Parenting Stress in Mothers of Preschool Children Recently Diagnosed with Autism Spectrum Disorder

by

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ABSTRACT OF THE DISSERTATION

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Parenting stress is a significant psychological phenomenon when individuals feel difficulty with parental role fulfillment. Greater parenting stress is expected theoretically and experienced empirically by parents of children with Autism Spectrum Disorder (ASD). Theorists postulate maternal parenting stress is influenced by the perception of aberrant child behavior severity, future expectations, perceived availability and utility of social support, and maternal age.

Previous literature has insufficiently addressed the theoretical propositions that correlate these factors to parenting stress in mothers of recently diagnosed young children. The purpose of this study was to assess parenting stress and possible associated variables in mothers of young children during the first year after an ASD diagnosis. It was hypothesized that perceived severity of aberrant behavior and maternal age would be positively related to parenting stress. Parental expectations and social support levels were anticipated to be inversely related to parenting stress in mothers.

A convenience sample of 75 biological mothers of children with ASD aged 5 years or less whose diagnoses were made less than 12 months prior to study enrollment was recruited from a national sample. A demographic questionnaire and 4 paper and pencil instruments were utilized. Bivariate correlation coefficients and a multiple regression were calculated for the variables under study.
A moderate, positive correlation between perceived severity of aberrant behavior and parenting stress was established. Low negative correlations between evaluations of family support and parenting stress and between future expectations and parenting stress were also found. Contrary to the hypothesis, a low negative correlation between maternal age and parenting stress was substantiated. Maternal expectations and perceived severity of aberrant behavior proved most significant, accounting for 32% of total variance in reported levels of parenting stress.
Dedication

This dissertation is dedicated to my first born son, whose bravery and perseverance are so inspiring. You have taught me what it really means to be a parent, and the mother of a child with ASD. Although I have learned so much from your struggles, I realize we have far to travel yet. The following work is part of my lifelong commitment to you, the other children with ASD, and their families.

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Most importantly, none of this would have been possible without the love and patience of my family who have been a constant source of love, concern, support and strength all these years.

My parents have been ideal role models for the many aspects of parenthood. Their examples initiated an interest in studying the discipline of parenting. They have served as emotional anchors throughout a doctoral education. They inspired me to always set high goals and provided the confidence with which to achieve them. I love you both so very much.

My husband, my life-partner, and co-parent. You continued to be both proud and supportive of my work during the years of uncertainties, challenges, and sacrifices needed to complete this dissertation. You are both husband and friend.

To my youngest child, my second son. Born into a life of academe, you always share a space on mamma’s lap with a text book. I love you, sweetheart, and thank you for your patience.
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Chapter 1

The Problem

Parenting stress is a significant psychological phenomenon that occurs when the responsibilities of parenting is appraised as exceeding one’s resources, leaving individuals to feel they have difficulty filling the role as a parent. The stress the parent experiences is theoretically believed to be an outcome of parent and/or child characteristics, and may be a result of parent-child interactions. Often, parenting stress is attributed to caring for a child who has physical or developmental attributes that are perceived by the parent to be difficult to manage and lead to a feeling of dissatisfaction (Abidin, 1990). Parenting stress differs from family stressors, as it develops from within the family system, as opposed to external sources such as economic inflation or unemployment. Parenting stress may overwhelm the parent’s ability to cope with the stressor and result in several negative outcomes for the parent, child and family (McCubbin & Figley, 1983).

Autism Spectrum Disorder (ASD) is theorized to be the most challenging developmental disability. Empirical studies support the hypothesis that parents of children with ASD experience more parenting stress than those raising children with other developmental disabilities, or than those of typically-developing children (Bouma & Schweitzer, 1990; Dumas, Wolf, Fisman, & Culligan, 1991; Holroyd, Brown, Wikler, & Simmons, 1975; Hoppes & Harris, 1990; Kasari & Sigman, 1997; Mickelson, Wroble, & Helgeson, 1999; Piven et al., 1994; Rodrique, Morgan, & Geffken, 1990; Seligman & Darling, 2007; Weiss, 2002; Wolf, Noh, Fisman, & Speechley, 1989). Parenting stress has been studied in parents of children with ASD for three decades, attempting to define
the level of stress experienced, antecedents and consequences of stress, and the variables associated with the development of this phenomenon.

ASD are a group of neurobiological conditions defined by significant lack in social skills, impairment in communication development, and the ongoing presence of aberrant behaviors and uncommon interests for children. Symptoms may present by 12 months of age, and a firm diagnosis is usually made by the age of three years (Chawarska, Klin, Volkmar, & Powers, 2008; Couteur, Haden, Hammad, & McConachie, 2007; DHHS, 2007; Rutgers, Van Ijzendoorn, Bakermans-Kranenburg, & Swinkels, 2007). The *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR) (American Psychiatric Association, 2000) categorizes ASD as pervasive developmental disorders that include Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

The diagnostic criteria for ASD have changed throughout the years. The earliest indication in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) was found in the DSM-II (1968) where the word “autism” appears under the diagnostic category for schizophrenia, childhood type. The first diagnostic criteria for “Infantile Autism” and Pervasive Developmental Disorder were published in the DSM III (1980), and later revised to PDD-NOS in the DSM-III-R (1987). It was not until 1994, when the DSM-IV contained diagnostic criteria for the above mentioned ASD categories, and has since been refined again in the DSM IV-TR (2000) (Grinker, 2007).

Therefore, in the literature published before the 1980s, the term "autism" was used primarily to refer to what is now classified as autistic disorder on the ASD spectrum.
Many empirical studies published after 1990, used the improved diagnostic criteria that included the broader spectrum of disorders (DDHS, 2009). Children of the participants in these studies were diagnosed with Autistic Disorder, PDD-NOS, or Asperger’s Disorder, although the term “autism” is still used as synonymous with ASD. The improved diagnostic standards are believed to have raised the prevalence rates of children with ASD, and additionally assist in reducing measurement error in the literature (Shattuck, 2006).

According to the *Diagnostic and Statistical Manual of Mental Disorders* DSM IV-TR (2000), the diagnostic criteria for Autistic Disorder includes the presences of three impairments: 1) a qualitative dysfunction in social interaction that is manifested by either a marked impairment in the use of multiple nonverbal behaviors to regulate social interaction (lack of eye-to-eye gaze, facial expression or body postures), failure to develop peer relationships, and/or lack of social or emotional reciprocity; 2) A qualitative impairment in communication manifested by a delay or lack in the spoken language unaccompanied by alternative attempts to communicate, impairment to initiate conversations in individuals with adequate speech, and/or the use of stereotyped, repetitive, idiosyncratic language; and 3) The presence of repetitive and stereotypical patterns of behavior, interests and activities that elicit a preoccupation that is considered abnormal in either intensity or focus. The child can be inflexible to changes in specific routines and rituals, may demonstrate repetitive motor mannerisms, and may have a persistent preoccupation with parts of objects (American Psychiatric Association, 2000, pp.69-70).
The diagnostic criteria for PDD-NOS include a severe impairment in the development of reciprocal social interaction, either verbal or nonverbal communication, and may be accompanied with stereotyped behavior, interests, and activities, but the criteria are not met for Autistic Disorder usually due to sub-threshold symptomology (American Psychiatric Association, 2000, pp.77-79).

The diagnostic criteria for Asperger’s Disorder includes the presence of a qualitative impairment in social interaction, and restricted repetitive and stereotyped patterns of behavior, interests, and activities, causing a clinically significant impairment in functioning. Children with Asperger’s Disorder do not have a significant delay in spoken language, development of age-appropriate self-help skills, adaptive behavior, or cognitive development (American Psychiatric Association, 2000, pp.75-77).

Researchers have attempted to identify which of the impairments relate to the perceived stress in parents. Significant sources of stress in parents of children with ASD have been identified to include the unpredictability of aberrant or difficult to manage externalizing behavior, ambiguity of diagnosis, poor acceptance of stereotypical or repetitive behaviors by society and family members, and concern over the life-span duration of the diagnosis (Bebko, Konstantareas, & Springer, 1987; Boyd, 2002; Bromley, Hare, Davison & Emerson, 2004; Gabriels, Cuccaro, Hill, Ivers, & Goldson, 2005; Hastings, 2003; Holroyd et al., 1975; Kasari & Sigman, 1997; Konstantareas & Homatidis, 1989; Konstantareas & Papageorgiou, 2006; Lecavalier, Leone, & Wiltz, 2006; Seligman & Darling, 2007; Sharpley & Bitska, 1997). The diminished social responses of the child with ASD were found to result in lower perceived parent-child attachments, decreased maternal gratification, and increased stress (Hoppes & Harris,
Negative outcomes have been predicted for parents of children with ASD with high parenting stress levels, including the development of anxiety, depression, anger, and reduced marital intimacy (Boyd, 2002; Bristol, Gallagher, & Holt, 1993; Bromley et al., 2004; Duarte, Bordin, Yazigi, & Mooney, 2005; Fong, 1991; Mickleson et al., 1999; Moes, Koegel, Schreibman, & Loos, 1992; Sharpley & Bitsika, 1997). Studies have revealed that parenting stress may increase the risk for development of dysfunctional parenting behavior and affective disturbances in both parent and child (Duarte et al., 2005; Phetrasuwan & Miles, 2009; Rodrique et al., 1990; Tomanik, Harris, & Hawkins, 2004).

Parenting stress has been found in several studies to be higher in mothers of children with ASD than in fathers (Bebko et al., 1987; Boyd, 2002; Hastings & Brown, 2002; Little, 2003; Moes et al., 1992; Sharpley & Bitsika, 1997). Yet other studies have revealed no distinction in levels of parenting stress when comparing mothers and fathers of children with ASD (Hastings, 2003; Hastings et al., 2005; Holroyd et al., 1975; Konstantareas & Homatidis, 1989; Milgram & Atzil, 1988). As the usual primary caregiver of children with ASD, mothers have been identified as the parent who develops a unique relationship with their children. Their attributes and problems have become the focus for many research efforts examining parenting stress. This stress has been found in mothers of different ages, many ethnicities, and is present in a number of geographical areas (Bishop, Richler, Cain & Lord, 2007; Boyd, 2002; Dale, Jahoda, & Knott, 2006; Duarte et al., 2005; Hoppes & Harris, 1990; Koegel et al., 1992; Mantymaa, Puura, Luoma, Salmenin, & Tamminen, 2006; Rodrique et al., 1990; Tomanik et al., 2004).
In studies in which mothers were asked to recall their feelings regarding time of diagnosis, participants report that the years immediately before diagnosis, as well as the time up to one year post-diagnosis, were characterized by great increases in stress (Dale et al., 2006; Gray, 2002; Howlin & Asgharian, 1999; Norton & Drew, 1994; Whittaker, 2002). Despite theoretical premises and empirical findings, there have been few adequate studies exploring maternal reactions at the time of diagnosis. Theorists posit that the diagnosis of an ASD disability may result in a crisis in the task of parenting for which few are prepared. Post-diagnosis, defined as up to one year after diagnosis, is a period in which definitive information is gathered or confirmation of potentially chronic disability established. This time period is believed to be the most stressful when evaluating the years devoted to parenting. Parents may be poorly prepared to meet the special needs of the child, lack the capacity for therapeutic care, lack awareness of accessible resources, or lack knowledge of existing community services (McCubbin & Figley, 1983; Seligman & Darling, 2007).

Several antecedent factors to parenting stress have been examined empirically at various times after diagnosis. Younger children and those with more severe aberrant behavior relating to ASD symptoms have been perceived to be more stressful (Bebko et al., 1987; Bishop et al., 2007; Couteur et al., 2007; Duarte et al., 2005; Hastings et al., 2005; Kassari & Sigman, 1997; Koegel et al., 1992; Little, 2003; Rodrique et al., 1990; Tomanik et al., 2004; Webster-Statton, 1990).

Expectations that parents hold for their child’s future may influence parenting stress in this population. Lower expectations may lead to higher stress levels in parents of a child with a developmental disability (Ivey, 2004; Dale et al., 2006, Seligman & Darling,
2007; Wong & Heriot, 2007). Dunst and Trivette (1986) assert that the higher the expectations held for the child’s future, the more likely the parent expects the child to live independent of the family. Low expectations in regard to the child’s future potential to be financially independent, care for self, and manage one’s affairs can affect parental well-being. In one study, parental expectations for their child were surveyed at the time of diagnosis and found to vary from limited to very high. This study, however, did not examine a relation to parental stress specifically (Dale et al., 2006).

Advanced maternal age has been positively correlated to higher parenting stress levels, but has not yet been tested as a predictor of stress (Duarte et al., 2005; Koegel et al., 1992, Konstantareas et al., 1989; Pakenham, Samios, & Sofronoff, 2005; Rodrique et al., 1990). Older mothers are believed to have less energy than younger mothers, and may find childcare more difficult and exhausting. Peers and family support may be less available to older mothers. Peers age 35 and older may have older children and teenagers, and may not carry the same perspective as a mother of a toddler or preschooler. Family supports may also be lacking as grandparents may be older, and not be as able to assist with childcare to the extent that younger grandparents may (McKinney, James, Murray & Ashwill, 2005).

A potential strong predictor to parenting stress is social support. Social support has been found to be to have an inverse relationship to stress (Bishop et al., 2007; Bromley et al., 2004; Bristol, 1987; Gill & Harris, 1991; Konstantareas & Homatidis, 1989; Hastings et al., 2005; Sharpley & Bitsika, 1997; Pakenham et al., 2005; Webster-Statton, 1990), and as a moderating variable to stress (Dunn, Burbinem Bowers & Tantleff-Dunn, 2001; Wolf et al., 1989).
There is a gap in the literature testing the theoretical proposition that at the time of diagnosis, advanced maternal age, low parental expectations, aberrant behaviors of the child, and limited or inadequate social support predicts the development of parenting stress. The purpose of this study is to examine the level of parenting stress and associated variables in mothers of children with ASD within the first year of diagnosis. The findings from this study may assist in predicting parenting stress at time of diagnosis and the year that follows. Future nursing interventions for stress reduction in the form of providing anticipatory guidance and formal social support can be developed and then tested to reduce parenting stress in mothers of young children recently diagnosed ASD.

**Statement of the Problem**

What are the relationships among perceived severity of problem behavior, maternal expectations for the child, maternal age, social support and parenting stress in mothers of preschool aged children diagnosed with ASD within the first year following diagnosis?

**Subproblems**

In the first year following diagnosis:

1. Is perceived severity of aberrant behavior a predictor of parenting stress in mothers of preschool aged children diagnosed with ASD?
2. Are maternal expectations for the child a predictor of parenting stress in mothers of preschool aged children diagnosed with ASD?
3. Is maternal age a predictor of parenting stress in mothers of preschool aged children diagnosed with ASD?
4. Is social support a predictor of parenting stress in mothers of preschool aged children with ASD?

**Definition of Terms**

Parenting stress is defined as a relationship between the parent and the environment in which the parent appraises the demands of being a parent as exceeding one’s resources, leaving the parent to feel she or he has difficulty filling the role of parent (Abidin, 1990). Parenting stress will be operationally defined by the total score on the Parenting Stress Index-short form (PSI-SF) (Abidin, 1995).

Autism Spectrum Disorders (ASD) is a group of developmental disabilities characterized by significant impairments in social interaction and communication and the presence of unusual behaviors and interests (American Psychiatric Association, 2000). Autism Spectrum Disorder will be operationally defined as the type of ASD reported by the participant in the demographic questionnaire.

Recently-diagnosed is defined as a unit of time during which parents process a confirmation of their child’s unanticipated chronic disability (Seligman & Darling, 2007). Recently diagnosed will be operationally defined as a date indicated on the demographics questionnaire that is within one calendar year from enrollment.

Preschool age is defined as the years prior to entering kindergarten. The young child of this age is exposed to more people outside the family and initiates new activities and responsibilities than was true earlier in life. The child may be developmentally ready to be exposed to pleasant stimuli and receive positive feedback from an adult in a school setting (Ball, Binder & Cohen, 2009). Preschool age child will be operationally defined
as being less than 60 months of age at the time of enrollment as reported on the
demographic questionnaire.

Severity of aberrant behavior is defined as the child’s characteristics and symptoms
related to ASD that are perceived as by the parent as difficult to manage. Such behavior
is described as maladaptive, inappropriate, antisocial and disruptive (Aman, Sing,
Stewart, & Field 1985). Severity of aberrant behavior will be operationally defined as the
total score on the Aberrant Behavior Checklist-Community (ABC-C) (Aman & Sing,
1985).

Child expectations are the beliefs held by a parent in regard to their young child’s
future progress in behavioral competencies and capabilities (Dunst & Trivette, 1986).
Child expectations will be operationally defined as the total score on the Child
Expectations Scale (CES) (Dunst & Trivette, 1986).

Maternal age is defined as the age of the mother at the time of the study. “Older”
mothers are defined as mothers age 35 and older. “Younger” mothers will be defined as
participants through age 34 (McKinney et al., 2005). Maternal age will be operationally
defined as the age of the participants collected on a demographic sheet.

Social support is using physical assistance, resource and information sharing for
purposes of emotional and psychological attitude transmission that may come from
informal sources or formal services (Dunst, Trivette & Jenkins 1986). Social support will
be operationally defined as the total score on the Family Support Scale (FSS) (Dunst et
al., 1986).
Delimitations

The sample for this study was delimited to accessible, biological mothers of children diagnosed with ASD five years of age or under by a qualified health care provider. The mother of the diagnosed child had to live with, provide care for and raise the child. Mothers also had to be registered with the Interactive Autism Network (IAN) community online research registry and reside in the United States. To reduce measurement error, the sample was delimited to mothers who read English and demonstrated the ability to use a computer, send and receive email, and access the internet. The mother must report diagnosis was made within one year of enrollment by a valid and reliable screening tool or multi-professional team during the preschool-age years. This is consistent with the average age of and professional standards for diagnosis (Couteur et al., 2007; Filipek et al., 2000).

