domain score was computed by averaging the Organization and Control scales. Again, this sample mean was close to the manual mean.

Table 46

Means, Standard Deviations and Ranges of FES Scores

Scale	*M*	*SD*	Range
Cohesion	49.98	15.31	11-65
Expressiveness	48.75	11.86	16-65
Conflict	51.00	11.53	23-80
Independence	44.72	11.17	13-69
Achievement	47.41	10.07	25-67
Intellectual	49.85	12.07	19-69
Active/Recreation	45.14	12.81	23-69
Moral	49.87	10.88	32-71
Organization	53.28	11.61	26-69
Control	53.26	10.83	32-70
Relationship Domain	53.58	9.66	29-68
System Maintenance	53.27	8.74	34.5-69.5

Note. *N* = 85.

Language and Family Environment. Hypothesis 5 posits that language measures will be positively correlated with mothers' ratings of family functioning. Table 46 summarizes the correlations between language measures and FES scores. Caregiver-rated language levels yielded one significant correlation with the subscales of the FES. There was a weak correlation of .22 between caregiver rated language scores and the

Intellectual subscale, suggesting that the higher the child's language level, the higher the level of interest in political, intellectual, and cultural activities in the family.

Interestingly, for the verbal children, there was one significant correlation between the GCC scores and the Conflict subscale. This suggests that the less general communication skills the child had, the more likely anger was openly expressed by family members. The social language/SIDI score yielded one significant and positive correlation with the Active/Recreational subscale. This suggests that the more relative social language a child had, the more involved the family was in social and recreational activities. But with only 3 significant correlations out of 36, Hypothesis 5 is not supported. Two of the 3 significant correlations could be due to chance. Please see Table 47 for a summary of these results.

Table 47

Correlations between Language Measures and FES Scores

	Caregiver-rated Language Scores[a]	GCC[b]	SIDI[b]
Cohesion	.115	.230	.294
Expressiveness	.050	.019	.242
Conflict	-.012	-.307*	.049
Independence	.165	.080	-.013
Achievement	.132	-.144	.047
Intellectual	.223*	-.005	-.023
Active/Recreation	.088	-.007	.351*
Moral	-.037	-.208	.186
Organization	-.015	-.247	.181
Control	.090	.000	-.070
Relationship Domain	.086	.273	.235
System Maintenance Domain	.045	-.194	.097

[a]*N* = 85 . [b]*N* = 43.

*****$p <$ 0.05 level (two-tailed)

Home behavior and family environment. Hypothesis 6 states that Externalizing and Internalizing behavior scores will be inversely correlated with family functioning. Interestingly, of the all the FES (Moos & Moos, 2001) scales, Conflict and Expressiveness yielded the most significant correlations with caregivers' ratings of children's behavior. Both scales tap into how the family communicates emotions. Of all of the FES (Moos & Moos, 2001) subscales, the Conflict subscale produced the most significant correlations. The Caregiver Externalizing score was strongly and moderately correlated with the Conflict subscale. This suggested that the more externalizing behavior the child exhibits, the more openly anger was expressed among family members. A weaker correlation was found between Caregiver Internalizing score and the Conflict subscale, suggesting a relationship between higher internalizing behavior and openly expressed anger in the family.

Thus, not surprisingly, a strong moderate correlation was found between caregiver Total score and the Conflict subscale. As the reader may remember, the Total CBCL score contains subscales that are sensitive to specific symptoms of Autism (Duarte et al., 2003; Sikora et al., 2008). Mild moderate and negative significant correlations were found with caregiver Externalizing and Internalizing subscales and the Expressiveness scale. Thus, children in this sample who exhibit externalizing and internalizing behaviors had families with less encouragement to express their feelings openly. Another significant correlation was found between the Control subscale and caregiver Internalizing score, although it was small. This suggested that children displaying internalizing behavior had families that followed set rules and procedures that are used to run the family.

In terms of the Domain scores, all correlations between caregiver ratings of child behavior scores and the Relationship Domain were significant. The strongest of these was between Externalizing and the Relationship Domain. Thus, families with children who displayed externalizing and internalizing behaviors were more likely to have families with weaker relationships among family members. Again, the caregiver Total CBCL score also produced a low, but significant negative relationship with the Relationship

Domain. Finally, there was a small correlation between caregiver Total score and System Maintenance Domain. Because System Maintenance Domain is comprised of Organization and Control subscales, this correlation may be influenced by the contribution of the Control subscale. Keeping in mind that the Total CBCL contains subscales sensitive to Autism symptoms, it is interesting to find a relationship that suggested that the higher the Total scale score, the more effort needed to keep the family running smoothly on a day to day basis. In terms of caregiver-reported child behavior and family environment, only 10 of the 36 correlations were significant. Thus, there is minimal support for Hypothesis 6. Please see Table 48 for a breakdown of correlations between caregiver CBCL scores and the FES scales.

Table 48

Correlation between Caregivers' CBCL and FES Scores

	Caregiver Externalizing	Caregiver Internalizing	Caregiver Total
Cohesion[a]	-.211	-.113	-.166
Expressiveness[a]	-.222*	-.236*	-.136
Conflict[a]	.317**	.258*	.301**
Independence	-.078	-.027	.016
Achievement	-.049	.059	-.007
Intellectual	.001	-.027	.066
Active/Recreation	-.152	-.137	-.114
Moral	.159	.022	.137
Organization[b]	.070	.038	.123
Control[b]	.195	.248*	.217
Relationship Domain	.-.328**	-.259*	-.263*
System Maintenance Domain	.167	.179	.216*

Note. $N = 85$.

[a] Relationship Domain scales. [b] System Maintenance Domain scales.

* $p < 0.05$ level (2-tailed) **$p < 0.01$ level (2-tailed)

Classroom behavior and family environment. Teacher CBCL (Achenbach & Rescorla, 2001) scores and caregivers' FES (Moos & Moos, 2002) scores yielded two moderate correlations. These were significant relationships between Teacher Externalizing and Total scores with the Conflict FES subscale. This is a similar but weaker pattern when compared to the caregiver CBCL scores and this FES subscale. This suggests that a child's acting out behavior in a classroom was related to the amount of openly expressed anger among family members. This pattern was also found with the Teacher Total CBCL score. As mentioned above, it may be that Autism symptoms are related to how families communicate feelings. Also, the Teacher Total CBCL score produced a significant negative correlation with the Relationship Domain. Again, as the CBCL Total score is sensitive to symptoms of children on the Autism Spectrum, the classroom behavior of children on the Spectrum may be inversely related to the quality of the relationships among family members. However, with only 3 of 36 correlations significant, there is little support for the relationship between family environment and classroom behavior (Hypothesis 6). Please see Table 49 for the summary of the correlations between Teacher CBCL and FES scores.

