

RAISING YOUNG CHILDREN ON THE AUTISM SPECTRUM: PARENTAL
STRESS AND PERCEIVED SOCIAL SUPPORT

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ABSTRACT

Raising a child with autism generates a variety of issues for the family involved. It is a disorder that is particularly stressful for the family as a whole, and much research has shown elevated levels of stress in parents raising a child with autism (Dabrowska & Pisula, 2011; Lee, 2009). Past research has shown that social support (both formal and informal) has been able to reduce levels of parental stress. The purpose of the current research was to explore the relationship between parental stress and perceived social support while raising a young child with autism. The present study hypothesized that perceived social support would be negatively correlated with levels of parental stress of mothers raising a young child with autism. Participants were 25 mothers who had a child 10 years old or younger with an autism spectrum disorder. Mothers were asked to complete the *Parenting Stress Index—Short Form IV (PSI-SF-IV)*, the *Autism Behavior Checklist (ABC)*, the *Family Support Scale (FSS)*, and a brief demographic questionnaire. Bivariate one-tailed correlational analyses showed medium-strength negative correlations between both the Formal and Informal Support total score on the *FSS* and the Total Stress Index on the *PSI-SF-IV*. Additionally, the Informal Support total score on the *FSS* was associated with decreased levels of parental stress on all three indices of the *PSI-SF-IV*: Parent-Child Dysfunctional Interaction, Difficult Child, and Total Stress. Results indicated that the more overall social support a mother perceives herself to receive, the lower her overall parental stress.

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Chapter 1

Introduction

Overview

Autism spectrum disorders have risen in prevalence over the past several decades. Current reports state that 1 in 68 children today are diagnosed with autism (Baio, 2014). With the prevalence rates on the rise, a thorough understanding of the way in which this disorder directly affects families is of increased significance. Raising a child with autism generates a variety of issues for the family involved. It is a disorder that is particularly stressful for the family as a whole, and much research has shown elevated levels of stress in parents raising a child with autism (Dabrowska & Pisula, 2011; Lee, 2009).

Additionally, mothers and fathers who have a child on the autism spectrum experience increased rates of both depression and anxiety as compared to their peers (Hartley, Seltzer, Head & Abbeduto, 2012). Important to note, the increased level of parent stress can have significantly negative impact on parenting skills and child outcomes (Anthony et al., 2005; Bonds, Gondoli, Sturge-Apple, & Salem, 2002; Hastings & Beck, 2004)

Due to high levels of parent stress and its potential impact on child outcome (Anthony et al., 2005; Bonds, Gondoli, Sturge-Apple, & Salem, 2002; Hastings & Beck, 2004), clinicians must identify ways in which they can effectively help reduce the stress experienced by mothers and fathers of children with autism. Previous research indicates that social support can help reduce parenting stress (Benson, 2006; Boyd, 2002; Siman-Tov & Kaniel, 2011) though the differential impact of various forms of social support is unclear. The current study sought to clarify the research by investigating the impact of formal and informal social support on parenting stress. To better examine this

relationship, it is important to first understand the myriad of parenting stressors while raising a child with autism, as well as the role of social support in reducing parenting stress.

Parental Stressors

Parenting itself can be considered generally stressful (Lazarus, 1991; Mash & Johnston, 1983), and many conceptual issues are important in understanding the construct of everyday stressors in parenthood. According to the general stress model (Lazarus, 1991), a child and/or the parenting role serves as the causal external agent for the stress experience. Parents then must appraise child behavior or parenting events as stressful, and parental coping interacts with stress to determine the degree of the effect of stress. Within this framework, parenting stress is defined as “the aversive psychological demands of being a parent” (Deater-Deckard, 1998, p. 315). It is described as an experience of “negative feelings toward self and toward the child or children, and by definition these negative feelings are directly attributable to the demands of parenthood” (Deater-Deckard, 1998, p. 315).

While some degree of parenting stress is considered normal, parents who experience an extreme level of stress may suffer psychologically and be less able to implement interventions to help their children (Theule, Wiener, Rogers, Marton, 2010). Psychological issues related to parental stress include, but are not limited to, increased levels of depression and anxiety (Theule et al., 2010), decreased quality in the parent-child relationship, and poorer parenting practices (Bonds et al., 2002; Rodger, 1998, as cited in Theule et al., 2010). Research has also found that both stressful life events and daily parenting hassles predicted negative affect and problem behaviors in a sample of

typically developing preschool-aged children over a period of 2 years. Additionally, high parental stress predicts fewer gains in parenting skills during behavioral interventions for severe problem behavior in children with intellectual disabilities (Theule et al., 2010). Parents often struggle with proper discipline as well as facilitating positive interactions with their children when they are suffering from a great deal of parental stress (Theule et al., 2010).

A study by Anthony and colleagues (2005) investigated the relationship between parenting stress, parenting behavior, and preschoolers' behavior problems in the classroom. Results of the study indicated that there is a small relationship among parenting stress and positive parenting practices ($r = -.22$). Further, parenting practices were shown to be associated with the preschoolers' behavior in the classroom. More positive parenting practices were associated with better child behaviors as well as social competence (Anthony et. al, 2005). Webster-Stratton (1990) investigated the relationship between parental stress, parenting behaviors, and child problem-behavior. She found that parenting stress caused some parents to be more irritable, critical, and punitive, and that such parenting behaviors were associated to a medium degree with increased likelihood of childhood conduct problems. The relationships between parental stress, parenting practices, and child behavior gives way to the importance of understanding how parental stressors can be assuaged.

Stress Related to Parenting a Child with Autism

Parenting has proven to be a generally stressful life event (Mash & Johnston, 1983), and the manifestation of major and persistent child problems may be a significant cause of increased parental stress. Research has shown that mothers of children

exhibiting hyperactivity, conduct disorders, and developmental delays typically participate in interactions with their children that are more stressful, less regarding and provide considerably less positive feedback than mothers of neurotypical children (Mash & Johnston, 1983). For example, Dyson (1997) conducted a study using 30 pairs of fathers and mothers who had school-aged children with cognitive impairment and other disabilities. The parenting stress level of these parents was compared to 32 mother-father dyads of children without a disability. Results showed that parenting a child with a disability yielded higher scores on a stress measurement scale than was observed in parents of neurotypical children.

