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THE IMPACT OF SOCIAL SUPPORT AND FAMILY RESILIENCE ON PARENTAL STRESS IN FAMILIES WITH A CHILD DIAGNOSED WITH AN AUTISM SPECTRUM DISORDER

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Abstract

Families of children with autism spectrum disorders (ASD) experience significant stress relative to other families. To date, little research has examined the relationship between social support, family resilience and parental stress in families with a child diagnosed with ASD. This study explored the links between perceived social support, family resilience and parental stress in a sample of 50 primary caregivers of children between the ages of 6 and 12 diagnosed with ASD. The Social Support Index (SSI), Family Resilience Assessment Scale (FRAS), and the Parenting Stress Index-Short Form (PSI-SF) were used in this cross-sectional study. Results indicate that most families experienced clinically high levels of stress. Greater family resilience was associated with lower levels of stress. Unexpectedly, higher levels of perceived social support were associated with increased parental stress. This may suggest that families who are experiencing clinically significant levels of stress seek out community supports at higher rates than other families. It may also suggest that some social connections - such as attending religious services and parenting groups - may potentially elevate stress in parents of children with ASD. This and other possibilities are explored with implications for social work intervention. The findings of this study shed new light on the role of social support and family resilience on parental stress in families with a child diagnosed with ASD. Since the results of this study show that more resilient families report less parental stress clinicians need to focus on programming for families that enhance key processes of family resilience and reduce stress.

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Jennifer C. Plumb

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DEDICATION

I dedicate this to all the families who participated in this research. Thank you!

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I would like to thank my dissertation committee for giving their time, support, and feedback. You have helped me to grow as a researcher and as a clinician.

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ABSTRACT

THE IMPACT OF SOCIAL SUPPORT AND FAMILY RESILIENCE ON PARENTAL STRESS IN FAMILIES WITH A CHILD DIAGNOSED WITH AN AUTISM SPECTRUM DISORDER

Jennifer C. Plumb

David S. Mandell, ScD

Families of children with autism spectrum disorders (ASD) experience significant stress relative to other families. To date, little research has examined the relationship between social support, family resilience and parental stress in families with a child diagnosed with ASD. This study explored the links between perceived social support, family resilience and parental stress in a sample of 50 primary caregivers of children between the ages of 6 and 12 diagnosed with ASD. The Social Support Index (SSI), Family Resilience Assessment Scale (FRAS), and the Parenting Stress Index-Short Form (PSI-SF) were used in this cross-sectional study. Results indicate that most families experienced clinically high levels of stress. Greater family resilience was associated with lower levels of stress. Unexpectedly, higher levels of perceived social support were associated with increased parental stress. This may suggest that families who are experiencing clinically significant levels of stress seek out community supports at higher rates than other families. It may also suggest that some social connections - such as attending religious services and parenting groups - may potentially elevate stress in parents of children with ASD. This and other possibilities are explored with implications for social work intervention. The findings of this study shed new light on the role of social support and family resilience on parental stress in families with a child diagnosed with ASD. Since the results of this study show that more resilient families report less parental stress clinicians need to focus on programming for families that enhance key processes of family resilience and reduce stress.

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Chapter 1: Introduction

Over the past decade, there has been an increase in the number of children diagnosed with an autism spectrum disorder (ASD). According to the Center for Disease Control and Prevention (2007), 1 out of every 110 children in the United States meets criteria for an ASD. Previous research has shown that having a child with a disability such as ASD presents a unique set of challenges that impacts the entire family unit and individual family members' health, well-being, and experiences across the life span (Patterson, 2005; Turnbull, Turnbull, Erwin, & Soodak, 2006). These stressors include challenges navigating the myriad of educational, medical, and behavioral services; financial hardships related to the cost of care; and emotional aspects of having a child with a disability (Plant & Sanders, 2007). The behavioral challenges often associated with ASD can leave families feeling isolated (Woodgate, Ateah, and Secco, 2008). In addition, studies have demonstrated that parents of children diagnosed with an ASD experience greater amounts of anxiety, depression, stress, and strained martial relationships than parents of typically developing children or parents of children with other types of developmental delays (Dumas, Wolf, Fisman, & Culligan, 1991; Plant & Sanders, 2007).

However, recent literature on families of individuals diagnosed with an ASD or other childhood chronic illnesses and disabilities have noted that these chronic conditions can also have positive implications for some families (Bayat, 2007; Marcus, Kunce, & Schopler, 2005). Such positive outcomes include a new or renewed sense of spiritual connectedness, emotional growth, a sense of purpose, and a larger community network (Scorgie, Wilgosh, & McDonald, 1996; Twoy, 2007). Social support has been cited as a contributing factor in counteracting the negative outcomes of stress. Social support develops from the relationships and interactions between the individual, family, peer group, and larger social systems (Boyd, 2002). This ecological perspective of social support focuses on the transactional nature of the relationships between the family and outside systems, acknowledging that many different variables serve as protective or risk factors to a family's ability to adapt to challenges. Therefore, stress, defined as a risk factor, can influence or offset the protective qualities of social support. The study of resilience is aligned with the social work profession's strengths-based philosophy of care and counseling (Greene, 2006). For families struggling with the stressors associated with raising a child on the autism spectrum, understanding the role of social support and family resilience on parental stress must be explored.

This paper attempts to inform the literature on families of individuals diagnosed with an ASD by examining the relationships between social support, family resilience, and parental stress. Drawing upon the Family Resilience Theory (Walsh, 1998; Walsh, 2003) this study predicts a relationship between family resilience, social support, and parental stress. The next chapter will provide background information and further context for this study by reviewing and critiquing the relevant literature on families of children with autism.

Chapter 2: Literature Review

What is an Autism Spectrum Disorder?

The American Psychiatric *Association's (APA, 2000) Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR), defines ASD as a group of disorders that include autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger's Disorder. The core deficits associated with an ASD are impairment in social interaction and communication, as well as the presence of unusual behaviors and/or interests (APA, 2000). ASDs occur in all racial, socioeconomic, and ethnic groups and are four times more likely to occur in boys than in girls.

Autism spectrum disorder is considered to be a severe disability secondary to the intense lifelong effects it has on the diagnosed individual and his or her family (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). ASD is classified as a spectrum disorder because of different degrees of impairment in the core diagnostic areas. Other behavioral, developmental, psychiatric, and medical problems can co-occur with autism. Often, these co-occurring problems present the family with the most difficult challenges to manage. According to Newschaffer et al. (2007), behavioral difficulties may be associated with, or related to, the core symptoms of autism (e.g., aggression, disruption, hyperactivity, self-injury, or sensory differences). Newschaffer et al. (2007) report that the three predictors of functional outcomes are: (a) cognitive status, (b) age of language acquisition, and (c) age of diagnosis. Families often have to interact with a variety of systems in order to get their child the appropriate educational, medical, and behavioral services.

Diagnostic criteria

To date, there are no reliable biological markers for ASD. Diagnosis of ASD is based on behavioral observation, parental interview, developmental history, and clinical impression (Dawson & Murias, 2009). The “gold standard” diagnostic tools often used in conjunction with the above mentioned are the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) and the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 2000). The ADOS is a play-based semi-structured assessment of communication, social interaction, and play skills. It is designed to elicit social and communicative behaviors. There are four different modules to the ADOS. The module utilized is determined by the developmental and language level of the individual being assessed (Lord et al., 2000). The ADI-R is a standardized caregiver interview used in the differential diagnosis of ASDs (Martínez-Pedraza & Carter, 2009). Although not within the scope of the paper, note that there are many additional screening and diagnostic tools available to clinicians to screen children for ASD. A comprehensive review of assessment instruments is presented by Goldstein and Naglieri (2009).

Prevalence

According to the Centers for Disease Control and Prevention (2007), 1 out of every 110 children in the United States meets criteria for an ASD. ASD is now considered to be the second most common developmental disability affecting children in the United States (Newschaffer et al., 2007). Again, the disorder is characterized by impairments in reciprocal social interaction and communication and by the presence of repetitive, inflexible behavior (Zwaigenbaum et al., 2009).

Family Resilience Theory

Family resilience theory serves as the conceptual foundation guiding the study described in this paper. This theory builds on a competence-based and strength-oriented family paradigm that allows a greater understanding of how families display resilience when challenged by adversity (Walsh, 1998; Walsh, 2003). McCubbin et al., (1998) define family resilience as “characteristics, dimensions, and properties of families which help families to be resilient to disruption in the face of change and adaptive in the face of crisis situations” (p. 247). The concept of resilience has roots in two bodies of literature: the psychological aspects of coping, and the physiological aspects of stress (Tusaie & Dyer, 2004). According to Greene et al. (2006), the study of resilience grew out of the discipline of epidemiology. Early developmental theorists recognized the importance of studying both atypical and normative development as a way to better understand human functioning and adaptation. The study of resilience stems from the empirically based knowledge of human behavior and contributes to the social work profession’s strengths-based philosophy of care and counseling (Greene, 2006).

According to Luthar, Cicchetti, and Becker (2000), research on family strength during times of crisis dates back to the early 1900s. Although the term “resilience” was not part of the descriptive language used in the literature at that time, the concepts described might be viewed today as akin to resilience. Research on resilience and family strength began to appear in the scientific literature in the early 1970s (Luthar, Cicchetti, & Becker, 2000). During this time, a great deal of empirical research was conducted on resilience among individuals with schizophrenia. Based on this work, many researchers concluded that individuals with schizophrenia were capable of adaptive patterns, competency in work, healthy social relationships, and fulfillment of life responsibilities

In the mid-1970s, "childhood resilience" began to emerge as a major theoretical and empirical topic of study. The research predominantly focused on identifying qualities that were characteristic of "resilient children." This work became the catalyst for further research into understanding individual variations in response to adverse situations. In 1971, Werner conducted a study of 700 children in Hawaii that examined multiple adverse conditions impacting adaptation. Areas of focus included socioeconomic disadvantages and associated risks such as maltreatment, poverty, violence, chronic illness, and other catastrophic life events (Luthar et al., 2000). Werner's (1993) work is often hailed as the groundbreaking study of resilience in children. Researchers began to acknowledge the role of external and environmental factors on resilience in children. Masten and Garmezy (1985) described three sets of external factors implicated in the development of resilience: attributes of the children themselves, aspects of their families, and characteristics of their wider environment (Luthar et al., 2000).