Table 49

Correlations between Teacher CBCL and FES Scores

	Teacher Externalizing	Teacher Internalizing	Teacher Total
Cohesion[a]	-.173	-.058	-.195
Expressiveness[a]	.079	-.135	-.014
Conflict[a]	.327**	.105	.347**
Independence	-.102	.094	.008
Achievement	.051	-.023	.014
Intellectual	-.017	-.041	-.032
Active/Recreation	-.013	-.135	-.091
Moral	.011	-.199	-.189
Organization[b]	-.102	-.076	-.108
Control[b]	-.031	.100	-.017
Relationship Domain	-.188	-.129	-.247*
System Maintenance Domain	-.087	.011	-.083

Note. *N* = 71.

[a] Relationship Domain scales. [b] System Maintenance Domain scales.

* $p < .05$ level (2-tailed) **p < 0.01 level (2-tailed)

Summary. While this study yielded several significant correlations, none of the six hypothesis received full support. Table 50 summarizes the results of hypotheses testing by presenting the number and percentage of significant correlations associated with each hypothesis. Only one of the hypotheses (Hypothesis 4) was supported, because the majority of its correlations (79%) were significant and in the predicted direction. Thus, children's behavior, both at home and at school, related to caregiver stress. Higher levels of both externalizing and internalizing behavior were associated with greater caregiver stress.

There was also partial support for Hypothesis 1 (with 56% of the 18 correlations reaching significance). This indicated a tendency for children's externalizing and internalizing behavior to be positively related to each other. All other hypotheses received only minimal support with a third or fewer of their correlations achieving significance. Overall, only 35% (51 of 144) of the study's correlations reached significance.

Table 50

Number and Percentage of Significant Correlations Associated with Hypotheses

Hypothesis	# Significant/ Total # of Correlations	Percentage of Significant Correlations
HO1: Externalizing and Internalizing scores on the CBCL will be significantly correlated.	10/18	56%
HO2: Caregiver language ratings and CCC-2 scores will correlate significantly and inversely with Externalizing and Internalizing CBCL scores.	5/18	28%
HO3: Caregiver language ratings and CCC-2 scores will be inversely correlated with caregiver scores on the PSI-SF.	4/12	33%
HO4: Externalizing and Internalizing scores on the CBCL will be positively correlated with PSI-SF scores.	19/24	79%
HO5: Caregiver language ratings and CCC-2 scores will be positively correlated with FES scores.	3/36	8%
HO6: Externalizing and Internalizing scores on the CBCL will be inversely correlated with FES scores.	10/36	28%

Additional Analysis

A post hoc regression analysis was performed in order to determine if caregiver PSI-SF Total Stress scores could be predicted from some of the variables that were highly related to caregiver stress from the original hypotheses testing. A stepwise regression was performed using the following scores to predict caregiver stress as measured by the PSI-SF: caregiver CBCL Externalizing score, caregiver CBCL Internalizing score, FES Relationship Domain score, and the CCC-2 General Communication Composite score. The regression analysis revealed that the FES Relationship Domain score (negative relationship) and caregiver-rated child Externalizing behavior (positive relationship) significantly predicted caregiver stress as assessed by the PSI-SF Total Stress score. No other variable added significantly to the amount of variance explained by these two variables. Thus, negative family relationships together with externalizing behaviors on the part of the children with Autism relate to greater caregiver stress. Readers should note that because the CCC-2 scores were included, the analysis used scores from only about half of the participants. Please see Table 51 for results of the regression analysis predictors of Maternal PSI-SF Total Stress scores.

Table 51

Predictors of Caregiver PSI-SF Total Stress scores

		Model 2	
Variable	Model 1 *β*	*β*	95% CI
Constant	227.60**	153.02**	[110.94,195.09]
FES Relationship Domain	-2.32**	-1.93**	[-2.42,-1.44]
Caregiver CBCL-External		.91**	[.50,1.32]
R^2	.63	.75	
F	71.25**		61.60**
ΔR^2		.12	
ΔF		19.90	

Note. *N* = 43. CI = confidence interval.

**p* < .05 ***p* < .01

Analyses were performed to determine if the parental stress and family measures differed when children were either verbal or non-verbal. A child was defined as verbal if (s)he achieved a valid CCC-2 score as determined by the consistency check. A child without a valid CCC-2 consistency check was defined as non-verbal. The verbal group consisted of 43 children and the non-verbal group consisted of 42 children. The means of the two groups were then compared using key demographic factors (dependent variables): age *(in months*), gender (*male, female*), diagnosis (*Autism, Asperger's, PDD-NOS*), age of diagnosis *(in months*), presence of comorbidities (*one or more comorbities, no comorbidities*), type of school (*therapeutic, small class, general education*), primary caregiver age (*years*), primary caregiver employment (*employed or not employed*), primary caregiver education (rated from *1= less than 7th grade to 8=graduate degree*), eligibility for free lunch (*yes, no*) and English as a home language (*yes, no*). These factors were chosen because they may have some relationship to Primary Caregiver stress and family climate and therefore may interfere with the interpretation of the results. If these comparisons yielded no significant difference between the means of the verbal/non-verbal group and the dependent variables, the null hypothesis that these factors are independent of each other would be satisfied and the primary caregiver stress and family climate measures then could be compared between the verbal and non-verbal groups with some confidence.

T-tests were performed on all comparisons. A Pearson X^2 was further performed on those factors that had nominal variables (gender, diagnosis, comorbidities, school type, Primary Caregiver employment, eligibility for free lunch and home language). Due to the small number of children in each group, Fisher's Exact Tests were also performed on those with nomimal factors in order to confirm the X^2 outcomes.

Results found no differences between means of the verbal/non-verbal groups and the factors of age, gender, comorbidities, Primary Caregiver age, employment status, education, eligibility for free lunch and English as a home language. Significant differences were found between verbal and non-verbal children and the factors of diagnosis, age of diagnosis and school type.

Results comparing all three diagnoses of Autism, Asperger's and PDD-NOS found significant differences according to whether or not the children were verbal or non-verbal (see Table 53). X^2 analyses found higher percentages of children with Autism were classified as non-verbal relative to children with Asperger's. Also, a higher percentage of children with Autism were non-verbal relative to children with PDD-NOS. These results seem reasonable as Asperger's and PDD-NOS are considered less severe on the continuum of the Autism Spectrum, and therefore children with Asperger's and PDD-NOS are more likely than those with Autism to be verbal.

A *t*-test (see Table 52) found a significant difference between verbal and non-verbal groups in terms of age of diagnosis. Verbal students were diagnosed at a later age than were non-verbal students.