Any form of a chronic illness or disability represents a serious challenge to not just the afflicted individual but family as well (Gray, 1993). According to Gray (1993), however, few disorders pose a greater threat to a family's well-being than autism. Autism is a disorder with which it is difficult to cope and parenting stress has been one of the most frequently researched aspects of family life among families of children with autism. Autism has been shown to be associated with an exceptionally significant burden and stress for parents (Dabrowska & Pisula, 2010; Lee, 2009). Research has shown that demands placed on parents caring for a child with autism contribute to a higher overall incidence of parental stress, depression, and anxiety beyond that typically observed in parents of typically developing children or children with other disabilities (Dabrowska & Pisula, 2010; Lee, 2009). These demands include child discipline, behavior management, and an overall organization of the needs of a young child with autism (Dabrowska & Pisula, 2010; Lee, 2009). Parents of children with autism have also reported higher levels of fatigue and greater physical health impairments than parents of both typically

developing children and children with intellectual disabilities (Karst & Vaughan Van Hecke, 2012), which may generate an increased sense of stress in these parents.

Many factors related to the autism diagnosis have been shown to exacerbate stress levels in parents of children with autism. One of the most consistent predictors of parenting stress for both mothers and fathers is the level of their child's skill delays and deficits. For instance, parental stress while raising a child with autism has been linked to many specific features of autism such as communication impairment, uneven cognitive abilities and problems in social relations (Baker-Ericzen, Brookman-Frazee & Stahmer, 2005; Davis & Carter, 2008). In a study conducted by Davis and Carter (2008), it was found that the most consistent predictor of parenting stress were the deficits in social skills.

Research has also shown that parental distress is predicted by the occurrence of child problem behavior, typically related to stereotypical and repetitive behavior, aggression and a general lack of compliance (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004; Baker, Blacher, & Olsson, 2005; Davis & Carter, 2008; Olsson & Hwang, 2001; Peters-Scheffer, Didden, & Korzilius, 2012). In a study by Abbeduto and colleagues (2004), mothers with children diagnosed with autism, Down syndrome, or fragile X syndrome all completed the *Autism Behavior Checklist (ABC)*, which measures the severity of autism problem behavior in children. Results showed that the strongest and most consistent predictor of maternal outcomes (i.e., maternal stress and psychological well-being) was the extent and severity of behavioral symptoms as measured by the *ABC*. Higher scores on the measure were correlated with greater maternal depressive symptoms ($r = .19$) (Abbeduto et al., 2004).

Feelings of stress in parents of children with autism is consistently related to parent gender (Gray, 1993; Peters-Scheffer, Didden, & Korzilius, 2012). Mothers appear to be the most severely affected members of the family when it comes to distress in relation to parenting a child with autism (Peters-Scheffer et Al., 2012). Previous research documents high levels of depressive symptoms and distress in mothers raising a child with ASD (Davis & Carter, 2008). Moreover, past research has indicated that mothers of children with autism report less perceived parenting competence, marital satisfaction, and family adaptability than mothers of typically developing children (Dunn, Burnine, Bowers, & Tantleff-Dunn, 2001). All of the aforementioned have the potential to be directly related to an increased level of maternal stress (Gray, 1993; Peters-Scheffer, Didden, & Korzilius, 2012).

Raising a child with a disability is filled with constant transitions, uncertainty, and a general lack of control. These states can easily be linked to an increased sense of parental stress (Dyson, 1997; Mash & Johnston, 1983). Consistent with other research regarding the relation between parental stress and child outcome, Brinker, Seifer and Sameroff (1994) demonstrated that high parental stress among parents of children with cognitive disabilities predicts less beneficial outcomes for children in early intervention (EI) programs. This finding again highlights the importance of identifying ways in which service providers can alleviate some of the stress and psychological suffering parents experience. Support from formal services (i.e., EI, preschool programs, etc.) and informal networks such as family and friends is especially imperative due to the fact that much previous research on stress has indicated that social support can help reduce parental stress (Benson, 2006; Boyd, 2002; Siman-Tov & Kaniel, 2011).

Role of Social Support in Mediating Stress

Boyd (2002) found the three factors that contributed most strongly to the stress of a parent of a child with autism to be (1) concern over permanency of the condition, (2) poor acceptance of autistic behaviors by society and other family members, and (3) very low levels of social support received by parents. Of particular importance here, social support appears to be significantly related to parenting stress. Social support is a multidimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support (Boyd, 2002). Social support may refer to formal services such as those received from professional organizations, or informal support from friends and family (Boyd, 2002).

Parents' experiences of stress and psychological problems such as anxiety and depression have often been linked to the perceived, rather than actual, level of support they receive from professional organizations, friends and family (Benson, 2006; Boyd, 2002; Siman-Tov & Kaniel, 2011). Research in the field of developmental disabilities has often assessed the relationships between social support and parental well-being. Past studies have yielded mixed results, some showing that both formal and informal social support are associated with reduced stress (Benson, 2006; Boyd, 2002; Siman-Tov & Kaniel, 2011) and others demonstrating that only formal support from non-familial members is associated with reduced parental stress (Ekas & Lickenbrock, 2010; Gray & Holden 1992; Hastings & Beck, 2004). A review of these studies follows.

Informal social support. Previous research has shown that parents' perceptions of social support have been identified as critical factors in reducing the negative psychological effects of raising a child with a disability, in particular autism (Ekas,

Lickenbrock, & Whitman, 2010). Moreover, informal support, such as that from friends and family, has been shown to be effective in reducing stress among mothers raising a child with autism. Mothers who perceive social support as more accessible report fewer stress-related somatic problems and depressive symptoms (Boyd, 2002; Ekas, Lickenbrock, & Whitman, 2010; Gray & Holden, 1992). In addition, Sipal and Sayin (2012) found that social support from friends and family was a predictor of depression, such that greater social support was associated with lower levels of depression ($r = -.24$). Moreover, research has indicated that social support from other family members has been shown to be associated with both lower levels of parental stress ($r = -.33$) and increased parenting skills ($r = -.35$) (Bonds, Gondoli, Sturge-Apple & Salem, 2002).

