Grandmother Support, Family Functioning, and Parenting Stress in Families with a Child with a Disability

by

Natasha Tumbarello

A dissertation submitted to the Graduate Faculty in Educational Psychology in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York

2010

This manuscript has been read and accepted for the
Graduate Faculty in Educational Psychology in satisfaction of the
dissertation requirement for the degree of Doctor of Philosophy.

Marian C. Fish, Ph.D.

_____	_____
Date	Chair of Examining Committee

Mario A. Kelly, Ed.D.

_____	_____
Date	Executive Officer

Georgiana S. Tryon, Ph.D. _____

Jay Verkuilen, Ph.D. _____
Supervisory Committee

THE CITY UNIVERSITY OF NEW YORK

Abstract

GRANDMOTHER SUPPORT, FAMILY FUNCTIONING, AND PARENTING STRESS IN FAMILIES WITH A CHILD WITH A DISABILITY

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Natasha Tumbarello

Advisor: Marian C. Fish, Ph.D.

This study examined the relationship among grandparent support, family functioning, and parental stress on families with children with and without disabilities between the ages of 2 and 12 years. Families are viewed as an ever-changing complex system with reciprocal interactions. One possible stressor on the family system is the birth of a child with a disability. Parenting stress levels seem to fluctuate in the family system over time depending on the age of the child with a disability, developmental stage, and demands of the age and stage. Studies show that social support, specifically that from grandmothers, can buffer some of the stress related to parenting a child with a disability (Kuster & Merkle, 2003; Mitchell, 2007; Trute, 2003). The current study addressed the following research questions: 1) Do families with a child with a disability differ from families without a disabled child with regard to grandmother support, family functioning, and parental stress? 2) What are the relationships among grandmother support, family functioning, and parental stress in families with a child with a disability?

Fifty-three mother-grandmother dyads completed surveys regarding their support, parent stress, child stress, life stress, family cohesion, and family flexibility. Results for the current study revealed that the groups were comparable on most family demographic variables, such as mother age, grandmother age, ethnicity, and highest level of education. Significant differences

were observed in the ages of the target child and annual income between groups. Significant differences were also observed between groups with regard to overall stress, parenting stress, and child stress. Total stress, parent stress, and child stress were higher in families with a child with a disability than in families with a child without a disability. Grandmother support was positively associated with family flexibility and inversely related to life stress. Grandmother support abated some stress related to major life events and enhanced family flexibility. Support from grandmothers did not, however, enhance family cohesion or reduce stress related to raising a child with a disability.

In sum, the experience of parenting stress, child stress, and overall stress was higher in families with a child with a disability, and grandmother support was associated with reduced life stress and enhanced family flexibility; however, grandmother support was not found to enhance family cohesion, or diminish parenting stress, child stress, or overall stress experienced by mothers.

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CHAPTER 1

Introduction

This study examined the relationship among grandparent support, family functioning, and parental stress on families with children with and without disabilities. Systems theory views the family as a complex, open, and dynamic set of individuals and interactions, organized by a hierarchy of power, subsystems, and sets of rules that the family changes depending on their stage of development (Nichols & Schwartz, 2004; Walsh, 2002). Change increases the stress in the family system, and the family acts as a self-regulating system that attempts to maintain homeostasis (Ritvo & Glick, 2002; Walsh, 2002). Most families pass through the stages of the family life cycle with adaptive outcomes; yet, some experience unforeseen stress or off-time changes and have a much more difficult time adapting (Britner, Morog, Pianta, & Marvin, 2003; DeMarle & Le Roux, 2001). The birth of a child with a disability may be considered an unforeseen stress on a family system.

Families with a child with a disability experience financial, day-to-day, and social-emotional adjustments all of which make daily living very different from that of families with typically developing children (Fish, 2002; Trachtenberg & Batshaw, 1997). Financial stressors include medical insurance, child care, professional services, equipment, transportation, and work disruptions depending on the severity and type of disability. Day-to-day stressors include feeding, toileting, dressing, transporting, housekeeping, and self-care. Social-emotional adjustments include changes in hopes, dreams, expectations, anxiety, depression, and distress. Each of these stressors can impact family functioning.

One model of family functioning is the Circumplex Model of Marital and Family Systems (Olson & Gorall, 2003). The model has three dimensions: cohesion, flexibility, and

communication. Family cohesion is the sense of togetherness that a system maintains. Family flexibility refers to the adaptability of a system. Last, communication is considered a facilitating dimension, making every family system unique. Overall, a balanced family system will have moderate levels of cohesion and flexibility, and high levels of communication. Unbalanced families typically have extreme levels of cohesion and flexibility, and poor communication skills.

Stress can also impact a family system and family functioning. Stress is a "perceived imbalance between demands and coping resources" (Tröster, 2001, 624), and individual responses to stress depend on the stressor, strain, coping resources, and coping strategies (Lessenberry & Rehfeldt, 2004). Models of stress and coping, such as the general model of transactional stress (Lazarus & Folkman, 1984), the Double ABCX model (McCubbin & Patterson, 1983), stress proliferation (Pearlin, 1999), and the risk-resilience framework (Wallander, Varni, Babani, & Banis, 1988) were developed to explain how certain stressors affect family functioning, and how families react differently to stress.

One way to cope with stress is through the use of social support. Several studies show that one's having supportive people, both professional and nonprofessional, correlates inversely with negative psychological and physical symptoms and disorders (Cutrona & Russell, 1990; Dunst, Trivette, & Hamby, 1994; Hobfoll & Freedy, 1990). Studies also show that social support correlates positively with physical and mental health, and moderates the effects of stressors on family functioning (Boyd, 2002; Salisbury, 1990). Social support as a buffer can advance the process of adaptation (Britner, Morong, Pianta, & Marvin, 2003). Overall, social support is a powerful coping resource for parents with a child with a disability (Kuster & Merkle, 2004).

Grandparents are unique and important sources of social support to families with a child with and without a disability. Research generally finds that grandparent support is the most common form of familial support next to spousal support (Green, 2001). Interestingly, research has shown that grandmothers are perceived as more supportive than grandfathers (Trute, 2003). More specifically, maternal grandmothers are perceived to be more supportive than paternal grandmothers (Trute, 2003).

While a great deal of research has been conducted in each of the aforementioned areas, very little research has been conducted on the impact that grandmother social support provision has upon family functioning including flexibility, cohesion, and parenting stress. The current study addressed the paucity of research and answered the following research questions: 1) Do families with a child with a disability differ from families without a disabled child with regard to grandmother support, family functioning, and parental stress? 2) What are the relationships among grandmother support, family functioning, and parental stress in families with a child with a disability?

The two groups in the sample for this study were comparable on most family demographic variables, such as mother age, grandmother age, ethnicity, and highest level of education. Significant differences were observed in the ages of the target child and annual income between groups.

Significant differences were also observed between the groups with regard to overall stress, parenting stress, and child stress. The experience of parenting stress, child stress, and overall stress was higher in families with a child with a disability, and grandmother support was associated with reduced life stress and enhanced family flexibility; however, grandmother support was not found to enhance family cohesion, or diminish parenting stress, child stress, or

overall stress experienced by mothers.

CHAPTER 2

Literature Review

This literature review provides a summary of family systems from a general systems perspective followed by how a disability can act as a stressor in a family system. Family variables, including family stress and family functioning are reviewed. The discussion then addresses social support as a coping resource when a family experiences stress. Next, grandparents as sources of unique social support are discussed. Finally, a rationale for the current study is presented.

Family Systems

Family systems theory is a blend of a systems view of interactions, cybernetics, and interpersonal psychology (Ritvo & Glick, 2002). Based on the general systems theory of biologist Von Bertalanffy (1968), families are viewed as intricate, complex, and interacting systems. Due to the dynamic nature of any system, all elements of the system are considered interrelated and interacting. Families as systems are organized and accommodate to changes in their organization in terms that are borrowed from the theory of cybernetics (McDonald, Poertner, & Pierpont, 1999; Walsh, 2002).

According to cybernetics (Walsh, 2002), systems have control instruments that communicate and relay information and adjust according to the monitoring systems' information. Like machinery, families are thought to be homeostatic environments that use certain devices and strategies to maintain a balanced system. There is a circular causality that regulates the system of the family. The back-and-forth communication between different mechanisms in the monitoring system is called a feedback loop. For example, families have both positive and negative feedback loops that provide information about changes in the family environment and

adjust according to the type of input. When negative feedback is received, the system adjusts by returning to the average or normal state of the system. When positive feedback is received, the system itself actually changes to accommodate the feedback (Nichols & Schwartz, 2004).

Relating these ideas to families and adaptation, family systems have feedback loops to maintain constancy in their balance of organization. This balance within the family system is called homeostasis, and the feedback loop provides information to the family about how to adapt when any influences, either positive or negative, arise (Ritvo & Glick, 2002). Homeostasis in a family also refers to the system's stability, strength, security, and balance. If the family is impacted by a stressor or disequilibrating force, the feedback loop will return the family system to its homeostasis and balance. It may not mean that the family returns to its former functioning, but a regulatory pattern of interactions is maintained via the feedback loop and homeostasis. This is particularly true when a family meets a crisis event or developmental stage change (Ritvo & Glick, 2002).