Additionally, X^2 results found significant differences in the proportion of verbal and non-verbal children in the three school types (see Table 53). A higher proportion of verbal children tended to be placed in General Education schools in comparison to therapeutic schools which tended to have non-verbal children as students. This seems reasonable because Therapeutic school placement is more restrictive and so can provide more support to the non-verbal students who would require more educational support than verbal children.

The differences between non-verbal and verbal children in key demographics could affect caregiver stress and family climate. A larger sample could have allowed the use of covariates in tests of the effects of verbal vs. non-verbal children on Primary Caregiver stress and family climate. Since the present sample was small, however, I did not attempt further comparisons.

Table 52

T-tests for Differences in Means for Verbal vs. Non-verbal Groupings According to Demographic Variables

Dep. Var.	F[a]	*p*	*t*	*df*	*p* (2-tailed)	*M* Difference	Stand. Error Difference	95%CI Difference
Age	2.58	.112	-.426[b]	83	.671	-2.41	5.66	-13.66,8.84
Gender	8.04	.006	-1.38[c]	78.61	.173	-.114	.083	-.278, .051
Diagnosis	11.34	.001	-4.17[c]	79.00	.00	-.738	.177	-1.09,-.385
Age of Dx	4.54	.036	-2.06[c]	77.41	.043	-8.21	3.98	-16.14,.278
Comorbidities	3.56	.063	.982[b]	83	.329	.102	.104	-.105, .310
School Type	38.39	.000	2.68[c]	54.75	.010	.348	.130	.088, .608
PC Age	.84	.363	-1.54[b]	83	.127	-.252	1.63	-5.77, .734
PC Employ	.038	.846	.641[b]	81	.524	.120	.187	-.252, .491
PC Education	1.46	.231	-.473[c]	82	.638	-.119	.252	-.620, .382
Free Lunch	15.88	.000	-1.95[c]	65.63	.055	-.199	.102	-.402, .004
Home Lang	3.30	.073	-.877[b]	83	.372	-.075	.083	-.240, .091

Note. *N* = 85.

[a] Leven’s test for equality of variances.

[b] equal variances assumed.

[c] equal variances not assumed.

Table 53

Chi-Square and Fisher's Exact Test for Differences in Means for Nominal Variables in Verbal vs. Non-Verbal Groupings According to Demographic Variables

Dependent Variable	X^2	*df*	p^a	Fisher's Exact Significance
Gender	1.88	1	.170	.255
All Diagnoses	20.80	2	.001	
Autism vs. Asperger's	13.26	1	.001	.001
Autism vs. PDD	12.28	1	.001	.001
Asperger's vs. PDD	2.46	1	.117	.296
Comorbidities	.98	1	.323	.369
Schools (all three)	7.09	2	.029	
General Ed vs. Small Class	.12	1	.725	1.00
General Ed vs. Therapeutic	6.10	1	.014	.029
Therapeutic vs. Small Class	.19	1	.276	.461
P.C. Employ	2.94	1	.587	.647
Free Lunch	3.75	1	.057	.065
Home Language	.817	1	.366	.407

Note. *N* = 85

[a] two-tailed.

Similar analyses were performed to determine if children with and without comorbid diagnoses differed according to demographic characteristics. A child who exhibited one or more comorbidities was assigned to the comorbid group, while a child without any comorbidities was assigned to the no-comorbid group. The comorbid group consisted of 30 children and the no-comorbid group consisted of 55 children. The means of the two groups were then compared using the demographic factors.

As before, *t*-tests were performed on all comparisons. Pearson X^2 was further performed on those factors that had nominal variables and a Fisher's Exact Test was also performed to confirm the X^2 due to small number of children in each group. No differences in means between comorbidities and no-comorbidities groups were found in regard to age, gender, age of diagnosis, verbal/non-verbal CCC-2 scores, school type, Primary Caregiver age, eligibility for school lunch and English as a home language.

In terms of Primary Caregiver employment status, results suggested that the Primary Caregivers with children classified as having at least one comorbidity were more likely to be employed than were Primary Caregivers whose children did not have a comorbid diagnosis (see Table 55). Primary Caregiver education status was also found to significantly differentiate among children with and without comorbidities. It appears that education levels of Primary Caregivers were higher for he children classified as having one or more comorbidities (see Table 54).

Because significant differences were found in Primary Caregiver employment status and education, comparing stress and family climate measures among those with and without comorbidities were not conducted as the comparisons may be influenced by differences in these factors. Please see Tables 54 and 55 for summary of the comparisons between means of comorbid and no-comorbid groupings.

Table 54

T-tests for Differences in Means for Comorbid and No Comorbid Groupings According to Demographics

Dep. Var.	F^a	*p*	*t*	*df*	*p* (2-tailed)	*M* Difference	Stand.Error Difference	95%CI Difference
Age	4.12	.046	$.820^c$	69.28	.415	4.5	5.60	-.6.58, 15.76
Gender	.672	.415	$-.416^b$	83	.679	-.036	.087	-.210, .138
Diagnosis	9.74	.002	1.29^c	70.28	.203	.245	.191	-.135,.626
Age of Dx	.012	.913	$-.470^b$	79	.639	-2.02	4.29	-10.55,6.52
Verb/Non	.150	.700	$.982^b$	83	.329	.112	.114	-.115, .339
School Type	.020	.887	$.106^b$	83	.916	.015	.143	-.268, .299
PC Age	.001	.973	$.580^b$	83	.564	1.00	1.73	-2.44, 4.44
PC Employ.	7.10	.009	-1.42^c	72.46	.159	-.257	.180	-.616, .130
PC Edu.	3.17	.079	-2.03^b	82	.045	-.522	.257	-1.03, -.011
Free Lunch	.329	.568	$.281^b$	71	.779	.031	.110	-.188, .250
Home Lang.	8.89	.004	-1.49^c	75.87	.139	-.118	.079	-.276, .039

Note.· [a] Leven's test for equality of variances.

[b] equal variances assumed.

[c] equal variances not assumed.

Table 55

Chi-Square and Fisher's Exact Test for Differences in Means for Nominal Variables in Comorbid and Non-Comorbid Groupings According to Demographic Variables

Dependent Variable	X^2	*df*	p^a	Fisher's Exact Significance[a]
Gender	.18	1	.674	.768
All Diagnoses	4.93	2	.085	.184
Autism vs. Asperger's	1.76	1	.184	.254
Autism vs. PDD	2.15	1	.142	.192
Asperger's vs. PDD	4.85	1	.028	.072
Verbal vs. Non-Verbal	.98	1	.323	.369
Schools (all three)	1.86	2	.394	
General Ed vs. Small Class	1.67	1	.197	.401
General Ed vs. Therapeutic	.01	1	.937	1.000
Therapeutic vs. Small Class	1.84	1	.175	.355
PC Employ	6.12	1	.013	.016
Free Lunch	.08	1	.776	1.00
Home Language	1.87	1	.172	.238

Note. $N = 85$

[a] two-tailed.