Contributions to Resilience: Risk and Protective Factors

A common theme throughout the research on individual resilience is the ability to navigate successfully through life challenges, thereby “overcoming” adversity (Alvord & Grados, 2005; Luthar, 2003; Ungar, 2004). Walsh (2002) sees the process of overcoming adversity as the interplay of risk and protective operations. Demands and risks are widely viewed as factors that influence or increase the statistical probability of the onset of stress or a negative outcome following adverse events (Fraser & Richman, 1999). Risk-related life events include natural disasters, poverty, racism, child abuse, peer rejection, chronic illness, and family conflict. According to Fraser (1997), risk factors may be situational or chronic in nature. Protective factors are also situational and increase the likelihood of healthy adaptation. According to Dyer and McGuiness (1996), protective factors are specific attributes or situations that enable the process of resilience to occur. Protective factors can be characteristics specific to the individual, such as good problem-solving skills and temperament, but they can include broader resources like helpful family patterns and access to external supports. Based on an extensive literature review, Benzies and Mychasiuk (2009) identified and described nine specific protective factors: (a) locus of control, (b) emotional regulation, (c) belief systems, (d) self-efficacy, (e) effective coping skills, (f) education, skills and training, (g) health, (h) temperament, and (i) gender. Protective factors also shield those at risk from the negative impact of adversity.

According to Patterson (2002), most researchers view resilience as a process in which risk and protective factors interact, relative to a specified outcome. Tusaie and Dyer (2004) describe the balance between risk and protective factors as a dynamic process, noting that a risk factor at one point in time may be considered a protective factor at another point in time or in another context. Waller (2001) also suggests that risk and protective factors have a "ripple effect" that can lead to further risk or protection. The literature identifies a strong social network and social competence other important protective factors. Ungar (2004) describes a constructionist approach to resilience as the outcome of negotiations between an individual and their environment that enable the individual to remain healthy despite conditions that are collectively viewed as adverse. Ungar (2004) explains that "researchers of resilience continue to conduct studies in the hope of revealing ways to inoculate children against person, familial, and environment's acute and chronic stressors" (p. 342-343). He further clarifies the constructionist view of resilience as focusing on factors unique to each individual and their social grouping, noting that personal challenges impact the individual relative to their lived experience.

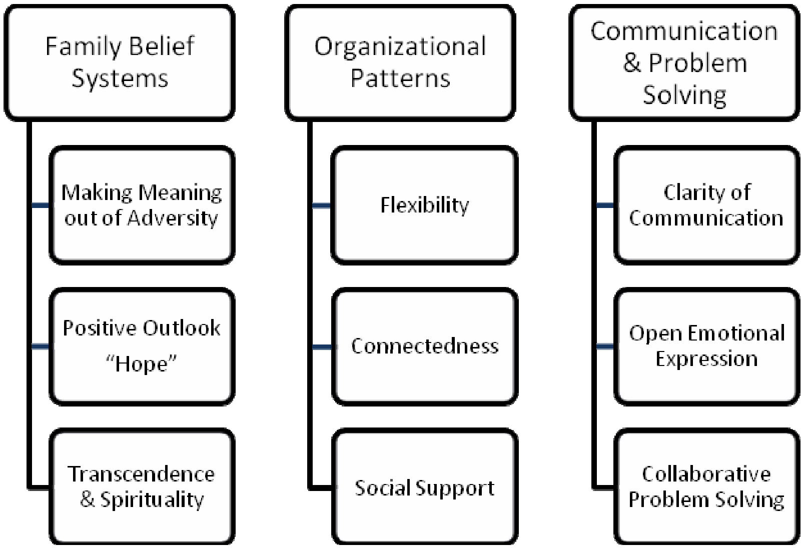
The risk and resilience theory builds on a stress perspective and seeks to identify and address sources of individual stress. This theory takes a holistic approach to assessing resilience by considering a person's ability to successfully adapt to a situation within the context of developmental stages. It examines human behavior through a multiple systems approach, and emphasizes bio-psychosocial and spiritual functioning as contributing factors to resilience. According to Greene (2006), this theory also "addresses how the client has functioned over time, the timing of family life events and the historical and cultural changes associated with them" (p. 58).

Key Processes in Family Resilience

Walsh's theory (1998; 2003) on family resilience outlines the following three domains, which are further broken down into sub-constructs:

Figure 1. Walsh's Family Resilience Model

Family Resilience



Family Belief Systems

According to Walsh (1998), family belief systems include values, attitudes, biases, assumptions, and concerns. Humans live in the context of communities that are influenced by the larger social context. Resilient families are those whose belief systems allow them to make sense of a crisis or event that they would not consider typical. By normalizing the experience, families can make it manageable and meaningful, as well as use it to strengthen family coherence. Families that remain optimistic about the future during a crisis actively seek the tools needed to maximize a successful outcome.

Family Organizational Patterns

Walsh (1998) asserts that families need to organize themselves, particularly during challenging times. This organization often provides a level of stability and comfort, establishing a foundation of trust that allows connections with outside resources and supports. Resilient families often have family rules that are age appropriate, acknowledged, and predictable (Black & Lobo, 2008). Walsh (1998) notes that that family relationships change over the course of the lifecycle, emphasizing that families must continually assess their current level of connectedness to ensure that each family member’s needs are being met. While Olson (2000) acknowledges that families tend to prefer stable and orderly patterns, they often function best when a balance is achieved between moderate amounts of structure and flexibility.

Other important components of family organizational patterns include social and economic resources. During times of adversity, resilient families are able to tap into their social and professional networks for concrete financial, educational, and therapeutic resources.

Communication/Problem Solving

Clear communication is vital to family resilience. As Walsh (2003) states, “clarity and congruence in messages facilitate effective family functioning” (p. 12). This concept works hand-in-hand with open emotional expression. Families that are able to share feelings with one another empathize with each other's unique experiences. Positive interactions and feelings of connectedness provide strength for coping, and resilient families demonstrate the ability to brainstorm potential ways to approach a problem (Walsh, 1998).

Like Walsh, McCubbin has been exploring family stress and coping since the early 1980s. Over the last decade, both researchers have expanded the focus of their work to include resilience. McCubbin et al., (1998) conceptualizes family resilience as behavioral patterns and functional competencies that help families negotiate and cope with crises and hardships. Similar to Walsh’s theory, this idea asserts that families may even thrive in the face of adversity, resulting in a healthier outcome. The Family Adjustment and Adaptation Response Model (FAAR), an ecologically based model that evolved from family stress theories, focuses on pre- and post-crisis family factors that contribute to the ability to adapt in the face of adversity. The model consists of two phases: the adjustment phase and the adaptation phase.

Families experience the adjustment phase when they attempt to regain balance after confronting a real or perceived threat and/or stressor to family functioning. Twoy et al. (2007) define a stressor as a constraining force or influence that produces a change in a family equilibrium that leaves it vulnerable. This disruption forces families to rely on previous patterns of coping and resources. Family resources serve as supports at the micro, mezzo, and macro system levels. Individual resources may include intelligence level, personality traits, and physical and/or emotional health. Family-level resources include decision-making and conflict resolution skills. At the macro/community level, institutional supports include religious organizations and healthcare facilities (Twoy et al., 2007). Family members use these problem-solving resources to address and manage both the stressor and new demands placed on the family (McCubbin et al, 1998).

Conceptually, family resilience builds on the development of a competence-based and strength-oriented family paradigm to help gain an understanding of how families display resilience when challenged by adversity (Walsh, 1998; Walsh, 2003). According to Walsh (2002), “the family resilience framework serves as a conceptual map to identify and target key family processes that can reduce stress and vulnerability in high-risk situations, foster healing and growth out of crisis, and empower families to overcome prolonged adversity” (Walsh, 2002, p. 130).

Empirical Findings: Parental Stress, Family Resilience, and Social Support in Families with ASD

Parental Stress.

The resiliency literature identifies stress as a threat to family equilibrium. Families of children with autism experience a unique set of stressors compared to families of children with other disabilities (Deater-Deckard, Pinkerton, and Scarr, 1996). Initial stressors include those associated with identifying the child's specific difficulties. Martínez-Pedraza and Carter (2009) report that parents, although unable to accurately pinpoint the specific nature or degree of the problem in their child, can correctly recognize developmental problems—for instance, noticing that the child has lost skills after experiencing a time of typical development. A number of parents report that something was “just not right” since the child's infancy. This uncertainty about the child’s problem, combined with difficulties in obtaining a diagnostic assessment, can increase parental stress levels. Delays in confirming diagnostic status may be due to such deterrents as long waiting lists to see an ASD diagnostic specialist; expectations of rapid developmental changes, which may lead parents and health care professionals to postpone formal evaluation; and inconsistent child symptom presentations, in which very young children with ASD may appear to have age-adequate social skills in limited contexts (Martínez-Pedraza & Carter, 2009).

The process of acquiring and processing a diagnosis such as autism is often likened to bereavement (Dale, Jahoda, and Knott, 2006). With the loss of the hopes and dreams that they had for their child, parents often experience grief when their child receives a diagnosis of autism (Ariel & Naseef, 2006). In addition, parents of young children with ASD report higher levels of stress secondary to autism-associated behavior difficulties and deficits in social relatedness. As Martinez-Pedraza and Carter (2009) describe, “parents of children with ASD could experience stress, anxiety, and isolation related to their inability to control their child, who in most cases appears to be physically normal” (p. 649). To deepen clinical understanding of these emotional processes, Woodgate, Ateah, and Secco (2008) conducted a qualitative study of the experience of parents with children diagnosed with ASD. In this study, the researchers identified experiences of isolation due to external sources (e.g., society’s lack of understanding) as major sources of familial stress. This research challenged the results of previous studies suggesting that parents tended to isolate themselves from social contact to avoid awkward encounters with outsiders (Gray, 1997).

Following a diagnosis, the ambiguity and uncertainty of the child's prognosis provides another source of stress for parents. For example, in a study examining the impact of uncertainty on caregivers, researchers found that perceived uncertainty regarding the course of the illness became a significant predictor of the caretaker's future distress (Sanders-Dewey, Mullins, & Chaney, 2001). Research suggests that parental distress results from such factors as the intensity, magnitude, duration, and unpredictability of ASDs (Noh, Dumas, Wolf, & Fisman, 1989).

A number of studies focus on how families manage and cope with ASD-related stress. Among these was a case study conducted by Dale, et al. (2006) that examined the psychological characteristics of families with children with autism. Findings indicated that feelings of anger, shock, denial, self-blame, and guilt were often reported at the time of diagnosis. In addition, mothers who felt that they were the sole caretakers for their child suffered feelings of depression and isolation. Researchers found that the role of social support and the accessibility to support services significantly reduced maternal stress levels. As Dale, et al. (2006) noted, psychological characteristics of families, including "perceived self-efficacy, one's ability to positively handle stress, and coping strategies are attributes that assist in developing a strong sense of accomplishment and over all family well-being" (p. 465).