Families are also viewed as open, living systems. By open, the systems are considered permeable, and are not only communicating within their own system, but are communicating with the multiple systems with which the family interacts. Information is transmitted within and between systems. There is complementarity or reciprocity among all family interactions, wherein every family member's behavior influences every other family member's behavior. Along with complementarity is a similar concept of circular causality. Circular causality, when applied to family systems, suggests that problems in a family are not one person's responsibility, but are the result of ongoing reciprocal interactions that effect change in all parts of the family system. While complementarity and circular causality explain how ever-changing and mutually influential family members are to one another, all families have equifinality. Equifinality

suggests that that there are many ways for a family to realize a final goal. There is no one right way, and all paths reach the same end (Nichols & Schwartz, 2004).

Families also share several concepts related to family structure. Family structure refers to the way a family is internally organized. Subsystems are one way that families are organized (Minuchin & Fishman, 1981). Subsystems are family units within a family system that may be based on age, gender, or function of group members. Examples of subsystems are parents, children, siblings, caregivers, females, males, etc. Subsystems and whole family systems separate themselves from others by the use of boundaries. Boundaries are imaginary walls surrounding a system or subsystem that keep it independent from others (Minuchin & Fishman, 1981). Boundaries help organize the family system, as stated in the general systems theory above, and can be inferred or apparent, meaning that boundaries can be subtle and unspoken, or clear and well-defined. Regardless of its type, clear boundaries are considered essential for a healthy functioning family both inside and outside of the system (Ritvo & Glick, 2002). Depending on the rigidity of the boundaries, systems and subsystems can be so autonomous that they are isolated from others, or so flexible that they are codependent on each other (Nichols & Schwartz, 2004). Within the family system, the use of boundaries helps to regulate the subsystems and levels of power in the family. Hierarchical organization refers to the ways in which the family defines those who have more or less power in a family. Oftentimes, parents hold the highest level of power in a family, and older children more power than younger children.

In sum, families are viewed as a whole or a system with complex interactions, within which each individual's behavior effects change in every other individual's behavior. The interactions and relationships among and between individuals in any family affect the whole

system of the family. No individual can be viewed as a detached unit, and must be regarded in the context of his or her family structure. Families are open systems, dynamic and ever-changing based on the input from the outside world. Positive interactions have positive overall effects on the system; negative interactions have overall negative effects on the system.

While families share many concepts regarding systemic organization and regulation, not all families develop in the same way. Normal family development depends on society, culture, religion, and perspective. Largely, there is no one view of "normal" in describing family development. Family can be thought of in terms of its functioning. Systems theory considers certain patterns of interaction as prototypical in normal family development. The general function of a family unit is to support its members, including offspring and extended family. All families have belief systems, which are shared morals and values passed on generationally. These can include religious beliefs, cultural values, and personal traditions (Walsh, 2002).

Theories of normal family development state that functional families share many features. According to Ritvo and Glick (2002) and Hanson and Carta (1996), families define themselves as a "family" based on their connections with, commitment to, and care for one another. Family members are united and committed to one another as a unit. Family members care for each other and promote each others' interests. Family members accept diversity within their family unit, and encourage independence and autonomy. Couples within a family share a respectful, encouraging, honest, and fair relationship. Parents in a family maintain authority and appropriate limits and power, but focus on the development of the children in the family. The organization of the family has homeostasis, balance, and the boundaries and structure are clear and consistent. The family is adaptable or is able to change and acclimate when both predicted and unpredicted stressors arise. Functional families share ideas by communicating openly, and

resolving concerns with a problem-solving process. Family members share values and beliefs that are part of their extended family's traditions. Lastly, the families provide both physically and emotionally for the immediate and extended family members (Ritvo & Glick, 2002).

While homeostasis and balance are essential elements of any family system, the systems outside of the family are in constant flux, and are shaping the family unit developmentally toward growth. Change occurs in all families and is unavoidable. At times, change is predictable, as in developmental or age-related changes; however, unexpected change is also natural, and all families cope with change differently. Problem-solving and coping mechanisms that sustain homeostasis vary from family to family (DeMarle & Le Roux, 2001). Typical changes that are expected for families from a developmental perspective can be viewed in the family life cycle (Carter & McGoldrick, 1999). However, unexpected stresses are extraordinary and are not shared by every family. Some expected stresses also occur at unexpected times, making them more challenging to the family system.

Family Life Cycle

The family life cycle provides a framework to view normal family system change and development over time, and recognizes that different changes are required in every family during each part of the cycle (Carter & McGoldrick, 1999). The family life cycle has six stages, each of which describes expected relational changes, crises or concerns that are often found as a result of the relational change, and adaptations needed for healthy functioning (Nichols & Schwartz, 2004). In each stage, emotional and status changes are necessary for the family to progress developmentally. It is considered normal to experience stressors at transitions between stages (Walsh, 2002).

Stage one of the family life cycle involves single young adults leaving home. When a

single young adult leaves home, he or she becomes financially responsible and emotionally adept. Stage two of the family life cycle occurs when a couple marries or unites, joining two families. A new system is formed at this time, and extended family relationships are formed.

During stage three, families have young children. The family system changes at this stage to incorporate the child or children, roles are developed and reorganized around the needs of the child, and extended family relationships adjust to the addition of a child or children. The configuration of this new family modifies with the birth of every child thereafter. The family with young children shares a unique intimacy as the focus is primarily on raising the children, and the marital relationship becomes secondary. As parents, responsibilities increase dramatically, and the parents must find ways to adapt their relationship needs or meet their relationship needs in new ways.

Stage four of the family life cycle involves families rearing adolescents. Adolescence is a time of growing independence for the youth in a family, and in response to that increasing autonomy, families must become more flexible in their boundaries, marital relationships adjust, and extended family member caregiving may take place. Once grown children leave the home for college, work, etc., the fifth stage of the family life cycle begins. This stage is regarded as a time to support grown children in moving out and moving on independently. The marital subsystem is highlighted again now, extended family relationships expand, and the possible death of an elder loved one may be addressed. In the sixth and last stage, adult family members are aging and focusing on expanding interests, changing roles, and preparing upcoming generations. There is also possible decline in physical and mental functioning, and the death of a loved one (Nichols & Schwartz, 2004).

While the family life cycle appears to have distinct stages, one family may be in several

stages at once, repeat stages, and/or skip stages entirely. The theory recognizes the multigenerational quality and changing roles of all families. As a family moves from stage to stage, developmental stressors are expected and adaptation to the stressors affects the entire family system. The family life cycle is a view of a developing family spanning from single adulthood to death, and discusses common transitional challenges often encountered by predicted changes in the family system (Carter & McGoldrick, 1999, Nichols & Schwartz, 2004).

While all families experience growth and potential differentiation as a result of the developmental changes within the family life cycle, a family's ability to adapt to changes is influenced by a number of factors. Families adapt better or worse depending on the family's resources, the family's social support network, family functioning, and transitions through the family life cycle (DeMarle & Le Roux, 2001).

In sum, systems theory views the family as a complex, open, and dynamic set of individuals and interactions, organized by a hierarchy of power, subsystems, and sets of rules which the family changes depending on their stage of development (Nichols & Schwartz, 2004; Walsh, 2002). Change increases the stress in the family system, and, as in cybernetics, the family acts as a self-regulating system that attempts to maintain homeostasis (Ritvo & Glick, 2002; Walsh, 2002). Most families pass through the stages of the family life cycle with adaptive outcomes; yet, some experience unforeseen stress or off-time changes and have a much more difficult time maintaining homeostasis in their system (Britner, Morog, Pianta, & Marvin, 2003; DeMarle & Le Roux, 2001). One stressor on the family system is the birth of a child with a disability.

Families with Children with a Disability

This section reviews research on disabilities in children. It begins with definitions of

disability and estimations on prevalence in the United States. Next, the birth of a child with a disability and the impact on the family system is discussed with respect to family dynamics, stressors, and outcomes on the family. Lastly, coping strategies of families with a child with a disability are briefly discussed. A more thorough discussion of coping strategies is reviewed in a later section of this paper.

There are almost 50 different definitions of disability in federal law. The Americans with Disabilities Act has one of the more common definitions, which states that a person with a disability has "a physical or mental impairment that substantially limits one or more of the major life activities, a record of such an impairment, and [is] regarded as having such an impairment." (OSERS, 2008, para. 1)

There is limited information on the exact demographics of children with disabilities in the United States (Banks, 2003). Using the U.S. Census (2005), it is estimated that over 5.2 million people ages 5-20 were diagnosed with any disability, or approximately 8.1% of the US population. Little information is available on those children with disabilities who are under 5 years old, because often only those children who have been diagnosed and are currently receiving treatment or intervention are included in census information. Many children with disabilities are unidentified until they become school age.