Sanders and Morgan (1997) examined the support provided by formal agencies for parents raising a child with autism, Down syndrome, and neurotypical children. Results of the study showed that, beyond the effects of formal support of the agencies, a lack of informal social support can lead parents to withdraw from the larger community because of the stigma associated with negative characteristics that are related to their child's disability. It was found that mothers of children with autism were the most stressed of the three groups and that they had the most difficulty obtaining community-based forms of informal social support, such as support from religious groups and parent support groups. Subsequently, researchers have concluded that effective interventions for families raising a child with autism should provide access to informal sources of social support in addition to parent training in effective treatment for autism (Boyd, 2002).

Formal support. Formal support is described as the degree to which a parent feels he/she is supported through the therapists' work with his/her child. The support

received from professional organizations also involves direct treatment of the child, inclusion of parents in treatment, and helping the parents feel an overall level of competence when it comes to managing their child. Results of the study conducted by Ekas, Lickenbrock, and Whitman (2010) demonstrated that social support received from non-family members (i.e. formal support such as professional agencies) was associated to a medium degree with increased life satisfaction, positive affect and psychological well-being, whereas support from family members, including the spouse, was only associated with increased psychological well-being. Therefore, non-familial support may be most significant in reducing stress for parents raising a child with autism.

Past research has generally shown that support from services is unlikely to exacerbate parental stress, and may well be useful for parents. For example, results of a study conducted by Hastings and Beck (2004) showed that typical appropriate supports provided by services for children with intellectual disabilities and their families made some contribution to reduction in parental stress. These supports included consultation with professionals and direct service from professionals to the child with the disability.

Summary

Raising a child with a disability has been shown to create higher parental stress in parents as compared to parents raising a neurotypical child. Moreover, research has shown that raising a child with autism generates exceptionally high levels of parental stress. Increased stress levels have been shown to be most prominent for the mothers raising a child with ASD (Davis & Carter, 2008; Peters-Scheffer, Didden, & Korzilius, 2012).

Previous research has indicated that both formal and informal social support has the potential to act as a buffer against elevated levels of stress (Benson, 2006; Boyd, 2002; Siman-Tov & Kaniel, 2011). There also has been a body of research that has shown that formal support, more so than informal support, is associated with reduced parental stress (Ekas & Lickenbrock 2010; Gray & Holden 1992; Hastings & Beck, 2004). Results from such studies indicate that support from professional agencies such as therapists and pediatricians is a stronger buffer against parental stress than is support that comes from a parent's family and friends. Understanding the sources of support that are the most beneficial to parents is vital to supporting parents raising a child with autism. To that end, the aim of the current study was to replicate findings from past research and bolster studies that indicate a negative correlation between parental stress and both perceived informal and formal social support. Thus, the present study investigated the way in which perceived social support, both formal and informal, affects parental stress levels while raising a young child, 10 years old or younger, with autism. It was hypothesized that parental stress and perceived levels of social support would be negatively correlated, such that mothers who report a greater degree of perceived formal and informal social support would score lower on measures of parenting stress.

Chapter II

Methods

Participants

A power analysis indicated that 22 participants were necessary to detect a large effect size in correlational research (Cohen & Cohen, 1983). Therefore, the primary investigator recruited 25 biological, adoptive or resource mothers in the state of New Jersey who had a child who was diagnosed with an autism spectrum disorder (Autistic Disorder, Asperger's Disorder or Pervasive Developmental Disorder-Not Otherwise Specified). Two stages of recruitment were conducted. The first stage specifically targeted parents whose children were currently transitioning from the EI system to assess the importance of social support during this transition. Due to poor response rate, a second stage of recruitment was conducted that expanded recruitment to mothers of children with autism 10 years of age or younger.

Participants were recruited through the New Jersey Early Intervention Services (NJEIS), as well as a variety of local agencies and private schools that serve young children with autism. Cover letters (Appendix A) describing the study were sent to agencies providing early intervention or early education services in the state of New Jersey, requesting that they distribute fliers (Appendix B) to families who were eligible to participate. In the first stage of recruitment, the agencies were requested to distribute the fliers to families who have a child with autism who fell within the window of transition from EI, which was defined as 6 months before his/her third birthday and 6 months after. In the second stage of recruitment, agencies were requested to distribute fliers to families who had a child diagnosed with autism who was 10 years of age or younger. The fliers

contained information as to how to contact the Principal Investigator if the family was interested in participating. It was made explicitly clear to all potential participants that their participation in the present study would in no way affect current or future services for their child. Due to the fact that the recruitment fliers were distributed by various agencies and not by the Principal Investigator, the total number of distributed recruitment fliers is unknown. Combined across both stages of recruitment, 33 mothers contacted the Principal Investigator expressing interest in participating. All 33 were sent survey packets, and 27 mothers returned the questionnaire packet to the Principal Investigator. The 25 mothers who completed the survey in its entirety, without missing data, were included in the final sample.

Procedure

The primary investigator recruited participants through NJEIS as well as agencies and schools serving young children with autism using the recruitment procedures described above. Once mothers contacted the Primary Investigator by phone, e-mail, or mail and provided their name, address, and age of child, they were mailed a cover letter (Appendix C) and an informed consent form (Appendix D), as well as the packet of questionnaires. The mothers were asked to sign the consent form, complete three short questionnaires, and mail their responses back to the investigator in a self-addressed, stamped envelope. Total completion time was expected to be 30 minutes. This concluded their participation in the study. If participants had not returned their completed questionnaires within 2 weeks of their initial mailing, a follow-up phone call was made to remind parents to complete the packet of questionnaires. Participants were randomly assigned an identification number, which was the sole form of identification on all

questionnaires. At the time of receipt, participants' completed responses were entered into a password-protected spreadsheet.

Measures

Demographics Questionnaire. The demographics questionnaire included questions related to parent age, the age and gender of their child with autism, and the highest level of parental education achieved (Appendix E). Parents who indicated that they had a child transitioning from EI to preschool answered additional questions addressing their perceptions of the transition. These questions inquired about the length of time their child received EI services, previous experience with EI services (i.e., with an older child), and the mother's overall feeling of preparedness for the transition. The final question addressed whether or not the mother felt satisfied with her child's transition from EI to preschool.