In another study, Twoy, Connolly, and Novak (2007) utilized survey research to explore coping strategies in parents with children who have ASD. A convenience sample of 94 families was given the Family Crisis Orientated Personal Evaluation Scales (F-COPES) (McCubbin, Olsen, & Larson, 1991). Researchers used this measure to determine coping strategies and levels of adaptation that are both internal and external to the family system (Twoy et al., 2007). These coping strategies include: (a) acquiring social support, (b) reframing, (c) mobilizing family to acquire and accept help, (d) seeking spiritual support, and (e) passive appraisal. Twoy et al.(2007) concluded that parents of children with ASD were likely to use support systems within the family's social network, thus becoming a main family coping strategy: "Mobilization of family support was highly utilized as families struggle to cope, to understand the disorder, and seek further information about the disorder" (p. 258). The results of the study indicated that families adapt to the challenges of caring for and raising a child with autism; however, they often employed passive appraisal to cope with their child's ASD-related behaviors (Twoy et al., 2007). Using passive appraisal as a coping strategy suggests that, rather than dealing directly with ASD related behaviors, passively ignoring or not acknowledging them was used as the means to cope. It is important to note that, although passive appraisal may be an effective short-term coping strategy, it can often lead to long-term maladaptive strategies. Several limitations to this study should be noted. While anonymity of study participants is generally preserved in self-report questionnaires, the risk of socially desirable reporting bias remains a concern. In addition, the influence of service utilization on coping may affect the ability to generalize the survey findings. In a study examining the association between autism symptoms, coping strategies, and maternal wellbeing of mothers of toddlers and mothers of adolescents with ASD, found that higher levels of problem-focused coping strategies were associated with better maternal wellbeing (Smith, Seltzer, Tager-Flusberg, Greenberg, and Carter, 2008).

To date, the literature includes a limited number of empirical studies examining the relationship among family belief systems, adaptation, family stress, coping, and resilience. King et al. (2006) conducted three focus groups with 15 parents and four service providers. Participants were recruited through referrals from community organizations, selecting families based on their ability to talk openly about their experiences as a parent of a child with a disability. Analysis of the focus group transcripts revealed that family belief systems change and adapt over time. This process of adaptation enables families to develop different perspectives that culminate in a newly found sense of control (King et al., 2006). Although these findings have contributed to the limited body of knowledge about the process of changing family belief systems, this study should be interpreted with caution, since the influence of participating service providers on the focus group discussions remains unknown.

Research has shown that having a child with a disability or chronic illness can have a positive impact on the family (Scorgie, Wilgosh, & McDonald, 1998). Stainton and Besser (1998) conducted a qualitative study examining how a child with an intellectual disability impacts family life. They selected participants from a membership list of a parents association for families of children with intellectual disabilities. Six fathers and nine mothers from nine family units participated in two focus groups, and two families participated in a single family interview (Note that the families knew of the researcher's interest in learning about positive experiences in this context, and that this knowledge may have influenced participant responses). Using a constant comparative method to analyze the data, nine themes emerged: The child provided the family unit with (a) source of joy and happiness, (b) increased sense of purpose and priorities, (c) expanded personal and social networks and community involvement, (d) increased spirituality, (e) a source of family unity and closeness, (f) increased tolerance and understanding, (g) personal growth and strength, (h) positive impacts on others/community, and (i) interaction with professional and the service system (Stainton & Besser, 1998).

In a study examining coping, expectations, and resilience among families with a child with a disability, Heiman (2002) found that all participating families in the study responded to the challenges associated with child rearing with strength and fortitude. Researchers selected 32 families from three schools specializing in physical, emotional, or intellectual disabilities, and stratified participants into groups based on the category of their child's disability. To gain a better understanding of how resilience emerges in a family with a child with a disability, researchers interviewed families by phone using the Parents' Perception Interview (Heiman, 2002), asking about parental responses to receiving a diagnosis, patterns of adjustment, and future concerns and expectations. Participant perceptions were examined through qualitative data analysis, and the data was coded and categorized through the constant comparative method of analysis (Heiman, 2002). A key finding of this study was the need for families to maintain an optimistic, yet realistic, view of their child's future (Heiman, 2002), even though a number of families expressed feelings of anger, frustration, and/or guilt related to rearing a child with a disability. This study did not take into account disability-specific challenges that families must endure. For example, a child with a physical disability may disrupt a family’s daily routine differently than a child with a behavioral or cognitive disability.

Social Support

Having a child with an ASD can be difficult but rewarding experience for a family. Although the core deficits of autism have been found to be associated with increased feelings of parental distress they can also be the catalyst for families seeking out supportive networks. According to Fischer, Corcoran, & Fischer (2007), social support “has been found in a number of studies to be an important buffer against family crisis factors, and to be a factor in family resiliency promoting family recovery, and as a mediator of family distress” (p. 413) The research on the use of social support by families of children with ASD has focused on mothers, giving less attention to the impact such support may have on fathers, siblings, or the family unit. This choice may reflect the mother's traditional role as primary caregiver, particularly when the child has a disability, or it may suggest that social support impacts mothers and fathers differently; however, the importance of social support in the overall wellbeing of the mothers of children with ASD is clear (Boyd, 2002). According to Gray and Holden (1992), mothers who perceived higher levels of informal and formal social support reported lower levels of depression, anxiety, and anger. The researchers also found that lower levels of social support served as the most powerful predictor of depression and anxiety in parents of children with autism. Furthermore, the inability to locate or access social support can affect a mother's overall wellbeing. Often, informal maternal support comes from the spouse or significant other and, as suggested by Herman and Thompson (1995), husbands provide some of the most beneficial support to mothers. While beyond the scope of this proposed study, the clinical implications of the role of social support in fathers needs to be explored further.

The literature discusses several types of social support, both formal and informal. Schopler and Mesibov (1984) define *formal social support* as “the assistance that is social, psychological, physical, or financial and is provided either for free or in exchange for a fee through an organized group or agency, while defining *informal support* as “a network that may include the immediate and extended family, friends, neighbors, and other parents of children with disabilities” (p. 297). Herman and Thompson (1995) found that parents report that informal supports provided the most assistance, while formal support opportunities, such as parent groups, social clubs, and day care centers were not available.

Family Resilience with ASD

Several studies suggest that families with a child with ASD become more resilient as a result of their coping with the illness. For example, Wickham-Searl (1992) found that some parents of disabled children pursue careers in areas where they can provide support to other families with similar experiences. In a qualitative study conducted by Wickham-Searl (1992), researchers interviewed 14 mothers of children between the ages of 5 and 32 to understand better the transformation from the role of caregiver to that of public servant, and to explore how care giving experiences at home influence careers in disability work. Three factors influenced the decision to pursue a career in disabilities: (a) the inability to access services for their own children; (b) the perceived inappropriateness of the services offered; and (c) the concern for the lack of supportive services for parents and caregivers. According to Wickham-Searl (1992), "the uniqueness of mothering children with disabilities allowed women to transfer their knowledge and skills from their own homes to the homes of other families with similar kinds of problems" (p. 16).

Similarly, Bayat (2007) presented findings from a sample of 167 families that suggested that many families of children with autism display characteristics of resilience and report gaining strength as a result of the child's disability. In this qualitative study, researchers mailed families a packet of questionnaires that asked 3 open-ended questions: (a) describe the positive and/or negative effects of autism on their family life; (b) describe the positive and/or negative effects of autism on their personal life; and (c) describe the child. Data analysis categorized themes that emerged from the study according to the theoretical framework supporting Walsh's theory on family resilience. These themes included the abilities to coordinate resources, to stay connected to support systems, and to make meaning out of adversity. As noted by Bayat (2007), the major limitation of this study concerns the demographic profile of the sample. More than half of participants were upper- to middle class and self-identified as White (Bayat, 2007). Furthermore, the process of collecting information through written responses to open-ended questions may have excluded families unable to clearly express themselves in written language.

Conclusions

This chapter reviewed the theoretical and empirical research on the experiences of families with children living with ASD. To further the understanding of the relationships between social support, family resilience, and parental stress in families with a child diagnosed with ASD, a study was conducted which specifically explored the relationship between these variables. The following chapter discusses this study in detail.

Chapter 3: Methods

Research Design

In order to examine the relationship between social support, family resilience, and parental stress in families with a child with ASD a cross-sectional survey design was implemented. It was hypothesized that higher levels of social support, as measured by the Social Support Index (SSI), would correlate with lower levels of parental stress, as measured by the Parental Stress Index- Short Form (PSI-SF); and that higher levels of family resilience, as measured by the Family Resilience Assessment Scale (FRAS), would correlate with lower levels of parental stress (as measured by the PSI-SF).

Sample

The study utilized data collected from 50 family members/caregivers of individuals diagnosed with an ASD. For the purposes of the study, *parent* or *primary caregiver* refers to the individual who assumes the responsibility of caring for and making major treatment decisions for the child with ASD. Inclusion criteria included being the primary caretaker of a child between the ages of 6 and 12 with a diagnosis of either autistic disorder, PDD-NOS, or Asperger's Disorder as defined in the *DSM-IV-TR* (APA, 2000). A question on the demographic information section of the survey ascertained diagnostic information. The age range of 6 to 12 was chosen to narrow the focus, decrease the variance, and allow for a moderate effect size among variables being measured. In addition, by 6 years of age, an ASD diagnosis is often stable in the presentation of symptoms.

Participants were recruited through an autism research registry, *autism*Match, a research tool that helps link individuals and families interested in participating in research studies to researchers studying different aspects of ASD. This registry is voluntary and enrollment is participant initiated. The information collected and included in the registry are name, address, date of birth, gender, diagnoses information and history, results of current assessments such as IQ testing and behavioral testing. The registry also collects family background information such as race, ethnicity, current income, education, and languages spoken. For this research, to protect the identity of the families, a research assistant working with *autism*Match distributed flyers to potential participants meeting the study criteria. The procedure section contains a more in-depth discussion of the recruitment procedures.

Measures

In order to measure social support, family resilience, and parental stress the following measures were utilized.

Parenting Stress Index-Short Form

Parenting stress was measured using the PSI-SF (Abidin, 1995). This self-report measure has been used in numerous studies with families of children with psychiatric and developmental disorders to measure the level of parental stress in the parent-child dyad. According to Abidin (1995), the PSI-SF contains 36 statements three subscales: parental distress (PD), parent-child dysfunctional interaction (P-CDI), and difficulty of child (DC). Possible scores range from 36 to 180, indicating the overall amount of stress experienced in the parenting role as a function of the three subscales.

The PSI-SF was rated on a 5-point Likert scale, ranging from 1 (*strongly agre*e) to 5 (*strongly disagree*). The scale was scored by reordering the items so that 5 = 1, 4 = 2, 3 = 3, 2 = 4, and 1 = 5. To determine the subscale (PD, P-CDI, or DC) and total stress scores, all subscales were summed, with the overall score indicating the total level of stress. In the analysis, the higher the total score, the higher the level of stress; the lower the total score, the lower amount of stress.

On the PSI-SF, stress levels considered normal are between the 15th and 80th percentile. Scores in the 90th percentile indicate that the individual experiences clinically significant high levels of stress. It is important to note that the total score on the PSI-SF only indicates the overall level of stress perceived by the parent in their role as a parent and does not take into account life stressors outside that role. It is also important to note that the total score on the PSI-SF reflects the stress associated with parenting, the parent-child interaction, and the child.