Significance

The spectrum of autism disorders has gained widespread attention due in part to its rapidly increasing rate of diagnosis. Currently, an estimated one in every 110 children is diagnosed in the United States each year (DHHS, 2009). This is an increase from the previous ASD estimate in 2006 of one in every 150 children (DHHS, 2007). ASD’s are more prevalent than other developmental disabilities, such as Down syndrome, which occurs in about 1 in 800 children. It is also higher than other childhood illnesses, such as Juvenile Diabetes, and childhood cancer, with prevalence rates of 1 in 400 children, and 1.5 in 10,000 children, respectively (DHHS, 2007). These estimates suggest that one in every 110 parents will be at significant risk for development of parenting stress because
of their child’s ASD diagnosis and therefore in danger of developing negative health outcomes.

The theoretical literature speculates that when a child is diagnosed with ASD, parents will report a high level of parenting stress (Abidin, 1990; McCubbin & Figley, 1983; Seligman & Darling, 2007). Empirical findings suggest there are significant relationships among the mother’s perceived severity of the diagnosed child’s aberrant behavior, expectations for the child, maternal age, perceived social support, and level of parental stress are directly related and possibly predictable. High levels of aberrant behavior, low expectations for the child, advanced maternal age, and low levels of social support may be predictors of the development of parenting stress.

Despite the theoretical beliefs and empirical findings, there have been few adequate studies exploring maternal reactions at the time of diagnosis. The findings from this study will assist in understanding and predicting maternal stress at time of diagnosis. Nurses who work with families raising children with this disability continually seek ways to improve family functioning. Nurses working in settings that provide ongoing contact with the affected child and family have the opportunity to develop a trusting, long-term relationship, with the goal to limit the stress parents experience as a result of the diagnosis of ASD. Another objective is to restrict the development of detrimental health consequences in both parent and child. Scarcity of professional resources and a lack of structured social support have been found to contribute to increases in reported parental stress at varied intervals post diagnosis (Rodrigue et al., 1990; Whitaker; 2002). The findings from this study can assist in the development and testing of nursing interventions as a part of a social support network to reduce stress in these mothers.
Chapter 2

Review of the Literature

This research study examined the relationships among parenting stress in mothers of recently diagnosed preschool age children with ASD, contexts of maternal age, levels of perceived social support, apprehension of severity of the aberrant behavior, and the evolving expectations for the diagnosed child. Theoretical and empirical literature related to these variables and relationships are discussed in the present chapter. The chapter’s first section reviews theories related to the development of parenting stress as a dependent variable. Established empirical literature regarding parenting stress in parents of children with ASD follows. The second section presents theoretical literature relevant to aberrant behavior and parenting stress followed by empirical support for the relationship between these variables. Expectancy theory and empirical support relevant to both expectations for the child and parenting stress are the next concerns. Theoretical literature pertaining to maternal age as precursor of parenting stress, followed by empirical literature supporting the relationship between maternal age and parenting stress is then introduced. Finally, theoretical literature related to social support and the empirical literature supporting its relationship with parenting stress in parents of children with ASD is discussed.

Theories of Parenting Stress

In 1995, Abidin’s publication of a tool for measuring parental stress marked a significant milestone in the understanding of this stress. He defines parenting stress as a chronic emotional phenomenon that a parent experiences as part of this primary role and direct interaction with children. Parenting stress is understood to be a psychological
feeling of ‘being trapped’ by parenting responsibilities. This stress results from the perception that the requirements of parenting exceed an individual’s resources. Complex and demanding parental duties involved in raising a child with a physical or developmental disability within the context of limited personal, physical, and financial resources are antecedents of this response. If a parent senses deficient skills when attempting the tasks of parenting, apprehension for both immediate and future failure in this role can develop and lead to continual parenting stress.

Stress in the parenting system during the first three years of life is a critical factor in a child’s emotional and behavioral development. It is also foundational in the creation of the parent-child relationship. The effects of stress are theorized to contribute to poor parental and child outcomes. Parenting stress can lead to the development of problems in parental health, lack of both recognition and rewards within the parenting role, and ultimately, dysfunctional parenting itself (Abidin, 1995).

The antecedents for the development of parenting stress are theorized as multidimensional and can be attributed to three major domains. The first two involve either or both parental distress and difficult child characteristics. These two domains can also interact to create a third domain and a dysfunctional parent-child interaction pattern. Distress in any of these domains can subsequently lead to parenting stress (Abidin, 1995).

Parental distress results after those personal factors necessary to functioning in the role of a parent and subsequent execution of parenting tasks are utilized. Its components include an impaired sense of parenting competence, stress from other roles in one’s life, conflict with the child’s other parent, a lack of social support, and the presence of depression (Abidin, 1995).
The perception of a difficult child is an antecedent to parental stress, arising from the appraisal that this child’s characteristics make him or her hard to parent. Difficult children are described as having a complex temperament, problems with self-regulation, or those who may have practiced patterns of defiant, noncompliant, and/or demanding behavior. The child may adapt poorly to change and transitions, display aggression and hyperactivity, and possess other socially undesirable characteristics. The child’s needs become a continuous drain on the parent’s energy in management and produce a feeling of dissatisfaction within the parenting role (Abidin, 1995).

Both parental and child attributes can interact to create the third antecedent to the development of parenting stress, a dysfunctional parent-child interaction. This is the parent’s perception that the child does not meet expectations, and that their reciprocal interactions do not reward the role of the parent. All three of the antecedents are posited to be additive and to stem primarily from parental perceptions (Abidin, 1995).

Parents of young children with developmental disabilities have also been theorized to be at higher risk for the development of parenting stress. Seligman and Darling’s (2007) conceptual framework finds more sources of parenting stress associated with childhood illness and disabilities. They include the dimensions of intellectual, instrumental, emotional, and existential stress.

Seligman and Darling (2007) posit that parenting a child with a disability may be analyzed within four specific time periods for the parent: post diagnosis, school-entry, school completion, and when the parents themselves become elders. Post-diagnosis, the crisis of definitive information or the confirmation of a chronic disability is theorized to
carry the highest risk for stress development. Although stress at this time may produce a negative reaction in some parents, it may also serve to strengthen cohesion in families.

During the post-diagnosis time frame, the parent of a young child with a developmental disability can experience intellectual stress associated with the quest for information regarding etiology, prognosis, and treatment. Further intellectual stress is experienced in the attempt to understand the disability and absorb a vast amount of information. Parenting strain increases when the additional duties of integrating the child’s care into the lifestyle of the parents and family become evident. Parents must attend to their child’s disability needs at the same time as their own. Disequilibrium may result if the parent is ill equipped to attend to the child’s cumulative needs (Seligman & Darling, 2007).

Emotional stress is a response to the demands of caring for a child with a developmental disability. Its characteristics include lack of sleep, loss of energy, and excessive worry and anxiety. Pervasive uncertainty regarding a child’s prognosis can compromise the parent’s sense of control (Seligman & Darling, 2007).

Existential stress is also theorized to occur in parents of children with a developmental disability. Existential stress describes a parent’s inability to construct a meaningful explanation for this experience. The continuing presence of the child’s disability may be perceived as a reflection of a parent’s inadequacy. Parents who are unable to cope with their child’s disability as part of a particular and meaningful philosophy of life may develop this type of stress (Seligman & Darling, 2007).

In summary, parenting stress is theoretically defined as a psychological phenomenon that results from an imbalance between the demands of the parenting role
and the available resources required to fulfill the parenting responsibility. Parental attributes can be part of the infrastructure in parenting stress. A parent’s perception of specific characteristics associated with a developmental disability can serve to generate parenting stress. The interaction between parental attributes and the child’s characteristics may accelerate its development. The year following diagnosis is theorized to be the time with the greatest potential for its progression (Abidin, 1995).

In this framework, parents of young children recently diagnosed with an ASD are theorized to be at an increased risk for parenting stress. Parenting stress is theorized to lead to the development of a dysfunctional parenting pattern. Consequences for children often result in behavioral and emotional problems. Parents may relate physical and psychological symptoms (Seligman & Darling, 2007).

**Parenting Stress in Parents of Children with Autism Spectrum Disorder: Empirical Support**

Holroyd et al., (1975) conducted a systematic study designed to quantify parenting stress in parents of children with autism in California. The sample consisted of 29 parents of children who were diagnosed with autism between the ages of 1-18 years (\(M=10.5\) years, \(SD=4.4\)). The children were either institutionalized or living at home. The length of time since diagnosis and maternal ages at the time of the study were not included. Parenting stress was measured using the Questionnaire on Resources and Stress (Holroyd, 1974). Mothers and fathers were analyzed separately. The researchers hypothesized that the consequences of child institutionalization would result in a reduction in stress for parents of institutionalized children. However, independent \(t\) tests found that the conditions of severity of impairment, physical incapacitation (\(t=2.27\),
Difficult personality characteristics ($t = 3.17, p = .005$) were sources of maternal stress in both mothers of institutionalized and non-institutionalized children. Overall, mean stress scores were moderate to high in 74% of their sample. These findings support that regardless of placement, mothers of a school-child with autism experienced parenting stress. A possible predictor of this stress could be found in the child’s rather than the parent’s characteristics.

Wolf et al., (1989) compared stress in 31 parents of children with autism to that of 31 parents of children with Down syndrome, and to 62 parents of typically developing children in southwestern Ohio. The parents in this study all had children who were school-aged, ranging in age from 7-14 years, ($M = 9.34$ years, $SD = 4.6$). Time since diagnosis was not indicated in the study. The relationship between mean maternal age of 33.97 years and stress was not analyzed in its relationship to stress. Parenting stress was assessed using the Parenting Stress Index (Loyd & Abidin, 1985). As predicted, mean parenting stress scores were significantly higher for parents of children with autism than in other groups ($F = 22.36, p < .01$). These findings support the theoretical assumption that parents of children with ASD are at a higher risk for the development of parenting stress than are either parents of children with other developmental disabilities or those of typically developing children.

Factor, Perry, and Freeman (1990) investigated parenting stress in relation to the use of respite care in 36 parents. Nineteen parents of school-age children with autistic disorder or the general category of pervasive developmental disorder (PDD) were users of a relief program, while 17 were nonusers. Children’s mean ages were 11.6 years in the user group and 10 years, 5 months in the nonuser group. The period of time from
diagnosis and the maternal ages were not indicated in this study. Parenting stress was measured using the Questionnaire on Resources and Stress-Short Form (Friedrich, Greenberg, & Crnic, 1983). Independent $t$-tests yielded no significant difference between stress in mothers and fathers. A significance difference in difficulty of child characteristics was found in the user group on the Questionnaire on Resources and Stress-Short Form subscale ($M=8.45, SD=3.61$) as compared to the nonuser group ($M=5.88, SD=5.88, t=2.43, p=.02$). As seen in previous studies, these findings support the theoretical belief that parents of children with ASD are at an increased risk for development of parenting stress.

Hoppes and Harris (1990) examined child attachment behaviors and maternal gratification when comparing 17 mothers of children with autistic disorder to 21 mothers of children with Down’s syndrome living in New York and New Jersey. The mothers in this study had children ranging in age from 4 to 10 years, ($M=7.01$ years, $SD=2.15$). The time since diagnosis was not indicated. Mean maternal age of participants was 35.19 years ($SD=5.11$), however maternal age was not analyzed in relation to parenting stress. Parenting stress was measured using the child reinforces mother subscale of the Parenting Stress Index (Loyd & Abidin, 1985). ANCOVA revealed statistically significant differences between the two groups of mothers in stress as related to maternal perception of attachment ($F=46.33, p<.0001$) as well as stress in relation to gratification ($F=39.53, p<.0001$). As predicted, mothers of children with autism were found to be significantly different in perceived attachment and gratification than were mothers of children with Down syndrome, with mothers of children with autistic disorder having lowered perceptions of attachment and gratification. This study was significant, as it
provided further support that mothers of children with ASD are at an increased risk for the development of parenting stress. A child’s characteristics may be possible predictors of stress.

Bouma & Schweitzer (1990) compared the different patterns of stress reported by 24 Australian mothers of children with autism, based on the DSM-III criteria (American Psychiatric Association, 1980), 24 mothers of children with cystic fibrosis, and 24 mothers of typically developing children. The children’s ages ranged from 5 to 12 years, \((M=7.7\text{ years}, SD=2.50)\) for children with autism. The time since diagnosis was not identified in this study. The mean maternal age was also not reported. Parenting stress was measured using the Questionnaire on Resources and Stress- Short Form (Friedrich et al., 1983). As predicted, ANOVA identified that the mothers of children with autism reported higher stress scores than did mothers of children with cystic fibrosis and those of typically developing children \((F=36.846, p=<.001)\). Additionally, mothers of children with autism reported greater stress in dependency and management. This was a reflection of parents’ perceptions of their child’s behavior \((p=<.05)\). This study confirmed results seen in earlier empirical literature where mothers of children with autism had higher stress than did mothers of children with other developmental disorders or chronic illnesses.

Similarly, Dumas et al., (1991) compared the levels of parenting stress in 30 mothers of children with autism, 30 mothers of children with Down syndrome, 30 mothers of children with behavior disorders, and 30 mothers of typically developing children in Ontario, Canada. The children with autism had a mean age of 9.16 years \((SD=4.10)\). The time since diagnosis was not indicated. The mean maternal age of those
mothers of children with autism was 33.79 years ($SD=2.64$). Maternal age was not analyzed in relation to stress. Parenting stress was assessed using the Parenting Stress Index (Loyd & Abidin, 1985). MANCOVA found that parenting stress scores on the child domain were significantly increased for parents of children with autism and behavior disorders as compared to parents of children with Down syndrome and those of typically developing children for mothers ($F=9.11$, and $p<.0001$) and fathers ($F=8.05$, and $p<.0001$). This study added to the existing body of knowledge, confirming that mothers of children with autism experienced more stress than those with other developmental disorders.

Moes et al., (1992) examined stress profiles in 18 mothers and 12 fathers of early school-age children with autism in California using the Questionnaire on Resources and Stress (Holroyd, 1974). Parents had children ranging in age from 3 to 14 years with a mean of 6 years. Time since diagnosis was not identified. Parental ages ranged from 30 to 57 years ($M=40$ years), and was not analyzed in relation to stress. Mothers and fathers were analyzed separately. Independent $t$-tests revealed stress was significantly higher for mothers than fathers ($p=0.04$).

Koegel et al., (1992) examined stress profiles in 50 mothers of children with autism diagnosed according to DSM-III-R criteria (American Psychiatric Association, 1987). They ranged in ages, functioning levels, and cultural and geographic environments. This was the first study to examine children’s ages in relation to stress. Again, the length of time since diagnosis was not identified. Mothers in this study had children whose ages ranged from 3.1-23.1 years. Participants within three cultural/national groups (California, Appalachian states, and Germany) were bracketed
into 3 groups: mothers of preschool children, school age mothers, and those of young adults. Maternal age was categorized into 3 groups: 20-30, 31-40, and over 40 years, however was not further analyzed in relationship to stress. Parenting stress was measured using the Questionnaire on Resources and Stress (Holroyd, 1974). As predicted, parenting stress was high and consistent across all groups ($p < .001$). The stress profile for mothers of younger children ($< 7$ years) was higher than that of mothers of older children ($>7$ years) ($r = .932, p < .001$). This study supported the theoretical conviction that stress among mothers of children with ASD will be high, despite variations in culture and geographic location. This was the first study to find that mothers of younger children were considered to be more stressed than those with older children.

Kasari and Sigman (1997) examined the relationships among parental stress, child temperament, and observed parent-child interactions in 28 parents of young children with autism diagnosed according to DSM-III-R criteria (American Psychiatric Association, 1987), 28 parents of children with intellectual disability, and 28 parents of typically developing children. The parents in this study had children with a mean age of 42.39 months ($SD=11.61$), although the time since their diagnosis was not indicated. Parental age was not indicated by the researchers. Parenting stress was assessed using the Parenting Stress Index (Loyd & Abidin, 1985). An ANOVA yielded a significant difference comparing parents of children with autism and intellectual disability in the child domain subscale to those of typically developing children ($F= 27.02, p = <.0001$). This study added support to the conclusion that parents of children with ASD are at a greater risk for development of parenting stress. Additional support was recommended for parents of young children.
Hastings and Johnson (2001) explored predictors of stress for primary parental caregivers in United Kingdom families. The participants were involved in intensive home-based behavioral intervention programs for young children with autism. A total of 141 parents of children with a mean age of 4.98 years ($SD=1.50$) took part in this project. The mean time since diagnosis was 13.47 months at the time of the study. Although parental age ranged from 26 to 53 years ($M=37.41$, $SD=1.50$), age was not tested in its relation to stress. Parenting stress was assessed by the Questionnaire on Resources and Stress-Short Form (Friedrich et al., 1983). A regression analysis revealed that lower parenting stress was predicted by adaptive coping strategies, informal social support, and efficacy beliefs ($t=2.10$, $p=<.05$). Higher autism symptomology was associated with higher reported stress ($t=4.26$, $p=<.001$). This study was significant as it was the first to identify the time since diagnosis as an important demographic variable. Hastings and Johnson did not however examine the relationship between time since diagnosis and stress.

Hastings (2003) examined the difference in stress between 18 mothers and 18 fathers of children with autism. The participants’ children ranged in age from 8 to 17 years ($M=11.8$ years, $SD=2.6$). The mean age of mothers was 41.2 years ($SD=4.6$), while the mean age of the fathers was 43.4 years ($SD=5.0$). Parental age was not analyzed as to its possible relationship to stress. Parenting stress was assessed using the Questionnaire on Resources and Stress-Short Form (Friedrich et al., 1983). Results in this study indicated that mothers and fathers did not differ significantly in their level of stress ($p=0.12$). However, mean stress scores were higher than the normative data. A
child’s behavior problems were positively associated with the mother’s stress. \((r=0.67, p=<.001)\).