Chapter V

Discussion

This chapter summarizes and discusses this study's results in terms of how caregivers ratings of language and caregiver/teacher ratings of home/school behavior relate to caregiver stress and family functioning in a sample of children on the Autism Spectrum.

Results of the Study

The purpose of this study was to examine the range of caregiver-rated language and caregiver and teacher ratings of behavioral symptoms in a sample of children on the Autism Spectrum and their relationships to self-reported caregiver stress and caregiver ratings of family functioning. Of the six hypotheses, only two received enough support to be considered partially supported.

The scores of the language measures supported Tager-Flusberg's (2001) descripton of the language functioning of children with Autism because children in both samples exhibited a wide range of functioning. As rated by their caregivers, 58.8% (50 of the 85 sample children) of the children in this sample were either non verbal, pre-verbal, or had phrase speech. Fifty percent (43 sample children) were considered verbal because caregivers were able to rate them on the CCC-2 (Bishop, 2006), which is a measure for verbal children only. Indeed, these verbal children displayed a wide range of formal language/GCC scores as well as a wide range in pragmatic/social language/SIDI scores. Unfortunately, none of the hypotheses regarding children's language and behavior and children's language and caregiver stress and family functioning received support.

The means of both caregivers' and teachers' ratings of sample children's behavior on the CBCL (Achenbach & Rescorla, 2001) Externalizing and Internalizing scales were elevated but did not reach the Borderline Range. Correlations between caregivers' and teachers' ratings of children’s behavior were generally significant but not large, ranging from .29 to .33, which supports results found by Hertig et al. (2009) who found similar correlations and attributed them to situational differences between home and school. There was a significant relationship between ratings of children with Autism’s externalizing and internalizing behaviors, particularly when rated by caregivers, and both externalizing and internalizing behaviors related positively to caregivers’ stress levels.

The Parenting Stress Index (Abidin, 1995) scores in this sample of caregivers with children with Autism were all quite high according to the manual norms (Hoppes & Harris, 1990; Rodrigue, Morgan, & Geffen, 1990). Donnenberg and Baker (1993) also found a relationship between child externalizing behavior and parental stress. The present finding of a relationship between children’s internalizing behavior and caregiver stress adds to the literature in this area.

Family environment scores for this sample were generally close to the FES (Moos & Moos, 2002) manual norms supporting Dyson's (1993) findings that children's disability did not necessarily result in deviant family functioning. However, negative family relationships in conjunction with children’s externalizing behavior predicted caregiver stress.

Implications of this Study for Practice

One important function of school psychologists is to provide service delivery to children with disabilities and their parents. As the rate of diagnosis of Autism in children is on the rise (Chakabarti & Fombonne, 2005), there has been a concomitant growth of treatment for Autism (National Research Council, 2000). Studies have found that training parents as therapists for their children produced increased therapy benefits for the children (Brookman-Frazee, 2004; Williams & Wishart, 2003). Some results indicated reduced stress in parents involved in their children's treatment, but this was not a consistent finding (Hastings & Johnston, 2000). Results of this dissertation suggest that it is important to examine the relationship between the symptoms of Autism, particularly externalizing behaviors, and parental stress and family functioning. Results of this study suggest that targeting children with Autism's externalizing behaviors may reduce caregiver stress and improve family functioning.

Patterson and Fleishman (1979) found that failing to assess the role of the family relationships may limit the effectiveness of interventions, the results of this dissertation could aid in the development of better treatments that would not only relieve maternal stress and improve family functioning, but also increase therapeutic gains for children with Autism.

As mentioned earlier, Blackledge and Hayes (2006) noted that the state of treatment for parents with children on the Autism Spectrum has not changed significantly for 20 years. Koegel et al. (1992) suggested developing programs aimed at reducing parental stress through addressing symptoms presented by children with Autism that produce stress.

Limitations

There are several limitations of this study that may have influenced the results. Future research in this area should note these limitations and work toward eliminating them. First, the sample of 85 participants is small. The small sample sized limited both the type and the power of statistical analyses. This is especially true of the analyses concerning formal and pragmatic language that included only 43 participants.

The study’s small sample may not be representative of the population of families with children with Autism. The caregivers in this sample were mainly older, well-educated, professional, and married. Many of these characteristics may serve to lessen the stress of having a child with Autism. Caregivers who are younger, single, less educated, and/or from a lower SES may have provided different results from those of this sample. Additionally, most of the children in this sample attended therapeutic schools specifically for children with ASD. Thus, these results may not be representative of children with Autism who attend community schools. Also, the sample represented a small subsample (around 25%) of those solicited. Feedback from some potential participants indicated that the time and effort required to complete questionnaires served as a deterrent to participation.

Because I did not collect demographic information from teachers, there is no way of knowing if they are typical of teachers who generally work with children with Autism. There is also no way to know if their training and/or experience related to how they rated the children.

This sample of children with Autism was between the ages of 6 to 12 years. This range was chosen specifically because it did not include preschoolers or adolescents who often present with other developmental issues related to parental stress. For this reason, these results may not apply to other age groups within the population of children with Autism.

In addition, results of this study may not be specific to the population of children with Autism. There were no contrast groups of typically developing children or children with other disabilities. Almost half (45%) of the study's sample had comorbid diagnoses and it is possible that some of the externalizing and internalizing behaviors could have been related to these comorbidities or their combination with Autism symptoms. Finally, although this study found relationships between caregiver- and teacher-rated child behavior and caregiver stress, this does not mean that the child's behavior caused caregivers' stress.

The language measures used in this study were less than ideal. The SIDI index provides an assessment of the difference between formal and social language (Bishop, 2006), but does not provide a measure of pragmatic language per se. Thus, it was not possible to examine the relationship of pragmatic language to parental stress and family functioning.

The Family Environment Scale (FES) provides a number of subscales but no overall measure of family functioning (Moos & Moos, 2002). While the test authors indicate that the 10 subscales represent 3 dimensions (Relationship, System Maintence, and Personal Growth), they do not provide norms for these dimensions or any information about their psychometric properties or scoring.

Future Research

This study was exploratory in nature. It included several measures, some with many subscales, and intercorrelated scores from all of them. This resulted in many correlations, two-thirds of which were not significant. Future research should study the relationship between the language and behavior of children with Autism and caregiver stress and family functioning in a more focused way. Instead of using several measures with many subscale scores, researchers should make more specific predictions informed by the literature using instruments that target specific behaviors. Future studies should also include larger samples that are more representative of the population of families of children with Autism, study various age groups, and include comparison groups of children.