Unexpected or non-normative stressors on a family system, such as the birth of a child with a disability, are disruptive to the family system and its members, as the expectations, responsibilities, and coping resources are affected (Benson, 2006). The birth of a child with a disability is a stressor on a family that impacts and changes a family system from the moment of birth. Having a child with a disability does not unavoidably lead to poor family functioning; it does, however, cause change in any family system (DeMarle & Le Roux, 2001).

Considerable research has addressed the impact of the birth of a child with a disability on the family system (Fish, 2002; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Murray & Greenberg, 2001; Parish & Cloud, 2006; Sarimski, 1997; Sen & Yurtsever, 2007; Trachtenberg & Batshaw, 1997). It may result in financial adjustments (Parish & Cloud, 2006; Sen & Yurtsever, 2007), day to day adjustments (Sen & Yurtsever, 2007), social-emotional adjustments (Murray & Greenberg, 2001, 2006; Sarimski, 1997), or marital strain (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006).

Families with a child with a disability experience financial adjustments that make daily living very different from that of families with typically developing children (Parish & Cloud, 2006; Sen & Yurtsever, 2007). Financial stressors include medical insurance, child care, professional services, equipment, transportation, and work disruptions, depending on the severity and type of disability. Mothers of children with a disability reported having inadequate financial support (Sen & Yurtsever, 2007). Additionally, research shows that families with a child with a disability are at greater risk of living in poverty when compared to families with a child without a disability (Parish & Cloud, 2006).

Social-emotional adjustments related to having a child with a disability include changes in hopes, dreams, expectations, anxiety, depression, distress, and both familial and nonfamilial relationships (Murray & Greenberg, 2001, 2006; Samrinki, 1997; Sen & Yurtsever, 2007). The relationship between the child with a disability and his/her parents has been shown to be associated with behavioral and social-emotional qualities of the child (Murray & Greenberg, 2006). Children with more severe disabilities also were found to have more social-emotional and behavioral concerns than those with less severe disabilities (Murray & Greenberg, 2001; Sarimski, 1997). In a study by Tröster (2001), parents of a child with a disability expressed

concern and distress in many areas, including concern for their child's future, uncertainty about meeting their child's needs, difficulty in finding professional support, and not having time for their personal relationships.

Marital strain has been found to be greater in families with a child with a disability. In one study, approximately 25% of the couples with a child with a disability reported distressed marital relationships (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). In a study of 2,000 families with a child with a disability, almost half reported that they felt greater marital strain due to the disability (Contact a Family Directory of Specific Conditions and Rare Disorders, 2003). Approximately one-tenth of the couples were separated due to the stress on the family, and one-sixth of the couples had divorced. One factor that reportedly influences marital distress is severity of behavior associated with a disability.

Research has also shown that mothers are more greatly affected by the challenges of raising a child with a disability than are fathers. Research has demonstrated that parents of children with a disability not only report higher levels of stress, but also lower togetherness and poorer health than parents of children without a disability (Oelofsen & Richardson, 2006). In a comparison study of 104 families with a preschooler, half of whom had a disability and half of whom did not have any disability, parents completed a variety of questionnaires. Using the Sense of Coherence questionnaire, the Parenting Stress Index, the Health Perceptions Questionnaire, and the Family Support Scale, Oelofsen and Richardson (2006) examined coherence, stress, health, and support in families with disabilities including autism, cerebral palsy, muscular dystrophy, Down syndrome, Fragile X, Prader-Willi syndrome, and developmental delays. It was revealed that mothers of children with a disability reported poorer health, lower coherence, and higher levels of parenting stress than fathers of children with a

disability, but this was not the case in mothers and fathers of children without a disability. Parents of children without a disability reported no significant differences between their ratings of health, coherence, and stress (Oelofsen & Richardson, 2006).

Further investigating mothers and stress, Wallander, Pitt, and Mellins (1990) studied maternal stress, child independence, and maternal adaptation. Questionnaires were completed by 119 mothers of children with cerebral palsy, spina bifida, or hearing impairments between the ages of 2 and 18 years old. Wallander et al. (1990) assessed child independence using the Vineland Adaptive Behavior Scales, Life Experiences Survey, Daily Hassles and Uplifts Scale, and Handicap-Related Problems for Parents Inventory. Maternal adaptation was assessed using the Physical Health Measure, Mental Health Inventory, and the Social Contacts and Resources Questionnaire. Results showed that maternal stress was directly related to maternal mental health, and adaptation was not related to his/her child's independence.

Another chief, persistent source of stress for many families of children with special needs is dealing with behavioral challenges that may exist (Benson, 2006). Depending on the type of disability, behavioral challenges associated with the disability can cause great stress on a family. Research has shown a relationship between a child's emotional or behavioral challenges and family distress, family dysfunction, high irritability, overprotection in families, and parent levels of depression (McDonald, Poertner, & Pierpont, 1999).

For example, Tröster (2001) described family stress and a disability in a family with relation to the type and severity of disability:

> It has been found that parents of children with disabilities experience particularly strong stress in areas that relate closely to demands arising from the children's behavior or behavioral competencies, for example, limited adaptability, hyperactivity, or a difficult

temperament, but that they are no more or only slightly more stressed in areas of parental functioning, such as health, partnership, and social relations (p. 624).

While it is well established that an enormous amount of stress surrounds a family with a child with a disability, it has also been shown that the stress can affect the emotional functioning of other members of the family system such as the mother. Baker, Blacher, and Olsson (2005) assessed depression, optimism, and behavioral problems in parents of 214 preschool-aged children between the ages of 3 and 5 who were classified as developmentally delayed, borderline, or nondelayed. Children were administered the Bayley Scales of Infant Development, and parents completed the Child Behavior Checklist, the Family Impact Questionnaire, the Center for Epidemiologic Studies Depression Scale, the Dyadic Adjustment Scale, and the Life Orientation Test. A negative relationship was found between child behavior problems and mothers' well-being and optimism (Baker et al., 2005).

In a study of parenting stress, McDonald, Poertner, and Pierpont (1999) surveyed 259 families on characteristics of a child between the ages of 3 and 14, coping strategies of parents, perceptions of the child, and parenting stress. Child characteristics were measured with the Child Behavior Checklist, coping strategies was assessed using the Coping Health Inventory for Parents and the Family Index of Regenerativity and Adaptation, perceptions of child were examined with the Positive Contribution Scale, and the Press' Stress Measure was used to explore parenting stress. Findings revealed various clusters of caregiver, child, family, and environmental characteristics as predictors of parenting stress. Child characteristics, such as internalized and externalized behavioral problems contributed to stress, and in particular, the more severe internalized problems were associated with higher levels of parenting stress (McDonald et al., 1999).

Caring for a child with a disability forces a family to adjust to extraordinary physical, financial, and emotional stressors. Parents of children with a disability often report lower scores on subjective wellbeing and higher scores on feelings of depression than parents of children without special needs (Oelofsen & Richardson, 2006). A number of studies have shown that much of the stress reported by mothers of children with disabilities is related to the increased responsibilities and demands in raising, caring for, and providing for their children due to the disability (Horton & Wallander, 2001; Tröster, 2001). Horton and Wallander (2001) studied resilience factors of 111 mothers with children with special needs. Children between the ages of 5 and 18 years old with spina bifida, cerebral palsy, and diabetes were included in the study. Mothers completed the Severity of Physical Handicap Scale, the Hope Scale, the Brief Symptom Inventory, the Social Support Questionnaire, and the Parents of Children with Disabilities Inventory. Mothers of children with a disability report more psychological distress than mothers of children without a disability.

In another examination of psychological functioning in families of children with a disability, 48 mothers and 41 fathers of children with autism between the ages of 2 and 4 were assessed on child characteristics, parenting stress, and parent mental health. Parents completed the Developmental Behavior Checklist, Vineland Adaptive Behavior Scale, Autism Screening Questionnaire, Hospital Anxiety and Depression Scale, Questionnaire on Resources and Stress, and the Kansas Inventory of Parental Perceptions Positive Contributions scale. Mothers of children with autism had higher ratings of depression than fathers, but also more positive perceptions of their children than fathers of children with autism (Hastings, Kovshoff, & Ward, 2005). Within each family, mothers and fathers respond differently to the outcomes associated with having a child with a disability, but clearly both are affected in terms of psychological

functioning, stress, and coping.

Parent perceptions, stress, anxiety, and depression were also studied by Hastings (2003) in 18 parent dyads. Hastings (2003) assessed stress and mental health in parents with children with autism between the ages of 8 and 17 using the Developmental Behaviour Checklist, the Hospital Anxiety and Depression Scale, and the Questionnaire on Resources and Stress. Mothers in the study had higher levels of anxiety than fathers, and mothers' stress ratings were related to behavioral challenges associated with the child's disability. However, mothers' and fathers' ratings were generally similar with regard to their perceptions of their child.