Each PSI-SF subscale consists of 12 questions. The PD subscale denotes the level of distress as a result of personal factors associated with the demands of child rearing. Examples of statements within this subscale include “I feel alone and without friends,” and “I feel trapped by my responsibilities as a parent.” The P-CDI subscale measures parents’ dissatisfaction with the interactions with their child. Examples of statements within this subscale include “My child rarely does things that make me feel good,” and “My child smiles much less than I expected.” The DC subscale measures/assesses the parents’ perception of their child’s self-regulatory skills. Examples of statements within this subscale include, “My child seems to cry or fuss more often than most children,” and “I feel my child is very moody and easily upset.”

According to Abidin (1995), the test-retest reliability coefficients of the PSI-SF have been reported as follows: 0.84 for total stress, with 0.85 for PD, 0.68 for P-CDI, and 0.78 for DC. The internal reliability alpha coefficients are 0.91 for total stress, with 0.87 for PD, 0.80 for P-CDI and 0.85 for DC (Abidin, 1995). For this study, the internal reliability alpha coefficients are: 0.91 for total stress, with 0.89 for PD, 0.69 for P-CDI, and 0.87 for DC. Parental stress as measured by the PSI-SF served as the dependent variable.

Social Support Index

Social support was measured by the SSI (McCubbin, Patterson, & Glynn, 1982). This tool was developed to measure family social support, as well as the amount of community-based social support families believe exist in the community. The SSI is an important measurement tool because it also measures the extent to which social support is an ingredient in family resilience (Fischer et al., 2007). The SSI is comprised of 17 questions that ask respondents to indicate their agreement or disagreement with a statement. A higher score indicates a higher level of social support. The SSI has strong internal consistency, with an alpha across several samples of .82; it is also reported to have a test-retest stability correlation of .83 (Fischer, et al., 2007). The SSI has been found to be an important predictor of family resilience and has been positively correlated with families' confidence in coping with situations (Fischer et al., 2007). This widely used tool has also been used in minority and underserved communities.

The SSI uses a 5-point Likert scale from 0 to 4. Respondents were asked to rate their responses to the questions from 0 (*strongly disagree)* to 4 (*strongly agree*). The range in score on the SSI is 0 to 68. Items 7, 9, 10, 13, 14, 15 and 17 were reverse scored, i.e., 4 = *strongly disagree* to 0 = *strongly agree*. All scores were summed, with a higher score indicating a higher level of social support. In this study, the sample produced an internal consistency alpha of .69. Social support in this study serves as the independent variable.

Family Resilience Assessment Scale

As previously noted, family resilience is conceptualized as behavioral patterns and functional competencies that help families negotiate and cope with crisis and hardships (McCubbin et al, 1998). For this study family resilience serves as an independent variable. To measure family resilience, this study utilized the Family Resilience Assessment Scale (FRAS) developed by Tucker Sixbey (2005) using Walsh's (2006) theoretical framework of family resilience.

The measure uses a 4-point Likert Scale that ranges from *strongly disagree* to *strongly agree*. The FRAS contains six subscales. The overall internal consistency of the FRAS according to Tucker is $\alpha = 0.96$. Three well known and widely utilized instruments were tested and found to have good concurrent criterion validity with and reliability with the FRAS. These were the Family Assessment Device 1 (α = 0.91), Family Assessment Device 2 (α = 0.85), and the Personal Meaning Index (α = 0.85) (Tucker Sixbey, 2005). A higher score indicates a high level of family resilience, and a low score indicates a low level of resilience. The FRAS consists of sixty-six questions and one open ended question. The open ended question was not used in this study. The total score of the FRAS can range from 66 to 204. Like the SSI, the FRAS uses a Likert scale with strongly disagree = 1 to strongly agree = 4. Items 42, 48, 57, and 62 are reversed scored, therefore for those questions, strongly disagree was coded as a four and strongly agree is converted to one. This scale has not been validated on families of children diagnosed with ASD. Three primary caregivers of children with ASD and two autism experts from the Regional Autism Center at the Children's Hospital of Philadelphia reviewed the questions to ensure that they applied to families with ASD. This review also established that thirty minutes was the approximate amount of time required to complete the surveys.

Due to a programming error, further discussed in Chapter 5, the FRAS was administered without question twelve; "We are able to work through pain and come to an understanding," question sixty-five: "We understand communication from other family members," and question sixty-six: "We work to make sure family members are not emotionally or physically hurt." As a result, these questions were excluded for computations of internal consistency. For all other analysis the technique of mean imputation was used. This is done by taking the mean score of each subscale from which the missing questions are from and using that mean score as the missing value. This is a commonly used method to address missing values.

Internal consistency in Table 1 for this study was computed using Cronbach's Alpha. Cronbach's Alpha is calculated from the pairwise correlation between items and can be thought of as the average correlation between all possible split-halves reliability estimates. A reliability coefficient of .70 or higher is acceptable in social science research; the FRAS shows an acceptable level of internal consistency in all subscales except Family Connectedness (FC) (.61) and Ability to Make Meaning of Adversity (AMMA) (.65) The low reliability coefficient for the FC subscale might be attributed to the fact that the four reverse coded questions are part of this subscale.

Table 1

FRAS Internal Consistency

FRAS Subscales	α as reported by Tucker Sixbey	α Current Sample
Family Communication and Problem Solving (FCPS)	0.96	0.91
Utilizing Social and Economic Resources (USER)	0.85	0.81
Maintaining a Positive Outlook (MPO)	0.86	0.84
Family Connectedness (FC)	0.70	0.61
Family Spirituality (FS)	0.88	0.91
Ability to Make Meaning of Adversity (AMMA)	0.74	0.65
Total	0.96	0.76

Demographic Information

Family demographics have long been linked to stress outcomes in families with children with disabilities (Houser & Seligman, 1991; Keller & Honig, 2004). Therefore, demographic information was collected about participants and their children. Items included: gender, racial and or ethnic group, highest level of education, total yearly income, current marital status, relationship to the child with ASD, year that the child with ASD was born, gender of the child, and the child's specific diagnosis.

Procedures

Administrators of *autism*Match distributed emails and or flyers to all site registrants who met the study inclusion criteria. During the first round of recruitment, 74 families who met the study criteria were contacted. Sixty-one families were sent an email, four were mailed a flyer, and nine were contacted by phone. Because *autism*Match continuously enrolls families, a second query found an additional 15 families who met the study criteria and they received flyers via email. Overall, a total of 89 families were contacted and 60 families participated. However, due to missing data, ten participants were excluded in the final analysis. Therefore, the total number used for analysis is 50. Regulatory approval and oversight was obtained from the University of Pennsylvania's Institutional Review Board.

Participants

Convenience sampling was used to recruit participants for this study. To ensure an adequate sample size of a minimum of 50 and maximum of 150, there were two waves of recruitment. The first recruitment wave was through convenience sampling using a research directory, *autism*Match, which matches interested families to autism research studies. Informational flyers were sent to those families who met eligibility criteria. The flyer described the study's goal and purpose, listed eligibility criteria, and provided the website address for the surveys, as well as contact information for the principal investigator. Families who received the email invitation to participate online accessed the survey site through a hyperlink embedded in the email. Participants were required to read and complete an online consent form before taking the surveys. Participants who did not complete the online consent were unable to complete the questionnaires. For those families who did not have Internet access, the option to complete the questionnaires over the phone was available. Three participants chose to complete the questionnaires in this manner. During the telephone interview, the researcher logged in to the survey site to record the participant’s responses electronically. The consent was read to the participant who verbally agreed to participate before beginning the questionnaires.

Analytical Procedures

REDCap

Study data were collected and managed using Research Electronic Data Capture (REDCap) electronic data capture tools hosted at the University of Pennsylvania. REDCap is a secure web-based application designed to support data capture for research studies, providing an intuitive interface for validated data entry, audit trails for tracking data manipulation and export procedures, automated export procedures for seamless data downloads to common statistical packages, and procedures for importing data from external sources (Harris et al., 2009). The flyer allowed participants to access the surveys through an embedded hyperlink. For participants who accessed the study over the telephone, responses were entered into the REDCap system manually by the phone interviewer.

Data Analysis

All analyses were conducted using IBM® SPSS® Statistics Version 19.0.0. Descriptive statistical analyses were conducted. Measures of central tendency and measures of dispersion were used to look at the data of each scale and subscale. Because the focus of this study is on the linear relationship between quantitative variables, Pearson's correlation coefficient was used to explore the extent of linear relationships among the variables, and to quantify the strength and direction of the relationship. Cronbach's alpha coefficients were computed to determine the internal consistency for each measure and relevant subscales. Pearson's coefficient was used to explore the relationship between the independent variables (family resilience & social support) and the dependent variable (parental stress).

Chapter 4: Results/Findings

This chapter presents the findings of the study. First, the descriptive statistics are presented and the sample described. A discussion of the study measures is also provided, followed by results of the study's hypotheses.

Sample

Demographics

Table 2 summarizes the demographics of the caregiver sample in this study.

Table 2
Caregivers of Children with ASD: Demographic Findings

Caregiver Variables		
Gender	Frequency	Percent
Male	3	6.0
Female	47	94.0
Race/Ethnicity		
White (non-Hispanic)	44	88.0
Black, African, or African-American	3	6.0
Other or Mixed	3	6.0
Educational Level	Frequency	Percent
High school diploma	10	20.0
Associates/Vocational Degree	11	22.0
Bachelor's Degree	18	36.0
Master's Degree	8	16.0
Doctorate Degree	3	6.0
Family Yearly Income	Frequency	Percent
Under $20,000	1	2.0
$20,000 - $39,999	10	20.0
$40,000 - $59,9999	9	18.0

$60,000 - $79,999	10	20.0
$80,000 - $99,999	4	8.0
$100,000 - $124,999	8	16.0
$125,000 - $149,999	4	8.0
Over $150,000	4	8.0
Marital status	Frequency	Percent
Single	1	2.0
Married	42	84.0
Divorced	4	8.0
Separated	3	6.0
Relationship to child	Frequency	Percent
Biological father	3	6.0
Biological mother	46	92.0
Other, non-biological caregiver	1	2

Descriptive Statistics N=50

Ninety-four percent (94%) of the respondents were female, 88% identified themselves as "White (non-Hispanic)," 6% identified themselves as "Black, African, or African-American," and the remaining 6% identified themselves as "Other" or "Mixed." Family income ranged from under $20,000 to over $150,000. Eighty-four percent of participants indicated that they were married, 8% indicated that they were divorced, 6% indicated that they were separated and 2% indicated that they were single. Only one subject (2%) was not a biological parent.