Little (2003) examined the differences in stress and coping between 103 mothers and fathers of children with Asperger’s Syndrome in a national sample. The participants’ children ranged from 3 to 21 years, with a mean age of 10.57 \((SD=3.74)\). Parental age was not assessed in its relation to stress, and ranged from 28 to 57 years \((M=42\text{ years}, SD=5.32)\). The time since diagnosis was not indicated. Parenting stress was measured using the Questionnaire on Resources and Stress-Short Form (Friedrich et al., 1983). A repeated measure design revealed that mothers had higher stress than fathers \((F=37.7, p=<.001)\). This study was pertinent to nursing, as it was the first in which a nurse researcher studied parenting stress in parents of children with ASD.

Tomanik et al., (2004) investigated the relationship between behaviors exhibited by children with autism and the consequences of maternal stress in 60 mothers of young children aged 2 to 7 years, \((M=5.05\text{ years}, SD=1.57)\). Although the children’s specific time since diagnosis was not indicated, all children received their diagnosis before the age of 5 years. Maternal age ranged from 26 to 46 years \((M=35.75\text{ years}, SD=4.61)\). The age of the mother was not analyzed as to its possible relationship to stress. Stress was measured using the Parenting Stress Index (Loyd & Abidin, 1985). As predicted, mothers’ average total stress scores were elevated, and supported the theoretical proposition that parents of younger children with ASD experience high levels of parenting stress.

Hastings et al., (2005) explored the relationship between parent and child variables in developing parental stress in 48 United Kingdom parents of pre-school
children with autism. Although the time since diagnosis was not clearly indicated, the average age of children was 37 months. The mean parental age of participants was 34.46 years ($SD=4.07$). Stress was measured using the Questionnaire on Resources and Stress (Friedrich et al., 1983). Stress was correlated with anxiety ($p=<.02$) in mothers and anxiety and depression in fathers ($p=<.001$). This was the first study to delimit the population to parents of preschool age children.

Lecavalier et al., (2006) examined the correlates of caregiver stress over time in 293 Ohio parents and caregivers of children with ASD. Thirty-five percent of the sample consisted of parents or caregivers of preschool age children. The mean maternal age of the participants was 39.9 years ($SD=7.1$). The length of time since diagnosis was not indicated. Parenting stress was assessed using the Parenting Stress Index-Short Form (Abidin, 1995). As predicted, parental report of stress was stable over 12 months time ($p=<.0001$). This was the first longitudinal study to examine parenting stress.

In summary, these empirical studies supported the theoretical prediction that parents of children with ASD are at risk for the development of parenting stress. Research for the past 35 years quantified the level of parenting stress in parents of children with ASD, finding high stress levels as a possible universal worldwide phenomenon. Research has found high parenting stress in Canada (Dumas et al., 1991), Australia (Bouma & Schweitzer, 1990) Great Britain (Hastings & Johnson, 2001; Hastings et al., 2005), Germany (Koegel et al., 1992) as well as in the United States (Factor et al., 1990; Holroyd et al., 1975; Hoppes & Harris, 1990; Koegel et al., 1992; Lecavalier et al., 2006; Little, 2003; Moes et al., 1992; Tomanik et al., 2004; Wolf et al., 1989). In many studies, parenting stress was significantly higher for mothers than fathers
(Holroyd et al., 1975; Little, 2003; Moes et al., 1992). Several studied mothers alone (Bouma & Schweitzer, 1990, Dumas et al., 1991; Hoppes & Harris, 1990; Koegel et al., 1992; Tomanik et al., 2004). Much of the early research compared parenting stress levels of parents of children with what was classified at the time as autism, PDD, or now ASD to other groups of parents, mainly parents of children with Down syndrome or other developmental disabilities (Bouma & Schweitzer, 1990; Dumas et al., 1991; Kasari & Sigman, 1997; Hoppes & Harris, 1990; Wolf et al., 1989) supporting the theoretical assumption that parents of children with ASD are at a higher risk for the development of parenting stress than are either parents of children with other developmental disabilities or those of typically developing children. A possible predictor of parenting stress could be found in the child’s rather than the parent’s characteristics.

The majority of studies used convenience samples of parents of school-age children. Few of these studies, however, tested the theoretical belief of parental stress in parents of preschool age children. In those that did, the length of time since diagnosis was not clearly identified as an inclusion or exclusion criterion (Hastings & Johnson, 2001; Hastings et al., 2005; Koegel et al., 1992; Lecavalier et al., 2006). Further research is needed to test the theoretical belief that parents of recently diagnosed preschool age children are not only at risk for the development of parenting stress, but perhaps at a higher risk than parents of older children with ASD. It is crucial to understand the specific groups of parents at risk for stress as this can lead to the development of evidence based nursing intervention.
Theories of Aberrant Behavior and Parenting Stress

Children with ASD possess innate qualities which are manifested in significant impairment in many aspects of social relatedness and communication. The presence of restricted and repetitive behaviors can also illustrate inherent characteristics of ASD. This often includes an inflexible adherence to a nonfunctional routine followed by seemingly catastrophic reactions to trivial environmental changes. Children with ASD frequently adopt atypical body postures or movements such as hand clapping, finger flicking, and body rocking as responses to environmental or internal sensations. Unending fascination with common environmental movements, such as the opening and closing of doors, or rapid rotations of everyday objects, also can signal existence of this disorder. Unusual responses to environmental events are sometimes linked to a range of behaviors, including hyperactivity, a short attention span, impulsivity, aggressiveness, self-injurious behavior, and explosive temper tantrums. Such a child may have a higher than customary threshold for pain, oversensitivity to sound, an aversion to being touched, or an exaggerated reaction to light or odors. Additionally, children with ASD may manifest abnormalities in eating, sleeping, and/or mood (American Psychiatric Association, 2000).

These behaviors can help create a number of aberrant or maladaptive responses and lead to the development of parenting stress (Adibin, 1990). Parenting stress is theorized to occur from situational and stimulus-specific behavior. Societal reactions to aberrant behavior are marked by communal aversion. Many parents have had limited experience with individuals with ASD before the birth of their own child. Compounding this unfamiliarity may be exposure to the stereotypes and stigmatizing attitudes common
to our culture. Parents may appraise their skills in managing these behaviors as inadequate and become frustrated and then overwhelmed by the requirements of parenting. Those parents who label these behaviors as inappropriate may find themselves vulnerable to the criticism of others. Chronic parenting stress can generate a skeptical or cynical attitude regarding access to, and value of, advice and knowledge about the child’s behavior. The effect then is to make it even harder to appraise the stressors or evaluate and modify parenting efforts. Believing the child’s aberrant behavior to be intentional may increase the potential of harsh parenting reaction. The theoretical position that perceived aberrant behavior contributes to parenting stress thus becomes confirmed by cumulative case evidence. Perceived severity of aberrant behavior is directly correlated to experience of parenting stress (Abidin, 1995; Deater-Deckard, 2004; Seligman & Darling, 2007).

**Severity of Child Behavior and Parenting Stress: Empirical Support**

Research has identified the severity of the child’s behavior or ASD symptomology as an antecedent to the development of parenting stress. This is a unique predictor apart from common characteristics to children with developmental disabilities, such as adaptive needs or delays in development. Bebko et al., (1987) assessed perceived severity of symptoms in children with autism and their impact of stress in 40 Canadian mothers and fathers. Participants had children who ranged in age from 6 to 18 years (median: 9 years). The length of time since diagnosis was not indicated. Ages of the participants was not identified. Perceived severity of autism symptoms and parental stress was measured using the Childhood Autism Rating Scale (Schopler, Reichler, DeVellis, & Daly, 1980). Participants were asked to rate the severity of each symptom and an
additional rating from 1-4 indicating the stress the symptom produced (1 not at all, 4 extreme). An ANOVA was used to test the relationship between autism symptoms and stress. Overall symptom severity was positively related to stress. The “stress” scale in this study was not a validated measure of parenting stress. Common behaviors of children with ASD, such as aggression and self-injury, are not measured in this scale, a drawback to this research.

Milgram and Atzil (1988) examined life satisfaction in 46 Tel-Aviv parents of children with autism and their perceptions of a child’s maladaptive behavior. It was hypothesized that perceived severity of a child’s behavior by parents will be strongly related to the adult’s mental health. The parents in Milgram and Atzil’s study had children who ranged in age from 7 to 14 years ($M=10.04$ years, $SD=2.60$). The time since diagnosis was not indicated. However, the authors stated that the majority of children attended the school from 1 to 3 years prior to the study. Age of the participants was not identified. Perceived severity of child behavior was measured using the Child’s Adaptive and Symptomatic Behavior Schedule (Lambert, Windmiller, Cole, & Figuera, 1974). Parental mental health was assessed using the Personal Life Satisfaction Scale (Shaver, 1972). The findings supported the theoretical proposition that that maladaptive behaviors (stereotyped behavior, unacceptable behavior, self-injury, hyperactivity, and psychological disturbance) were directly related to stress and inversely related to life satisfaction ($F=-36$, $p<.05$).

Konstantareas and Homatidis (1989) assessed 44 Canadian parents of children with autism according to the DSM-III criteria (American Psychiatric Association, 1980). Parents in this study had children that ranged in age from 2 to 12 years, with a mean age
of 6 years, 10 months. The time since diagnosis was not indicated. Parental age ranged from 23 to 46 years ($M = 34.7$ years). Age was not analyzed in relation to stress. A variable of interest was perceived symptom severity of autism and its relation to parenting stress. Symptom severity and parenting stress were both measured using the Childhood Autism Rating Scale (Schopler et al., 1980). First, participants used the scale to identify the severity of symptoms. Second the participants were asked to reflect degrees of stress created by each autism behavior. Mothers were analyzed separately from fathers. As predicted, in both mothers and fathers the severity of the child’s symptoms was positively correlated with stress. Self-injurious behavior was the strongest predictor of perceived stress ($F = 4.46, p = <0.01$). Furthermore, mothers indicated that their children’s near-receptor preoccupations (smelling, licking, rubbing) were also a predictor of parenting stress ($F = 4.34, p = <0.05$), while fathers indicated that impaired communications was perceived as stressful ($F = 4.34, p = <0.05$). Empirical support for the theorized relationship between aberrant behavior and stress was thus beginning to develop.

Dumas et al., (1991) compared perceived child behavior problems, dysphoria, and parenting stress in 272 Canadian parents. Their children were typically developing, had autism, Down syndrome, or displayed behavior disorders. The mean age of the children with autism was 9.16 years ($SD=4.10$), and time since diagnosis was not indicated. The mean age of the parents of children with autism was 33.79 years ($SD=2.64$). Perceived severity of child behavior problems was measured using the Eyberg Child Behavior Inventory (Eyberg & Ross, 1978). Parenting stress was measured using the Parenting Stress Index (Lord & Abidin, 1985). Dysphoria was assessed using the Beck Depression
Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). As predicted, the intensity of the child’s behavior was significantly related to both the child domain on the Parenting Stress Index and to the degree of dysphoria ($F=1.54, p=.0001$).

Kasari and Sigman (1997) examined the relationship between child temperament and behavior to that of parenting stress. They studied parents of children with autism using the DSM-III-R criteria (American Psychiatric Association, 1987), intellectual disability, and those of typically developing children. Twenty-eight parents of children with autism participated. The mean age of the children was 42.39 months ($SD=11.61$). Neither age of the participants nor time since diagnosis was indicated. Temperament and behavior were measured using the Autism Behavior Checklist (Krug, Arick & Almond, 1979) and the Behavior Style Questionnaire (Carey & McDeritt, 1978). Parenting stress was measured using the Parenting Stress Index (Lord & Abidin, 1985). As predicted, the ANOVA yielded a significant difference among the parental groups. Parents of children with autism and intellectual disability reported greater stress in the child domain on the Parenting Stress Index than did those of typically developing children ($F=27.02, p<.0001$). A Pearson correlation was used to test the relationship between behavior and stress. As predicted, a significant association was found between perception of child temperament difficulties and parenting stress ($r=.73, p<.001$).

Hastings and Johnson (2001) explored predictors of stress in 141 United Kingdom families who were participating in intensive home-based behavioral intervention for young children with autism. Parents in this study ranged in age from 26 to 53 years ($M=37.41, SD=4.87$) and had children with a mean age of 4.98 years ($SD=1.50$). The average time since diagnosis was 13.47 months. Autism symptoms were measured using
the Autism Behavior Checklist (Krug et al., 1980). Parenting stress was assessed using the Questionnaire on Resources and Stress-Short Form (Friedrich et al., 1983). As predicted, regression analysis revealed that greater perceived autism symptomology was associated with higher stress ($t=4.26, p<.001$). These findings are consistent with those found in previous research investigating this relationship.

Hastings (2003) examined the relationship of perceived child behavior problems to differences in stress in 36 mothers and fathers of children with autism. The mean age of the children was 11.8 years ($SD=2.6$), and time since diagnosis was not indicated. The mean age of the participants was 41.2 years for mothers, and 43.4 years for fathers. Age was not analyzed in relation to stress. Child behavior problems were identified using the Developmental Behavior Checklist Parenting (Einfeld & Tonge, 1995). Stress was measured using the Questionnaire on Resources and Stress-F (Friedrich et al., 1983). Mothers and fathers were analyzed separately. As predicted, child behavior problems were found to be associated with mothers’ stress. ($r=0.67, p<.001$). Findings support the theoretical proposition that child behavior problems are associated with stress.

Tomanik et al., (2004) investigated the relationship between aberrant behaviors exhibited by children with autism and maternal stress experienced by 60 mothers of children ranging from 2 to 7 years ($M=35.75$ months, $SD=1.57$). The age of the mothers in this study ranged from 26 to 46 ($M=35.75$, $SD=4.61$). Age was not analyzed in relation to the study’s variables. Although the time since diagnosis was not indicated, it was stated that all children received a diagnosis before the age of 5 years. Aberrant behavior was measured using the Aberrant Behavior Checklist (Aman et al., 1985). Parenting stress was measured using the Parenting Stress Index-Short Form (Abidin,
Regression analysis indicated that child maladaptive behavior accounted for a significant proportion (19%) of the variance in maternal stress. Child aberrant behavior significantly predicted parental stress ($F=2.511, p<0.05$).

Hastings et al., (2005) explored the relationship between parent and child variables on parental stress. Forty-eight parents of pre-school children ($M=37$ months, $SD=4.40$) with autism living in the United Kingdom participated in this study. Mean parental age was 34.46 years ($SD=4.07$). Neither age of the participants nor time since diagnosis was analyzed. The parents’ perception of children’s behavior was measured using the Developmental Behavior Checklist (Einfeld & Tonge, 1995), Autism Screening Questionnaire (Berument, Rutter, Lord, Pickles, & Bailey, 1999) and the Vineland Adaptive Behavior Scale (Sparrow, Balla & Cicchetti, 1994). Parental stress was measured using the Questionnaire on Resources and Stress Short Form (Friedrich et al., 1983). As theorized, regression analysis revealed that a child’s behavior problems significantly predicted maternal stress development ($B=.616, p=.000$).

Duarte et al., (2005) examined maternal stress and perceived severity of child behavior in 31 mothers of children with autistic disorder. The children’s age range was from 3 to 12 years, ($M=6.8$ years, $SD=5.27$). The mean maternal age was 32.9 years, ($SD=5.27$). The time since diagnosis was not identified. Child behavior was measured by the Child Behavior Checklist (Achenbach, 1991). Maternal stress was measured by the D score of the Rorschach test (Exner, 1995). The time since diagnosis was an average of 2.4 years, however this variable was not analyzed in relation to stress. Regression analysis revealed children’s interpersonal difficulties were significantly associated with stress ($B=.333, p=.008$).
Konstantareas and Papageorgiou (2006) examined effects of child temperament, symptom severity, and level of functioning on maternal stress in 43 mothers of children with ASD living in Greece. They hypothesized that greater degrees of maternal stress would be found where higher symptomatology is present. The children’s ages ranged from 2.3 to 26 years ($M=122.6$ months, $SD=71.8$). Neither maternal age nor the length of time since the diagnosis was identified. Temperament, symptom severity, and level of functioning were measured by the Child Autism Rating Scale (Schopler et al., 1980). Parental stress was measured by the Clarke Modification of the Holroyd Questionnaire on Resources and Stress (Konstantareas, Homatidis, & Plowright 1992). As predicted, children with higher physical activity and symptom levels were perceived as more stressful for mothers. High symptom severity was the strongest predictor of stress. Total symptomology accounted for 8 percent of the variance in maternal stress ($r=0.54$, $F=10.95$, $p<.025$). These findings support the hypothesis that a positive relationship is found associating severity of autism symptoms to development of parental stress.

Lecavalier et al., (2006) examined the correlates of caregiver stress over time in 293 Ohio parents of children with ASD and teachers. Thirty-five percent of this sample consisted of parents or teachers of children in preschool. Parental age ($M=39.9$, $SD=7.1$) was not analyzed in relation to stress. The time since diagnosis was not identified. Parental stress was measured by the Parenting Stress Index-Short Form (Abidin, 1995). Child behavior symptoms were measured by the Nisonger Child Behavior Rating Form (Aman, Tasse, Rojahn, & Hammer, 1996) and the Scales of Independent Behavior (Bruiniks, Woodcock, Weatherman, & Hill, 1996). As predicted and theorized, a regression analysis established that hyperactivity ($F=29$, $p<.0001$), stereotypy behavior
(F=.28, p= .0001) and ritualistic behavior (F=.31, p= .0001) were strongly associated with parental stress.