Keller and Honig (2004) examined child factors and stress in 30 families with a child with a disability between the ages of 7 and 12 years. The children in the study had disabilities including mental retardation, autism, learning disability, multiple disabilities, and sensory/physical conditions. Using the Parenting Stress Index, Family Environment Scale, and the Family Support Scale, Keller and Honig (2004) found higher levels of stress in mothers. The stress levels found in the mothers' ratings were related to higher ratings of child demandingness and neediness. Fathers' stress was unrelated to child demandingness and neediness, but was related to child's acceptability. Fathers had a more difficult time connecting and bonding with their child with a disability, which increased stress in the family. Family harmony and use of social support helped alleviate the stress that was found in both mothers and fathers. Positive coping was related to parent satisfaction with the family environment as well as stability of the marital system.

While a stable positive family system certainly would mediate some of the stress associated with having a child with a disability, especially depending on the presence and severity of the handicapping condition, families of children with special needs experience life

cycle changes that also affect the family system. Some differences between a family with a child with a disability and a family with a child without a disability may include the duration of each stage of the life cycle and the absence of some stages. The crises or expectations of each stage may also vary depending on the presence of a child with special needs. DeMarle and Le Roux (2001) explained it as:

> Every family, as it progresses through the life cycle, constructs its own developmental line. This developmental line will include some of the same features (births, deaths) as that of other families but may not include others (a child being toilet trained, high school or college graduation). It is extremely difficult for families of a child with a disability to hold onto their unique developmental time line because the rest of the world is, most of the time, on a very different time line. This daily experience of discontinuity can leave some families with a deep sense of continuously grieving their loss. This, in turn, can present great difficulties for these families in coming to terms with and valuing their own developmental line (p. 35).

As stated, most families with a child with a disability experience discontinuity in the stages of the life cycle that may compel the family system to change (DeMarle & Le Roux, 2001). For example, extended family or siblings may act as parenting partners due to the increase demand in responsibilities. In one study, Baker, McIntyre, Blacher, Crnic, Edelbrock, and Low (2003) examined family functioning and stress in 205 families with a preschooler with a developmental disability over the early part of a family life cycle. Baker et al. (2003) assessed the children with the Bayley Scales of Infant Development II, and had the parents complete the Child Behavior Checklist and the Family Impact Questionnaire. Baker et al. (2003) found that high levels of parenting stress increased child behavior problems, which increased parenting

stress in an escalating and cyclical pattern over time.

Adaptation to stressors is essential to resuming stable family functioning, yet there is no one description or process of adaptation that fits all families. When families adjust to stressors and change, they typically acquire dynamic mechanisms to regain equilibrium. The mechanisms or patterns can be either positive or negative, and can bring about harmony or further stress and disharmony depending on the outcome of the mechanism. The birth of a child with a disability can bring about a variety of possible reactions. Some of the possible reactions, such as acceptance or hope, can increase cohesion in a family, while other reactions, such as disappointment or isolation, can lessen cohesion in a family (DeMarle & Le Roux, 2001). All the while, a family continues to develop.

While developing, the adaptation, coping, adjustment responses of a family with a child with a disability may differ from the family of a child without a disability. The adaptation, coping, and adjustment responses of a family with a child with a disability are affected by the nature of the disability, culture, social class, ethnicity, religion, family system prior to the child's birth, current family system, structure and composition of family, sibling, and stage in life cycle. Better coping is related to strong support in the nuclear, extended, and marital relationships, network of nonfamilial support, and family functioning (Fish, 2002). Acceptance and perceptions of the child with a disability affect family functioning. Families who had greater acceptance and more positive views of the child and the disability also had less stress and distress, better family adjustment, and greater resilience (DeMarle & Le Roux, 2001).

Horton and Wallander (2001) studied perceptions of hope and social support as resilience factors in 11 families with 5- to 18-year old children with cerebral palsy, spina bifida, or diabetes mellitus. Using a variety of questionnaires, they found no differences in distress among mothers;

however, an inverse relationship with distress was found in mothers with regard to hope, social support, and distress, such that distress occurred with less hope and social support. "Perceptions of hope moderated the relationship between disability-related stress and maladjustment, suggesting a buffering effect when stress is high. However, hope did not appear to be a mediator of the relationship between social support and distress" (Horton & Wallander, 2001, p. 383).

Benson (2006) studied parent depression and the use of parent support, specifically informal and formal parent support, in 68 families with a child with special needs. The children in the study had a mean age of 7.2 years, and were diagnosed with Autism, Pervasive Developmental Disorder (Not Otherwise Specified), an unspecified autism spectrum disorder, or developmental delay. Parents completed a scale on the severity of autism symptomatology developed by the authors, the Effects of the Situation Questionnaire, the Family Support Scale, and the Center for Epidemiologic Studies – Depression Scale. Benson (2006) found that the use of informal social support was related to significantly fewer symptoms of parent depression, especially in families where the child's disability symptoms were not severe. This is contradictory to the stress buffering hypothesis that suggests that support will buffer stress in more serious situations where coping resources are strained. That is to say that in the case of a child with a disability, the natural coping resources can sometimes be adequate in buffering the stress related to the disability.

To summarize, stress in a family with a child with a disability may be related to stage in the life cycle, perceptions of the child and the disability, and environmental factors. Experiences of stress may also change over time, based on changing demands as the child and parents age (Britner, Morong, Pianta, & Marvin, 2003). Parenting stress levels seem to fluctuate over time dependent on the age of the child with a disability, developmental stage, and demands of the age

and stage.

Family Functioning

This section reviews family functioning. It begins with definitions of family functioning from the perspective of the Circumplex Model of Marital and Family Functioning (Olson & Gorall, 2003). Next, three different areas of family functioning are described in detail with examples. Last, a summary of the theory by Olson and Gorall (2003) is given.

Family functioning can be examined from a variety of perspectives. The Circumplex Model of Marital and Family Systems is a theory that describes family functioning and is often used for progress monitoring during family therapy (Olson & Gorall, 2003). It views the family as a system that has three integrated relational components: family cohesion, family flexibility and communication (Olson & Gorall, 2003).