Table 3
Children with ASD: Demographic Findings

Child Variables		
Gender	Frequency	Percent
Male	42	84.0
Female	8	16.0
Year Child Born (Age)	Frequency	Percent

1998 (12)	1	2.0
1999 (11)	6	12.0
2000 (10)	7	14.0
2001 (9)	7	14.0
2002 (8)	8	16.0
2003 (7)	9	18.0
2004 (6)	12	24.0
Child's Diagnosis	Frequency	Percent
Asperger's Syndrome	21	42.0
PDD-NOS	7	14.0
Autism	21	42.0
Don't Know	1	2.0
Descriptive Statistics N=50		

Eighty-four percent of respondents had a male child as the identified child with ASD. Twenty-one children (42%) were diagnosed with Asperger's Syndrome, twenty-one children (42%) were diagnosed with autism, and seven children (14%) were diagnosed with PDD-NOS.

Parenting Stress

As noted in Chapter 3, parenting stress was measured by the Parenting Stress Index-Short Form. The total scores for the PSI-SF ranged from 53 to 149 (*M* = 105.66, *SD* = 20.9). Of note, all of the parents scored above the 80th percentile ranks on all of the subscales of the PSI-SF. Particularly high percentile ranks were found on the Parent-Child Dysfunctional Interaction (P-CDI) with a mean raw score of 39.0, placing it in the 99th percentile. The second highest subscale was the Parental Distress (PD) subscale, with a percentile of 89 and a mean raw score of 35.78. Lastly, the lowest scoring subscale for participants in this study was the Difficult Child (DC), with a mean raw score of 31.4 and a percentile of 81%. In addition, the PSI-SF total score was unrelated to reported respondent ethnicity ($t(48) = 0.81$, $p = .42$), income ($r_s = 0.07$, $p = 0.63$, $n = .50$), marital status ($t(48) = 0.40$, $p = .69$), child's gender ($t(48) = -0.14$, $p = .89$), or child's diagnosis $F(3,46) = .580$, $p = .63$. These demographic variables were tested against the three PSI-SF subscales and also showed no significant relationships.

Social Support

As noted in Chapter 3, the Social Support Index (SSI) was used to measure the variable, social support. The total scores for the SSI ranged from 25 to 55 ($M = 42.0$, $SD = 6.5$). SSI was unrelated to reported respondent ethnicity ($t(48) = 0.07$, $p =. 95$), income ($r_s = 0.08$, $p = 0.59$, $n = .50$), marital status ($t(48) = 0.35$, $p = .73$), child's gender ($t(48) = -0.65$, $p = .52$), or child's diagnosis $F(3,46) = .396$, $p = .76$.

Family Resilience

To measure the variable family resilience the Family Resilience Assessment Scale (FRAS) was used. The total scores for the FRAS after imputing values for Questions 12, 65, and 66 ranged from 96 to 179 ($M = 138.3$, $SD = 17.5$). The FRAS total score was unrelated to reported respondent ethnicity ($t(48) = -1.16$, $p = .25$), income ($r_s = 0.13$, $p = 0.38$, $n = .50$), marital status ($t(48) = -0.71$, $p = .48$), child's gender ($t(48) = -0.00$, $p = .998$), or child's diagnosis $F(3,46) = .655$, $p = .58$.These demographic variables were tested against the FRAS subscales and showed no significant relationships.

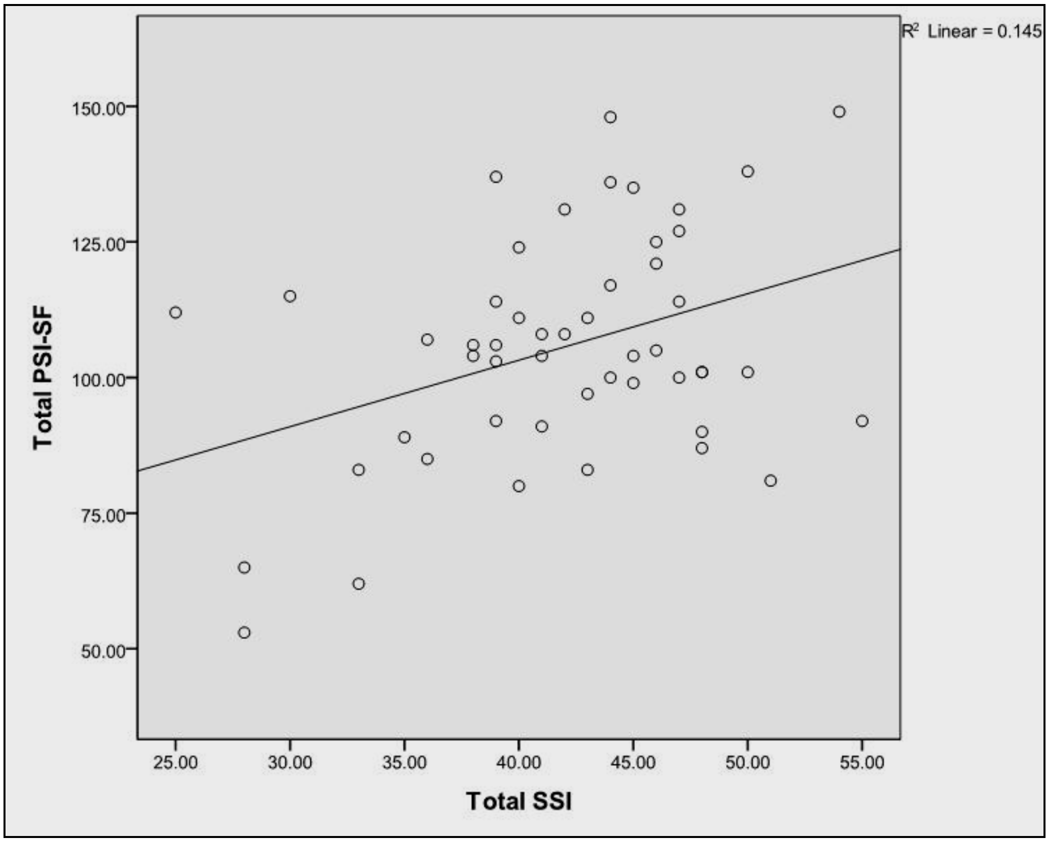
Main Hypotheses: Results

The results of the two main hypotheses this study sought to test were as follows:

Hypothesis 1: Higher levels of social support (as measured by the SSI) will be correlated with lower levels of parental stress (as measured by the PSI-SF).

This hypothesis was not supported. Higher scores on the SSI total scale correlated positively with higher scores on the PSI-SF total scale ($rp = 0.38$, $p < 0.01$, $n = 50$). Figure 2 shows the relationship between the SSI and the PSI-SF total scores.

Figure 2. The Relationship between the SSI and the PSI-SF total scores.



Hypothesis 2: Higher levels of family resilience, as measured by the FRAS, will be correlated with lower levels of parental stress (as measured by the PSI-SF).

The second hypothesis was supported, since higher scores on the FRAS total scale correlated negatively with higher scores on the PSI total scale (*rp* = -0.48, $p < 0.001$, *n* = .50). Figure 3 shows the relationship between the FRAS and the PSI-SF total scores.

Figure 3. The relationship between the FRAS and the PSI-SF total scores.

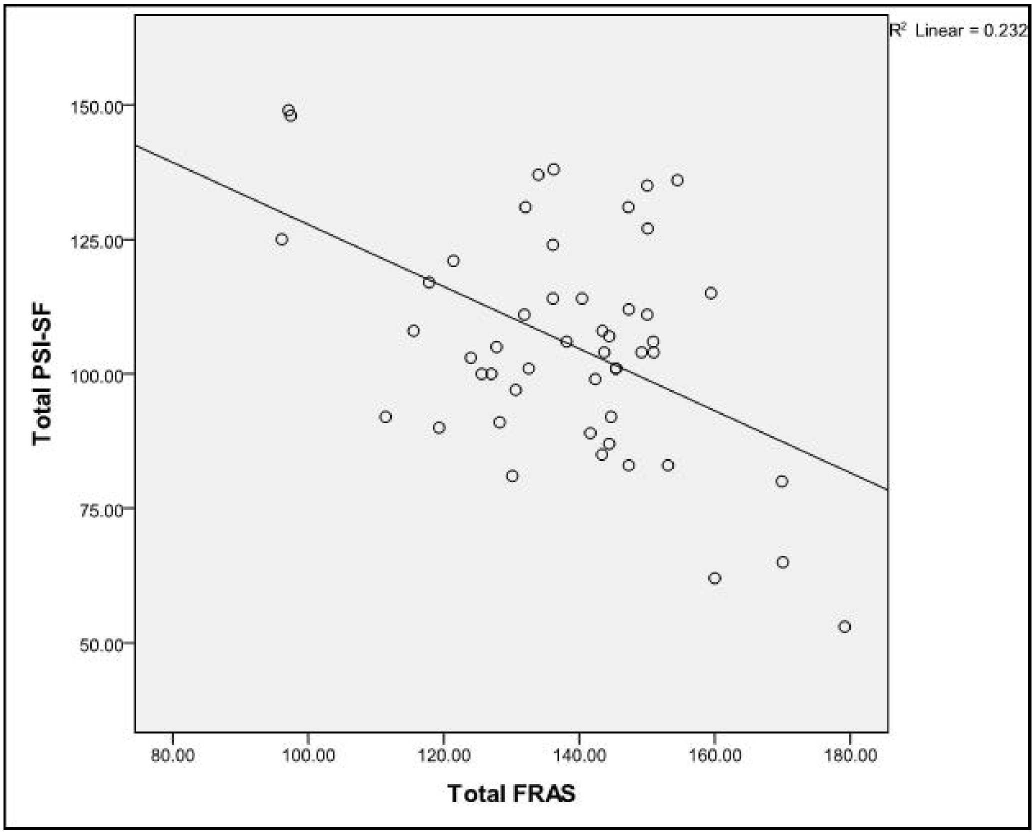


Table 4 contains a matrix of the correlations between all PSI-SF scale/subscales and all independent measurement scales/subscales.