Bishop et al., (2007) examined the effects of restricted and repetitive behavior in children with ASD on parental perceptions. One-hundred and ten mothers of children whose mean age was 9 years participated in this study. Both maternal age and time since diagnosis were not identified. Restrictive and repetitive behavior was assessed using the Autism Diagnostic Interview-Revised (Lord, Rutter & LeCouter, 1994) and the Vineland Adaptive Behavior Scale (Sparrow et al., 1984). Parental perceptions were assessed by using the Child and Adolescent Impact Assessment (Messer, Angold, Costello, & Burns, 1996). As predicted, regression analysis identified restrictive and repetitive behavior severity as a significant predictor of higher perceived negative impact (B=-0.23, p= <.01, B=-.22, p= <.01).

Davis and Carter (2008) examined the relationship between social and emotional problem behavior and parenting stress in parents of 54 toddlers with ASD. The mean parental age was 36.5 years (SD= 4.8), and average time since diagnosis was 3 months. Social and emotional behaviors were measured using the Infant Toddler Social Emotional Assessment (Carter & Briggs-Gowon, 2006). Parenting stress was measured using the Parenting Stress Index- Short Form (Abidin, 1990). As predicted, atypical and externalizing behaviors predicted 58% of the variance in parenting stress (F=8.83, p= <.001) providing empirical support for the theorized relationship between aberrant behavior and parenting stress in parents of recently diagnosed autistic children.

Recently, nurse researchers Phetrasuwan and Miles (2009) examined sources of parenting stress among 108 mothers of children with ASD ranging in age from 3-10
years. The mean maternal age was 37 years (SD=6.6). The time since diagnosis was not identified. Behavioral symptoms were hypothesized to be the primary source of maternal stress. Child behavioral symptoms were measured using the Childhood Autism Rating Scale (Schopler et al., 1980). Parenting stress was measured using the Parental Stressor Scale: Developmental Disabilities, an instrument developed by the researchers, that was assessed for content and face validity prior to use. Cronbach’s alpha indicated strong reliability, which was .94. In this study, contrary to predictions, there was no significant relationship between child behavior and stress. Using the Childhood Autism Rating Scale for a measurement of behavior symptoms may be inadequate, as it does not assess a full range of behaviors.

In summary, once parenting stress was identified to be a consistent phenomenon in parents of children with autism, researchers explored various antecedents and predictors of stress. As researchers compared parents of children with various developmental disabilities, stress was found to be higher among parents of children with ASD, supporting the theoretical belief that there is a unique aspect pertaining to the ASD diagnosis that contributes to parental stress. Although, early studies did not use a valid measure for stress (Bebko et al., 1987; Konstantareas & Homatidis, 1989) most other studies identified the severity of the child’s behavior, particularly the externalizing, repetitive, restrictive, or self-injurious behaviors as strong, significant predictors of stress. Again, this relationship was identified in many geographical locations including Canada (Bebko et al., 1987; Dumas et al., 1991; Konstantareas & Homatidis, 1989), Tel Aviv (Milgram & Atzil, 1988), Greece (Konstantareas & Papageorgiou, 2006), United Kingdom (Hastings & Johnson 2001; Hastings, 2003; Hastings et al., 2005) as well as the
United States (Bishop et al., 2007; Duarte et al., 2005; Kasari & Sigman, 1997; Lecavalier et al., 2006; Tomanik et al., 2004). Theorists posit that stress in parents of children with ASD will be at its highest during the first year following diagnosis. Three of these studies were conducted with the population of preschool parents (Hastings & Johnson, 2001; Hastings et al., 2005; Kasari & Sigman, 1997); however only one study delimited the population to recently diagnosed children (Davis & Carter, 2008). Therefore, further research is needed to test the hypothesis that the child’s behaviors, specifically aberrant behaviors, are positively related to the development of stress in parents of recently diagnosed preschool age children. Future nursing interventions can be developed and tested following this empirical evidence.

**Expectancy Theory and Parenting Stress**

Dunst and Trivette’s (1986) concept of parental expectation is theoretically defined as consisting of the set of perceptions of future capabilities of the child. Parental expectations may take a long-term view of a child and so modify their own beliefs and values when defining their child’s behavioral competency and capabilities. Parents’ pre-existing expectations for their child’s academic, financial, community functioning, and social independence will often need modification by experience, education, or intervention. These expectations are often influenced or determined by parent, family, or child characteristics. Parents who benefit from adequate social support develop higher expectations for future social competence than those who function in a greater degree of isolation. However, careful appraisal of a child’s characteristics can alter parental expectations (Abidin, 1995; Dunst & Trivette, 1986).
Children at risk for poor developmental outcomes often limit expectations in parents for their independent living as adults. When the child’s physical, intellectual, and emotional characteristics do not meet parental expectations, parenting stress can result. As competence in social functioning is valued highly, parenting stress can result from an apprehension of future inadequacies as the child becomes an adult (Abidin, 1995; Deater-Deckard, 2004; Dunst & Trivette, 1986).

The preschool years are marked by great changes in personal-social development (Ball, Binder, and Cohen, 2009). Attributes believed to be related to competence in social roles in the future are formed during this period. It is important to assess parents’ expectations for their child’s future (Sigel, McGillicuddy-DeLisi, & Goodnow, 1992). It is believed that there is a relationship between parental expectations for the child and parenting stress. Low expectations for the child’s future will result in higher parenting stress.

Child Expectations and Parenting Stress: Empirical Support

Ivey (2004) investigated the future expectations of 25 parents of children with ASD living in Midwestern states. The children’s ages ranged from 4-20 years (M=4.20 years). The time since diagnosis was not indicated. Parental expectations were measured from a 20 statement expectancy instrument adapted from Mutura (2001). Neither parental age nor time since diagnosis was identified. Participants were asked to rate how important a future expectation item was, as well as how likely they believed their child would achieve the item. Paired t tests identified a significant difference between the assessments (p<.01). Items that were identified to be of high importance were: developing a future support network, secure financial future, being safe from physical
harm, achieving higher education and having their own children. However parents believed their child with ASD was less likely than a typically developing child to achieve those outcomes. In this study, parent’s expectations were not tested in relation to stress.

Dale et al., (2006) investigated how parental expectations for their child correlated with the parenting stress in 11 parents of young children with ASD one year post diagnosis. The participant’s children ranged in age from 3-9 years. Maternal age ranged from 28-44 years. Child expectations were measured using the Child Expectations Scale (Dunst & Trivette, 1986). Parental stress was measured by the Parenting Stress Index (Abidin, 1995). The time since diagnosis was 3-15 months prior to the time of the study. Although, as predicted the average total stress score was significantly high, expectations for children’s future varied across mothers from limited to high expectations. There was considerable variability in responses relative to where parents felt their children would live as adults, the extent their children would be involved in the community and their child’s future social relationships ($r=-0.28$, $p=.02$).

Wong and Heriot (2007) examined parental expectations in a sample of 22 parents of children with autism in Australia. Parents in this study had a mean age of 37 years ($SD= 5.67$). The participants’ children ranged in age from 5 to 12 years old. The length of time since diagnosis was not identified. Parental expectations were measured using the Vicarious Futurity Scale (Wong & Heriot, 2007). Contrary to predictions, 80% of the
sample indicated low hope and high despair for their child’s future. Researchers state that the uncertainty about their child’s prognosis lowered parental expectations.

In summary, the theoretical proposition of the relationship between parental expectations and the development of parenting stress has been understudied. Dale et al., (2006)’s study examined the relationship between parental expectations for their preschool age child with autism in relation to the development of a perceived negative impact, not parenting stress. Further research is needed to test the theoretical belief of the relationship between low expectations and the development of parenting stress in parents of recently diagnosed preschool age children with autism. It is crucial to understand what antecedents may place parents at risk for stress development, as this can lead the direction of further research and future nursing interventions.

Theory of Maternal Age and Parenting Stress

Parental age has consistently remained a variable of interest in parenting research. Parental age varies across a wide continuum. In today’s society, women in their twenties are often considered “young” parents, while mothers who become parents in their late thirties or later are regarded as “older”. Theorists postulate that older parents with a previously stable life pattern that did not involve extensive exposure to children may experience difficulty in adjusting to a child with problematic characteristics (Deater-Decker, 2004). On average, older parents are more likely to face personal health issues and experience biological and psychological changes which all carry implications for stress. Older parents may lack the physical energy required to keep up with a child who manifests either hyperactivity or irregular sleep patterns. Theorists also presume that parenting stress may accumulate over time (Abidin, 1995, Deater-Decker, 2004).
Therefore, the theoretical proposition that guides research on parenting age is positively correlated with parenting stress.

**Maternal age and Parenting Stress: Empirical Support**

Koegel et al., (1992) were the first researchers to bracket maternal age collected in demographic data in 50 mothers of children with autism diagnosed according to DSM-III-R criteria (American Psychiatric Association, 1987) across 3 geographical locations. Instead of reporting the range and group mean, age was reported by number of mothers in 3 groups; mothers aged 20-30 years, mothers aged 31-40 years, and mothers over 40 years old at the time of the study. Maternal age was not further analyzed in relation to stress, however the age of the child was. Results indicated stress profiles for mothers of younger children (<7 years) was higher than mothers of older children (>7 years) \( r = .932, \ p = <.001 \).

Duarte et al., (2005) examined maternal stress and perceived severity of child behavior in 31 mothers of children with autistic disorder. The children’s age ranged from 3-12 years, \( M=6.8 \) years, \( SD=2.79 \). The mean maternal age was 32.9 years \( SD=5.27 \). The time since diagnosis was an average of 2.4 years ago at the time of the study.

Maternal age was selected as a variable that was hypothesized to predict stress. Parental stress was measured by the D score of the Rorschach test (Exner, 1995). Regression analysis revealed younger child contributed to increased stress \( p = 0.063 \). Older mothers, identified as 35-45 years were significantly associated with higher stress \( B=-0.1553, \ p = .03 \) than were younger mothers, age 34 years or less.

Pakenham et al., (2005) explored the relationships between maternal age, severity of behavior, and maternal depression and anxiety in mothers of children with Asperger
Syndrome living in the United Kingdom. The children ranged in age from 10-12 years and the time since diagnosis was a mean of 12.7 months. Maternal age was not measured as a demographic variable. Child symptoms was measured by the Childhood Aspergers Syndrome Test (Scott, Baron-Cohen, Bolton, & Brayne, 2002), parental stress was measured by the Eyberg Child Behavior Inventory (Eyberg & Pincus, 1998), and the Parental Stress in the Management of Asperger’s Syndrome Scale (Sofronoff, 2002). Although demographic maternal age of participants was not provided in the report, an ANOVA identified maternal age as being inversely correlated with depression ($r = -.31, p<.05$), social adjustment ($r = -.41, p<.001$), subjective health status ($r = 0.34, p<0.02$) and severity of the stressor ($r = 0.42, p<0.01$). In this study, younger mothers stress was associated with depression and anxiety.

In summary, maternal age was collected as an important demographic variable in the majority of studies evaluating parenting stress in mothers of children with ASD. Few studies tested the theoretical assumption that maternal age is related to the development of stress. Conflicting results have been documented in the empirical literature (Duarte et al., 2005, Pakenham et al., 2005). Therefore, it is important to test the theoretical belief that there is a relationship between advanced maternal age and the development of parenting stress in parents of recently diagnosed preschool age children with ASD. Understanding of the predictors to stress development can lead the direction of further research and future nursing interventions.

**Social Support Theory and Parenting Stress**

Social support is theoretically defined as the emotional, psychological, physical, informational, instrumental, or material assistance provided to others to maintain well-
being or promote adaptation to diverse life events, including those relative to raising young children. Social support is further separated into two categories: informal and formal support. Informal support is defined as family helpfulness among individuals who do not require the exchange of money and are not part of a formal organization. An individual’s spouse, child, extended family, friends, and neighbors may all be sources of informal social support. Formal support is defined as extra family support including that provided by professional services, programs, and agencies. The individual’s perception of the adequacy of this support can contribute to or alleviate parenting stress (Abidin, 1985; Dunst & Trivette, 1985; Seligman & Darling, 2007).

Social support theory has been applied to parenting by several theorists. Theorists postulate that social support proactively affects parents’ behavior, attitudes, values and expectations (Dunst & Trivette, 1985). Perception of the adequacy of this social support is influenced by the intensity, durability, reciprocity, and frequency of contacts. The degree of helpfulness and multidimensionality in relationships also help to shape perception of support. Social support functions to nurture and strengthen links among parents in day-to-day parenting tasks as well as in times of need or crisis (Abidin, 1985; Dunst & Trivette, 1985; Seligman & Darling, 2007).

It is widely believed that adequate social support can relieve the intensity of parenting stress, and that its lack can promote development of stress. When informal support is insufficient, parents can experience stress. Parents are seen as isolated, depressed, doubtful, and experience fewer positive outcomes in its absence. Formal support provides a forum for catharsis, information, emotional support, mutualism, and advocacy (Abidin, 1985; Dunst & Trivette, 1985; Seligman & Darling, 2007).
Social support functions to buffer corrosive effects of stress and impact of stressful events by decreasing the parental demands of child care. Social support may alter the parents’ perception of their child’s characteristics and improve parent-child interactions. Social support can mediate the stressful event and intervene between the stressor and the stressful reaction. Social support can also function as a source of information, financial aid, or to transmit messages of self-affirmation. This can increase the parents’ sense of wellbeing, resilience, and impressions of competence. A positive parenting attitude can be maintained despite the chronic nature of the stressor, even when the stressors are a problematic child’s characteristics (Abidin, 1985; Dunst & Trivette, 1985; Seligman & Darling, 2007).

In summary, social support reduces the subjective distress of families while encouraging positive personal, family, and child functioning. Social support enables parents to maintain a sense of normalcy despite raising a child with a disability.

**Social Support and Parenting Stress: Empirical Support**

Bristol (1987) hypothesized an inverse relationship between informal and formal social support and maternal depressive symptoms. Forty six mothers of children with autism and communication-impaired children participated in this study. Social support was measured using the Carolina Parent Support Scale (Bristol, 1978). Depression was measured by the Center for Epidemiologic Studies Depression Scale (Radloff, 1977). The children’s ages ranged from 2-10 years (M= 5.3 years, SD=2.82). The mothers in this study ranged in age from 19-47 years (M=31, SD=5.6). The time since diagnosis was not identified. As predicted, greater perceived adequacy of formal social support (F= 11.15, r=.53, p=002) was correlated with less maternal depression. However, in this study
informal social support was not significantly related ($F= 1.17$, $r=.07$, $p>=.05$) to the development of depressive symptoms.

Konstantareas and Homatidis (1989) examined the relationship between perceived family support and parenting stress in 44 Canadian parents of children with autism, diagnosed according to DSM-III criteria (American Psychiatric Association, 1980). The participants children ranged in age from 2-12 years ($M= 6.10$ years). Maternal age ranged from 23 to 46 years, with a mean age of 34.7 years. The time since diagnosis was not identified. Konstantareas and Homatidis predicted an inverse correlation between perceived support and stress exists in both mothers and fathers. Social support was measured in a scale developed by the researchers, where participants were asked to rate from 1-3 amount of support felt by parents, siblings, in-laws, friends, neighbors, workplace, church and community. Internal consistency of 0.94 was achieved. Stress was measured by using the Childhood Autism Rating Scale (Schopler et al., 1980) administered by an interviewer. The participants were asked to rate on a 4 point scale how stressed they felt by each autism symptom. As predicted, there was an inverse correlation between perceived support and stress scores in mothers ($r= -.246$, $p=<.05$) and fathers ($r= -.317$, $p=<.025$).

between stress and dysphoria. The participants’ children ranged in age from 7-14 years 
\((M= 9.34 \text{ years}, SD=4.16)\). The mean age for the mothers was 33.97 years \((SD=11.67)\) 
and 38.31 \((SD=8.05)\) for the fathers. The time since diagnosis was not indicated and 
participant age was not analyzed further. Social support was measured using the Revised 
Kaplan Scale (Turner & Associates, 1981). Parenting stress was measured by the 
Parenting Stress Index (Loyd & Abidin, 1985). Dysphoria was assessed using the Beck 
Depression Inventory (Beck, 1961). Regression analysis revealed that social support 
explained 24-27% of the variance for mothers, and 18-25% of the variance for fathers. 
The impact of stress on depression was diminished by social support. Stress was 
moderated by social support.

Gill and Harris (1991) examined social support as a predictor of psychological 
discomfort in 60 mothers of children with autism living in New Jersey. The participants 
children ranged in age from 2 to 18 years \((M=9.9 \text{ years})\) and the time since diagnosis was 
not indicated. Maternal age ranged from 24-57 years \((M=38.8)\) Social support was 
measured using the Interpersonal Support Evaluation List (Cohen & Hoberman, 1983) 
and the Inventory of Socially Supportive Behavior (Barrera, Sandler & Ramsay, 1981). 
Psychological discomfort was measured by the Malaise Inventory (Ruttler, Tizard & 
Whitmore, 1970) and Beck Depression Inventory (Beck, 1978). As predicted in a 
regression analysis, mothers who perceived greater social support experienced fewer 
stress-related somatic problems and depressive symptoms \((r= -.698, p= <.01)\).

Dunn et al., (2001) examined the relationship between social support and negative 
outcomes among 58 Floridian parents of children with autism. The children’s ages 
ranged from 3-15 years \((M= 7.47 \text{ years}, SD=3.31)\). The time since diagnosis was not
indicated. Parental age ranged from 25 to 67 years ($M=36.84, SD=9.21$). Social support was measured by the Inventory of Socially Supportive Behaviors (Barrera et al., 1981), and parenting stress was measured by the Parenting Stress Index (Loyd & Abidin, 1985). It was hypothesized that lack of social support would predict negative outcomes, and the relationship between stressors and negative outcomes would be moderated by social support. The hypothesis was supported, higher levels of social support corresponded to fewer spousal problems. Social support was found to be a significant moderator between stress and isolation ($F=8.46, p=.01$).