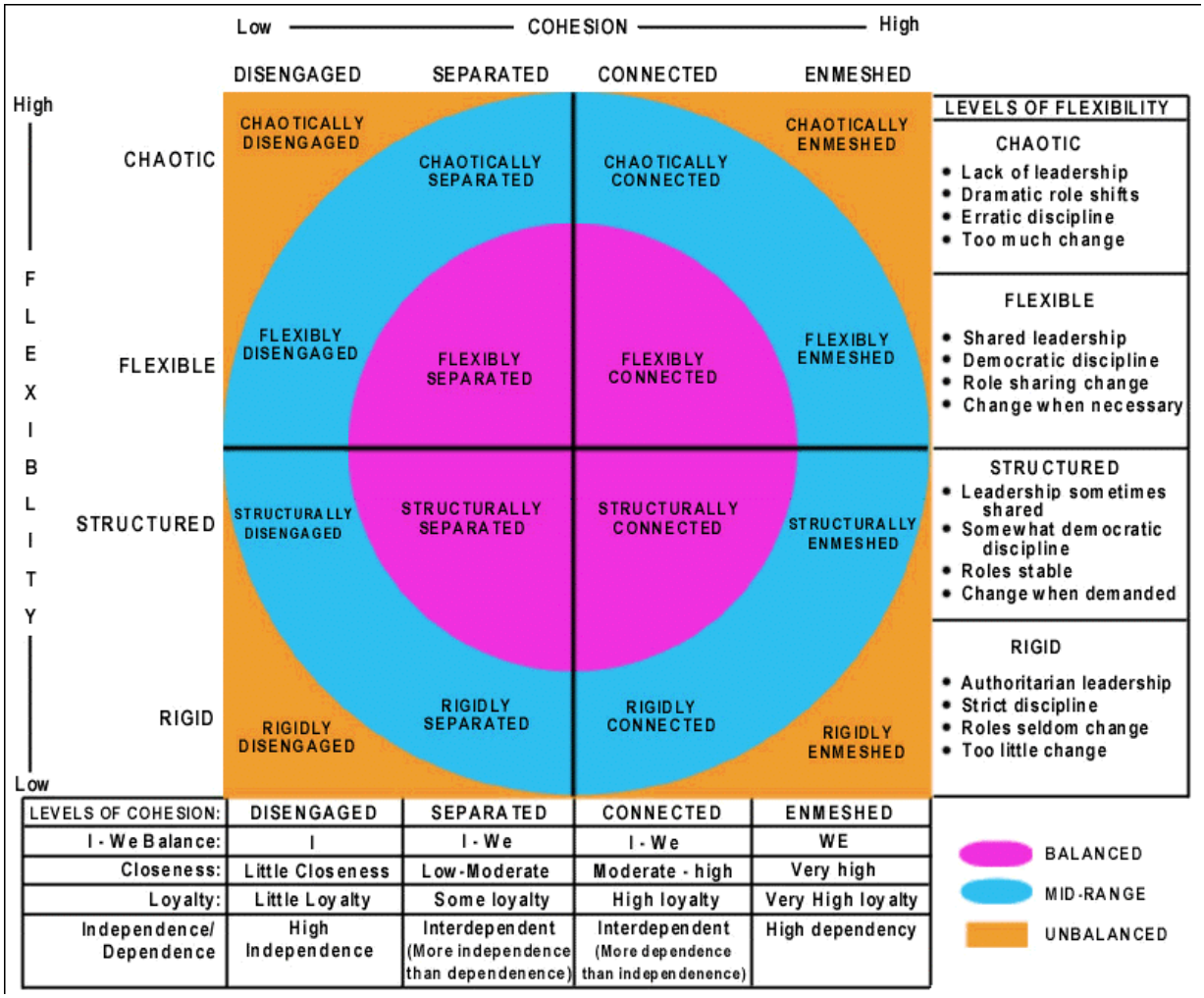
Cohesion

Family cohesion is "the emotional bonding that family members have toward one another" (Olson & Gorall, 2003, p. 516). Cohesion includes family systems concepts such as commitment, attachment, intimacy, boundaries, social networks, problem-solving skills, and leisure activities. A family system has different levels of cohesion depending on how separate or together the family functions, and the levels range from disengaged to enmeshed (See Figure 1). Balanced, functional families are thought to be in the ranges between disengaged and enmeshed, called separated and connected. However, if a family is either disengaged or enmeshed, their levels of connectedness may be too far or too close for the family to function in a balanced fashion (Olson & Gorall, 2003).

When a family is rated as disengaged, the family is disconnected and overly independent or distant from one another. For example, family members may make major life decisions, even

those affecting others in the family, and not discuss the decision with any other family member

Figure 1: Circumplex Model: Couple and Family Map



Olson, D. H. & Gorall, D. M. (2003). Circumplex model of marital and family systems. In F. Walsh (Ed.), *Normal Family Processes* (3rd Ed.). New York: Guilford (pp. 514-547).

first. In contrast, when a family is rated as enmeshed, the family is overly involved with one another, and autonomy and differentiation are minimal (Olson & Gorall, 2003). For example, no family member may make a decision without consulting and agreeing with all other family members.

Flexibility

Family flexibility refers to "the amount of change in its leadership, role relationships and relationship rules" (Olson & Gorall, 2003, p. 519). Flexibility can also be thought of as adaptability, and includes concepts such as leadership, compromise, roles, rules, and stability. A flexible system maintains balance in its ability to adapt to incoming stressors and change. According to the Circumplex Model of Marital and Family Systems (Olson & Gorall, 2003), flexibility ranges from rigid to chaotic, with structured and flexible being in between (See Figure 1).

Families are constantly evolving and changing, and flexibility addresses the system's ability to cope and grow appropriately with change. Balanced types of flexibility include structured and flexible types. For example, a family that has a "family meeting" to make family decisions or to address problems while maintaining a hierarchy of power would be considered more structured and/or flexible, and therefore, healthier over time.

When a family is rated as rigid or chaotic using the Circumplex Model of Marital and Family Systems (Olson & Gorall, 2003), homeostasis is difficult to maintain. In a rigid family system, one parent may be described as authoritarian or militant, and discipline is harsh and strict. On the other hand, a chaotic family system seems to have no leadership or ineffective leadership, and discipline is inconsistent. In either case, families are unable to maintain roles and rules with any balance.

Communication

The Circumplex Model of Marital and Family Systems (Olson & Gorall, 2003) also describes a third dimension that is critical to all relationships: communication. Communication is considered a facilitating dimension to all interactions and affects both flexibility and cohesion. According to Olson and Gorall (2003), communication includes listening, affect management, speaking, turn-taking, self-disclosure, focus, clarity, and consideration. Communication is a linear dimension ranging from low to high.

Taken as a whole, the Circumplex Model of Marital and Family Systems (Olson & Gorall, 2003) was developed to assess the overall balance in a couple or family, and the model has three dimensions: cohesion, flexibility, and communication. Family cohesion is the sense of togetherness that a system maintains, and it ranges from disengaged to enmeshed. Family flexibility refers to the adaptability of a system, and ranges from rigid to chaotic. Lastly, communication is considered a facilitating factor and ranging from low to high, making every family system unique. Overall, a balanced family system will have moderate levels of cohesion and flexibility, and high levels of communication. Unbalanced families typically have extreme levels of cohesion and flexibility, and poor communication skills. The Circumplex Model of Marital and Family Systems (Olson & Gorall, 2003) provides a systemic view of three variables found in all couples and families, and influences the way one differentiates high functioning families from inconsistent or low functioning families. These three dimensions are measured using the Family Adaptability and Cohesion Evaluation Scale (FACES-IV), a scale developed to assess the adaptability, cohesion, and communication styles of families (Olson, Gorall, & Tiesel, 2004). A number of studies support the use of FACES-IV to assess family functioning (e.g., Craddock, 2001; Franklin, Streeter, & Springer, 2001).

Family Stress

This section discusses family stressors and reactions to stress. It begins with a description of stress and its components, and then moves on to describe four different theories of stress and coping. Next, research related to the effects of stress on family functioning is reviewed. Lastly, a summary of the findings on stress is given.

Stress can be defined as a "perceived imbalance between demands and coping resources" (Tröster, 2001, p. 624). Stress is a personal response to any real or imagined threat to homeostasis (Janssen, Schuengel, & Stolk, 2002). It often arises when demands of a situation outweigh the capacity of an individual to respond.

Stress has four components: the stressor, strain, coping resources, and coping strategies (Lessenberry & Rehfeldt, 2004). The stressor can be thought of as the real or imagined event that causes an adverse reaction. Strain includes the physical symptoms of stress, such as body aches, fatigue, low frustration tolerance, headaches, changes in appetite, or changes in sleep. Coping resources are considered any readily available support, such as family, friends, professionals, community based organizations, or religious groups. Lastly, coping strategies are the techniques or manners in which coping resources are utilized in a way that effectively reduces perceived stress, such as problem-solving skills, use of respite, talking with family, or going to religious mass (Lessenberry & Rehfeldt, 2004).

Stressors can impact a family system and all interactions within the system. The systems' homeostasis is affected by how an individual in the system perceives the stressor, how the system reacts to the stressor, and the use of coping techniques to resolve the stressful event (McDonald, Poertner, & Pierpont, 1999).

From a systems perspective, a family member's reaction to stress is related to several

interacting factors that can be grouped into either contextual factors or dynamic factors. Contextual factors that influence an individual's response to stress include: traits of the child, the family system, the parents, and the surrounding community. Dynamic factors that influence an individual's response to stress include: formal services, informal social support, education, and professional resources. Dynamic factors are supporting resources for a family. When considering both contextual factors and dynamic factors, neither is more important than the other; however, the interaction of the factors supports or hinders a family's ability to cope with stressors and stress (McDonald et al., 1999).

Several theories on stress and coping have been developed that can be applied to parenting and especially with relation to parenting a child with special needs. Four theories on stress and coping will be discussed in the following section: a model of transactional stress (Lazarus & Folkman, 1984), stress proliferation (Pearlin, 1999), the risk-resilience framework (Wallander et al., 1988), and the Double ABCX model (McCubbin & Patterson, 1983).

Lazarus and Folkman (1984) developed a general model of transactional stress that has been used to conceptualize the stress and coping process of families with a child with a disability. The model of transactional stress is a two-stage process, wherein the first step is a threat assessment and the second step is a coping assessment. During the first stage of the process, an individual evaluates an incident and determines how much the incident will disrupt homeostasis in his or her life, and the stressor is rated as either threatening or nonthreatening. When the event is assessed as a minimal disruption or non-disruption, the incident is deemed nonstressful. If the stress is perceived as a threat, the process moves to step two.

The next step is to assess the availability and appropriateness of the personal and social-ecological coping resources that a family possesses. When the event is assessed as a disruption

to the balance of the individual's system, the biological and psychological systems react. Coping resources are then examined for their ability to reduce the stressful circumstances (Janssen, Schuengel, & Stolk, 2002). Once coping resources are weighed, the individual may feel a reduction in stress or an increase in perceived stress (Janssen, Schuengel, & Stolk, 2002; Lovallo, 1997). That is to say that if an individual evaluates his or her coping resources and feels they would be ineffective, stress increases. Conversely, if coping resources are judged as potentially effective, proactive problem-solving and use of positive coping strategies ensues and reduces perceived stress. Once a coping strategy is applied, the threat is reassessed. Lazarus and Folkman (1984) viewed coping as an interactive and ever-changing process. This model focuses on the value of psychosocial coping resources as mediators of coping and adaptation.