Table 4*: Correlations Between PSI-SF and Independent Measurement Scales*

Measure		Total PSI-SF	PSI PD	P-CDI	DC
Total SSI	Pearson Correlation	.380	.504	.123	.268
	Sig. (2-tailed)	.006	.000	.396	.060
	N	50	50	50	50
Total FRAS	Pearson Correlation	-.482	-.579	-.227	-.348
	Sig. (2-tailed)	.000	.000	.112	.013
	N	50	50	50	50
Family Communication & Problem Solving (FCPS)	Pearson Correlation	-.384**	-.499**	-.131	-.280*
	Sig. (2-tailed)	.006	.000	.363	.049
	N	50	50	50	50
Maintaining a Positive Outlook (MPO)	Pearson Correlation	-.407**	-.468**	-.216	-.294*
	Sig. (2-tailed)	.003	.001	.132	.038
	N	50	50	50	50
Family Connectedness (FC)	Pearson Correlation	-.496**	-.524**	-.309*	-.381**
	Sig. (2-tailed)	.000	.000	.029	.006
	N	50	50	50	50
Family Spirituality (FS)	Pearson Correlation	-.406**	-.525**	-.111	-.314*
	Sig. (2-tailed)	.003	.000	.444	.026
	N	50	50	50	50
Ability to Make Meaning of Adversity (AMMA)	Pearson Correlation	-.320*	-.344*	-.156	-.272
	Sig. (2-tailed)	.023	.014	.280	.056
	N	50	50	50	50
Utilizing Social and Economic Resources (USER)	Pearson Correlation	-.423**	-.387**	-.325*	-.326*
	Sig. (2-tailed)	.002	.006	.021	.021
	N	50	50	50	50

**. Correlation is significant at the 0.01 level (2-tailed) *. Correlation is significant at the 0.05 level (2-tailed).

Table 4 shows the correlations between the FRAS and SSI against the PSI-SF subscales. The correlation between the SSI and PSI-SF total score shows a positive correlation of .380 with a p-value of .006, indicating that the two variables are significantly correlated. Similar results were found when examining the correlations between the SSI and the PD subscale. There was a significant positive correlation of .504 and a p-value of .000. A comparison of the P-CDI with social support found a positive correlation of .123; however, this was not a significant correlation, as indicated by the p-value of .396. Likewise, the Pearson correlation of .268 indicates a positive relationship between the DC subscale and social support; however, with a p-value of .060, it was not considered to be strong.

A significant negative correlation was found between the FRAS and the total score on the PSI-SF, with a Pearson correlation of -.482 and a p-value of less than .001. There was also a strong negative correlation on the PSI-SF subscales, with the PD as the most significant with a -.579 Pearson correlation and a p-value of .000. The correlation between the FRAS and DC subscale was significant with r-.348, p-value .013.The correlation with the P-CDI was also negative with -.227 but not as statically significant with a p-value of .112.

The total score on the PSI-SF is significantly negatively correlated with all the FRAS subscales. This relationship suggests that as family resilience increases, parental stress decreases. The two subscales that the PSI-SF seemed to have the most statistically significant correlations with are Utilizing Social and Economic Resources (USER) (r= -.423, p-value .002) and Family Connectedness (FC) (r= -.496, p-value .000). The subscale most strongly correlated with the FRAS total score and subscale scores was the Parental Distress (PD) subscale, specifically with the subscales Family Connectedness (FC) (r= -.524, p-value .000) and Family Spirituality (FS) (r=-.525, p-value .001).

A significant relationship was found between the Parental-Child Dysfunction Interaction (P-CDI) subscale and the total score on the FRAS. The most significant was with the subscale; Utilizing Social and Economic Resources (USER) (r=-.325, p-value .021). Less significant negative correlations were found on all other FRAS subscales. There was a negative correlation between the FRAS total score and the Difficult Child (DC) subscale. The Family Connectedness (FC) subscale had the most significant negative correlation (r= -.381, p-value .006). The least significant correlation was with the Ability to Make Meaning of Adversity (AMMA) (r= -.272, p-value .056).

Chapter 5: Discussion

The results of the study indicate that a positive relationship exists between perceived social support and parental stress. Results also indicate that higher levels of family resilience are correlated with lower levels of with parental stress in families with a child diagnosed with ASD. No significant relationships were identified between demographic variables and the family resilience constructs and sub-constructs. This chapter will discuss these findings. Study limitations will be presented and implications of the findings to clinical social work practice and theory will be explored. Lastly, recommendations for further inquiry will be presented.

Sample

The current study sample characteristics are representative of those in other studies of families impacted with ASD. It was expected that the number of mothers participating in the study would be higher than that of fathers. Other studies have attributed this to the fact that mothers are more likely to be the primary caretakers of their children with ASD (Boyd, 2002). In this study eighty-eight percent of the sample indicated being “White (non-Hispanic).” The racial composition of many studies with families impacted with ASD tends to have less minority representation; thus it was not surprising that the racial composition was distributed the way that it was. However, given the racial composition of the local urban area, one would expect to see greater variability. The distribution by diagnosis represented in this sample was somewhat unexpected. According to the Interactive Autism Network (www.IANproject.org, 2011), the distribution of ASD among children in the United States based on parent report suggests that 39% of the total number of children are diagnosed with autism, 31% with PDD-NOS, and only 15% with Asperger. Given this breakdown it was surprising that the number of families with a child diagnosed with Asperger was so high in this study. In addition, based on the largest group represented in national numbers, one would expect a higher percentage of participants with a diagnosis of PDD-NOS in this study. The level of income that was represented in this study suggests variability; however the percentage of those in the study living close or below the poverty level is of note.

Parental Stress

The findings of this study are consistent with numerous other studies that indicate that parents with children diagnosed with ASD are experiencing high levels of stress (Dumas et al., 1991; Eisenhower et al., 2005; Koegel et al., 1992; Phetrasuwan et al., 2009; Tomanik et al., 2004).

Table *5: Breakdown of PSI-SF Total Score and Subscales*

PSI-SF	Mean Score	SD	Total Range*	Study Range	Clinically Significant (CS)
Total Score	104.66	22.28	36-180	53-149	97%
PD	35.78	10.17	12-60	15-56	89%
P-CDI	38.98	7.25	12-60	22-51	99%
DC	31.46	9.02	12-60	12-51	81%

*Based on information obtained from PSI-SF manual (Abidin, 2005).

While all subscales are in the clinically significant range, the Parent–Child Dysfunctional Interaction (P-CDI) subscale is at the 99th percentile. Again, The P-CDI subscale assesses the nature of the interactional system between the parent and child through items such as, ‘‘Most times I feel that my child does not like me and does not want to be close to me.” While there was no correlation between child diagnosis and overall parental stress, this finding is suggestive of the stress is related to the parent child relationship and not the autism related behaviors. Much of the research on parental stress in families with ASD attributes the high levels of stress on the behavioral challenges that are often inherent to ASD (Sharlpey & Bitsika, 1997). Based on prior research, it was expected that parents would have higher scores on the difficult child (DC) subscale; however, this study did not produce the same results. Parents scored highest on the P-CDI scale in this study, which measures the interaction between the parent and child. When comparing the findings of other studies with similar samples, participants in this study seem to score higher on the PSI-SF. For example, in a study done by Davis & Carter (2008) participants scored slightly lower on the PSI-SF, total scale and subscales. The mean score on the PSI-SF total score was 81.9, P-CDI: 25.9, PD: 27.3, and DC: 28.5. In addition only 33% of the sample scored in the clinically significant range on total score. However with respect to the pattern of subscales scores, Davis and Carter (2008) do report a similar profile in that the most clinically significant subscale was the P-CDI. Since previous researchers have attributed the increased stress to behavioral characteristics associated with ASD (Duis &Summers, 1997; Podolski & Nigg, 2001; Tomanik, Harris, & Hawkins, 2004; Pisula, 2007) and severity of symptoms (Beck, Daley, Hastings, & Stevenson, 2004; Konstantareas & Papageorgiou, 2006), further exploration in the relationship between the core social deficits of ASD and parental stress is needed.

Stress levels may also be elevated as a result of parental depression. While this study did not measure parental depression, there is research to suggest that mothers of children with ASD have higher rates of depression (Ingersoll & Hambrick, 2011). The stress related findings in this study might also have been influenced by the fact that participants who are highly stressed are more likely to enroll or choose to participate in research where stress is being studied. From a clinical perspective this is concerning as families experiencing debilitating levels of stress are not the families participating in research.

Social Support and Parental Stress

The literature has documented the role of social support on parental stress. This study hypothesized that higher levels of social support (as measured by the SSI) would be correlated with lower levels of parental stress (as measured by the PSI-SF). Sharpley & Bitsika (1997) reported that social support acts as a buffer against stress for parents of children with ASD. Ello and Donovon (2005) reported similar findings, asserting that social support serves to moderate parental stress. The findings of this study provide a unique view of the role that social support plays in the levels of parental stress. Unlike the work of Gray and Holden (1992), who found social support to be a powerful predictor of maternal depression, anxiety, and anger, this study indicates that higher levels of social support were associated with higher levels of parental stress.

One possible explanation for these findings is that while families do perceive themselves as having social support, the type of social support is not helpful in reducing stress levels. The following case example illustrates this point.

Figure 4: Case Study

Mr. and Mrs. B. have an 8 year old daughter, Emma, who has been diagnosed with autism. Emma is non-verbal and can be physically aggressive at times. For many years the B. family has been active members of their local church. Every Sunday morning they attend services as a family. The church community has been very supportive and has been very accepting of Emma. Accommodations to help make the environment more accessible to families with disabilities have also been made. One change in particular was starting a Sunday school classroom for children who have more significant behavioral challenges. The volunteer in the classroom is a well liked special education teaching in the community and Mr. and Mrs. B. feel very comfortable leaving Emma with her. Having this available allowed Mr. and Mrs. B. to attend services together, which they felt was extremely helpful for them as a couple to be able to do together. However, it is ritual in the church that after communion all of the children in the Sunday school programs are brought into the sanctuary of the church for the remainder of the service with their parents. Because of the disruptive behaviors exhibited by Emma this often becomes a very stressful experience for Mr. and Mrs. B., resulting in one of them having to leave the church early with Emma.

This case may shed light on the findings of this study as they relate to social support and parental stress. While a family might perceive themselves as having social support, social support may not always result in lower levels of stress. In fact, many times, it is the seeking out of social support that can lead families to feel isolated. In the case illustrated above, Family B. perceives themselves as having social support but engaging in this type of social support exacerbates stress. There is research suggesting that support groups also have the potential to not be therapeutic and can lead to a negative experience. Avoiding critical or unpleasant social interactions within the therapeutic context is essential (Hogan, Linden, & Najarian, 2002).

A second interpretation of these findings is that those individuals who are experiencing elevated levels of stress are more likely to seek out support; therefore, resulting in the positive association between the two variables. The cross-sectional nature of this study does not allow for the researcher to describe the directionality or causality of these two variables. Lastly, one might consider that the act of raising a child with ASD may impose a ceiling effect on parent stress, such that parents' experiences of social support add little variance to the pre-existing elevated level of parenting stress.

Family Resilience and Parental Stress

The second hypothesis tested in this study was the relationship between family resilience and parental stress. It was theorized that the presence of family resilience would reduce levels of parental stress. The results supported this hypothesis, indicating that a significant negative relationship exists between the total score on the FRAS and the total score on the PSI-SF. Overall, the areas of family resilience that best correlate with parental stress are family connectedness and the ability to utilize social and economic resources. Based on clinical experience, this researcher expected these results, which have been well described in the literature. However, the literature has neglected the relationship between family resilience and parental distress. The results of this study indicate that a strong negative relationship exists between FRAS and the PD subscale; furthermore, every subscale of the FRAS had a strong negative correlation with the parental distress (PD) subscale. This outcome suggests that increased parental stress, unrelated to direct parenting, correlates with less family resilience. In other words, it is the parent's own feelings of distress that correlates with a decreased sense of family resilience. The most significant correlations between family resilience and parental distress seem to be around family communication and problem solving, family connectedness, and family spirituality.