Future research should explore the role of pragmatic/social language in the functioning of children with Autism. Results of the studies by Kjelgaard and Tager-Flusberg (2001) and Venter et al. (1992) point out the subtle relationship between language and cognition as well as language and social functioning. Indeed, Twactman-Cullen (2000) noted that the concept of social communication is relative new and that study of social/pragmatic language functioning can be confounded that of more formal language and cognitive measures. As reliable and valid pragmatic language measures are developed and become more available, researchers should use them to explore the relationship between pragmatic language and caregiver stress

Finally, more research should be devoted to the study of internalizing behavior in children with Autism and its relationship to caregiver stress and family functioning. Donnenberg and Baker (1993) found that parents of children with externalizing problems reported a greater negative impact of children's symptoms and less positive feelings toward parenting than those of typically developing children. Indeed, I have found a plethora of literature concerning the relationship of externalizing behavior to parent and family functioning, but was quite hard-pressed to find studies concerning the impact of internalizing behavior upon parents and families.

Conclusions

This study represented an exploration of the relationship between caregiver stress and family functioning and the language and behavior of children with Autism. It attempted to answer the criticism of past research concerning the wide range of language levels posed by Tager-Flusberg (2001) and behavioral levels posed by Lecavalier (2006). Both complained that the wide range of levels in these areas interfered with fully elucidating the effects of these levels on child and family functioning. Both suggested a possible answer to this is to study the range of functioning *within* this population. They suggested that this would aid in identifying important aspects and their relationships with caregiver stress and family functioning within this syndrome. Thus this study was designed to categorize and measure language and behavioral levels in a sample of children with autism in a different manner than in past research and then relate them to caregiver stress and family functioning. While most of the hypotheses were not supported, the study provides a number of possible relationships that future researchers should explore in a more targeted, systematic manner.

Appendix A

Diagnostic Criteria for Autistic Disorder
(APA,2000, p.75)

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:
- (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye contact, facial expression, body postures, and gestures to regulate social interaction
- (b) failure to develop peer relationships appropriate to developmental level
- (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by lack of showing, bringing, or pointing out objects of interest)
- (d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:
- (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
- (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
- (c) stereotyped and repetitive use of language or idiosyncratic language
- (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
- (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal in either intensity or focus
- (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
- (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flaping or twisting, or complex whole -body movements)
- (d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3: years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rhett's Disorder or Child Disintegrative Disorder.

Diagnostic Criteria for Asperger's Disorder
(APA, 2000, p.84)

A. Qualitative impairment in social interaction as manifested by at least two of the following:
  (1) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social social interaction
  (2) failure to develop peer relationships appropriate to developmental level
  (3) a lack of spontaneous seeking to share enjoyment, interests, or achievement with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
  (4) lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal in intensity or focus
  (2) apparently inflexible adherence to specific, nonfunctional routines or rituals
  (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  (4) persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (i.e., single words used by age 2 years, communicative phrases used by age 3 years).

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

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Diagnostic Criteria for Pervasive Developmental Disorder - Not Otherwise Specified
(APA, 2000, p.84)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism"-presentations that do not meet the criteria for Autistic Disorder because of the late age at onset, atypical symptomatology, or subthreshold syptomatology, or all of these.

Appendix B

IRB Approval

Office of the Vice President for Research and Sponsored Programs
Committee on the Protection of Human Subjects

The Graduate School and University Center
The City University of New York
365 Fifth Avenue
New York, NY 10016-4309
TEL 212.817.7523 FAX 212.817.1629

TO: Ms. Abigail Connolly
Educational Psychology

FROM: Richard G. Schwartz, Ph.D.
Graduate Center IRB

SUBJECT: IRB Approval (Expedited Review)

STUDY: **09-09-1836 The Impact of Pragmatic Language and Behavioral Levels of Children with Autism on Maternal Stress and Family Climate**

DATE: December 21, 2009

The Graduate Center IRB has approved the above study involving humans as research subjects. This study was Approved - Expedited Category: 7 - based on 45CFR46.

IRB Number: 09-09-1836 This number is a Graduate Center IRB number that should be used on all consent forms and correspondence.

Approval Date: 12/21/09
Expiration Date: 12/20/10

THIS APPROVAL IS FOR A PERIOD OF ONE-YEAR OR LESS. YOU SHOULD RECEIVE A COURTESY RENEWAL NOTICE BEFORE THE EXPIRATION OF THIS PROJECT'S APPROVAL. HOWEVER, IT IS YOUR RESPONSIBILITY TO INSURE THAT AN APPLICATION FOR CONTINUING REVIEW APPROVAL HAS BEEN SUBMITTED BEFORE THE EXPIRATION DATE NOTED ABOVE. IF YOU DO NOT RECEIVE APPROVAL BEFORE THE EXPIRATION DATE, ALL STUDY ACTIVITIES MUST STOP UNTIL YOU RECEIVE A NEW APPROVAL LETTER. THERE WILL BE NO EXCEPTIONS. IN ADDITION, YOU ARE REQUIRED TO SUBMIT A FINAL REPORT OF FINDINGS AT THE COMPLETION OF THE PROJECT.

Consent Form: All research subjects must use the approved and stamped consent form. You are responsible for maintaining signed consent forms for each research subject for a period of at least three years after study completion.

Mandatory Reporting to the IRB: The principal investigator must report, within five business days, any serious problem, adverse effect, or outcome that occurs with frequency or degree of severity greater than that anticipated. In addition, the principal investigator must report any event or series of events that prompt the temporary or permanent suspension of a research project involving human subjects or any deviations

Appendix C

Email Cover Letter to Directors

Dear (Principal's or Director's name):

My name is Abbie Connolly. I am a doctoral candidate in the educational Psychology PhD program at the Graduate Center of the City of New York (CUNY). I am hoping that you would be interested in helping me with my research involving mothers and families with children with Autism Spectrum Disorder.

The subject of my research is the possible connection between language and behavioral functioning of children on the Spectrum to maternal stress and family functioning. I am hoping my findings will help programs like yours develop more effective strategies for parents and families of children on the Spectrum in coping with the symptoms of autism. Of course you know this will, in turn, lead to better functioning of the children as well as alleviate stress in the home.

The data will consist of a series of well-known questionnaires and background information for the mother to complete as well as one questionnaire for the child's teacher. (Technical issues preclude fathers). So there will be little intrusion in the child's daily life. I assure you that there are several steps to ensure the confidentiality of the data. In fact, I have received approval of CUNY's Independent Review Board (09-09-1836).