Parental Stress Index—Short Form (PSI-SF-IV). The *PSI-SF-IV* is a 36-item self-report questionnaire, which yields scores on three subscales: Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI), and Difficult Child (DC). The *PSI-SF-IV* is a one-page questionnaire that requires parents to rate a variety of statements about their child on a 5-point Likert scale (1 = Strongly Agree, 2 = Agree, 3 = Not Sure, 4 = Disagree and 5 = Strongly Disagree). Scores on the three subscales (PD, PCDI and DC) all range from 12-60, where higher numbers indicate higher stress. The coefficient alpha of the three subscales are as follows: .75, .78, and .80, respectively. The Total Stress score ranges from 36-180. The coefficient alpha reliability of the Total Stress index is .96 (Abidin, 2012).

Family Support Scale (FSS). The self-report *FSS* measures parents' satisfaction with the support they receive in raising a young child. The scale comprises 18 items that assess sources of support as the immediate family, relatives, friends and others in the family's social network, social organizations, and specialized and generic professional services. In addition, the scale provides two open items for parents to assess other sources of support not included in the 18 items. The parent rates each source of support on a 5-point Likert scale ranging from not at all helpful (1) to extremely helpful (5). The scale provides index scores on the amount of formal and informal support reported by the parent. Scores on the *FSS* range from 0 to 90, where higher scores indicate greater levels of perceived social support. Analysis of the scale's Total Support index reliability resulted in a Cronbach's alpha coefficient of .79 (Dunst, Trivette & Jenkins 2007). The reliability for the Formal Support Index for the purposes of the present study was calculated to be .59, and the reliability coefficient for the Informal Support index was calculated to be .84.

Autism Behavior Checklist (ABC). The *ABC* was designed to offer a method to assess the severity of autism symptoms in children. The scale utilizes an observer's rating of the child's behavior to quantify behaviors typically associated with autism. The *ABC* comprises 47 items across five scales: Sensory, Relating, Body and Object Use, Language, and Social and Self-Help. The items are scored dichotomously (i.e., yes/no). The internal consistency of the total score for the *ABC* is .87 (Krug, Arick & Almond, 1979; Krug et al., 1980).

Plan of Analysis

Data were analyzed using the statistical software package, SPSS. First, descriptive analyses were run in order to generate the means and standard deviations for the indices on each of the questionnaires, as well as the demographic information collected. Of the returned questionnaire packets, two included missing data. Because the amount of data missing precluded calculating scores on the measures, these two participants were not included in analysis. A series of correlational analyses were conducted to investigate whether, as hypothesized, a significant negative relationship exists between mothers' perceived sense of formal and informal social support and parental stress level. The next step was to compute confidence intervals for the significant result. After transforming Pearson r to z^1 , using Cohen and Cohen's (1983) table, 95% confidence intervals were calculated. Due to the nature of the hypothesis of the present study, only one-tailed confidence intervals were calculated. The upper bound confidence intervals selected for the current study indicate that it can be stated with 95% confidence that the true value of the correlation falls below the upper bound value. In other words, the confidence interval indicates that the true value falls between -1.00 and the upper bound limit. Calculating confidence intervals supports the associations found with the correlation statistic. For example, if the upper bound confidence interval indicated that the true population correlation could fall at zero, this would indicate that the relationship between the two variables might not exist due to the fact that a correlation of zero denotes no relationship.

Lastly, reliability analyses were conducted for the measures used by entering participants' responses at the item level.

Chapter III

Results

The participants of the present study were 25 mothers living within the state of New Jersey. The mothers had a young child diagnosed with an ASD who ranged in age from 2.5 to 10 years ($M = 4.3$, $SD = 1.69$). The mean age of the participants was 38 years ($SD = 5.27$), and the mothers' average level of education was a high school diploma. Additionally, all 25 participants' children received early intervention services, either presently or when the child was of the appropriate age. Descriptive statistics were generated for each of the three ratings scales. These statistics are reported in Table 1.

Table 1

Means and Standard Deviations for the PSI-SF-IV, FSS and ABC

<i>Variables</i>	<i>M</i>	<i>SD</i>
<i>PSI-SF-IV Indices</i>		
PD	32.12	9.92
PCDI	27.44	7.08
DC	35.32	9.48
Total Stress	95.00	22.31
<i>ABC</i>	13.84	8.23
<i>FSS ($\alpha = .45$)</i>		
Informal Support	30.08	8.02
Formal Support	10.12	3.76
Total Support	40.20	9.08
<i>FSS ($\alpha = .87$)</i>		
Informal Support	42.24	9.91
Formal Support	12.48	2.96
Total Support	56.00	14.53

Note. M = mean; SD = standard deviation; α signifies version of *FSS* scores used to calculate descriptives.

An internal consistency reliability analysis was conducted on both the *FSS* and the *PSI-SF-IV*. Coefficient alphas were detected to be .45 and .91, respectively. Due to the fact that the literature indicates that the reliability of the *FSS* has been shown to be between .77 and .88 in the past, the Principal Investigator chose to investigate this further. The participants were asked to score the degree to which various items were helpful to them in raising their child, scores ranged from 1 (“Not at All Helpful”) to 5 (“Extremely Helpful”). The participants were also, however, given the option to score an item as “Not available,” abbreviated as “NA.” For the purposes of the *FSS*, when utilized to calculate the subscales and total support score, NA was scored as a 0. NA is not well-defined on the scale, however, and because NA often serves as an abbreviation for “Not Applicable,” it is possible that participants utilized various interpretations when scoring an item as NA.

To assess the impact of NA responses on the reliability of the measure, *FSS* scores were recoded such that items on which parents responded that the form of support was “Not Available” were entered into the data set as a score of 1 (“Not at All Helpful”), 2 (“Sometimes Helpful”) or 3 (“Generally Helpful,” or the mid-range score). Reliability analyses were run again for each substituted value, and the resulting coefficient alphas are found in Table 2. The coefficient alpha was highest when the NA responses were scored as a 3, and the detected alpha of .87 fell in line with previously previous literature. Subsequently, correlational analyses were run using both the original and recoded measure, but due to the fact that the recoded coefficient alpha appeared more consistent with the literature, it was decided to utilize the recoded version to interpret the significant correlations.