Family communication and problem solving, is defined as a family's ability to convey information, feelings and facts clearly and openly while recognizing problems and carrying out solutions. Examples of items in this subscale are; "Our family structure is flexible to deal with the unexpected,""We all have input into major family decisions," and "we discuss problems and feel good about the solutions." To return to family resilience theory, the family's ability to identify an actual problem and then take steps toward resolving the problem can result in a sense of unity among family members (Walsh, 2003). The correlation between maternal depression and family connectedness is also reported in the literature (Olsson & Hwang, 2002; Oelofsen & Richardson, 2006). Family connectedness refers to a family's ability to organize and bond together for support while still recognizing individual differences among members. Family connectedness and family spirituality go hand in hand to help families normalize and make difficult situations manageable. Lastly, family spirituality has shown to correlate with parental distress. This refers to as a family's use of a larger belief system to provide guidance and to help define life as meaningful. The role of spirituality in families with a child diagnosed with ASD has been reported, however information about its efficacy on overall wellbeing has been mixed. Some researchers report that religious activities have shown to have a positive effect on psychological well-being, while other research has found organized religion not to be ameliorative (Tarakeshwar and Pargament 2001). As seen in the case example, it is possible that the challenges associated with taking a child with ASD to religious services can be stress producing in and of themselves (Baker-Ericzen et al. 2005; Ekas, Whitman, & Shivers, 2009). Therefore, while the research on the spirituality and religion is mixed, the results of this study suggest a correlation with lower levels of parental stress. Further research is needed to better understand this phenomenon. This is an important finding as social workers develop interventions that seek to enhance family resilience. Services should focus on addressing parent's psychosocial wellbeing. A more in-depth discussion of the clinical implications of this study is presented later in this chapter.

Limitations

The following section will discuss the limitations of this study and provide suggestions for further research. First, a limitation to this research is that, as a cross-sectional study, inferences regarding the direction of the relationships between variables are tentative at best. Further research into the predictive value of variables is needed and should include multi-method research designs.

Secondly, the small sample size and gender composition limits generalization to a larger group. With the majority of participants being female the ability to generalize findings to male primary caregivers is limited. Given the paucity of research on paternal stress responses and experiences among fathers and primary care givers, additional studies are needed in this area. The fact that participants were recruited through a research registry also suggests that a parent/caregiver who maybe be more motivated by research opportunities may represent a certain profile.

Since this study used self-report measures, participants may have answered the questions in a socially desirable way. Because the participants were encouraged to complete the surveys online, there is a possibility that families who could have participated, but did not have computer and internet access, were excluded from participating. Another possible limitation is the timing of survey distribution to participants. The timing of the distribution of surveys during a holiday period may have negatively affected the response rate.

Another possible limitation to the study is the potential for measurement bias. The order in which the measures were presented to the participants could have possibly biased the answers. Participants who completed the survey might have been biased in their answers based on their reaction to prior questions. For example, the potential for a participant to feel a sense of empowerment and satisfaction with the way in which he or she is coping and managing the family dynamics based on the questions asked may influence the way in which they responded to the following questions. On the other hand, there is a chance that, based on the questions, a participant may become more aware of how difficult their situation is, thus feeling less successful with the challenges.

The use of the PSI-SF to assess for parental stress could also be considered a limitation in this study. As previously noted, there has been recent research on the use of the PSI-SF with families with ASD which suggests that caution should be shown when interpreting the results of the PSI-SF specifically within the population of this study. The subscales of measuring the P-CDI and the DC subscales do not take into account the specific behavioral characteristics of children with ASD and/or how parents understand how ASD affects the parent child interaction. Again, while the PSI-SF is a valid measure for assessing parenting stress related to several factors, a tool that measures parenting stress specifically related to potential challenges of parenting a child with a disability could be useful for more accurately capturing sources of stress in this population.

Another limitation in the study was that the FRAS was administered to participants with three questions missing. The three questions were not identified as being excluded until data analysis began and data collection had been stopped. This researcher was not able to re-contact participants because no identifying information was collected. As discussed in Chapter 3, the mean score for the subscale for each participant was entered as missing data values. While this is a commonly used method to address the issue of missing items, it does limit the ability to interpret the results. Issues that need to be considered when interpreting results when this technique is used are possible underestimates of standard deviations and the chance that mean imputation will distort relationships between variables by pulling estimates of correlation toward zero (Little & Rubin, 2002).

The inability to describe the behavioral characteristics of symptom presentation of the child with ASD is another possible study limitation. By asking participants to self-report what diagnosis their child had does not allow for the research to confirm this by using any standardized diagnostic tools. Because the participants all did come through *autism*Match, one can confidently say that each of the children did have a diagnosis of an ASD confirmed by standardized measures. But due to confidentiality, a diagnosis was not independently confirmed.

Lastly, a limitation, as well as strength, in this study was the use of a newly developed internet based survey tool. This research study utilized REDCap to create, manage, and store all of the participants' survey responses. Because there were a number of participants who started the survey but did not finish, there is a chance that it was the method of completing the surveys that resulted in non-participation/completion. As with any new technology, there will be a subgroup of people who are less willing to participate in something that requires them to move out of their “comfort zone”. Those who are less comfortable with technology may have been inadvertently excluded from participating, despite efforts to offer alternative means of participating such as by phone.

Future Research

Based on the study limitations, there are several recommendations for future research. First, future studies should involve a larger and more diverse group of families, including a more ethnically and racially diverse sample. This would allow further study of the ways that culture and ethnicity play a role in perceived social support and parental stress as they relate to family resilience. Future research should also include a more accurate way of describing the behavioral profile of the children with ASD, which would enable a better understanding of a child’s behavioral and autism symptomatology, and its influence on parental stress levels and access to social supports, since these play a strong role in developing family resilience. Furthermore, looking at cognitive functioning and parental stress to see if there is a relationship between cognitive functioning and social support and parental stress is also recommended.

More research is required on the topic of family resilience. This study provides the groundwork for further exploration. Further research should include a qualitative component, which would provide the opportunity to learn more about the lived experience of families. In addition, data collection from more than one family member would also be useful. A wider data circle would provide a greater in-depth look into the family care-giving unit as a whole.

Further research is needed into the role of social support and the different types of social support, both internal and external to the family system. It would be useful to further explore the types of social support being utilized. Also, further exploration into the role of spirituality as a potential resource and source of support for families is warranted based on the findings of this study. A better understanding of spirituality and the role that it plays in the daily lives of families with ASD could assist in defining clinical applicability.

A better understanding of the role that risk and protective factors play in the family is also needed. In addition, further exploration into the satisfaction and ability to obtain community services and therapies specifically focused on the treatment of ASD and the impact on family functioning.

Further research is needed on the use of the PSI-SF in this particular population. As noted earlier, the PSI-SF may not be the most appropriate measure of parental stress because it aims to assess the behavioral difficulties intrinsic to autism. Questions asked in the P-CDI subscale include the following; “My child smiles at me much less than I expected,” “my child doesn’t learn as quickly as most children, and “it takes a long time and it is very hard for my child to get used to new things.” These examples highlight some of the core social difficulties that characterize the diagnosis of ASD. The questions in this subscale also identify or highlight parental expectations. Research into parent's expectations of their child’s developmental trajectory and stress level would provide valuable information that could be helpful to clinicians. Lastly, further testing of the FRAS in the ASD population is needed.

Implications for Practice

The literature details the significant stress experienced by parents of children with autism. This study's findings confirmed what is found in the literature. Social workers play a key role in assessing parental distress, as well as referring families to appropriate mental health services. Since the results of this study show that a more resilient family reports less parental stress, clinicians need to focus on programming for families that enhance their abilities to readjust coping strategies. A study by Osborne, McHugh, Saunders, and Reed (2008) found that high levels of parenting stress counteracted the effectiveness of early interventions. Thus, interventions that promote stress management and stress reduction will not only benefit the parent/caregiver's well-being, but also directly benefit the child with ASD.

Furthermore, social workers play a critical role in developing interventions that target healthy family functioning. Interventions that are aimed at increasing family resilience as a means to decreasing parental stress need to focus on providing parents with the coping skills needed to directly impact their own well-being. Because parents in this study scored the highest on the parental distress subscale it is essential that interventions incorporate cognitive behavioral strategies for stress management. The strategies of Cognitive Behavioral Therapy such as "stressful event and physiological reaction self-monitoring, muscle relaxation skills, and modification of cognitions associated with distress" may be useful (Singer et al., 1988 p. 272). Stress management combined with additional support services has demonstrated clinically significant improvements in levels of parental distress (Singer et al., 2007).

Lastly, the conceptualization of family resilience into teachable and learnable skills, suggests that families can be taught to become more resilient through psycho-education programs. Psycho- educational based group interventions focused on learning skills associated with family resilience would also provide the opportunity to develop peer networks. Using a tool such as the FRAS to identify areas of family strength and areas of family need can help guide both families and clinicians as they develop treatment plans.

Conclusion

Over the last decade the numbers of families impacted with ASD has risen. To this end, this study utilized family resilience theory to conceptualize the experience of families and to better understand the relationships between social support, family resilience, and parental stress. In addition the study provided more evidence for the significant stress families, mothers in particular, are experiencing. This study also demonstrated an unexpected positive relationship between social support and parental stress, indicating that perceived social support did not result in a decrease in parental stress, which is a relationship not seen in the literature.

Finally, the results of this study also suggest that social support is a complex phenomenon and may act in different capacities given the literature on the role it has on parental stress. The primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of those who are most vulnerable (Miley, O’Melia, & DuBois, 1998). A defining feature of social work is the profession’s focus on individual well-being in a social context and the well-being of society. Fundamental to social work is attention to the environmental forces that create, contribute to, and address problems in living (NASW, 1996). Therefore social workers should work with families to improve family communication and problem solving skills, assist in helping families develop coping mechanisms that help to maintain a positive outlook, while building social connections, and supportive networks. The results of this study can assist social workers better assess parental stress and to seek resilience qualities that can be enhanced.

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APPENDIX A

Social Support, Family Resilience, & Parental Stress

Dear Parent/Caregiver.

I'm a social worker and doctoral candidate at the University of Pennsylvania School of Social Policy and Practice. Currently there is a research study that you can participate in that is looking at the role of family resilience, social support, and parental stress in families with a child diagnosed with an Autism Spectrum Disorder (ASD). By you sharing your experiences it will help us to better understand the impact that having a child diagnosed with an autism spectrum disorder has on a family. The study seeks to enroll at least 50 participants and data collection begins on August 9, 2010 and will continue until December 2010. I know your time is valuable and participating should take approximately 30 minutes. I do hope you will agree to be a part of this important study.