I have attached a formal letter of introduction which covers most concerns of your Independent Review Board. If you have any questions, or would like to discuss any details, you may contact me at this email address: connollycuny@aol.com or by my cell phone: 718-781-5130.

Sincerely,

Abbie Connolly

Appendix D

Introduction Letter to Directors

Ph.D. Program in Educational Psychology

The Graduate School and University Center
The City University of New York
365 Fifth Avenue
New York, NY 10016-4309
TEL 212.817.8285 FAX 212.817.1516

Date

Director Name
School
Address

Dear M,

My name is Abigail Connolly and I am a student in the Educational Psychology Ph.D. Program at the Graduate Center of the City of New York (CUNY). I am conducting a study to investigate patterns of the needs of families with an autistic child that may be connected to the child's language level and/or behavior. I am hoping this information would help schools/programs like yours tailor their services to the needs of the families they serve.

In order to do this, I would like your permission to contact the mothers in your school/program. I am also going to ask them to fill out one questionnaire concerning parental stress, another questionnaire that assesses family stress, one checklist concerning the child's language another concerning their child's behavior. This should take them no more than 45 minutes to complete. The mothers will also be given a questionnaire to give to her child's teacher to complete. The mothers are free to withdraw from this study at any time without penalty or prejudice.

I assure you that all information will be held confidential and that the information gleaned from this would only be used for research purposes. I do not foresee any risks to the children or their parents. However, if a parent believes that her child is a threat to self or others, I will tell the parent to notify her child's teacher so that the proper school personnel could be alerted. There are no direct benefits to the participants themselves, but I hope the information gleaned from this project would help programs like yours.

I may publish the results of the study as well, but names of schools/programs or people will not be used in any publications. I would be happy to share the results of the study with you.

I will be contacting you in the near future in order to discuss this with you. You can contact me at CONNOLLYCUNY@aol.com, or my advisor, Georgiana Tryon, Ph.D. at Gtryon@gc.cuny.edu. You may also contact Kay Powell, IRB Administrator, (212) 817-7525, kpowell@gccuny.edu.(IRB# 09-09-1836) Thank you for your time and I look forward to speaking with you.

Sincerely,

Abigail Connolly, MA,MSEd

http://www.gc.cuny.edu

THE GRADUATE CENTER IS CUNY

The Graduate School and University Center is The City University of New York's doctorate-granting institution, which operates in consortium with all the CUNY campuses: Baruch College ○ Borough of Manhattan Community College ○ Bronx Community College ○ Brooklyn College ○ City College ○ The Sophie Davis School of Biomedical Education ○ City University School of Law at Queens College ○ The Graduate School of Journalism ○ Hostos Community College ○ Hunter College ○ John Jay College of Criminal Justice ○ Kingsborough Community College ○ LaGuardia Community College ○ Lehman College ○ Medgar Evers College ○ New York City College of Technology ○ Queens College ○ Queensborough Community College ○ College of Staten Island ○ York College

Appendix E

Introduction Letter to Mothers

Ph.D. Program in Educational Psychology

The Graduate School and University Center
The City University of New York
365 Fifth Avenue
New York, NY 10016-4309
TEL 212.017.0205 FAX 212.817.1516

Dear Mother of a child with ASD,

My name is Abigail Connolly and I am a student in the Educational Psychology Ph.D. Program at the Graduate Center of the City of New York (CUNY). I am conducting a study on the effect of autism on Mothers' Stress. I am trying to find a pattern of the needs of families with an autistic child that may be connected to the child's level of verbal and behavioral functioning. I am hoping that if I do find a pattern, this information would help schools/programs tailor their services to the specific needs of the families they serve.

In order to do this, I am asking you to fill out questionnaires that measure family and parental stress and a checklist that describes you child's language level. This should take you no more than 45 minutes. I am also asking you to give your child's teacher a questionnaire measuring your child's behavior. All questionnaires will be accompanied by a self addressed stamped envelope for everyone's convenience.

I assure you that all information will be held confidential and that the information gleaned from this study will only be used for research purposes. I do not foresee any risks to you or your child. However, if you indicate on one of the questionnaires that you believe that your child presents a danger to self or others, you should notify your child's teacher so that the proper school personnel could be alerted.

The results of this study should help all children with autism and their families by documenting their different needs. This information would help the programs that serve the specific subpopulations within autism tailor their services to meet these specific needs. Your participation would also help your school since I plan to share the results gleaned from this school/program with the principal/director. Again, I assure you that no specific child or parent or specific answers will be revealed to the principal/director, but scores from the school as a whole will be shared to help him/her know the needs of you and your children.

If you have any questions about my study, you may contact me at CONNOLLYCUNY@aol.com, or my advisor, Georgiana Tryon, Ph.D. at Gtryon@gc.cuny.edu. If you have questions about your rights as a participant in this study, you may also contact Kay Powell, IRB Administrator, (212) 817-7525, kpowell@gccuny.edu. Thank you for your time. (IRB#09-09-1836)

Sincerely,
Abigail Connolly

http://www.gc.cuny.edu
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The Graduate School and University Center is The City University of New York's doctorate-granting institution, which operates in consortium with all the CUNY campuses: Baruch College ○ Borough of Manhattan Community College ○ Bronx Community College ○ Brooklyn College ○ City College ○ The Sophie Davis School of Biomedical Education ○ City University School of Law at Queens College ○ The Graduate School of Journalism ○ Hostos Community College ○ Hunter College ○ John Jay College of Criminal Justice ○ Kingsborough Community College ○ LaGuardia Community College ○ Lehman College ○ Medgar Evers College ○ New York City College of Technology ○ Queens College ○ Queensborough Community College ○ College of Staten Island ○ York College

Appendix F

Instructions

Instructions

If you agree to participate in my study, please read and sign the enclosed consent form. I will add the "code number" when you return it to me with the completed questionnaires in the enclosed self addressed stamped envelope.

Included in the packet of questionnaires I am sending you is an envelope containing a questionnaire with another self addressed stamped envelope for your child's teacher. It is open so that you can see the teacher's questionnaire. Please put your child's name on that envelope (so the teacher knows who it is for) and seal it and give it to your child's teacher.

Also, if you do not want to fill in the Request for Copy of results form, please put a return address on the self addressed stamped envelope so that I can send you a copy of your signed consent form for your records.

I assure you that your privacy will be protected as much as possible and you may withdraw at any time without penalty or prejudice.

Thank you for helping me help parents with a child with ASD.