Hastings and Johnson (2001) explored social support as a predictor of stress in 141 primary caregivers in UK families. The mean age of the participants’ children was 4.98 years ($SD=1.50$). Parental ages ranged from 26 to 53 years ($M=37.41, SD=4.87$). The time since diagnosis was a mean of 13.47 months. Social support was measured by the Family Support Scale (Dunst et al., 1986). Parenting stress was measured by the Questionnaire on Resources and Stress (Friedrich et al., 1983). As hypothesized, parental stress was predicted by informal social support ($t=2.10, p<.05$).

Weiss (2002) assessed the effects of social support on the level of stress in mothers of children with autism, intellectual disability, and typically developing children. It was hypothesized that mothers of children with autism would report greater stress than the other two groups of mothers in the study. Within the mothers of children with autism, it was predicted that those who experienced less parenting stress would perceive greater social support. The participants’ children ranged in age from 2-7 years. The time since diagnosis was not indicated. Age of the mothers ranged from 24 to 48 years. Social support was measured by Interpersonal Support Evaluation List (Cohen & Hoberman,
1983) and Inventory of Socially Supportive Behavior (Barrera et al., 1981). Stress was measured using the 10 question scale developed by the US Department of Health, Education and Welfare (Caplan, Cobb, French, Van Harrison, & Pinneau, 1975). As predicted, an inverse relationship between social support and stress was identified. Mothers who reported higher degrees of social support reported lower depression ($r=0.33$). There were significant differences among the groups ($F=10.58, p<.002$). Mothers of children with autism perceived social support to be less available than mothers of children with intellectual disability or typically developing children.

Bromley et al., (2004) explored social support, family characteristics, mental health status and satisfaction with services on wellbeing in 68 mothers of children with ASD in a national sample. Neither maternal age nor the time since diagnosis was indicated. The children ranged in age from 5-18 years. Social support was measured by the Family Support Scale (Dunst et al., 1986). Parental distress was measured using the General Health Questionnaire (Goldberg & Williams, 1988). Half of the mothers with low levels of social support indicated they had significant psychological distress. Women were more likely to report lower levels of social support if they were a single mother, living in poor housing, and had a boy with autism. Single mothers reported less family support than women living with a partner ($z=2.12, p=.05$) as well as those living in poor housing ($z=2.14, p=.005$). Having a child with a high score on disruptive behavior was related to less perceived family support ($r= -.032, p=.005$) and was significantly associated with maternal distress.

Bishop et al., (2007) examined social support, autism symptoms, parental ethnicity and the relationship of these variables to perceived negative impact in 110
North Carolina mothers of children with ASD. The children had a mean age of 9 years old. Neither maternal age of the participants nor time since the child’s diagnosis was reported. Social support and perceived negative impact was measured by the Child and Adolescent Impact Assessment (Messer et al., 1996). African American mothers reported lower levels of perceived negative impact than Caucasians ($B = -0.36$, $p < .001$). Autism symptoms ($B = -.23$, $p < .01$) and less perceived social support ($B = -.33$, $p < .001$) were significant predictors of higher perceived negative impact.

Recently, Tehee, Honan and Hevey (2009), explored the relationship between accessed support and parenting stress in 23 mothers and 19 fathers of children with ASD living in Ireland. The mean ages of the mothers was 40.9 years ($SD = 5.7$). The children ranged from 3-18 years old. The time since diagnosis was not identified. Social support was measured by the Support Questionnaire developed by the researchers. Parenting stress was assessed using the Family Stress and Coping Questionnaire (Minnes & Nachsen, 2003). As predicted, a statistically significant strong inverse relationship was found between social support and parenting stress in mothers ($r = -.54$, $p < 0.025$).

In summary, the theoretical relationship between perceived family support and parenting stress has been tested in parents of children with ASD. Studies have tested the inverse correlation between perceived support and stress scores finding social support to be a significant moderator between stress and other psychological negative outcomes. However, this relationship has been tested mainly in parents of school-age children. One study did focus on preschool age children, however the specific length of time since diagnosis was not an inclusion characteristic. Therefore, it is important to test the predicted correlation between social support and the development of parenting stress in
parents of recently diagnosed preschool age children with ASD. Nursing intervention in the form of formal social support can thus be developed and tested in this population.

**Theoretical Rationale**

Parenting stress is theoretically defined as a chronic emotional phenomenon which a parent experiences as part of the primary role and direct interaction with children. Theorists postulate parenting stress, in parents of children with developmental disabilities is related to the parent’s perceived severity of their child’s aberrant behavior, expectations for the child’s future, age of the parent, and perceived helpfulness of available social support (Abidin, 1995; Deater-Deckard, 2004; Seligman & Darling, 2007).

Aberrant behavior is defined as the externalizing, nonfunctional, maladaptive behavior demonstrated by children with ASD. The parent’s perceived severity of the behavior is theorized to correlate with parenting stress. Perceived severity of aberrant behavior has both shown to be positively related to experience of parenting stress (Abidin, 1995; Deater-Deckard, 2004; Seligman & Darling, 2007).

Parental expectations for the child are theoretically defined as the consisting set of perceptions the parent holds for the future capabilities of their child. Parental expectations are theorized to have an inverse relationship with parenting stress (Abidin, 1995; Deater-Deckard, 2004; Dunst & Trivette, 1986; Sigel et al., 1992).

Theorists postulate that older parents, defined as a parent in their later thirties or older, particularly those with a history of a previously stable life pattern with limited exposure to children, may experience difficulty in adjusting to a child with problematic characteristics, such as those seen in a child recently diagnosed with ASD. Theorists
postulate that parenting age is positively correlated with parenting stress (Abidin, 1995, Deater-Decker, 2004).

Social support is theoretically defined as the emotional, psychological, physical, informational, instrumental, or material assistance provided to others to maintain well-being or promote adaptation to diverse life events, as parenting a young child with ASD. Social support is theorized to have an inverse relationship with parenting stress (Abidin, 1985; Dunst & Trivette, 1985; Seligman & Darling, 2007).

The following hypotheses were investigated in the present dissertation in parents of recently diagnosed preschool age children with ASD.

1. Perceived severity of aberrant behavior is positively related to parenting stress in mothers of preschool age children recently diagnosed with ASD.

2. Parental expectations for their child is inversely related to parenting stress in mothers of preschool age children recently diagnosed with ASD.

3. Advanced maternal age is positively related to parenting stress in mothers of preschool age children recently diagnosed with ASD.

4. Social support is inversely related to parenting stress in mothers of preschool age children recently diagnosed with ASD.
Chapter 3

Methods

This chapter discusses the methods of the present descriptive correlational study that examined the relationship of the dependent variable parenting stress to each of the independent variables of (a) perceived severity of child aberrant behaviors, (b) parental expectations for a child, (c) maternal age, and (d) helpfulness of social support. This section describes the research setting, the sample, instrumentation, and data collection procedures.

The Research Setting

The Interactive Autism Network (IAN) community research registry served as the research setting for the study. IAN is a research initiative project of the Kennedy Krieger Institute of John Hopkins University, which is sponsored by Autism Speaks and the National Institute of Mental health. The IAN is composed of a nationwide community of family members of individuals with ASD or adults with ASD who are interested in participating in research. IAN employs subject recruitment assistance, sending recruitment letters to those who match study eligibility from information recorded in the registry database.

The Sample

Power analysis for Pearson correlation and multiple regression was employed to determine the sample size. Using a medium effect size ($r=.13$), four predictor variables (perceived severity of aberrant behavior, parental expectations for child, maternal age, and perceived helpfulness of social support), and a significance of .05, 85 subjects was needed to obtain a power of .80 (Faul, Erdfelder, Lang, & Buchner, 2007).
A sample was obtained using the Rutgers, the State University of New Jersey’s Institutional Review Board (IRB) approved recruitment letter (Appendix A) was emailed to 494 registered members of the Interactive Autism Network (IAN) community online research registry who met the inclusion criteria. After the email invitation was sent, followed by an identical repeat email invitation one month later, a total of 82 eligible participants contacted the study’s principal investigator by phone or email indicating interest in participation. Seven of these 82 participants did not return a study packet to the principle investigator despite reminder emails and a third mailing. It is unknown why they chose not to participate. A final sample of 75 participants was therefore recruited, a response rate of 91%. This final sample of 75 slightly affected the study’s power. A post-hoc analysis using G-power 3 (Faul et al., 2007) for a sample size of 75, a medium effect size ($r=.13$), and a significance of .05, determined the actual power of this study to be .75.

This convenience sample consisted of biological mothers of children with ASD, aged 5 years and under. Of the participants, 50.7% were identified as “younger” mothers, aged 34 years or less, and 49.3% were identified as “older” mothers, aged 35 years and up. The age of the mothers ranged from 23 to 49 years. Each mother of a diagnosed child affirmed that she lived with, provided care for, and raised her child with ASD. All study participants demonstrated the ability to use a computer, access the internet, and communicate via email. The children had been diagnosed with ASD by a qualified health care provider within 12 months of study enrollment. All of the children were under the age of 6 years at diagnosis. The majority of the children were diagnosed with Autism or Autistic Disorder ($n=43$), followed by Pervasive Developmental Disorder-Not
Otherwise Specified (PDD-NOS) \((n=20)\), Autism Spectrum Disorder (ASD) \((n=5)\), Asperger’s Syndrome \((n=5)\), and Pervasive Developmental Disorder (PDD) \((n=2)\).

Participants represented 28 different states. The greatest numbers of participants were from California, Florida, New York and Texas. Remaining participants were from Arkansas, Colorado, Georgia, Illinois, Indiana, Kentucky, Maine, Maryland, Massachusetts, Michigan, Missouri, New Hampshire, New Jersey, New Mexico, North Carolina, Ohio, Oklahoma, Pennsylvania, Tennessee, Washington, West Virginia, Wisconsin, and Wyoming. The demographic information on the sample is presented in Table 1 and Table 2.

**Instruments**

Four instruments and a demographic form were completed by the participants. The surveys included the 36-item Parenting Stress Index-Short Form (PSI-SF) (Abidin, 1995), the 58-item Aberrant Behavior Checklist-Community (ABC-C) (Aman & Singh, 1985), the 8-item Child Expectations Scale (CES) (Dunst & Trivette, 1986), and the 18-item Family Support Scale (FSS) (Dunst et al., 1986).

**Parenting Stress Index-Short Form**

The Parenting Stress Index-Short Form (PSI-SF) (Abidin, 1995) is a 36 item scale used to measure parental stress (Appendix C). It is an abbreviated version of the 120 item Parenting Stress Index (PSI) (Loyd & Abidin, 1985). Stress is measured on the PSI-SF on a five-point Likert Scale from (1) strongly agree to (5) strongly disagree. The PSI-SF can yield both a total stress score and scores on three subscales: Parental Distress, Difficult Child, and Parent-Child Dysfunctional Interaction. The respondent’s raw scores are converted into percentile scores. The normal range of scores is found within the 15th
to 80th percentiles. High stress scores are considered to be those at or above the 85th percentile (Abidin, 1995).

Reitman, Currier and Stickle (2002) investigated the psychometric properties of the Parenting Stress Index-Short Form in a sample of 196 mothers of preschool age children. Construct validity supported through confirmatory factor analysis yielded a three-factor solution, consistent with the theoretically constructed PSI-SF. Concurrent validity of the PSI-SF was established in this sample. Reitman et al., examined the PSI-SF subscales with related criterion measures including maternal demographic information, and results of the Conners’ Parent Rating Scale (Conners, 1997) and the Brief Symptom Inventory (Derogatis & Melisaratos, 1983) in a series of multiple regressions. Maternal symptomology accounted for 40% of the variance in the Difficult Child subscale, maternal psychological symptoms accounted for 22% of the variance in the Parent-Child Dysfunctional Interaction subscale, and 17% of the variance in the Parental Distress subscale. Reitman et al., established internal reliability with a Cronbach’s alpha among the three scales: Parental Distress .88, Parent-Child Interaction .88, and Difficult Child .89. Total Stress yielded a high internal consistency of .95.

Haskett, Ahern, Ward, and Allaire (2006) examined the psychometric properties of the Parenting Stress Index-Short Form in a sample of 185 parents of young children. Construct validity was supported through correlations of subscales and related scales. Scores on the Parental Distress subscale was significantly related to the Global Severity Index scale ($r = .54, p < .001$). Scores on the Difficult Child subscale was related to the Eyberg Child Behavior Inventory ($r = .61, p < .001$). Twenty-one parents of the original sample were re-tested one year later. PSI-SF results were stable, demonstrating
predictive validity and test-retest stability ($r=.61, p<.005$) for the Parent Distress scale and ($r = .75, p = <.001$) for the total scale.

**Aberrant Behavior Checklist-Community**

The Aberrant Behavior Checklist-Community (ABC-C) is a 58 item scale that measures parent’s perceptions of their child’s problem or maladaptive behaviors at home or school (Aman & Singh, 1985) (Appendix D). The ABC-C is made up of five subscales: Irritability/Agitation, Lethargy/Social Withdrawal, Stereotypic Behavior, Hyperactivity/Noncompliance, and Inappropriate Speech. Respondents rate items on a 4-point Likert scale ranging from (0) “not at all a problem” to (3) “the problem is severe in degree”. The ABC-C subscale scores are calculated by totaling the scores of the subscale items, and then comparing that total to the normative data in the ABC-C manual. The behavior is considered problematic if the subscale’s score exceeds the 85th percentile for his or her normative group.

The psychometric properties of the Aberrant Behavior Checklist were established in samples of parents of young children with ASD. Brinkley et al., (2007) established construct validity in a sample of 275 parents of children ranging in age from 3 to 21 years with ASD. Principle component analysis with varimax rotation revealed five factors with an eigen value greater than one, accounting for 76% of the variation in the data.

Congruent and criterion validity was examined in a sample of 93 parents of toddlers and preschoolers with autism and other behavior disorders. Participants completed the Aberrant Behavior Checklist (ABC) along with the Autism Behavior Checklist (AuBC), and the Child Behavior Checklist (CBCL). Internal consistency for the ABC subscales was moderate to high, and was found to be significantly correlated
with the CBCL \((r = .73)\) and the AuBC \((r = .71)\). The ABC subscales revealed significant differences among the diagnostic groups. The lethargy/social withdrawal and stereotypic behavior subscales were significantly higher in the children with autism (Karabekiroglu & Aman, 2009).

**Child Expectations Scale**

The Child Expectations Scale (CES) (Dunst & Trivette, 1986) is an 8-item measure of parental expectations for their disabled or developmentally delayed child’s future school achievement, financial independence, and adult living arrangements (Appendix E). The respondent circles a response to each item on a 5 point Likert scale. A choice of (1) indicates that the parent expects the child to be fully dependent in the category. A response of (5) indicates that the parent perceives the child will function independently in the category. The final sum of the CES scale can range from 8-40. The sum of these items provides a global index of parental expectations for the child. The higher the score, the more the respondent expects the child to live independently of the family of origin.

Dunst and Trivette (1986) investigated the psychometric properties of the Child Expectations Scale (CES) in a sample of 137 parents of preschool age children with disabilities or developmental delays. Construct validity was supported through a principal factor analysis using varimax rotation. A two-factor solution accounting for 74% of the variance was the result. Criterion validity was established in this sample through additional administration of several family and parent functioning dimensions of the Questionnaire on Resources and Stress (QRS) (Holroyd, 1974). The total CES score was significantly related to several QRS subscales: parent’s personal wellbeing \((r = 0.36,\)
$p$ = <.001, family integrity ($r$ = 0.33, $p$ = <.001), social support ($r$ = 0.27, $p$ = <.005) and time demands ($r$ = 0.33, $p$ < .001). Both intrapersonal and interpersonal characteristics of the parents in this sample influenced the degree to which they expected success for their children as adults.

Internal consistency of the Child Expectations Scale was supported in Dunst & Trivette’s (1986) study. Participants completed the CES at two month intervals. The coefficient alpha remained stable for the total score ($r$ = 0.96, $p$ = <.001), and for individual items ($r$ = 0.85, $p$ < .001).

**Family Support Scale**

The Family Support Scale (FSS) (Dunst et al., 1986) is an 18-item scale that measures parents’ perceptions of support resources made available to families raising a young child (Appendix F). It has been tested empirically in parents of children with ASD (Bromley et al., 2004; Hastings & Johnson, 2001). The FSS was designed to enable providers to identify those areas within a family that need to be strengthened or accessed in order to meet the family’s needs. It assesses the parent’s perception of support during the past 3 to 6 months on a 5-point Likert scale. Responses range from (1) Not at All Helpful to (5) Extremely Helpful. Support sources include the family’s immediate family, relatives, friends, and others in their social network. The scale also inquired about support in social organizations as well as specialized and generic professional services. Respondents can also write in 2 additional sources of support that may not have been listed upon reaching the end of the assessment. The sum of the respondent’s scores reflects a total for the degree of support, with the higher the score the higher the perceived support. The five subscales: Kinship, Spouse/Partner, Informal,
Programs/Organizations, and Professional Services can also be evaluated. The parent’s responses on the total scale range from either 19-95, or from 21-105 if the respondent fills in the 2 open-ended items.

Dunst, Jenkins, and Trvitte (2007) examined the reliability and validity of the Family Support Scale (FSS) in a sample of 224 parents of children with disabilities. A principle factor analysis using varimix rotation supported construct validity, after which five factors emerged. Within this sample, concurrent predictive validity was also supported. After correlation with the Questionnaire on Resources and Stress (QRS) (Holroyd, 1974), the FSS found that higher levels of support were associated with lower levels of personal and family problems in the Poor Health/Mood ($r = -.25$, $p < .025$), Excessive Time Demands ($r = -.22$, $p < .025$), and Family Integrity subscales ($r = -.17$, $p < .025$).

Hanley, Tasse, Aman, and Pace (1998) investigated the psychometric properties of the Family Support Scale in a sample of 224 parents of preschool age children who were not identified with any disability. Exploratory factor analysis again yielded a five-factor solution which accounted for 61% of the variance. Internal consistency for the total score was .85, with subscales alpha ranging from .60-.78. Test-retest reliability was established as parents in this sample completed the FSS two weeks later. The total alpha score was .73, with subscales alpha ranging from .60-.78.