Stress proliferation is another theory of stress that is similar to the idea of stress pile-up (Pearlin et al., 1999). Stress is thought to be an influence that does not affect only one part of the system, but the entire system as a whole. Stress proliferation means that one area of stress spreads into other areas of a person's life, which brings about stress in numerous other areas of one's life and the lives of others. The initial stressors are called primary stressors and the resulting stress that swells out both directly and indirectly is considered secondary stress. Due to stress proliferation, a stressor that may be manageable unto itself causes stress in so many other areas of one's life, that an individual's capacity to cope diminishes (Benson, 2006).

Behaviors associated with a child with a disability and parenting distress may be mediated by stress proliferation (Benson, 2006). Stress proliferation does not occur in all families with a child with a disability, and can occur in families with a child without a disability. In addition, family functioning and use of coping resources prior to the birth of a child with a disability may reduce the distress experienced by the family.

> Stress proliferation was found to be a powerful predictor of parent depression, uniquely accounting for a highly significant increment in the variance beyond that explained by child symptom severity alone. Thus while some of the impact of child symptom severity on parent depression was direct, some of symptom severity's effect on depression was indirect, with higher levels of child symptom severity resulting in higher levels of stress proliferation, which, in turn, resulted in higher levels of parent depressive symptoms (Benson, 2006, p. 692).

Another view of stress and coping is called the risk-resilience framework (Wallander et al., 1988). Risk factors are those influences that are considered possible threats or hazards to homeostasis, while resilience factors are those influences that protect a family or individual from stressors. Some risk factors include characteristics of the child, presence of a childhood disability or disease, increased responsibilities, and psychosocial stress. Resilience factors include social support, parenting traits, personal beliefs, attitudes, and repertoire of coping skills (Wallander & Venters, 1995).

The last model of stress and coping is McCubbin and Patterson's (1983) Double ABCX model which has been used to conceptualize coping in families of a child with a disability. In the Double ABCX model, interaction among: (A) the stressor, (B) coping resources, and (C) the family definition of the stressor, leads to (X) the family system's sense of crisis. Therefore, the impact of the child as stressor (A) is moderated by parental resources (B), and parental cognitions (C), to result in an outcome of stress or some other indicator of adjustment (X). The Double ABCX model has a similar two-step appraisal process as the transactional model, but factors in a form of stress pile-up that the transactional model lacks.

Renty and Roeyers (2007) examined the stress and coping of 21 parents of children under

18 years of age with autism using the Double ABCX model. Parents completed the Autism-Spectrum Quotient, the Social Provisions Scale, the Camberwell Assessment of Need, the Ways of Coping Questionnaire, the Symptom Checklist-90, and the Dyadic Adjustment Scale. Renty and Roeyers (2007) found that support from spouse, family, friends, and acquaintances were formidable coping resources that buffered the feelings of stress associated with having a child with autism, and helped reduce the perception of a crisis.

The four theories on stress and coping all share a view of stress as a threat to the homeostasis of a system. All of the four stress and coping theories also suggest that the system reequilibrates using a variety of coping strategies. In the transactional model and stress proliferation theory, one's perception of stress and coping directly impacts levels of stress, while in the stress-buffering model and Double ABCX model, utilization of a variety of coping resources is assumed to impact change in the system. For the current study, the Double ABCX stress and coping model (McCubbin & Patterson, 1983) will be used due to its unique application to the family with a child with a disability.

In sum, stress is a "perceived imbalance between demands and coping resources" (Tröster, 2001, p. 624), and individual responses to stress depend on the stressor, strain, coping resources, and coping strategies (Lessenberry & Rehfeldt, 2004). Models of stress and coping, such as the general model of transactional stress (Lazarus & Folkman, 1984), the Double ABCX model (McCubbin & Patterson, 1983), stress proliferation (Pearlin et al., 1999), and the risk-resilience framework (Wallander et al., 1988) were developed to explain how certain stressors affect family functioning, and how families react differently to stress. The stress and coping theories view stress as a threat to the homeostasis of a system, and suggest that each system adapts with a range of coping strategies. The models differ in their emphasis on the

interpretation of the stressful event or the coping technique used to reduce the stress in the system. McCubbin and Patterson's (1983) Double ABCX model has been used widely to explain stress and coping in families with a child with disability.

Parenting Stress

One form of stress commonly found is that related to parenting. A fundamental indicator of disequilibrium is level of parenting stress (Britner, Morong, Pianta, & Marvin, 2003). Parent perceptions of child-related personality, health, and behavioral characteristics influence parenting stress. In turn, parenting stress has been linked to poor parenting and disconnection from the child (Britner et al., 2003). One commonly used measure of parenting stress is the Parenting Stress Index (Abidin, 1995), which measures the stress related to characteristics of the child, parenting and spousal concerns, and life events that are known to be expected stressors. The long version contains 120 items grouped based on the above three categories, two domains that are rated on a 5-point Likert scale. The life events category is rated yes or no for their presence. The short version contains 36 items using the same categories. Within each category, several subscales are measured. Characteristics of the child include items related to flexibility, demandingness, mood, distractibility/hyperactivity, acceptability of child to parent, and child's reinforcement of parent. Parenting and spousal concerns, or parent characteristics, include measures of depression, attachment to child, social isolation, sense of competence in the parenting role, relationship with spouse/parenting partner, role restrictions, and parental health (Abidin, 1995).

Several studies have been conducted on stress in families with a child with a disability using the Parenting Stress Index. For example, Smith, Oliver, and Innocenti (2001) studied levels of parenting stress in families with a toddler with a developmental delay. Eight-hundred, eighty

families were assessed with the Parenting Stress Index to measure perceived stress related to parenting, and the Family Support Scale and the Family Resource Scale to measure perceived support, time, and resources in the family. Smith et al. (2001) found that the more severe the child's disability and the fewer the family's resources, the greater the parent stress in the family.

Social Support

This section reviews social support and related research. It begins with definitions of social support, types of social support, gives examples of social support, how social support is measured, and then discusses the process of social support as a buffer to stress. Next, research related to the effects of different types of social support on families is reviewed, and lastly, a summary of the findings on social support is given.

Research has shown that social support is one positive coping strategy that can be powerful in reducing stress in a family system. Social support refers to "resources provided by those outside the family" and includes informational, instrumental, emotional/psychological, and physical/material support (Keller & Honig, 2004, p. 338). Dunst, Trivette, and Cross (1986) defined social support as "a multidimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support" (p. 119). Social support can also be described as the range of assistance that people give and receive from one another, and it is most often grouped into two major categories: emotional and instrumental. Social support research has also investigated both formal support and informal support.

Bristol and Schopler (1983) defined formal support as "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" (p. 252). They defined informal support as "a network

that may include the immediate and extended family, friends, neighbors, and other parents" (Bristol & Schopler, 1983, p. 252). Generally, informal support is the preferred mode of support over formal support (Boyd, 2002). Support from family, friends, and professionals has been shown to reduce stress and responses to stress (Dunst et al., 1990; Honig & Winger, 1997).

Informal support was studied by Benson (2006) in 68 parents of an elementary age child with autism spectrum disorder. Parents completed a questionnaire on the severity of their child's autism, the Effects of the Situation Questionnaire, the Family Support Scale, and the Center for Epidemiologic Studies Depression Scale. Benson (2006) found that parent depression and the accumulated effects of stress were reduced with the provision of informal support for parents.

House (1981) differentiated four different types of support: emotional, instrumental, informational, and appraisal. Emotional support refers to non-tangible assistance, such as listening, sympathy, empathy, encouragement, and praise. Emotional support from extended family and self-esteem were found to be predictive of mother's stress related to parenting (Trute, Worthington, & Hiebert-Murphy, 2008). Instrumental support refers to tangible assistance, such as childcare, housekeeping, transportation, or money. Informational support refers to the provision of information and resources, such as community agencies, professional advice, and online resources. Instrumental and informational support both provide non-emotional assistance and are often grouped together. Thus, across all studies social support is primarily characterized as emotional or instrumental.

Social support has been measured in a variety of ways, for example, in terms of the structure of support resources, by perceptions of the supportiveness of their relationships, by the number of individuals in the social support network, by the perceived quality of support, and by professional or nonprofessional categorization (Leavy, 1983). The most frequently used measure

of social support is perceived quality of support received and satisfaction with it (Osseiran-Waines, Nahid, Elmacian, & Sarkis, 1994).

The process by which support alleviates stress is not well understood or studied thoroughly. One theory that attempts to explain how social support alleviates stress is the "stress buffering hypothesis" (Cohen & Wills, 1985). Unlike the main effects hypothesis that states that social support has a positive effect on a family regardless of whether a family is experiencing stress, the buffering hypotheses states that social support has positive effects primarily for persons under stress (Cohen & Wills, 1985; Horton & Wallander, 2001). The stress buffering hypothesis affirms that when a person is in a great deal of stress, the benefits of social support are immense. It is presumed that when stress levels are low, coping skills are independent of social support and stress is thought to be more internally managed (Benson, 2006). Social support alone does not address all of the stressors in a family. It does, however, act as a buffering factor or moderator to the stress in a family. Other buffering factors include the repertoire and number of coping skills, parental or marital relations, stability of support, and problem-solving skill (Keller & Honig, 2004).