Participation in this study involves providing some basic demographic information and completing three scales.

There are no known risks associated with participating in this study. There are no right or wrong answers and all information will be kept confidential and anonymous. Your privacy will be strongly upheld. I as the researcher will not be able to associate answers with particular participants as I'm not collecting identifiable information. There are no costs or payment associated with participation other then the reward of knowing you contributed to important family research.

You are free to choose not to participate at any time. Your participation in this research is voluntary and you may discontinue the survey at any time. If you have questions about your participation in this research study or about your rights as a research participant you may contact me anytime at 267-626-8365. You may also call the Office of Regulatory Affairs at the University of Pennsylvania at (215) 898-2614 to talk about your rights as a research subject.

Again, your participation is confidential and anonymous. By answering "yes" you are indicating your consent to participate.

Thank you in advance for your participation.

Sincerely,

Jennifer Plumb. MSW/LSW

Doctoral Candidate

University of Pennsylvania School of Social Policy and Practice

267-626-8365

Plumb@email.chop.edu

☐ Yes ☐ No

About YOU, please answer the following questions about yourself.

What is your gender?	☐ Male ☐ Female
Which racial and or ethinic group best describes you? (Select as many that apply)	☐ White (non-Hispanic) ☐ Asian or Asian-American ☐ Black, African, or African-American ☐ Hispanic or Latino (e.g., Puerto Rican, Mexican, Central or South ☐ Middle Eastern ☐ Pacific Islander ☐ American-Indian, Eskimo ☐ Black, Caribbean (e.g., Haitian, Jamaican) ☐ Other
What is your highest level of educational completion?	☐ High school, no diploma ☐ High school diploma ☐ Specialists degree ☐ Associates/Vocational degree ☐ Bachelors degree ☐ Masters degree ☐ Doctorate degree
What is your family's total yearly income?	☐ Under $20,000 ☐ $20,000 - $39,999 ☐ $40,000 - $59,999 ☐ $60,000 - $79,999 ☐ $80,000 - $99,999 ☐ $100,000 - $124,999 ☐ $125,000 - $149,999 ☐ Over $150,000
What is your current marital status?	☐ Single ☐ Married ☐ Widowed ☐ Divorced ☐ Separated ☐ Domestic partner
What is your relationship to your child?	☐ Biological father ☐ Step-father ☐ Foster father ☐ Biological mother ☐ Step-mother ☐ Foster mother ☐ Other biological caregiver ☐ Other non-biological caregiver

About YOUR CHILD, please answer the following questions about your child with an autism spectrum disorder.

What is your child's gender?	☐ Male ☐ Female

What year was your child with autism born? ______________________________

What is your child's diagnosis?

☐ Asperger's Syndrome
☐ PDD-NOS
☐ Autism
☐ Don't know

SOCIAL SUPPORT INDEX

Read the statement below and decide for your family whether you: (1) Strongly Disagree; (2) Disagree; are (3) Neutral; (4) Agree; or (5) Strongly Agree.

If I had an emergency, even people I do not know in this community would be willing to help.	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
I feel good about myself when I sacrifice and give time and energy to members of my family.	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
The things I do for members of my family and they do for me make me feel part of this very important group.	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
People here know they can get help from the community if they are in trouble.	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
I have friends who let me know they value who I am and what I can do.	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
People can depend on each other in this community.	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree

Members of my family seldom listen to my problems or concerns; I usually feel criticized.

☐ Strongly Disagree
☐ Disagree
☐ Neutral
☐ Agree
☐ Strongly Agree

My friends in the community are a part of my everyday activities.

☐ Strongly Disagree
☐ Disagree
☐ Neutral
☐ Agree
☐ Strongly Agree

There are times when family members do things that make other family members unhappy.

☐ Strongly Disagree
☐ Disagree
☐ Neutral
☐ Agree
☐ Strongly Agree

I need to be very careful how much I do for my friends because they take advantage of me.

☐ Strongly Disagree
☐ Disagree
☐ Neutral
☐ Agree
☐ Strongly Agree

Living in this community gives me a secure feeling.

☐ Strongly Disagree
☐ Disagree
☐ Neutral
☐ Agree
☐ Strongly Agree

The members of my family make an effort to show their love and affection for me.

☐ Strongly Disagree
☐ Disagree
☐ Neutral
☐ Agree
☐ Strongly Agree

There is a feeling in this community that people should not get too friendly with each other.

☐ Strongly Disagree
☐ Disagree
☐ Neutral
☐ Agree
☐ Strongly Agree

This is not a very good community to bring children up in.

☐ Strongly Disagree
☐ Disagree
☐ Neutral
☐ Agree
☐ Strongly Agree

I feel secure that I am as important to my friends as they are to me.

☐ Strongly Disagree
☐ Disagree
☐ Neutral
☐ Agree
☐ Strongly Agree

I have some very close friends outside the family who I know really care for me and love me.	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree
Members of my family do not seem to understand me; I feel taken for granted.	☐ Strongly Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly Agree

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FAMILY RESILIENCE ASSESSMENT SCALE

Please read each statement carefully. Decide how well you believe it describes your family now fro your viewpoint. Your family may include any individuals you wish.

Every family has problems.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
Everything we go through as a family happens for a reason.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
Our family structure is flexible to deal with the unexpected	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
Our friends are a part of everyday activities.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
Our friends value us and who we are	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
The rules in our family are not set in stone.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
The rules in our family change according to family needs.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree

The things we do for each other make us feel a part of the family.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We accept stressful events as a part of life.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We accept that problems occur unexpectedly.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We all have input into major family decisions.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We are able to work through pain and come to an understanding	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We are adaptable to demands placed on us as a family.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We are careful how much we do for friends.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We are careful what we say to each other.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We are open to new ways of doing things in our family.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We are understood by other family members.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We ask neighbors for help and assistance.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree

We attend church/synagogue/mosque services.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We believe friends can take advantage of us.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We believe we can handle our problems.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We can ask for clarification if we do not understand each other.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We can be honest and direct with each other in our family.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We can blow off steam at home without upsetting someone.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We can compromise when problems come up.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We can deal with family differences in accepting a loss.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We can depend upon people in this community.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We can question the meaning behind messages in our family.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We can solve major problems.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree

We can survive if another problem comes up.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We can talk about the way we communicate in our family.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We can work through difficulties as a family.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We consult with each other about decisions.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We define problems positively to solve them.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We discuss problems and feel good about the solutions.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We discuss things until we reach a resolution.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We do volunteer work in the community	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We feel free to express our opinions.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We feel good giving time and energy to our family.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We feel people in this community are willing to help in an emergency.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree

We feel secure living in this community.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We feel taken for granted by family members.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We feel we are strong in facing big problems.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We get upset if someone complains in our family.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We have close friends we really care for	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We have faith in a supreme being.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We have the strength to solve our problems.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We keep our feelings to ourselves.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We know there is community help if there is trouble.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We know we are important to our friends.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We learn from each other's mistakes.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree

We mean what we say to each other in our family.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We participate in activities specifically for our situation.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We participate in church activities.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We receive gifts and favors from neighbors.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We seek advice from religious advisors.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We seldom listen to family members concerns or problems	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We share responsibility in the family	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We show love and affection for family members.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We tell each other how much we care for one another.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We think this is a good community to raise children.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree
We think we should not get too involved with people in this community.	☐ StronglyAgree ☐ Agree ☐ Disagree ☐ StronglyDisagree

We trust things will work out even in difficult times.

☐ StronglyAgree
☐ Agree
☐ Disagree
☐ StronglyDisagree

We try new ways of working with problems.

☐ StronglyAgree
☐ Agree
☐ Disagree
☐ StronglyDisagree

We understand communication from other family members

☐ StronglyAgree
☐ Agree
☐ Disagree
☐ StronglyDisagree

We work to make sure family members are not emotionally or physically hurt

☐ StronglyAgree
☐ Agree
☐ Disagree
☐ StronglyDisagree

PARENTING STRESS INDEX - SHORT FORM

Read each statment carefully. For each statement, please focus on the child you are the most concerned about, and circle the response that best represents your opinion.

While you may not find a response that exactly states your feeings, please indicate the response that comes closest to how you feel. YOUR FIRST REACTION SHOULD BE YOUR ANSWER.

I often have the feeling that I cannot handle things very well.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

I find myself giving up more of my life to meet my children's needs than I ever expected.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

I feel trapped by my responsibilities as a parent.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

Since having this child, I have been unable to do new and different things.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

Since having a child i feel that I am almost never able to do things I like to do.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

I am unhappy with the last purchase of clothing that I made for myself.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

There are quite a few things that bother me about my life.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend).

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

I feel alone and without friends.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

When I go to a party, I usually expect not to enjoy myself.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

I am not as interested in people as I used to be.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

I don't enjoy things as I used to.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

My child rarely does things for me that make me feel good.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree
Sometimes I feel my child doesn't like me and doesn't want to be close to me.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree
My child smiles at me much less than I expected.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree
When I do things for my child, I get the feeling that my efforts are not appreciated very much.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree
When playing, my child doesn't often giggle or laugh.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree
My child doesn't seem to learn as quickly as most children.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree
My child doesn't seem to smile as much as other children.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree
My child is not able to do as much as I expected.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree
It takes a long time and is very hard for my child to get used to new things.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree

I feel that I am...

☐ Not very good at being a parent.
☐ A person who has some trouble bein
☐ An average parent.
☐ A better than average parent.
☐ A very good parent.

I expected to have a closer and warmer feeling for my child that I do and it bothers me.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

Sometimes my child does things that bother me just to be mean.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

My child seems to cry or fuss more often than most children.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

My child generally wakes up in a bad mood.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

I feel that my child is very moody and easily upset.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

My child does a few things which bother me a great deal.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

My child reacts very strongly when something happens that my child doesn't like.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

My child gets upset over the smallest thing.

☐ Strongly Agree
☐ Agree
☐ Not Sure
☐ Disagree
☐ Strongly Disagree

My child's sleeping or eating schedule was much harder to establish than I expected.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree
I have found that getting my child to do something or stop doing something is:	☐ Much harder than I expected. ☐ Somewhat harder than I expected. ☐ About as hard as I expected. ☐ Somewhat easier than I expected. ☐ Much easier than I expected.

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

Think carefully and count the number of things which your child does that bother you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, ect.	☐ 10+ ☐ 8-9 ☐ 6-7 ☐ 4-5 ☐ 1-3
There are some things that my child does that really bother me a lot.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree
My child had turned out to be much more of a problem that I had expected.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree
My child makes more demands on me than most children.	☐ Strongly Agree ☐ Agree ☐ Not Sure ☐ Disagree ☐ Strongly Disagree