**Demographics Questionnaire**

The demographic questionnaire was developed for this study by the primary investigator (Appendix G). Data were collected on maternal age, an independent variable, as well as months post-diagnosis, child’s gender, ASD diagnosis, the setting
where the diagnosis was made, the diagnosis provider and the geographic location where the family lived.

**Procedure for Data Collection**

To ensure that rights of participants were protected, the study protocol was reviewed by Rutgers, the State University of New Jersey’s Institutional Review Board (IRB) prior to data collection, and permission was obtained to proceed with the study. Participants who contacted the primary investigator expressing interest in the study, and met the inclusion criteria, were asked for their mailing address. Interested participants received a study packet at their home addresses by first class mail. The packet’s contents were assembled in the following order: (1) a detailed cover letter explaining the study, (2) the demographic form, containing inclusion and exclusion criteria, (3) the Parenting Stress Index-Short Form, (4) the Aberrant Behavior Checklist-Community, (4) the Child Expectations Scale, (5) the Family Support Scale, and (6) a stamped envelope addressed to the investigator for the return of the survey packet (Appendices C, D, E, F,G,H). A reminder/thank you email was sent to the participants one week after the survey packet was mailed (Appendix B). The primary investigator kept a record of non-responders. A second and third survey mailing was sent to non-responders four to eight weeks after the first study materials were issued. Each interested participant completed the 4 paper-and-pencil surveys, and the demographic questionnaire and returned the materials to the primary investigator in a pre-addressed, pre-stamped envelope. Participants were sent a $10.00 gift card, vial first-class mail in appreciation after completed questionnaires/surveys were received.
Human Subjects Protection

This research involves mothers of preschool age children who have been recently diagnosed with ASD. Potential risks to the subjects included any psychological emotions evoked through completion of the instruments. Evaluation of one’s parenting, child’s behaviors, and available social support are possible sources. Although four instruments were used, it is common within the empirical literature to use at least four and up to six measures with which to assess stress in this population (Bishop et al., 2007; Hastings & Johnson, 2001; Hastings et al., 2005). Based on the previous work, distress related to participation was expected to be minimal or nonexistent. Any stress that was experienced as a direct result of completion of the instruments is believed to be no greater than the possibility of harm encountered in daily life. The rights as a survey participant document (Appendix I) encouraged any distressed participants to contact the primary investigator by email and/or phone. Additionally the contact information for the Rutgers University Institutional Review Board (IRB) was provided. Although none of participants did experience distress, the primary investigator would have provided the participant with the phone number to request a free Autism Speaks 100 Day Kit, created especially for families with children aged 5 and under and recently diagnosed with ASD. It includes local resources and a contact number for an Autism Response Team Coordinator for additional assistance.

All participants were informed of the expected length of time to participate, an assurance of confidentiality, risks and benefits to participations, and the right to refuse to participate or discontinue participation at any time without penalty. Participants were
informed that completion of the questionnaires/surveys functioned as their consent to participate.

There are no direct benefits for participants other than compensation for participation. It is possible that participants may obtain benefit from having the opportunity to participate in research on this topic with the understanding that knowledge gained from this research will help others in the future. Theoretical literature asserts that a common characteristic of mothers with children newly diagnosed with a developmental disability is a sense of anomie and the desire for feelings of normalness (Seligman & Darling, 2007). Participation that may result in a feeling of greater stress has been acknowledged as a problem for this population.

The primary investigator maintained a computer list of participants’ names, email and home addresses. Each participant was assigned a code number. Participants were identified only by the code number on instruments. The computer files were password protected, and only the primary investigator had access to the password. Data collected from this study was entered into a computer data base (SPSS). Computer files were backed up onto a USB flash drive, which was maintained in a locket cabinet. Only the primary investigator has access to the cabinet.

There were no adverse events that needed to be reported to the IRB. Computer files will be deleted and the USB flash drive will be destroyed after the completion of the research study and the 3 year mandatory IRB data maintenance period.
Table 1  
*Sample Characteristics (N=75)*

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<td>Clinical Psychologist</td>
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<td>Neurologist</td>
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<tr>
<td>Team of School Professionals</td>
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<td>Speech and Language Pathologist</td>
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<table>
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<tr>
<td>Health care system (specializing in ASDs)</td>
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<td>Early Intervention Center</td>
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<td>14.7</td>
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<tr>
<td>Other</td>
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Table 2

*State of Participant’s Residence (N=75)*

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<tr>
<td>Florida</td>
<td>9</td>
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<tr>
<td>New York</td>
<td>8</td>
<td>10.7</td>
</tr>
<tr>
<td>Texas</td>
<td>5</td>
<td>6.7</td>
</tr>
<tr>
<td>Massachusetts</td>
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<td>5.3</td>
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<tr>
<td>Missouri</td>
<td>4</td>
<td>5.3</td>
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<tr>
<td>North Carolina</td>
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<td>5.3</td>
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<tr>
<td>Pennsylvania</td>
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<td>5.3</td>
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<tr>
<td>Michigan</td>
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<td>4.0</td>
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<tr>
<td>Arkansas</td>
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<td>4.0</td>
</tr>
<tr>
<td>Ohio</td>
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<tr>
<td>Indiana</td>
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<tr>
<td>Kentucky</td>
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<td>2.7</td>
</tr>
<tr>
<td>Illinois</td>
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<td>1.3</td>
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<tr>
<td>Oklahoma</td>
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<td>1.3</td>
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<tr>
<td>Washington</td>
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<td>1.3</td>
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<td>New Hampshire</td>
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<td>Colorado</td>
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<td>Georgia</td>
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<td>1.3</td>
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<tr>
<td>Wyoming</td>
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<td>1.3</td>
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<td>Wisconsin</td>
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<tr>
<td>New Mexico</td>
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<td>New Jersey</td>
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<td>1.3</td>
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<td>Tennessee</td>
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<td>Maine</td>
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Chapter 4

Analysis of the Data

This chapter discusses the analysis of the collected data. The purpose of this study was to explore the level of parenting stress and associated variables in mothers of preschool age children with ASD within the first year of diagnosis.

Statistical Description of the Variables

The scores on the study variables were found to approximate to a normal distribution with the exception of the total CES score. Scatterplots determined that the relationships among the variables were linear. Descriptive statistics, bivariate correlation coefficients, and a multiple regression were computed on the study variables. Data were analyzed using IBM SPSS Premium Edition Version 19.

Descriptive statistics were used to describe the demographics and to determine the frequency distribution for each variable in the study. The PSI-SF total score for this sample ranged from 56 to 156, (M= 111.29, SD= 22.68). The ABC-C total score ranged from 8 to 129, (M=63.39, SD=26.95). The CES total score ranged from 18 to 40, (M=33.12, SD=4.95). The FSS total score ranged from 7 to 66, (M=39.17, SD=12.73). Maternal age ranged from 23 to 49 years, (M=34.61, SD=5.77). Descriptive information for study variables is presented in table 3.

Psychometric Properties of Instruments

Internal consistency or reliability was obtained on the responses of the sample to the study instruments. A Cronbach’s alpha was performed on each instrument and subscale. The criterion used for acceptable reliability coefficients was .80 (Nunnally & Bernstein, 1994). The PSI-SF (r=.918), ABC-C (r=.945), CES (r=.859) and FSS (r=
.798) therefore demonstrated excellent internal consistency in this sample. Alpha coefficients are presented in Table 4.

**Hypotheses**

Four hypotheses were developed for this study and tested on a national sample of mothers of recently diagnosed preschool age children with ASD. The relationships among maternal age in years, perceived severity of child aberrant behavior, future child expectations, perceived usefulness of family support and parenting stress were investigated. A Pearson correlation coefficient was computed to determine the relationships. The bivariate correlation coefficients between the study variables and parenting stress are presented in Table 5.

**Hypothesis 1**

Mothers of preschool age children recently diagnosed with ASD reporting high levels of child aberrant behavior would also report high levels of parenting stress. This hypothesis was supported. There was a significant positive correlation between the ABC-C total score and the PSI-SF total score ($r = .521$, $p = .000$).

**Hypothesis 2**

Mothers of preschool age children recently diagnosed with ASD reporting lower expectations for their child’s future would also report high levels of parenting stress. This hypothesis was supported. In this sample, parental expectations for a child were inversely related to the level of parenting stress. There was an inverse relationship between the CES score and the PSI-SF total score ($r = -.397$, $p = .000$).
Hypothesis 3

The third hypothesis proposed advanced maternal age of the participants would be positively related to parenting stress. This hypothesis was not supported in the direction proposed. There was a significant relationship between maternal age in mothers of preschool age children recently diagnosed with ASD and parenting stress. However, the relationship was inverse ($r = -.205, p = .039$).

Hypothesis 4

Social support is inversely related to parenting stress in mothers of preschool age children recently diagnosed with ASD. This hypothesis was supported. Mothers in this sample who reported lower levels of perceived helpfulness of social support also reported high levels of parenting stress ($r = -.237, p = .020$).

Regression Analysis

As all variables displayed a correlation at a significance level of $p < .05$, the effects of predictor variables on parenting stress were tested using multiple linear regression analysis. Variables were entered into a stepwise regression analysis to determine which would account for most of the variance on the dependent variable, parenting stress. Two-tailed tests of mean differences were used throughout, with the traditional .05 significance level used as the criterion for determining statistical significance. All variables in the multiple regression equation were explored for their fit with the assumptions of multivariate analyses. Examination of Cook’s distance revealed that there were no influential data points (Cook’s distance was < 1). The scatterplot of the regression standardized residual and the standardized predicted value, and the assumptions of normality, linearity, and homoscedasticity were all met. Collinearity
statistics were met, as the variance inflation factor (VIF), was below 10 for all variables. As tolerance was close to 1, multicollinearity was not a threat to the analyses. Two models were analyzed. The predictor holding constant in model 1 was the ABC-C total score. The CES total score was added in Model 2. Two independent variables of maternal age in years, and perceived helpfulness of family support were excluded. This was because they did not make a significant change to the $R^2$ when added, and therefore did not contribute to further models. The overall regression analysis was significant ($F=27.17, p=.000$) for model 1 and ($F=17.05, p=.000$) for model 2. The mother’s perceived severity of the child’s aberrant behavior accounted for 27.1% of the variance in parenting stress in (model 1). When the mother’s future expectations for their child were added, 32.1% of the variance was accounted for by these two variables (model 2). The model summary for regression analysis is presented in Table 6.

**Summary of Findings**

As anticipated, findings from this study indicated a moderate, positive correlation between perceived severity of child aberrant behavior and parenting stress, ($r=.521, p=.000$), a low negative correlation between perceived helpfulness of family support and parenting stress, ($r=-.237, p=.04$), and a low negative correlation between future expectations for the child and parenting stress ($r=-.397, p=.000$). Nonparametric correlations were computed as the total CES score was significantly skewed. A Kendall’s tau also indicated a low negative relationship as well ($r=-.289, p=.000$), and a Spearman’s rho ($r=-.389, p=.001$). A low negative correlation between maternal age and parenting stress was found, ($r=-.205, p=.039$). However, this was in the opposite correlation direction than that which was hypothesized. Younger rather than older
mothers had a significant correlation with higher parenting stress. Mother’s perceived severity of the child’s aberrant behavior significantly predicted the level of reported parenting stress, independently accounting for 27% of the variance. The mothers’ level of expectations for their child’s future combined with perception of the child’s behavior increased the variance of parenting stress to 32%.
Table 3

Descriptive Statistics of Study Variables (N=75)

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<tr>
<th>Variable</th>
<th>Minimum</th>
<th>Maximum</th>
<th>M</th>
<th>SD</th>
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<td>ABC-C</td>
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Table 5

Correlation Coefficients of Study Variables and Parenting Stress (N=75)

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<tbody>
<tr>
<td>Maternal Age (years)</td>
<td>-.205*</td>
</tr>
<tr>
<td>Aberrant Behavior</td>
<td>.521**</td>
</tr>
<tr>
<td>Child Expectations</td>
<td>-.397**</td>
</tr>
<tr>
<td>Family Support</td>
<td>-.237*</td>
</tr>
</tbody>
</table>

*p > .05 (2-tailed)

**p > .001 (2-tailed)

Table 6

Multiple Regression Model of Predictors of Parenting Stress (N=75)

<table>
<thead>
<tr>
<th></th>
<th>Model 1</th>
<th>Model 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beta</td>
<td>.521</td>
<td>.567</td>
</tr>
<tr>
<td>R²</td>
<td>.271</td>
<td>.321</td>
</tr>
<tr>
<td>Adjusted R²</td>
<td>.261</td>
<td>.302</td>
</tr>
<tr>
<td>R² change</td>
<td>.271</td>
<td>.050</td>
</tr>
<tr>
<td>Significance</td>
<td>.000</td>
<td>.024</td>
</tr>
</tbody>
</table>

Predictors in Model 1: (Constant) Aberrant Behavior Checklist-Community Total Score
Predictors in Model 2: (Constant) Aberrant Behavior Checklist-Community Total Score, Child Expectations Scale Total Score
Dependent Variable: Parenting Stress Index-Short Form Total Score
Chapter 5

Discussion of the Findings

The purpose of the present study was to examine the relationships among perceived severity of problem behavior, maternal expectations for the child, maternal age, extent of social support and the dependent variable of parental stress in mothers of children diagnosed with ASD. The study was designed to ascertain which variables would emerge as the most reliable predictors of parenting stress. This chapter interprets the findings of parental stress and the hypotheses tested with reference to the theories that generated the propositions.

Parenting Stress in Mothers of Recently Diagnosed Young Children

Parenting stress is defined in theory as a psychological phenomenon resulting from an imbalance between the demands of the parenting role and the resources available for meeting the parenting responsibility. Parents can expect to experience some emotional stress when facing the demands, obstacles, and challenges of parenting. A parent’s perception of specific characteristics associated with a developmental disability can generate additional parenting stress above the norms and become clinically significant. Although such antecedents for development of parenting stress are considered multidimensional, they can be assigned to three major domains. The first two involve parental distress and difficult child characteristics occurring independently or in combination. These two domains can also interact to create a third domain featuring a dysfunctional parent-child interaction pattern. Distress in any of these domains can subsequently lead to the development of parenting stress (Abidin, 1995). The year following diagnosis is theorized to have the greatest potential for its progression. The
high demands of a child with ASD combined with little access to resources are surmised to place parents at an increased risk for parenting stress during the first year post diagnosis. Parenting stress is conjectured to lead to the development of a dysfunctional parenting pattern resulting in behavioral and emotional problems and their consequences for children (Seligman & Darling, 2007).

Scores above the 85th percentile rank on the PSI-SF place respondents in the high ranks. A PSI-SF total raw score of 90 (at or above the 90th percentile) indicates clinically significant stress (Abidin, 1995). The PSI-SF total score for participants in this sample was high ($M=111.29$, $SD=22.52$). These mothers, in the 99th percentile for total stress, provide empirical support for the theoretical stance that mothers of young children with ASD in the first year post-diagnosis will experience significant parenting stress.

Parenting stress is further interpreted within the domains of occurrence. These domains relate to parental distress, stress from parenting a difficult child, or stress from the parent-child interaction. In this sample, the mean stress for each subscale was highest for the difficult child domain, with scores above the 95th percentile ($M=43.04$, $SD=10.03$). This was followed by parental distress, with scores at the 90th percentile ($M=36.61$, $SD=9.17$). The parent-child interaction domain score, although somewhat lower, was still in the 90th percentile ($M=31.70$, $SD=8.01$).

Abidin (1995) recommends evaluating the parenting stress according to its domain. The items with the overall highest rating were from the difficult child subscale. Participants rated as the item “I have found that getting my child to do something or stop doing something is much harder than I expected” as the most stressful. This was followed by the item “My child reacts very strongly when something happens that my
child doesn’t like”. The next two highest ratings were from the parental distress subscale. Most participants rated items “I find myself giving up more of my life to meet my children’s needs than I ever expected” and “My child makes more demands on me than most children” as stressful. High scores on the difficult child subscale when produced by mothers of children 2 years of age and older are typically related to measures of child behavioral adjustment and behavioral symptoms. High scores on the parental domain indicates that the parent is experiencing stress directly related to an impaired sense of parenting competence with its concomitant restrictions on other life roles.

Mean scores at or above the 95th percentile may represent significant psychopathology. Parents here usually need professional assistance (Abidin, 1995). This sample’s PSI-SF total score and difficult child subscale score both were above the 95th percentile. The findings from this study are typical of studies of stress in families of children with ASD at various time points post diagnosis. This study’s PSI-SF mean of 111 was significantly higher than previous studies that examined parenting stress in mothers of older children (Lecavalier et al., 2006; Tomanik, et al., 2004). As theorized, it can be concluded that the high demands of the younger, newly diagnosed ‘difficult’ child with ASD correlates to significant parenting stress, necessitating the development of nursing intervention.

**Aberrant Behavior and Parenting Stress**

Hypothesis 1 stated that perceived severity of aberrant behavior is positively related to parenting stress in mothers of preschool age children recently diagnosed with ASD. This hypothesis was derived from theory suggesting that aberrant, externalizing,
or maladaptive behavior in a child is believed to lead to the development of parenting stress (Abidin, 1995; Aman & Singh, 1985). This hypothesis and underlying theory was supported in this study; there was a significant positive correlation between the ABC-C total score and the PSI-SF total score ($r=.521$, $p=.000$). Furthermore, perceived severity of aberrant behavior was found to be a valid predictor of parenting stress as it accounted for 27.1% of the variance. Scores on the ABC-C is likely a robust predictor of parenting stress during the post diagnostic time period. Mothers in this sample reported the most problematic behavior was when their children were irritable, hyperactive and resistant to change. This finding is consistent with other studies that have demonstrated a relationship between the behavior of children with ASD and parenting stress (Bishop et al., 2007; Davis & Carter, 2008; Duarte et al., 2005; Hastings & Johnson, 2001; Hastings et al., 2005; Kasari & Sigman, 1997; Lecavalier et al., 2006; Tomanik et al., 2004).