Table 2
Coefficient Alphas for the FSS

<i>FSS Indices</i>	0	1	2	3
Informal	.45	.53	.72	.84
Formal	.33	.41	.51	.59
Total Support	.45	.60	.74	.87

Note. Each column represents a recoded version of the FSS scores (0 = 0, 0 = 1, 0 = 2 and 0 = 3)

The study employed a correlational design that investigated the relationship between parental stress (*PSI-SF-IV*) and perceived informal and formal social support (*FSS*). Because it was predicted that parental stress would only correlate negatively with perceived social support, a series of bivariate one-tailed correlations were run. The data analysis yielded several significant correlations related to the present study's hypothesis (see Table 3). Parameters for strength of correlations were obtained from Cohen (1988). The confidence intervals indicate that there is 95% probability that the true correlations in the population fall within the determined range.

Informal Support

Four statistically significant correlations emerged in relation to perceived informal support. All of these correlations ranged from medium to large strength. Informal support was negatively correlated with the Parental Distress index on the *PSI-SF-IV*, $r(23) = -.51, p < .05$ (95% CI upper bound = $-.21$). The lower mothers' perceived level of informal support, the higher their parental distress scores. Informal Support negatively correlated with Parent-Child Dysfunctional Interaction, $r(23) = -.40, p < .05$ (95% CI upper bound = $-.07$) and the Difficult Child index, $r(23) = -.35, p < .05$ (95% CI

upper bound = -.01). Results indicated that lower parental report of perceived informal support was related to higher maternal ratings of stress due to interactions with their child with autism and the child's problem behavior. Lastly, Informal Support correlated negatively with the Total Stress Index, $r(23) = -.50, p < .05$ (95% CI upper bound = -.20), indicating that lower levels of perceived informal support reported by mothers were related to higher overall levels of maternal parenting stress.

Formal Support

Two statistically significant correlations were found for the Formal Support index and indices from the *PSI-SF-IV*. The correlation with the PCDI was of medium strength, and the correlation to the Total Stress Index was large. Formal Support was negatively correlated with the PCDI index, $r(23) = -.49, p < .05$ (95% CI upper bound = -.18) and the Total Stress index, $r(23) = -.50, p < .05$ (95% CI upper bound = -.20). Both correlations indicated that the lower mothers reported their perceived levels of formal support, the higher their reported total stress and stress related to dysfunctional parent-child interactions. Additionally, the Formal Support index showed a medium negative correlation with total autism symptoms listed on the *ABC*, $r(23) = -.47, p < .05$ (95% CI upper bound = -.16), indicating that mothers who rated their child as demonstrating greater autism symptomatology also reported lower formal support.

Total Perceived Support

The total *FSS* score obtained on the *Family Support Scale* was negatively correlated with all of the indices on the *PSI-SF-IV*. *FSS* and PD, PCDI and DC. The correlations ranged from medium to large degrees: $r(23) = -.56, p < .05$ (95% CI upper bound = -.27); $r(23) = -.52, p < .05$ (95% CI upper bound = -.22); $r(23) = -.46, p < .05$

(95% CI upper bound = -.15), respectively. The total FSS score also showed a large significant negative correlation with the mothers' Total Stress scores, $r(23) = -.61, p < .05$ (95% CI upper bound = -.34). These results suggested that the overall level of social support perceived (both formal and informal) is inversely related to mothers' overall level of parental stress.

Autism Behavior Checklist

The *ABC* was used to generate correlations around parental stress and levels of autism symptoms in their child. The *ABC* was positively correlated to a small degree with all indices of the *PSI-SF-IV*. *ABC* total score and PD index are positively correlated, $r(23) = .18, p < .05$ (95% CI lower bound = -.17). The *ABC* total score and the PCDI index were positively correlated, $r(23) = .28, p < .05$ (95% CI lower bound = -.06). The *ABC* total score was also positively correlated with both the DC and Total Stress indices, $r(23) = .20, p < .05$ (95% CI lower bound = -.15); $r(23) = .26, p < .05$ (95% CI upper bound = -.08), respectively. These results indicated that the higher the degree of parental stress reported, the higher the number of the child's autism symptoms reported.

Table 3
Correlations Among Variables

		PD	PCDI	DC	Total Stress	ABC	Informal Support	Formal Support	Total FSS
PSI-SF-IV Indices	1. PD	_____	.48*	.48*	.81*	.18	-.16	-.21	-.25
	2. PCDI	.48*	_____	.70*	.84*	.28	-.07	-.46*	-.12
	3. DC	.48*	.70*	_____	.87*	.20	-.04	-.35*	-.05
	4. Total Stress	.85*	.84*	.87*	_____	.26	-.08	-.39*	-.16
	5. ABC	.18*	.28*	.20*	.26*	_____	-.11	-.52*	-.13
FSS Indices	6. Informal Support	-.51*	-.40*	-.35*	-.50*	-.28	_____	.14	.44*
	7. Formal Support	-.30	-.49*	-.27	-.50*	-.47*	.62*	_____	.72*
	8. Total FSS	-.56*	-.52*	-.46*	-.61*	-.29	.67*	.91*	_____

Note. Correlations above the line were run using the original FSS scores. Correlations below the line used the recoded FSS scores (NA = 3)

* $p < .05$

Chapter IV

Discussion

Conclusions

Previous research has indicated that a high level of stress is associated with raising a young child with autism (Dabrowska & Pisula, 2011; Lee, 2009). A great amount of research has investigated ways in which to help negate some of the heightened stress involved in parenting a child with autism. Much of this research has indicated that a level of perceived social support (both formal and informal), often can serve as a buffer against feelings of stress associated with parenting a child with autism. Some past studies have indicated that both formal and informal support play an equal role in lowering self-reported rates of parenting stress (Benson, 2006; Boyd, 2002; Siman-Tov & Kaniel, 2011), while others have indicated that formal support (such as support coming from professional organizations) is the more significant type of social support in relation to buffering against heightened levels of parental stress (Ekas & Lickenbrock, 2010; Gray & Holden, 1992; Hastings & Beck, 2004). The present study sought to investigate whether, for a sample of mothers of young children with autism, both formal and informal support correlate negatively with parenting stress.