-Abbie

Appendix G

Caregiver's Consent Form

Ph.D. Program in Educational Psychology

The Graduate School and University Center
The City University of New York
365 Fifth Avenue
New York, NY 10016-4309
TEL 212.817.8285 FAX 212.817.1516

Consent Form

Name of Mother:____________________ Code Number:________

Name of Student:____________________ Date of Birth of Student:______

My name is Abigail Connolly and I am a student in the Educational Psychology Ph.D. Program at the Graduate Center of the City University of New York (CUNY). I am studying the effect of autism on mothers' stress. The research involves exploring how children with different levels of autism affect the family. I am asking you to fill out 5 questionnaires that I will send to you. I am also asking you to give a questionnaire to your child's teacher concerning his/her behavior. All information gathered will be kept strictly confidential, and will be stored in a locked file cabinet to which only I and my advisor will have access.

It will take about 30 to 45 minutes to complete the questionnaires. You can return the consent to me via the enclosed self-addressed, stamped envelope. You may withdraw from this study at any time without penalty or prejudice.

Since you will be filling out the questionnaires, I will have no contact with your child. Therefore, there are no foreseeable risks to you or your child. However, if there are indications that your child represents a danger to self or others, I will notify you so that the proper recommendations and/or referrals can be made. There are no direct benefits to the participants of this study, but the results may inform those who work with children with autism about the populations they serve and their families' needs.

I may publish the results of the study, but the names of people, or any identifying characteristics, will not be used in any of the publications. If you would like a copy of this study, please provide me with your address and I will send you a copy in the future.

If you have any questions about this research, you can contact me at (718) 437-7494 or CONNOLLYCUNY@aol.com, or my advisor Georgiana Tryon at gtryon@gc.cuny.edu. If you have questions about your rights as a participant in this study, you can contact Kay Powell, IRB Administrator, The Graduate Center/City University of New York, (212) 817-7525, kpowell@gc.cuny.edu. (IRB#09-09-1836)

Thank you for your participation. As stated earlier, you may withdraw from this study at any time without penalty. I will send you a copy of this form when you return it to me.

I agree to fill out the questionnaires that will be sent to me. Please circle: YES NO

______________________________ ______________________________

Participant's Signature/Date Abigail Connolly/Date

http://www.gc.cuny.edu

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Appendix H

Request for Copy of Results

Request for Copy

I would like a copy of the final written study of Abigail Connolly's study sent to the address below:

Name:___________________________________

Address:__________________________________

____

____
Signature/Date

Appendix I

Blog Flyer

Research Study: Request for Participation

By: Abbie Connolly

Finding a cure for autism is essential, but it is a long process. I am running a study which may help children with Autistic Spectrum Disorders and their families now. My name is Abbie Connolly and I am a doctoral candidate at the City University of New York. The subject of my research is the possible connection between language and behavioral levels of children with ASD and maternal stress and family functioning. I am hoping that my research may help programs develop more effective strategies for parents and families with children on the Spectrum in coping with the symptoms of autism

The participants in my study would be mothers of children with ASD. The children must be between the ages of 6-12 years old. They must be diagnosed with ASD (autism, Asperger's Disorder or PDD-NOS) by a medical doctor, neurologist, psychiatrist or licensed psychologist. The data will consist of a series of well-known questionnaires and background information for the mother to complete and one questionnaire for the child's teacher.

I assure you there are several steps to ensure the participants' privacy. I was approved by CUNY's Independent Review Board (#09-09-1836). If you would like to participate, please email your name and address to: connollycuny@aol.com and I will send you a letter of introduction and a consent form with a self addressed stamped envelope via post. When I receive signed consent, I will send you a packet of the questionnaires along with the teacher's questionnaire along with self addressed stamped envelopes. You may stop participation at any time. Please feel free to contact me at my email address if you have any questions.

Abbie Connolly

Appendix J

Demographic Questionnaire

Code Number: _______

Demographic Questionnaire

Please complete as fully and accurately as possible. Please feel free to add information.

YOUR CHILD:
General Information:
Child's Date of Birth: ______
Child's Age: ______
Child's Gender: _____
Eye Contact: yes / no / other: (explain):______________________________
Language Level: (Please Check):
    ______Non-Verbal= does not speak with words
    ______Pre-Verbal=uses gestures/one word utterances
    ______Phrase Speech=two/three word utterances
    ______Verbal=at least able to put words into simple sentences
Was your child diagnosed as being on the Autistic Spectrum? yes / no
    If so, by whom? (check)
    ______Medical Doctor
    ______Neurologist
    ______Psychiatrist
    ______Licensed Psychologist
    ______Other:____
    Diagnosis:
    ______Autism
    ______Asperger's Disorder
    ______PDD-NOS
    ______Other: ____
At what age was your child diagnosed as being on the Spectrum?_________
Does your child have any other diagnosis? (circle) yes / no
    If so, what are they?____
____
Does your child have any other medical issues? (circle) yes / no
    If so, what are they?____
Is your child on medication? (circle) yes / no
    If so, what is it and what is it for?____________________________
____

Appendix J (con't)

Code Number: ________

Your child's school:

What kind of school is your child in?

_____general education

______therapeutic school

What is the child:teacher ratio of your child's class?___________

Does your child receive additional Special Education services in school? yes / no

If so, what are they? (check all that apply and please add frequency, duration and group size)

_____________SETSS

_____________Speech/Language

_____________ABA

_____________Occupational Therapy

_____________Physical Therapy

_____________Counseling/Social Skills

Other: ____

Does your child receive Special Education Services at home? yes / no

If so, what are they?____

____

Your Involvement in Your Child's Education:

Are you involved in your child's therapy? Yes / no

If so, please describe: (e.g. ABA)_____________________________

____

How often do you do this?

______ times a day

______times a week

How were you trained? ___________________________________

____

What kind of supervision do you receive?_____________________

____

How often is the supervision?______________________________

____

YOUR HOME:

Mother's/Primary Caregiver's Information:

Age:______

Appendix J (con't)

Code Number: _______

Marital Status:
_____single
_____married
_____divorced
_____other:_________________
How long have you been in the current relationship (if applicable)?_____
Employment (check all that apply)
_____not employed
_____employed in the home
_____employed outside the home
_____part-time
_____full-time
Occupation: (please state) ______________________________
Please check last grade completed:
_____less that 7th grade
_____7th/8th grade
_____Junior High School (9th grade)
_____Some High School (10th or 11th grade)
_____High School Graduate
_____Some college or specialized training
_____College graduate
_____Graduate school
Were you born in this country? Yes / no
The best way to describe your ethnicity is:_______________

Father's/Secondary Caregiver's Information (if applicable)
Age:_____
Marital Status:
_____single
_____married
_____divorced
_____other: ____
Employment (check all that apply)
_____not employed
_____employed in the home
_____employed outside the home
_____part-time
_____full-time
Occupation: (please state)________________________________