Chronic parenting stress can also generate a skeptical or cynical attitude regarding possible access to, and value of, advice and knowledge about the child’s aberrant behavior and thus contribute to detrimental long-term consequences (Abidin, 1995; Deater-Deckard, 2004; Seligman & Darling, 2007).

Findings suggest the importance of stress reduction. As the relationship and predictors of stress were identified, nurses can assist in teaching mothers strategies to manage their child’s aberrant behavior in order to reduce their stress. Nursing interventions, therefore, should prepare mothers to anticipate parental distress and develop educational or supportive countermeasures. Their goal would be to keep parental evaluations in context during the critical first year. Teaching mothers more about ASD behaviors before and as they occur, in the early diagnostic period, would help
to prepare for or possibly lessen parental stress levels within the first post-diagnostic year.

Parenting stress is theorized to occur from situational and stimulus-specific behavior. Many parents have had limited exposure to individuals with ASD before the birth of their own child. Such unfamiliarity, particularly in a post-diagnosis time frame, may skew a parent’s self-appraisal of skills in managing these behaviors. Complex role requirements and needs of children may combine to be reflected in in low self-ratings, expressions of frustration, and a sense of being overwhelmed.

Aman and Singh (1985) state that parents whose total score on the ABC-C that exceeds the 85th percentile can be interpreted as a severe individual perception of the problem behavior. In this study’s sample, the mean score for the subscales rating irritability ($M=18.36$, $SD=10.9$), lethargy ($M=11.71$, $SD=7.15$), and stereotypic behavior ($M=6.41$, $SD=4.44$) all were between the 85-90th percentile when compared to the normative group close to the participant’s child’s age. The inappropriate speech subscale score ($M=4.02$, $SD=3.38$) was even higher, at a level between the 90-95th percentile. The hyperactivity subscale’s mean score ($M=23.29$, $SD=12.31$) was somewhat lower, within the 80-85th percentile. The overall level of perceived severity of child aberrant behavior was significant. Two items were found to exhibit the highest mean scores. One was from the irritability subscale “Has temper outbursts or tantrums when he/she does not get own way”. The other emerged from the hyperactivity subscale “Constantly runs or jumps around the room”. Mothers in this sample reported these two examples of aberrant behavior as the most problematic. It is not difficult to see why very active, rigid, change resistant children are stressful to their mothers. Children with ASD may have task
persistence. The child with ASD has a tendency to continue to engage in an activity and resist switching to a new task which in inevitability stressful for parents (American Psychiatric Association, 2000).

**Child Expectations and Parenting Stress**

Hypothesis 2 stated that the variable of parental expectations for their child is inversely related to parenting stress in mothers of preschool age children recently diagnosed with ASD. Child expectations, is theoretically defined as the long-term perceptions parents hold regarding their child’s future capabilities (Dunst & Trivette, 1986). Theory suggests that pre-existing expectations are often influenced by a parent’s appraisal of a child’s behavioral competencies and capabilities. Parent and family characteristics also play a role. Parenting stress can be an outcome of the child’s inability in terms of child’s physical, intellectual, and/or emotional characteristics to meet parental expectations. Therefore, it is theorized that low expectations for the child’s future will result in higher parenting stress (Abidin, 1995; Deater-Deckard, 2004; Dunst & Trivette, 1986). The hypothesis with its theoretical underpinnings was supported in the present study. Those mothers of preschool age children recently diagnosed with ASD relating lower expectations for a child’s future also reported high levels of parenting stress. Parental expectations for a child were inversely related to the level of parenting stress, ($r=-.397, p=.000$). Parental expectations was also a significant predictor of parenting stress, explaining an additional 32.1% of the variance in parenting stress when added to the level of aberrant behavior.

An interesting finding was that the total CES score for this sample was high ($M=33.12, SD=4.85$), the respondents were found to expect that their children would
live independently as an adult. Almost all the mothers in this sample anticipated that their children would go to college. The lowest maternal expectations were reported regarding a child’s future ability to be an active participant in the community. Assessment of mothers in the first year that reveals low expectations for adult independent living should be considered a risk for stress development. Again, these results establish a rationale for developing and testing nursing interventions designed to mitigate the effects of lowered maternal expectations during the first year of post-diagnosis.

**Maternal Age and Parenting Stress**

Hypothesis 3 stated that advanced maternal age is positively related to parenting stress in mothers of preschool age children recently diagnosed with ASD. This hypothesis was derived from theory which postulated that a difficult adjustment to a child with problematic characteristics may be experienced by mothers with specific attributes. These include becoming a parent in the late thirties or later, a previously stable life pattern, and a less than extensive prior exposure to children (Abidin, 1995, Deater-Decker, 2004). It is theorized that, on average, these older parents will be more likely to face personal health issues and experience biological and psychological changes. These crises and crossroads present implications for stress as they arise. Older parents may lack sufficient physical energy to keep up with a child manifesting either hyperactivity or irregular sleep patterns. Theorists also presume that parenting stress may accumulate over time (Abidin, 1995, Deater-Decker, 2004). These theoretical propositions provided the foundation for the hypothesis that advanced maternal age is positively correlated with parenting stress.
Mothers in this sample ranged from age 23 to 49 years, \( M = 34.61 \) years, \( SD = 5.77 \). The range of ages here spanned a large section of the spectrum of the childrearing population of mothers of young children. Overall, the sample’s mean can be interpreted as ‘older’ mothers, as the mean age can be rounded to 35 years of age. There was a significant relationship between parenting stress and the maternal age in mothers of preschool age children recently diagnosed with ASD. However, the relationship was inverse \( r = -0.205, p = 0.039 \). The hypothesis that advanced maternal age of participants would be positively related to parenting stress was not supported in the direction proposed. The data were scrutinized before accepting the findings. There was no methodological rational for the unhypothesized, yet significant finding. The theory regarding advanced maternal age, therefore does not apply to mothers of recently diagnosed young children with ASD in this sample. Maternal age is an important variable to consider in the development of parenting stress. There is a gap in the literature studying younger mothers of children with ASD and the effects of parenting stress, and comparative studies between groups of mothers according to age. Young mothers may at a higher risk, as in this sample, however a return to the theoretical literature in warranted to support the findings.

**Family Support and Parenting Stress**

Hypothesis 4 stated social support is inversely related to parenting stress in mothers of preschool age children recently diagnosed with ASD. This hypothesis was theoretically derived. Social support is theoretically defined as emotional, psychological, physical, informational, instrumental, or material assistance provided to others with the purpose of maintaining well-being or promoting adaptation to diverse life events (Dunst
et al., 1986). Such life events include those involved in raising young children.

Theorists further separate social support into two categories: informal and formal support. Informal support is defined as family helpfulness extended by individuals who do not require an exchange of money in compensation and are not part of a formal organization. Formal support is defined as extra-family support including that which may be provided by professional services, programs, and agencies. An individual’s perception of the adequacy of this support can either add to, or alleviate, parenting stress (Dunst & Trivette, 1985). A function of support is to foster and strengthen links between parents in day-to-day parenting tasks as well as to help in times of need or crisis (Abidin, 1985; Dunst & Trivette, 1985; Seligman & Darling, 2007).

The mothers in this sample were asked to evaluate helpfulness in various sources of social support available to families rearing a young child. These included resources typically available to the family of a child with a developmental disability, such as early childhood intervention, therapists, or public agencies. Overall, mothers did not express a feeling of strong support. Although the evaluation for the FSS total score could have been as high as 95, the mean score for helpful support was in the lower half ($M=39.29$, $SD=12.69$). However, several sources of support were rated as helpful by mothers in this sample. Three such informal support sources included a spouse or partner, early childhood intervention, and school or daycare. The most serviceable source of formal social support was in the form of professionals in the field of childcare. These included social workers, therapists, and teachers. The least beneficial sources of support included church members or ministers and the family or child’s physician. Dunst & Trivette (1985) have stated that low scores imply the potential for personal and family problems.
This was evidenced by the hypothesis testing in this study. The hypothesis was supported. Social support was inversely related to parenting stress in mothers of preschool age children recently diagnosed with ASD ($r = -.237, p = .020$).

Nurses who assess low levels of support should anticipate parenting stress. This sample stated one of the least helpful sources of support was the child’s physician, an area for improvement. As nurses are typically working in a practice environment with the physician, it is crucial to understand what characteristics about teachers and therapists the mothers find helpful. Nursing interventions, in the form of similar formal support can be developed and tested in hopes to improve stress levels in mothers of the recently diagnosed child with ASD.
Chapter 6  

Summary  

The purpose of this study was to examine the level of parenting stress and associated variables in mothers of young children with ASD within the first year after diagnosis. The findings from this study may assist in predicting parenting stress at time of diagnosis and the year that follows. Theorists postulate that parenting stress in mothers of children with ASD is related to maternal perceptions (Abidin, 1995; Deater-Deckard, 2004; Dunst & Trivette, 1985, McCubbin & Figley, 1983; Seligman & Darling, 2007). In this study, such perceptions included a mother’s appraisal of the severity of aberrant behavior, expectations for a child’s future, and assessment of available social support.

Mothers who classify their child’s behavior as aberrant may also rate many aspects of social relatedness and communication as impaired. Mothers who evaluate their own skills in managing these behaviors as inadequate may become frustrated and then overwhelmed by the requirements of parenting. Children at risk for poor developmental outcomes may develop in parents a lowered expectation for possible independent living as adults. Parenting stress can result from an apprehension of future inadequacies. It is widely believed that adequate social support can relieve the intensity of parenting stress, while a deficit in this area can accelerate its manifestation. Theorists also have postulated that maternal age is related to stress. That aspect appears in differences in adjusting to a child with problematic characteristics (Abidin, 1995; Deater-Deckard, 2004; Dunst & Trivette, 1985, Seligman & Darling, 2007).
Based on theoretical and empirical findings, hypotheses were developed for this study. Perceived severity of aberrant behavior and older maternal age would be positively related to parenting stress. Also, parental expectations for the child and level of social support would be inversely related to parenting stress in mothers of preschool age children recently diagnosed with ASD.

The study’s convenience sample comprised 75 biological mothers of children with ASD aged 5 years and under where diagnosis had been made less than 12 months from enrollment. The mothers were recruited for this study from the IAN research registry. Mothers ranged in age from 23 to 49 years, with a mean age of 34.6 years. The majority of participants were mothers of boys enrolled within 7 months after a diagnosis of Autism or Autistic Disorder of the ASD spectrum. Participants represented 28 different states, with the greatest numbers of participants from California, Florida, New York, and Texas.

Email and telephone were the methods of communication between the primary investigator and the participants. Participants received and returned 4 paper-and-pencil surveys and a demographic sheet by first class mail. Participants were sent a $10.00 gift card via first-class mail after completed questionnaires/surveys were received by the primary investigator. Descriptive statistics were used to describe the demographics and to determine the frequency distribution for each variable in the study. A Cronbach’s alpha performed on each instrument and subscale yielded excellent internal consistency. Study variables were found to approximate a normal distribution with the exception of the total CES score. All relationships between the variables were linear and fit the assumptions of multivariate analyses. Bivariate correlation coefficients and multiple regressions were calculated on study variables.
As anticipated, a moderate, positive correlation between perceived severity of child aberrant behavior and parenting stress, \( r = .521, p = .000 \), a low negative correlation between perceived helpfulness of family support and parenting stress, \( r = -.237, p = .04 \), and a low negative correlation between future expectations for the child and parenting stress \( r = -.397, p = .000 \) were all established. A low negative correlation between maternal age and parenting stress \( r = -.205, p = .039 \) was established in the opposite correlation direction, contrary to hypothesis. Maternal perceived severity of the child’s aberrant behavior and expectations were found to significantly predict the level of reported parenting stress. This accounted for 32% of the total variance.

**Conclusions**

A theoretical position can be advanced that development of parenting stress is predicted by advanced maternal age, low parental expectations, aberrant behaviors of the child, and limited or inadequate social support at time of diagnosis. This concept has not been comprehensively addressed in the literature. This study found that mothers of young children with ASD are highly stressed at time of diagnosis. Empirical studies have concluded that mothers of older children at various times post-diagnosis are a highly stressed group. It was unknown if this stress accumulates over the years or remains at a steady level. This study broke new ground in finding that parenting stress in mothers is prominent from time of diagnosis, and that levels of stress are related to identifiable variables. A unique aspect of this study was the assessment of the impact of perceived severity of child aberrant behavior. Many previous empirical studies have focused on levels of autism symptomology, intelligence, or adaptive behavior. This study also established that parenting stress may be related to difficulty in management of the child’s
response to change. Stress also results in a constriction of the parental role as a consequence of adaptation to ASD diagnosis in its first year.

**Implications for Nursing**

This study provides tangible evidence as to the investigation of stress in mothers of newly diagnosed young children with ASD. The goal of prevention or reduction of the negative effects of stress over time is paramount. The correlation between stress and negative health outcomes needs to be recognized and addressed. Nursing can develop specific assessments with which to identify stress and its associated variables in mothers post-diagnosis. Mothers who are considered to be at risk for development of parenting stress should receive intervention. Future studies can develop and test nursing interventions including recognition and utilization of available social support, reframing expectations, and improving management techniques for aberrant behavior on stress reduction.

**Recommendations**

Contrary to theory, younger mothers were found to have higher stress than older mothers in this sample. Future studies should assess additional personal characteristics of maternal participants so as to identify possible predictors beyond age alone. Consideration of personality factors, coping methods, socio-economic status, employment status, and their relationships to stress would be useful in assembling profiles of those mothers potentially at higher risk during the post-diagnostic period. It should be noted that this was a convenience sample of mothers seeking support and understanding by registering with IAN. Therefore, mothers who have not so registered may, in fact, present even higher stress levels. It is also possible that those mothers who
willingly registered with the intent of participating in research would be supported by knowing that such participation could help others in the future. Conversely, mothers in search of information and support post-diagnosis, and who are willing to participate in research may already be at heightened stress levels. Mothers who do not reach out for this type of help may not be in crisis or in danger of developing negative outcomes. This study’s sample may not be representative of all mothers of young children newly diagnosed with ASD. Longitudinal research on parents of children diagnosed with ASD will also add to our understanding of how to intervene with these parents.

Limitations to this study include a slightly lower sample size than anticipated, reliance on self-report data, cross-sectional design, and convenience sampling. Longitudinal data could be helpful to study the profile of stress over time.

Despite the admitted limitations, there are several strengths in this study, including the use of robust quantitative measures and theoretical models to guide the research. Future work can expand knowledge and a nursing model with which to identify and address the needs of these mothers. As nurses often work in practice settings where young children are diagnosed with ASD, understanding the attributes of maternal stress will contribute to assistance and professional support. As mothers of young children newly diagnosed with an ASD face their uncertain futures and the potential for negative health outcomes, they are worthy of the highest levels of scholarship and intervention that nursing may provide.
References


Dear IAN Research participant,

Based on your family profile, one or more members of your family may qualify for the study, below. You should contact the research team directly, using the information provided, if you are interested in joining. You do not have to participate in this study and your non-participation will neither affect the care you receive from any health provider nor your standing as a participant in IAN Research.

Please note that IAN Research is serving as a resource linking the autism community and researchers. This study is not endorsed by or performed under the auspices of the IAN Research project at Kennedy Krieger Institute/Johns Hopkins.

Name of Study: Parenting Stress in Mothers of Preschool Age Children Recently Diagnosed with an Autism Spectrum Disorder
Institution: Rutgers, The State University of NJ
Location: Mail-based study, no geographic limitation within the United States
Eligibility Criteria: Mothers of children with an autism spectrum disorder age 5 and under diagnosed within one year from study enrollment date.
Principle Investigator: Cheryl Shaffer, MS, PNP, ANP
Contact Information: shaffec@sunysuffolk.edu; 631-463-1639 Please include your name and mailing address.

Dear Parent,

You are invited to participate in an important research study. The purpose of this study is to examine parenting stress in mothers of preschool age children recently diagnosed with an autism spectrum disorder. This research will additionally examine the mother’s perception of their child’s problem behaviors, expectations for the child’s future, helpfulness of social support, and maternal age with the level of stress experienced.

Your responses are desperately needed to allow researchers to evaluate trends so as to respond more effectively to the needs of mothers in the first year of diagnosis.

This is a mail-based study. Participating mothers will be asked to complete four self-reported paper and pencil questionnaires and a demographic survey. You should be able to complete this study within 25 minutes.

For your participation in this study, you will be mailed a $10.00 Wal-Mart gift card after complete survey/questionnaires are received.

If you are interested in participating, please contact me, Cheryl Shaffer, by email at shaffec@sunysuffolk.edu or by phone at 631-463-1639. Please include your name and mailing address.
Thank you in advance for your time and assistance.
Sincerely,
Cheryl Shaffer, MS, PNP, ANP
Rutgers, The State University of NJ

IAN Ref: SR00339
Appendix B
Email Reminder Letter

Date

Dear Research Participant,

Last week a survey packet concerning parenting stress, perceived severity of aberrant behavior, parental expectations, maternal age, and perceived helpfulness of social support was mailed to you.
If you have already completed and returned the survey packet to me, please accept my sincere gratitude. If not, I would be especially grateful if you could complete it, so your experience can further the understanding of mothering a child with an ASD within the first year of diagnosis.
If you have not received a survey packet, or if it was misplaced, please contact me by email at shaffec@sunysuffolk.edu so I can get another packet to you in the mail.