Results indicated that both formal and informal social support were associated with decreased levels of parental stress. This result is consistent with previous research (Benson, 2006; Boyd, 2002; Siman-Tov & Kaniel, 2011) indicating that all forms of social support may serve as a buffer against heightened levels of parental stress. This finding is essential to understand when it comes to developing support for families raising a young child with autism. Professionals working with families who have a child

on the autism spectrum should be aware of the ways in which their services could potentially lower the stress levels of their consumers related to parenting a child with autism. For example, they should be cognizant of the fact that although their direct services impact parent stress (e.g., through therapy, behavioral consultation, etc.), they should also encourage parents to seek out less formal sources of support as well. Professional organizations should be knowledgeable of the types of informal support that exist in their consumer's community (e.g., parenting support groups) to recommend involvement in such activities.

While both informal and formal support were shown to be related to lower levels of overall stress, informal support was additionally associated with all three of the indices on the *PSI-SF-IV*, while formal support was only associated with the PCDI. In other words, informal support was associated with all types of parental stress: general parental distress, stress associated with a child exhibiting difficult behaviors, and stress associated with a challenging parent-child relationship. Formal support, in contrast, was only associated with stress related to a challenging parent-child relationship. The difference may be due, in part, to the availability and reach of each form of support. Informal support is largely comprised of support from family and friends who may be available to parents on a day-to-day basis. They can provide respite when needed and help with the daily care-taking responsibilities associated with raising a child with autism. As such, informal support may help alleviate stress related to parental distress, parent child interactions, and child functioning.

In contrast, formal support may be less available to parents than informal support. Parents may only have access to professional services such as pediatricians and therapists

by phone, and in person meetings may take place once a week or less. This less frequent form of support may have less impact on overall parental stress since it is limited in terms of the ways in which it can alleviate caregiving burden. Additionally, while formal support was inversely related to the mothers' overall levels of stress, it was only correlated with one index of the measure: the PCDI. This index measures stress associated with dysfunctional interactions between parent and child. Because the focus of formal support is often directed at helping the parent manage her child's behaviors, formal support may primarily alleviate a parents' stress related to dysfunctional interactions.

The *ABC* was entered into the correlation matrix to identify how autism symptoms may be associated with both social support and parental stress. The *ABC* was found to be correlated positively with all indices on the *PSI-SF-IV*. In other words, the higher the number of autism symptoms the mothers endorsed, the higher their scores on the indices measuring parental stress. This finding is consistent with previous research that shows a heightened level of parental stress associated with child problem behaviors (Baker-Ericzen, Brookman-Frazee & Stahmer, 2005; Davis & Carter, 2008). Results may indicate that parents experience significantly more stress when managing child problem behavior or, because the causal relation cannot be determined, parental stress impacts parents' ability to effectively manage child behavior.

The negative correlation between child symptomatology and perceived formal support may be explained by the impact of child problem behavior in parent mental health. According to Abbeduto and colleagues (2004), mothers who endorsed more autism symptoms on the *ABC* also endorsed more symptoms related to depression on a

psychological assessment. It is plausible that mothers who have a child displaying more severe behaviors are also feeling more depressed and therefore less likely to seek out additional support. Additionally, the correlation could be related to the fact that mothers who endorse higher autism symptoms for their children feel as though they are in need of higher degrees of formal support from agencies. Therefore, the average amount of support given to the families raising a child with autism may not be seen as adequate and therefore may receive lower ratings by the mothers. Finally, because the causal relation is unclear, it is also possible that parents who receive less formal support have less training for managing their child's behavior and thus report greater autism symptomatology.

Parental stress has been associated with increased levels of depression and anxiety (Theule et al., 2010), decreased quality in the parent-child relationship, and poorer parenting practices (Rodger, 1998, as cited in Theule et al., 2010). To make the parent-child relationship as successful as possible, it is imperative that professionals find ways to help alleviate the heightened levels of parental stress associated with raising a child with autism. Research has repeatedly shown that social support is one way to lessen the negative impacts associated with parental stress. Providing support to families through direct contact with the child with autism, the availability of therapists to answer questions, and helping parents identify forms of informal support such as family and friend networks and support groups should therefore be a regular component of all services geared towards families raising a child with an autism spectrum disorder.

Limitations

First and foremost, a significant limitation of the present study was the small sample size. The number of participants in this study only yielded enough power to detect

large effects. Though small and medium effects were in fact detected, some may have gone undetected. Further, analyses designed to examine the mediating effects of child symptoms on the relation between social support and parenting stress could not be assessed in the current study due to low sample size. For example, it is unknown whether child behavior accounts for the relation between formal social support and parenting stress in that parents who report less formal support also report greater child symptomatology, which is a known predictor of parenting stress. Additionally, the correlational nature of this study does not allow for the examination of the causal relations.

Because the first stage of recruitment targeted parents of children transitioning from EI services, the sample comprises 11 parents whose children fall between the ages of 2.5 and 3.5 years who were currently undergoing or had recently experienced the transition from EI. Past studies have shown that this transition is a particularly stressful period of time in the life of a parent raising a child with autism, and the structure of the EI system is inherently different from that of other programs (Hastings & Beck, 2004; Turnbull et al., 2007). Therefore, the over-representation of parents of these younger children may limit the generalization of the current findings to all families. Another limitation of the study is a potential response bias. Participation in the study was completely voluntary, and required interested mothers to contact the Principal Investigator. The mothers who contacted the Primary Investigator may differ from those who did not. They may be mothers who are more likely to reach out to seek support or who are less stressed overall than their peers. Due to this potential bias, generalization of the results must be done with caution.

Additionally, there is a significant limitation related to the reliability of one of the measures used. Due to the low reliability discovered for the *FSS* measure when the analysis was run as the measure was written, the measure needed to be recoded to increase the reliability. Doing so generated an increased number of significant correlations. This modification must be considered when interpreting the implications of the findings of the present study, as the results discussed are based on a recoded version of the measure.