Several studies have looked at the relationship between the size of one's social support network and level of stress in a family. Hodapp, Findler, and Smith (1998) found that the size of the social support network was directly related to the stressors and stress levels in a family with a child with a disability. That is to say that larger support networks were related to lower levels of stress. In a study of use of respite care by mothers of children with disabilities, Salisbury (1990) found that the size of the social support network was negatively correlated with reports of stress. Mothers of children with disabilities who had larger support networks had fewer reports of stress than mothers of children with disabilities who had smaller support networks.

Social support has been studied as a buffering factor for families with a child with a disability (Boyd, 2002; Dunst, Trivette, & Cross, 1986; Tröster, 2001). Being the parent of a child with a disability involves stress and disequilibrium in the family system. To cope with the stress and imbalance, a parent must find ways to alleviate the stress and bring about homeostasis. One way to adapt to stress is via social support (Boyd, 2002). While social support can be a great source of coping in some families, mothers tend to use social support as a coping mechanism moreso than fathers. Barnett et al. (1987) and Cutrona (1996) studied gender differences in seeking social support and found that mothers are more likely to ask for and receive help from both formal and informal social support networks. Fathers were found to rely on mothers or their internal coping skills to manage stress.

In a study of support as a buffer for stress, Wade, Taylor, Drotar, Stancin, Yeates, and Minich (2004) assessed psychological distress and adjustment in 189 parents of children with a disability. The children in the study had traumatic brain injuries and/or orthopedic impairments and ranged from 6 to 12 years of age. Wade et al. (2004) used the Life Stressors and Social Resource Inventory, Family Burden of Injury Interview, and the Brief Symptom Inventory to assess resources, stressors, and psychological adjustment; they found that greater support and resources and fewer stressors were associated with less psychological distress.

While it is well documented that psychological distress is related to resources and support, Holahan and Moos (1985) studied factors that buffer the stress-based effect on physical health rather than mental health. Two-hundred and sixty-seven participants were separated in two groups based on their levels of stress and related distress: a Distressed Group (high stress, high distress) and a Stress Resistant Group (high stress, low distress). Surveys on health and daily living, psychosomatic symptoms and depression, negative life events, personality

characteristics, coping strategies, and family support were given. Holahan and Moos (1985) found that the members of the Stress Resistant Group had different stress adaptation skills than the members of the Distressed Group. Those in the Stress Resistant Group used more proactive coping techniques, had more self-confidence, and had better social support networks than those in the Distressed Group, and the members of the Distressed Group used more avoidance coping and had more physical illness than those in the Stress Resistant Group (Holahan & Moos, 1985). Therefore, not only was stress related to psychological distress as previously stated, but stress and avoidance coping tactics negatively affected physical health, as well.

While some families have poor or negative coping strategies, many families use positive coping strategies to address stress in their system. Positive coping strategies may include acceptance of the child's disability and feelings toward the child, obtaining help with routine care of the household and children, providing support and education to family members about the disability, maintaining an active social support system, utilizing resources in the community, and having faith (Kuster & Merkle, 2004).

Research shows that people who perceive a strong active social support network are healthier both physical and mentally (Dunst, Trivette, & Hamby, 1994; Hodapp, Fidler, & Smith, 1998). For example, social support from immediate and extended family, friends and professionals was found to ease the feelings of stress in families with a child with special needs (Hodapp et al., 1998). Thirty-six families with a child with Smith-Magenis syndrome between the ages of 4 and 12 were administered the Vineland Adaptive Behavior Scales, the Child Behavior Checklist, the Questionnaire on Resources and Stress, the Family Support Questionnaire, and the Sleep Questionnaire regarding their child. The most salient predictor of stress levels was the size of the support network of the family, wherein lower stress levels were

related to a larger network, particularly the family network.

As shown, informal and formal social support is helpful to families of children with special needs. In a study of stress and coping in 47 families with children with visual impairments between the ages of 8 months and 7 years, Tröster (2001) assessed the severity of the visual impairment, additional disabilities/illnesses, functional impairments, daily stress, parenting stress, and perceptions of social support. Social support was found to have a buffering effect on the stress that came from raising a child with a disability (Tröster, 2001). However, parents of children with a disability perceived lower levels of both emotional and instrumental support.

A family's need for support varies over time as they move through different phases of the life cycle. Eventually, a family may move from leaning on support from within the immediate family, to support from the extended family, to support from professional organizations, to support from the larger community, and even strangers (DeMarle & Le Roux, 2001). Two main reasons that mothers of children with autism seek social support are levels of stress and feelings of depression. Mothers stated that they first sought spousal support, then immediate and extended family support. Informal support was perceived as more valuable than formal support with relation to experiences of stress and depression. Of the formal supports assessed, parent support groups were rated most helpful, but were not used by all participants. Generally, mothers who had both informal and formal social support networks had more positive relationships with their children with special needs (Boyd, 2002).

Hassall and McDonald (2005) found that a mother's decision to utilize social support was related to both child characteristics and parent characteristics. Child characteristics that influenced the attainment of social support were challenging behaviors and cognitive limitations.

Forty-six mothers of children, ages 6 to 16, with severe cognitive limitations completed the Vineland Adaptive Behavior Scales, the Family Support Scale, the Parenting Sense of Competence Scale, the Parental Locus of Control Scale, and the Parenting Stress Index. Mothers of children with severe impairments reportedly experienced significantly more stress than mothers of children with mild to moderate cognitive limitations. While the size of the support network was relatively comparable between groups, the perceived helpfulness of the support from the network directly related to stress levels in the groups. Behavioral challenges can impact the ability to obtain support, in that it may be difficult to find childcare while gaining formal support.

While support is one coping strategy to reduce stress, Taanila, Syrjälä, Kokkonen, and Järvelin (2002) examined the different coping strategies of families with a child with a disability. Eight families of children between 8 and 10 years old with physical and/or intellectual disabilities were interviewed twice. Three main coping strategies emerged from the interviews: gaining knowledge and acceptance, increasing family functioning (cohesion, flexibility, cooperation), and relying on social support from both formal and informal sources. As in previous studies, social support in any form was found to be a strong buffer to stress.

Parenting stress has been inversely associated with social support and cohesive family relationships. Specifically, support and relationships that have open communication and expression of feelings without judgment have been related to better family functioning. Social support in the form of friends, non-relatives, and professionals is also associated with better family functioning, especially for mothers (DeMarle & Le Roux, 2001). Caplan (1974) hypothesized that social support can enhance social-emotional functioning, attainment of information, and physical assistance when needed. Holahan and Moos (1985) found a negative

relationship between parent social-emotional well-being and social support.

In summary, a critical component of any social environment that influences adjustment to a stressor is the quality of the social support of an individual and family. Several studies show that the presence of supportive people, both professional and nonprofessional, correlates inversely with negative psychological and physical symptoms and disorders (Cutrona & Russell, 1990; Dunst et al., 1994; Hobfoll & Freedy, 1990). Studies also show that social support correlates positively with physical and mental health, and moderates the effects of stressors on family functioning (Boyd, 2002; Salisbury, 1990). When stressors occur, social support can act as a buffer and reduce the likelihood of negative outcomes such as anxiety and depression. Social support as a buffer can advance the process of adaptation (Britner et al., 2003). Overall, social support is a powerful coping resource for parents with a child with a disability (Kuster & Merkle, 2003).

Grandparents

This section describes grandparents as critically important members of family systems. Family systems frameworks suggest that grandparent-grandchild relationships are likely to figure prominently in children's development. These influences are likely to be both direct and indirect. Grandparents are also important figures as socializing influences, sources of support, and as transmitters of the family's history and culture (King, Silverstein, Elder, Bengston, & Conger, 2003). In addition, grandparents serve as a positive influence in the lives of their grandchildren by taking on various roles, such as caregiver, playmate, storyteller, friend, advocate, advisor, and mentor (King et al., 2003).

Historically, grandparents have provided additional support for the family in times of need. For example, during the 1940s, grandparents were viewed as rescuers of families and

grandchildren during war and postwar family crises (Szinovacz, 1998). Many families experienced disruption during these years, either by temporary absence of a parent or by permanent dissolution of the marital relationship through death or post-war separation. Given these strains on the family, grandparents often assisted by providing extra support and help with childrearing.

The interest in contemporary grandparenting began in the late 1970s and early 1980s as rates of divorce and remarriage increased (Szinovacz, 1998). At the same time, researchers became more interested in the complex nature of multigenerational relationships as more grandparents were involved in caregiving roles. As a group, three fourths of all grandparent caregivers are married, but only 63% of the grandmother caregivers are married, and 93% of all single grandparent caregivers are women (Chalfie, 1994). Even in households where there are two grandparents, the grandmother usually assumes the caregiving duties.