Sincerely,

Cheryl Shaffer, MS, PNP, ANP
Doctoral Candidate
Rutgers, The State University of NJ
College of Nursing
## Appendix C

### Parenting Stress Index-Short Form

<p>| | | | | | |</p>
<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>SA= Strongly Agree</td>
<td>A= Agree</td>
<td>NS=Not Sure</td>
<td>D=Disagree</td>
<td>SD= Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>I often have the feeling I cannot handle things very well.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>2.</td>
<td>I find myself giving up more of my life to meet my children’s needs than I ever expected.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>3.</td>
<td>I feel trapped by my responsibilities as a parent.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>4.</td>
<td>Since having this child, I have been unable to do new and different things.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>5.</td>
<td>Since having this child, I feel that I am almost never able to do things that I like to do.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>6.</td>
<td>I am unhappy with the last purchase of clothing for myself that I made.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>7.</td>
<td>There are quite a few things that bother me about my life.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>8.</td>
<td>Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend)</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>9.</td>
<td>I feel alone and without friends.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>10.</td>
<td>When I go to a party, I do not usually expect to enjoy myself.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>11.</td>
<td>I am not as interested in people as I used to be.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>12.</td>
<td>I don’t enjoy things as I used to.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>13.</td>
<td>My child rarely does things for me that make me feel good.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>14.</td>
<td>Sometimes I feel my child doesn’t like me and doesn’t want to be close to me.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>15.</td>
<td>My child smiles at me much less than I expected.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>16.</td>
<td>When I do things for my child, I get the feeling that my efforts are not appreciated very much.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>17.</td>
<td>When playing, my child doesn’t often giggle or laugh.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>18.</td>
<td>My child doesn’t seem to learn as quickly as most children.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>19.</td>
<td>My child doesn’t seem to smile as much as most children.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>20.</td>
<td>My child is not able to do as much as I expected.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
<tr>
<td>21.</td>
<td>It takes a long time and is very hard for my child to get used to new things.</td>
<td>SA</td>
<td>A</td>
<td>NS</td>
<td>D</td>
</tr>
</tbody>
</table>

For the next statement choose your response from the choices “1” to “5” below.

22. I feel that I am:
   1. Not very good at being a parent
   2. A person who has some trouble being a parent
   3. An average parent.
   4. A better than average parent
   5. A very good parent.

23. I expected to have closer and warmer feelings for my child than I do and this bothers me. | SA | A | NS | D | DS |
24. Sometimes my child does things that bother me just to be mean. | SA | A | NS | D | DS |
25. My child seems to cry or fuss more often than me. | SA | A | NS | D | DS |
26. My child generally wakes up in a bad mood. | SA | A | NS | D | DS |
27. I feel that my child is very moody and easily upset. | SA | A | NS | D | DS |
28. My child does a few things which bother me a great deal. | SA | A | NS | D | DS |
29. My child reacts very strongly when something happened that he/she doesn’t like. | SA | A | NS | D | DS |
30. My child gets upset easily over the smallest things. | SA | A | NS | D | DS |
31. My child’s sleeping or eating schedule was much harder to establish than I expected. | SA | A | NS | D | DS |
For the next statement choose your response from the choices “1” to “5” below.

32. I have found that getting my child to do something or stop doing something is:
   1. Much harder than I expected.
   2. Somewhat harder than I expected.
   3. About as hard as I expected.
   4. Somewhat easier than I expected.
   5. Much easier than I expected.

For the next statement, choose your response from the choices “10+” to “1-3”.

33. Think carefully and count the number of things which your child does that bothers you. For example: dawdles, refuses to listen, is overactive, cries, interrupts, fights, whines, etc.

34. There are some things that my child does that really bothers me a lot.

35. My child turned out to be more of a problem than I expected.

36. My child makes more demands on me than do most children.
Appendix D
Aberrant Behavior Checklist-Community

Please rate this child’s behavior for the last four weeks. For each item, decide whether the behavior is a problem and circle the number.

0 = not at all a problem.
1 = the behavior is a problem but in slight degree.
2 = the problem is moderately serious.
3 = the problem is severe in degree.

<table>
<thead>
<tr>
<th>Item</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Excessively active at home, school, work, or elsewhere.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. Injures self on purpose.</td>
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<tr>
<td>3. Listless, sluggish, inactive.</td>
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<tr>
<td>4. Aggressive to other children or adults (verbally or physically).</td>
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<tr>
<td>5. Seeks isolation from others.</td>
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<tr>
<td>6. Meaningless, recurring body movements.</td>
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<tr>
<td>7. Boisterous (inappropriately noisy and rough).</td>
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<tr>
<td>8. Screams inappropriately.</td>
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<tr>
<td>10. Temper tantrums/outbursts.</td>
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<tr>
<td>11. Stereotyped behavior: abnormal, repetitive movements.</td>
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<tr>
<td>12. Preoccupied: stares into space.</td>
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<tr>
<td>13. Impulsive (acts without thinking).</td>
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<tr>
<td>15. Restless, unable to sit still.</td>
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<tr>
<td>16. Withdrawn; prefers solitary activities.</td>
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<tr>
<td>17. Odd, bizarre in behavior.</td>
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<tr>
<td>18. Disobedient; difficult to control.</td>
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<tr>
<td>19. Yells at inappropriate times.</td>
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<tr>
<td>20. Fixed facial expression; lacks emotional responsiveness.</td>
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<tr>
<td>21. Disturbs others.</td>
<td></td>
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<tr>
<td>22. Repetitive speech.</td>
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<tr>
<td>23. Does nothing but sit and watch others.</td>
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<td></td>
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<td></td>
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<tr>
<td>24. Uncooperative.</td>
<td></td>
<td></td>
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<tr>
<td>25. Depressed mood.</td>
<td></td>
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<tr>
<td>26. Resists any form of physical contact.</td>
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<tr>
<td>27. Moves or rolls head back and forth repetitively.</td>
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<tr>
<td>28. Does not pay attention to instructions.</td>
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<tr>
<td>29. Demands must be met immediately.</td>
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<tr>
<td>30. Isolates himself/herself from other children or adults.</td>
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<tr>
<td>31. Disrupts group activities.</td>
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<td></td>
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<tr>
<td>32. Sits or stands in one position for a long time.</td>
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<tr>
<td>33. Talks loudly to self.</td>
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<td></td>
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</tr>
<tr>
<td>34. Cries over minor annoyances and hurts.</td>
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<tr>
<td>35. Repetitive hand, body, or head movements.</td>
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<tr>
<td>36. Mood changes quickly.</td>
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<tr>
<td>37. Unresponsive to structured activities (does not react).</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>38. Does not stay in seat (during lesson or training periods, meals, etc).</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>39. Will not sit for any length of time.</td>
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<tr>
<td>40. Is difficult to reach, contact, or get through to.</td>
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<tr>
<td>41. Cries and screams inappropriately.</td>
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</tr>
<tr>
<td>42. Prefers to be alone.</td>
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<td></td>
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</tr>
<tr>
<td>43. Does not try to communicate by words or gestures.</td>
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<td></td>
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</tr>
<tr>
<td>44. Easily distractible.</td>
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<td></td>
</tr>
</tbody>
</table>
45. Waves or shakes the extremities repeatedly. 0 1 2 3
46. Repeats a word or phrase over and over. 0 1 2 3
47. Stamps feet, bangs objects, or slams door. 0 1 2 3
48. Constantly runs or jumps around the room. 0 1 2 3
49. Rocks back and forth repeatedly. 0 1 2 3
50. Deliberately hurts himself/herself. 0 1 2 3
51. Pays no attention when spoken to. 0 1 2 3
52. Does physical violence to self. 0 1 2 3
53. Inactive, never moves spontaneously. 0 1 2 3
54. Tends to be excessively active. 0 1 2 3
55. Responds negatively to affection. 0 1 2 3
56. Deliberately ignores direction. 0 1 2 3
57. Has temper outbursts or tantrums when he/she does not get own way. 0 1 2 3
58. Shows few social reactions to others. 0 1 2 3
Appendix E

Child Expectations Scale

Parents often express concern about the future of their children. This questionnaire asks about your expectations for your child with special needs who has a developmental delay or disability. Each question asks you to indicate “what do you expect for your child?” Please circle the response that best represents your thoughts. Remember—There are no right or wrong answers. Please give your honest feelings.

1. How far do you expect your child to go in school?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Do not expect him or her to go to school</td>
<td>Special education program only</td>
<td>Grades 1 to 6</td>
<td>Grades 7 to 12</td>
<td>College</td>
</tr>
</tbody>
</table>

2. How financially independent do you expect your child to be as an adult?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
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<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Will always be financially dependent</td>
<td>Will mostly rely on help from others</td>
<td>Will contribute toward his or her support</td>
<td>Will be mostly self-supporting</td>
<td>Will be entirely financially independent</td>
</tr>
</tbody>
</table>

3. How well do you think your child will be able to physically care for himself or herself as an adult?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
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<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Will always need 24-hour-a-day care</td>
<td>Will need help most of the day</td>
<td>Will need some help every day</td>
<td>Will need help only in unusual situations</td>
<td>Will be entirely self-sufficient</td>
</tr>
</tbody>
</table>

4. How independent do you expect your child to become in planning and managing his or her own affairs?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
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<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Will need constant supervision</td>
<td>Will need someone to make day-to-day decisions</td>
<td>Will be able to make some decisions independently</td>
<td>Will need help/advice for major decisions only</td>
<td>Will be able to totally manage affairs independently</td>
</tr>
</tbody>
</table>

5. How active do you expect your child to be in church or community activities?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
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<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Will not be able to join the church or community organizations</td>
<td>Will be able to participate but not take any active roles</td>
<td>Will be able to participate some</td>
<td>Will be able to be an active church or community member</td>
<td>Will be able to take leadership roles in the church or community</td>
</tr>
</tbody>
</table>

6. How much do you think your child will be involved in social relationships?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Will not be able to socially relate to anyone</td>
<td>Will relate only family members</td>
<td>Will be able to participate some</td>
<td>Will be able to be an active church or community member</td>
<td>Will be able to take leadership role in the church or community</td>
</tr>
</tbody>
</table>

7. Where do you think your child will live as a teenager?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Will live in an institution</td>
<td>Will live in a group home</td>
<td>Will live in a residential school full-time</td>
<td>Will live in a residential school/go home on weekends and holidays</td>
<td>Will live with his or her own family</td>
</tr>
</tbody>
</table>
8. Where do you think your child will *live as an adult*?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Will live in an institution</td>
<td>Will live with responsible family members</td>
<td>Will live in a small group home with supervision</td>
<td>Will live in a group home without supervision</td>
<td>Will live in his or her own home or apartment</td>
</tr>
</tbody>
</table>

*This table represents the different living arrangements for an adult.*
Appendix F

Family Support Scale

Listed below are people and groups that oftentimes are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to your family. Please circle the response that best describes how helpful each source is to your family. Please circle the response that best describes how helpful each source is to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

How helpful has each of the following been to you in terms of raising your child(ren)?

<table>
<thead>
<tr>
<th>Source</th>
<th>Not Available</th>
<th>Not at All Helpful</th>
<th>Sometimes Helpful</th>
<th>Generally Helpful</th>
<th>Very Helpful</th>
<th>Extremely Helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My Parents</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. My spouse or partner’s parents</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. My relatives/kin</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. My spouse or partner’s relative/kin</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. My spouse or partner</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. My friends</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. My spouse or partner’s friends</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. My older child(ren)</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Neighbors</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Other parents</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Co-workers</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Parent group members</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Social groups/clubs</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. My family or child’s physician</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. Early childhood intervention</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. School/daycare center</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. Professional helpers (social workers, therapists, teachers, etc.)</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. Professional agencies (public health, social services, mental health, etc.)</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. _________</td>
<td>NA</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>21. _________</td>
<td>NA</td>
<td>1</td>
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</table>
Appendix G
Demographic Questionnaire

This section asks general questions about you and your child with an Autism Spectrum Disorder. Please circle or fill in the blank.

1. **Are you the biological mother of a child diagnosed with an Autism Spectrum Disorder?**
   a. Yes
   b. No

2. **Do you live with, provide care for, and raise this child?**
   a. Yes
   b. No

3. **What is your child’s sex?**
   a. Male
   b. Female

4. **What is your age in years?** ________________

5. **What state do you live in?** ________________

6. **What is your child’s Autism Spectrum Disorder?**
   a. Autism or Autistic Disorder
   b. Asperger’s Syndrome
   c. Pervasive Developmental Disorder (PDD)
   d. Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
   e. Child Disintegrative Disorder (CDD)
   f. Autism Spectrum Disorder (ASD) choose only if none of the above apply

7. **When did your child receive this diagnosis?** Please indicate, as accurately as you can, the month and year ________________

8. **How old was your child when he/she received this diagnosis?**
   a. Less than 12 months
   b. 12 months to 17 months
   c. 18 months to 23 months
   d. 2 years old
   e. 3 years old
   f. 4 years old
   g. 5 years old
9. Who gave your child this diagnosis?
   a. Pediatrician
   b. Primary care doctor (other than pediatrician)
   c. Developmental pediatrician
   d. Psychiatrist
   e. Clinical Psychologist
   f. Neurologist
   g. Team of Health Professionals
   h. Team of School Professionals
   i. Speech and Language Pathologist
   j. Other __________________________

10. Where did your child receive this diagnosis?
    a. Public School system
    b. Health care system (including a clinic or regional center specializing in ASDs)
    c. Early Intervention Center
    d. Other __________________________
Appendix H  
Cover Letter  

Dear Participant,  

Thank you for agreeing to participate in this important research which explores the experiences of mothers of preschool age children recently diagnosed with an autism spectrum disorder.  

Your participation is essential to learn more about parents’ experiences and how nursing can provide support to parents during this time.  

Enclosed you will find several short confidential surveys. The suggested order to complete the surveys is indicated by the sequence in which the surveys are assembled in this packet. It should take no longer than 20-25 minutes to complete. Your rights as a survey participant are summarized in the packet as well.  

Please set aside some time to complete these surveys, even if you can not finish them all in one setting. When you are finished, mail the completed surveys using the self-addressed, postage-paid envelope included in this packet. For your participation in this study, you will be mailed a $10.00 Wal-Mart gift card after complete survey/questionnaires are received.  

Thank you so much for your time.  

Sincerely,  

Cheryl Shaffer, MS, PNP, ANP  
Doctoral Candidate  
Rutgers, The State University of NJ  
College of Nursing
Appendix I

YOUR RIGHTS AS A SURVEY PARTICIPANT

You are invited to participate in a dissertation research study that is being conducted by Cheryl Shaffer who is a doctoral student in the Nursing Department at Rutgers University. The purpose of this study is to examine parenting stress in mothers of preschool age children recently diagnosed with an autism spectrum disorder. This research will additionally examine the mother’s perception of their child’s problem behaviors, expectations for the child’s future, helpfulness of social support, and maternal age with the level of stress experienced.

Approximately 85 adult (18 years of age and older) subjects will participate in the study, and each individual's participation will last approximately 20-25 minutes.

Participation in this study will involve the following: completing the demographic questionnaire, the Parenting Stress Index-Short Form, the Aberrant Behavior Checklist-Community, the Child Expectations Scale and the Family Support Scale. Following completion of the surveys/questionnaire, please mail back to the primary investigator in the preaddressed, postage paid envelope included in the research packet.

This research is confidential. Confidential means that the research records will include your name, mailing address, and email address. I will keep this information confidential by limiting individual's access to the research data and keeping it in a secure location. If you agree to take part in the study, you will be assigned a code number that will be used on each survey and the questionnaire. Your name will appear only on a list of subjects, and will be linked to the code number that is assigned to you. To assure your confidentiality, your name does not appear anywhere on the survey or demographic form. One document links the code with your name and address and is maintained in a secure location.

The research team and the Institutional Review Board at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. If a report of this study is published, or the results are presented at a professional conference, only group results will be stated. All study data will be kept for three years, and then destroyed.

There are no foreseeable risks to participation in this study. Although the study’s results may not benefit you directly, findings may support the understanding of mothers’ experiences in the first year post-diagnosis and guide and enhance future work in the development of nursing interventions. You will receive a $10.00 Wal-Mart gift card for completing the entire study. All four surveys and demographic form must be 90% completed to receive the gift card.

Participation in this study is voluntary. Return of the completed survey packet will indicate your willingness to participate. If you decide not to participate, please place your
uncompleted questionnaire/surveys in the stamped envelope provided and the primary investigator will remove your name from the research records. If neither a completed nor uncompleted packet is returned, you will receive a reminder email and a second survey packet over the next few weeks.

If you have any questions about the study or study procedures, you may contact myself, Cheryl Shaffer, MS, PNP, ANP by email at shaffec@sunysuffolk.edu or you can contact my advisor Mary Ann Scoloveno, EdD, RN at scoloven@rutgers.edu.

If you have any questions about your rights as a research subject, you may contact the IRB Administrator at Rutgers University at: Rutgers University, the State University of New Jersey, Institutional Review Board for the Protection of Human Subjects, Office of Research and Sponsored Programs, 3 Rutgers Plaza, New Brunswick, NJ 08901-8559 Tel: 732-932-0150 ext. 2104, Email: humansubjects@orsp.rutgers.edu

Sincerely,

Cheryl Shaffer, MS, PNP, ANP
Doctoral Candidate
Rutgers, The State University of NJ
College of Nursing
Curriculum Vitae

Cheryl Shaffer RN, MS, PNP, ANP
DOB 7-1-73, Port Jefferson NY

Education
Doctor of Philosophy, Rutgers The State University of NJ, 2006-2012
Master of Science in Nursing, Syracuse University, 1996-1998
Bachelor of Science in Nursing, Pennsylvania State University at Edinboro, 1991-1996

Principle Occupation
Professor of Nursing 2003-2012
School of Nursing, Suffolk County Community College, Selden NY

Adjunct Professor, 2004-2012
School of Nursing, Excelsior College, Albany, NY

Pediatric and Adult Nurse Practitioner 2001-2012
Family Care Medical Center, Wading River NY