The *FSS* measure in and of itself can be considered a limitation, aside from the reliability component. The measure was meant to assess participants' levels of perceived formal, informal, and total social support. The various items on the measure were broken down to sum each subscale. Some items and response choices appeared to be poorly defined. For example, on each item the response "N/A" was an option. It is possible that this item was endorsed by parents as "not available" as well as "not applicable," which have two different meanings. Further, the assignment of certain forms of support into the two categories (formal and informal) appeared somewhat arbitrary. For example, the item "school/daycare" was utilized to generate the informal social support subscale but the professionals who often make up a school (e.g., therapists, etc.) were included in the formal social support subscale. This example illustrates the ways in which some items (e.g., "school") may have been poorly defined for parents and could have affected how they endorsed items related to formal and informal social support.

Future Directions

Past research has shown that life cycle transitions can be particularly stressful events for parents (Pang, 2010) and social support may be a potential buffer against this stress (Benson, 2006; Boyd, 2002; Siman-Tov & Kaniel, 2011). The family life-cycle is a term that refers to the various significant transitions that occur through a family's lifetime. Examples of transitions families may undergo include the birth of a child, a child starting school, or a family moving. Transitions are times of change, and change is a concept that can be stressful for many individuals (Pang, 2010). In particular, previous research has shown that many of these transitions can be especially stressful for a child who has a disability, for they may be paired with much more anxiety and uncertainty than transitions for neurotypical children (Hanson et al., 2000; Pang, 2010). For example, for many families who have a child with a disability, the transition from EI services to preschool is the first major transition they experience and may therefore be the most challenging. Due to this notion, this transition is an important time period to understand the role of social support for these families. Future research in this area should focus on life-cycle transitions such as this (e.g., transitions to adult services or to inclusion settings) to learn more about the ways in which perceived social support could act as a buffer during a time when parental stress has been shown to be particularly high.

Implications for Practice

The present study chose to investigate the relationship between parental stress and perceived social support while raising a young child with autism. Past research has supported the notion that social support can act as a potential buffer against stressors associated with raising a child with autism. The findings of the study indicated that

support from friends, family, and parent groups (informal support), as well as professional organizations such as schools and pediatricians (formal support), is associated with lower overall parental stress ratings. These findings support the importance of clinicians not only providing direct services to children with autism, but serving as sources of support for the families as well. When working professionally with families raising a child with autism it is important to engage the families in the treatment process, be available to answer questions, as well as encourage the family to seek out alternative means of support from their friends, family members, and general social circle. By doing so it is possible that levels of parental stress will be lowered, which can be associated with better overall outcomes for the child with autism.

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Appendix A

Cover Letter Distributed to Agencies

To Whom it May Concern:

My name is Sarah Rutstein and I am a 3rd year Doctoral Candidate at the Graduate School of Applied and Professional Psychology at Rutgers University. As per our graduation requirements, each candidate is expected to complete a dissertation project during their graduate years. I have chosen to investigate the relationship between perceived social support and parental stress during their child's transition from Early Intervention services to Early Childhood Special Education. Furthermore, my research hopes to specifically target parents who have a child that has received a previous diagnosis of an Autism Spectrum Disorder. Due to this aspect of my research, it is important that I be able to specifically target parents who fit the aforementioned description.

I am asking that you distribute the enclosed fliers to mothers who you may believe fit the description of my target participants. I am hoping to recruit mothers whose child is beginning the process of their EI transition, in the middle of the transition, or has recently concluded it. Once you distribute the flier, your involvement is complete. It is then up to the participant to contact me if she is interested in participating.

Your support is truly appreciated and imperative to the success of my study.

Please contact me with any questions at all. I can be reached by phone at 609-213-9612 or email, sarah.rutstein45@gmail.com

With many thanks,

Sarah Rutstein
Doctoral Candidate, School Psychology Program
Graduate School of Applied and Professional Psychology
Rutgers, the State University of New Jersey

Appendix B

Recruitment Flier Distributed to Agencies

Opportunity to Participate in Research!

What is the study?

I am a doctoral student in school psychology at Rutgers University, and I am currently conducting a study on the experiences of mothers raising a child with autism as the child transitions from Early Intervention Services to Preschool. This study is open to all mothers (biological or adoptive) of children diagnosed with autism, Asperger's, or PDD-NOS who will transition to preschool in the next 6 months, or who have already transitioned to preschool in the past 6 months. This project is being conducted under the supervision of Dr. Kate Fiske Massey, Ph.D, BCBA-D, Clinical Assistant Professor at Rutgers University.

Examination of the experiences of parents during this early transition is important to the development of effective support groups for parents and trainings for professionals. Your help with this research would be immensely appreciated. **The study is not being conducted by NJEIS and the decision to participate will in no way affect the early intervention services your child is currently receiving or the services he/she will receive in the future.**

What is expected of you?

If you wish to participate, please contact me using the information below, and you will be mailed a packet of questionnaires for you to complete that should take no more than **30 minutes** of your time. You will then mail back your responses to me in a pre-paid self-addressed envelope. No travel is required for your participation in this study.

To learn more about this project or to participate in this study, please contact Sarah Rutstein at 609-213-9612 or at sarah.rutstein45@gmail.com

You may also complete the bottom portion of the flier and return to Sarah Rutstein at 184 Hampshire Court, Piscataway NJ 08854

THANK YOU!

Yes, I am interested in participating! Please contact me using this information:

Mother's Name: _____

Mailing Address: _____

Phone Address: _____ E-mail Address: _____

How old is your child? (Year, Months) _____

Appendix C

Cover Letter to Mothers

THANK YOU!

Dear Parent/Guardian,

Thank you for agreeing to participate in my research study on the experiences of parents raising a child with autism as they transition from early intervention to preschool. Examination of this time is important to the development of effective support groups for parents and trainings for professionals. I am currently a 3rd year Psychology Doctoral student at Rutgers University, and this study is my doctoral dissertation supervised by Dr. Kate Fiske Massey. Your help with this research is immensely appreciated.

I have enclosed with this letter the consent form for your participation in this study, as well as the questionnaires for you to complete. Please read the consent form carefully. You should consent to the study only if you agree with all of the statements in the form.

Furthermore, the current study is not a New Jersey Early Intervention Services Study, and the decision to participate will in **no way** affect the early intervention services your child is currently receiving or the services he/she will receive in the future.