Appendix J (con't)

Code Number: ________

Please check the last grade completed:
_____less than 7th grade
_____7th/8th grade
_____Junior High School (9th grade)
_____Some High School (10th or 11th grade)
_____High School Graduate
_____Some college or specialized training
_____College graduate
_____Graduate school
Was s/he born in this country? yes / no
The best way to describe his/her ethnicity is: _______________
____

Is your child eligible for school lunch? yes / no

Your Family:
How many adults (i.e. over 18 years) are living in your household? _______
How many children (i.e. under 18 years) are living in your household?_____
How many brothers and/or sisters of your child are living at home?
_____brothers
_____sisters
Your child's birth order is: _____of _____children

Are there any other siblings diagnosed with a disability? yes / no
If so, how many?_______
What is/are the diagnoses?________________________________
____

Is there contact with extended family not living in the home? yes / no
If so, how often?
_____daily
_____once or twice a week
_____weekly
_____monthly
_____on holidays/birthdays
Are they involved in more than 25% of your child's daily life? yes / no

Home Language:
Is English the only language in your home? yes / no
If not, what other language(s) is/are spoken? ____________________

Appendix J (con't)

Code Number: ________

How often is your child exposed to this language?
_____daily
_____weekly
_____infrequently
How does your child understand this language?
_____does not respond at all
_____can respond non-verbally to simple commands
_____can respond verbally to questions with one or two words
_____fluent

Support Systems outside the school:
What kind of support are you involved in? (check all that apply)
_____none
_____Individual Therapy
_____Family Therapy
_____Parent Support Group
_____Sibling Support Group
_____Other:____
How did you learn about this support?
_____through your child's school
_____community support group (e.g. Autism Society of America)
_____self
_____other:____
Is there any other support that is not mentioned? Please specify:

Thanks for your help!

Appendix K

Key Sheet

Code Number ______________

Key Sheet

Demographic Information

Child

Source of participation ___
Age ______
Gender____
Eye Contact_____
Language Level_____
Doctor_____
Diagnosis_____
Age of Diag_____
Cormorbidities_____
    What cormorbidities____________________________
Medical Issues_____
    What Issues__________________________________
Meds __________
    What Meds_________________________________

School

Type of school______________
Child:Teacher Ratio__________
Related Services
    SETSS___
    Sp/Lang_____
    ABA_____
    OT_____
    PT_____
    Counseling_____
Home Services_____

Parent Involvement

Involvement_____
Often Daily_____
    Weekly____
Trained_____
Supervision_____
Often Supervised________

Appendix K (con't)

Code Number ______________

Home

Primary Caretaker

Age_____

Marital Status_____

How long relation_____

Employment_____

Occupation_____

Education_____

Native of US_____

Ethnicity

Secondary Caretaker

Age____

Marital Status_____

Employment_____

Occupation_____

Education_____

Native to US_____

Ethnicity_____

Eligible for school lunch_____

Family

No. adults_____

No. children_____

Siblings Brothers_____

Sisters_____

Sibs with Disability_____

How many_____

Diagnosis_____

Contact with extended family_____

How often_____

Involvement more than 25%_____

Home Language

English only_____

Other Language______

Often exposed to second language______

Appendix K (con't)

Code Number _____________

How fluent_____

Support Systems_____
How learned about them?_____
How Many? ______
__None ___IndTheapy ___Group Therapy ___Support Grp ___Sib Support

CCC-2 (T scores)
Speech_____
Syntax_____
Semantics_____
Coherence_____
Initiation _____
Scripted Language_____
Context_____
NonVerb Comm_____
Social Relations_____
Interests_____
GEN COMM COMPOSITE_____
SIDI_____

CBCL -Parent (T scores)
Anxious/Dep_____
Withdrawn/Dep_____
Somatic Complaints_____
Social Probs_____
*Thought Probs_____
*Attention Probs_____
Rule breaking Behave_____
Aggressive Behave_____
EXTERNALIZING _____
INTERNALIZING_____
TOTAL PROBS_____

FES (standard scores)
*Relationship Domain_____
    Cohesion _____
    Expressiveness_____
    Conflict_____
Personal Growth Domain_____
    Independence_____
    Achievement _____
    Intellectual __
    Active/Rec___
    Moral___
System Maintenance_____
    Organization___
    Control ____
***Internal Workings____**
External Workings____

PSI-SF	Raw	%ile
(def respond)	___	___
Parental Distress	___	___
Parent-Child Dys	___	___
Difficult Child	___	___
Total Stress	___	___

Appendix K (con't)

Code Number ______________

CBCL-Teacher (T scores)
Anxious/Dep_____
Withdrawn/Dep_____
Somatic Complaints _____
Social Probs _____
*Thought Probs_____
*Attention Prbs _____
Rule breaking Behave_____
Aggressive Behave ______
EXTERNALIZING _____
INTERNALIZING _____
TOTAL PROBS _____

Appendix L

CCC-2 Subtest Scores

Table 30

CCC-2 scores

Scale	Range	*M*	*SD*
Speech	0-13	6.33	4.31
Syntax	0-12	4.85	4.04
Semantics	0-13	6.15	3.58
Coherence	0-10	4.96	2.83
Scripted Language	0-11	4.52	2.65
Context	0-10	5.04	2.84
Non verbal Comm.	0-13	4.41	2.80
Social Relations	0-10	4.54	2.81
Interests	0-12	4.59	2.99
GCC	**0-120**	**75.13**	**25.30**
SIDI	**-27 - +13**	**-2.93**	**10.48**

Appendix M

CBCL Parent Report Form Scores

CBCL-Parent Report Form scores

Scale	*M*	*SD*	Range
Anxious/Depressed	56.94	7.74	50-76
Withdrawn/Depressed	64.07	8.94	50-82
Somatic Complaints	56.56	8.26	50-80
Social Problems	63.12	9.29	49-98
Thought Problems	67.05	10.51	50-93
Attention Problems	70.02	12.72	50-100
Rule Breaking Behavior	65.87	89.95	50-83
Aggressive Behavior	62.04	9.93	50-89

Appendix N
CBCL-Teacher Report Form Scores

CBCL-Teacher Report Form Scores

Scale	*M*	*SD*	Range
Anxious/Depressed	55.11	5.64	50-73
Withdrawn/Depressed	59.82	8.29	50-86
Somatic Complaints	53.27	5.15	49-70
Social Problems	59.82	6.29	49-72
Thought Problems	67.14	6.82	51-80
Attention Problems	60.34	7.04	50-83
Rule Breaking Behavior	54.94	5.10	50-66
Aggressive Behavior	61.63	6.51	50-83

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