Once you have completed the consent form and questionnaires, please place them in the pre-paid envelope and mail them to me as soon as possible.

If you have any questions regarding this information, please feel free to contact Sarah Rutstein at 609-213-9612 or at sarah.rutstein45@gmail.com. Dr. Massey can be reached at 732-932-3017 or at kfiske@rci.rutgers.edu. The Rutgers University Institutional Review Board may be contacted at 848-932-0150, at humansubjects@orsp.rutgers.edu, or at 3 Rutgers Plaza, New Brunswick NJ 08901.

Thank you,

Sarah Rutstein
Doctoral Candidate, School Psychology Program
Graduate School of Applied and Professional Psychology
Rutgers, The State University of New Jersey

Appendix D

Informed Consent

Informed Consent for Research Participation

This form requests your consent for your participation in a research study on the experiences of parents raising a child with autism during the child's transition from early intervention to preschool. The project is being conducted by Sarah Rutstein, a doctoral candidate at the Graduate School of Applied and Professional Psychology at Rutgers University. The project is my doctoral dissertation conducted under the supervision of Dr. Kate Fiske Massey.

Your participation in this study is completely voluntary. You are one of approximately 50 mothers invited to participate. The research requires you to complete a series of questionnaires regarding you and your child's demographic information, the stress you currently experience in relation to raising your child, and the amount of social support you believe you receive. Participation in this study requires the completion of all the questionnaires by the mother in the household. You will be asked to complete the questionnaires in paper form, and they are provided to you in this packet. The questionnaires should take approximately 30 minutes to complete.

Potential benefits of this study broadly include a contribution to a greater understanding of the experiences of parents of children with autism during their child's transition to preschool. I am required to inform you of the risks of this study. Some questionnaires may contain items that may be difficult for you to answer or that may upset you. In addition, you may grow tired of responding to the items on the questionnaires. While these questions have been carefully chosen to identify areas of potential difficulty for parents, at any time you may choose not to answer a question if it causes distress.

While I am required to inform you that Rutgers University will not be responsible for compensation or treatment in the event of research-related adverse experiences, the procedure for this research study poses no foreseeable risks to your child and minimal risk to you. Distress that you may experience in the completion of this study is not expected to exceed that experienced in daily life. Should you find yourself upset by the completion of these questionnaires, however, please do not hesitate to contact me using the contact information provided below so that I may help you find appropriate resources.

The data collected during this study will be used only in the research study evaluating parental stress and will be viewed only by me (Sarah Rutstein) and my committee members (Dr. Kate Fiske Massey & Dr. Ryan Kettler). To preserve the confidentiality of questionnaire responses, any identifying information about you or your child (i.e. consent forms) will be kept separate from your responses to questionnaires and I will be the only person who can link your responses to your identity. To maintain security and confidentiality, I will store and maintain all information in a locked file box. When the material loses its scientific value, it will be destroyed to ensure no one else gains access

to it. However, if you disclose reports of child abuse, I am obligated to report the matter to the authorities.

_____ (initials)

If at any time you wish to decline participation in this study, you may do so without penalty and without impact on the treatment or services delivered to you or your child by New Jersey Early Intervention Services (NJEIS). The study is not being conducted by NJEIS and your participation will in no way affect the early intervention services your child is currently receiving or the services he/she will receive in the future.

If you have any questions regarding this information, please feel free to contact Sarah Rustein at 609-213-9612 or at sarah.rutstein45@gmail.com. Dr. Massey can be reached at 732-932-3017 or at kfiske@rci.rutgers.edu. The Rutgers University Institutional Review Board may be contacted at 848-932-0150, at humansubjects@orsp.rutgers.edu, or at 3 Rutgers Plaza, New Brunswick NJ 08901.

Sincerely,

(Principal Investigator) Sarah Rutstein
Doctoral Candidate, School Psychology Program
Graduate School of Applied and Professional Psychology
Rutgers, The State University of New Jersey

_____ I understand the terms of this consent and agree to participate in this study and for the responses I provide to be confidentially used for research purposes. **Please initial bottom of previous page if you consent to participation.**

_____ I decline to participate in this study.

Mother's Name (please print)

Mother's Signature

Date

Appendix E

Demographic Questionnaire

Demographic Questionnaire

*Please fill in the following information about **yourself**:*

Relationship to Child:

☐ Biological Mother

☐ Adoptive Mother

☐ Resource Mother

☐ Step-Mother

Parent Age: _____

Parent Marital Status:

☐ Married

☐ Divorced

☐ Widowed

☐ Single

Number of children in household, including child with autism: _____

Which of the following best describes your ethnicity? Please check all that apply

☐ Caucasian/White

☐ African American

☐ Asian

☐ Hispanic

☐ Pacific Islander

☐ Native American

How far did you go in school? (please check one)

☐ 8th grade or less

☐ More than 8th grade, but did not graduate from HS

- ☐ Went to business, trade, or vocational school instead of HS
- ☐ High School/GED
- ☐ Went to a business, trade, or vocational school after high school
- ☐ Went to college, but did not graduate
- ☐ Graduated from a college or university
- ☐ Professional training beyond a 4-year college or university
- ☐ Never went to school
- ☐ Don't know
-

*Please fill in the following information about your **child**:*

Gender:

- ☐ Male
- ☐ Female

Child's Current Age: _____

Child's age when he/she began receiving early intervention services: _____

Child's age when he/she transitioned or is expected to transition to preschool services:

Child's Diagnosis:

- ☐ Autism
- ☐ Asperger's Disorder
- ☐ PDD-NOS
- ☐ Other _____

How prepared did/do you feel for your child's transition from early intervention to preschool services? (please circle one)

- | | | | | |
|------------|----------|------------|----------|----------|
| 1 | 2 | 3 | 4 | 5 |
| Not at all | Somewhat | Moderately | Prepared | Very |
| Prepared | Prepared | Prepared | | Prepared |

Overall, rate your satisfaction in relation to your child's transition from early intervention to preschool services (circle one):

1	2	3	4	5
Not at all	Somewhat	Moderately	Satisfied	Very
Satisfied	Satisfied	Satisfied		Satisfied