Whereas grandparents are a welcome and positive presence in children's lives when family relationships are harmonious, the positive influence of grandparents may be enhanced under circumstances of family stress. Over the last decade, much of this public attention has centered on grandparents who assume parental responsibilities for their grandchildren. Similarly, grandparents are recognized for the active but temporary roles they assume during times of crises or special need. For example, Lussier, Deater-Deckard, Dunn, and Davies (2002) examined children's contact with and closeness with grandparents. Participants included 155 children, and interviews and questionnaires were administered to parents and children regarding the children's relationships with grandparents. Family differences in rate of contact with grandparents, and view about relationships were correlated. Greater closeness to grandparents was associated with fewer adjustment problems.

Grandmothers as Sources of Support

This section describes how grandparents, and grandmothers in particular, are a vital source of social support to families with a child with a disability. It begins with an overview of grandparents as social supports, and then moves into the different types of support provided, and closes with specific research related to grandmothers of children with disabilities as a source of support to the family system.

Research has shown that social support can often be found in the form of extended family. Until recently, the importance of the extended family, and in particular grandparents, has been largely overlooked as social support because the traditional definition of family implied a nuclear formation. Grandparents tackle numerous concerns and challenges in helping to raise and support their children and grandchildren (Jendrek, 1993). Parents with the active support of their kin generally have fewer mental health problems than parents without active support (Schilmoeller & Baranowski, 1998).

Grandparents provide a variety of supportive functions to their family, including practical help, emotional help, and financial help (Mitchell, 2007). Practical help can be seen as provision of childcare, help with errands or household chores, or escorts to and from errands such as doctor visits. Many grandparents assist in a parent's return to work by providing low-cost or free childcare (Mitchell, 2007). Emotional help consists of 'a shoulder to cry on,' active listening, empathy, nonjudgment, and love. Financial help consists of loans, gift-giving, and purchases made for the caregiver that directly relate to the grandchild.

Many studies show that grandparents' support, both practical and emotional is generally valued regardless of previous relationships (Baranowski & Schilmoeller 1999; Hornby & Ashworth 1994). Due to geographic proximity, health, and time, grandparents provide differing

extents of support. The provision of emotional support to a family is least affected by proximity and health (Baranowski & Schilmoeller, 1999). And with rapid changes in technology, emotional support may continue to be the most salient type of support that grandparents can provide when obstacles such as distance, time, and health are involved.

Being a grandparent to a child with a disability may be a different experience than being a grandparent to a child without a disability. As a phase of the life cycle, parents who become grandparents encounter new and wonderful experiences. Grandparenthood is often a joyous time of life, and a time to give back to the younger generations in a family. However, grandparents may have a difficult and less joyous approach to grandparenthood when a child is born with a disability. Research has revealed a period of mourning that accompanies the expected adjustments to having a grandchild when a grandchild is born with any special needs (Hastings, 2003). The act of balancing the sadness and grief with the joy and expectations of the birth of a grandchild with a disability is often influenced by well established patterns of interactions within the family system prior to the child's birth. When a grandparent has strained relationships with his/her children prior to the birth of the grandchild, the adjustment process can be very challenging (Schilmoeller & Baranowski, 1998).

Seligman, Goodwin, Paschal, Applegate, and Lehman (1997) examined perceptions of support from grandparents by mothers of a child with a disability. Forty-two mothers of children between the ages of 0 and 3 years old who had a variety of disabilities, including Down Syndrome, Cerebral Palsy, and developmental delays, completed a questionnaire regarding grandparent support. Seligman et al. (1997) found that grandmothers were rated as more supportive than grandfathers, and mothers perceived their own mothers to be more helpful than their mother-in-laws. Both maternal and paternal grandparents were reported to provide more

emotional support than instrumental support. Therefore, emotional support from maternal grandmothers seemed to be the most helpful of the supports studied.

Support in any form from a grandparent can also impact the parents' psychological well-being. Trute (2003) conducted a study to explore parents' perceptions of grandparents support and the impact of grandparent support on parent psychological adjustment in 59 mothers and 38 fathers of children with disabilities between the ages of 5 and 12 years old. The children in the study had a primary diagnosis of developmental delay, and many also had multiple handicaps and/or physical disabilities. Parents were individually administered the Parenting Stress Index, Brief Family Assessment Measure, Beck Depression Inventory, Rosenberg Self-Esteem Inventory, and Grandparent Support Index in a series of interviews. Trute (2003) found that the most significant predictor of parenting stress and psychological well-being was perceived levels of emotional support and involvement of their own mothers rather than mothers-in-law. Parents agreed that maternal grandmothers tended to supply more positive support than grandfathers. Unexpectedly, practical or instrumental support from grandparents did not show any relationship with parent psychological health (Trute, 2003).

Schilmoeller and Baranowski (1998) investigated how helpful and supportive grandparents were to their family with a child with a disability, and how helpful their support was perceived to be. Seventy grandparents (93% grandmothers) of children with Cerebral Palsy between the ages of 1 and 19 were interviewed on their concerns and worries about their grandchild, parent and support group helpfulness, affectional solidarity/proximity, and health status. In addition, the grandparents in the study completed the Grandparent Support Scale to assess types of support provided by the grandparents, and the Grandparent Involvement Scale to measure how helpful grandparents perceived themselves to be. Shilmoeller and Baranowski

(1998) found that the grandparents in the study reported providing emotional support most frequently, including listening, talking, answering questions, encouraging, and accepting the disability. Grandparents also reported providing instrumental support in the form of financial help, babysitting, and providing respite for the parents.

Further research on grandparents as primary supports to families with a child with a disability was conducted by Baranowski and Schilmoeller (1999). One-hundred and five mothers of a child with a disability between the ages of 1 month and 11 years old were assessed on their views of support, helpfulness, and involvement from grandparents in their lives. Disabilities included in the study ranged from developmental delays to physical anomalies. Parents completed the Grandparent Support Scale, the Family Support Scale, the Grandparent Involvement Scale, and a scale on affectional solidarity and residential proximity. The majority of mothers reported that maternal grandmothers were most supportive, helpful, and responsive to the needs of the mother. Support came in the forms of emotional support and instrumental support. Perceptions of support from paternal grandfathers were rated the least supportive and least involved.

With regard to types of involvement and support, Baranowski and Schilmoeller (1999) found that grandparents' provision of time and emotional support were perceived to be the most helpful types of support reported. Support from grandparents was also related to geographical proximity and emotional closeness to grandparents prior to the child's birth. Baranowski and Schilmoeller (1999) stated that "a grandparent was important mainly by virtue of *being* more than *doing*" (p. 440). Emotional support was valued more so than instrumental support, even when instrumental support was high. In fact, both maternal and paternal grandfathers reportedly gave more instrumental support, but maternal and paternal grandmothers' support, which by

nature was more emotional, was perceived as more helpful.

In a study of structural social support (size, range, and interconnectedness of contacts) and functional social support (emotional, instrumental, and informational) in 90 families with a child with Cerebral Palsy, Findler (2000) found that mothers of a child with Cerebral Palsy had higher professional support, but no differences were found between the groups on measures of nonprofessional support. Maternal grandmothers were rated the most important support in both groups, even above spouse. Mothers perceived receiving more emotional support from either grandparents than instrumental or informational support. Maternal grandparents were also rated more supportive than paternal grandparents, with paternal grandfather least supportive.

Mitchell (2007) outlined grandparent support research in the United Kingdom, and, as in the United States, grandparent support served different functions depending on the presence of a disability. When there is no disability in any child in the family, grandparent support was positive and found in the forms of practical support, such as informal childcare, emotional support, and financial support, especially from grandmothers. Grandparent support was negative when conflict or inappropriate support was provided. In families where a grandchild had a disability, grandparent support had increased practical purposes, including informal childcare, respite care, and domestic help. Emotional support was described in more detail as nonjudgmental advice, listening, and being there. A hierarchy of support was noted wherein maternal grandmother was the most supportive member outside of the nuclear family. All support in families with a child with a disability reported a reduction of stress related to the grandparent support, unless there was a bad relationship between grandparents and their children prior to the birth of the grandchild with a disability.

Scherman, Gardner, Brown, and Shutter (1995) studied ways in which grandparents

provided support to their grandchildren with a disability and their families. Scherman et al. (1995) interviewed 32 grandparents of children with disabilities, 63% of which were grandmothers. The grandchildren ranged in age from 20 months to 13 years and had disabilities such as mental retardation, metabolic/chromosomal disorders, autism, and severe attention deficit disorder. The study focused on assessing grandparents' knowledge of the disability, effect on grandparents' lives, and emotional response in the interview process. Sherman et al. (1995) found that "almost all the grandparents perceived their children as needing immediate support" (p. 265), which they provided in several forms. Some grandparents provided direct relief to their children while others directed their support toward their grandchildren. Few grandparents also sought personal support. The majority of grandparents stated that they provided emotional, practical, and financial support, and the minority of grandparents stated that they provided help for the siblings in the family, help through prayer, or information gathering. Emotional support took form as encouragement, calling frequently, and being available. Practical support took form as babysitting, hospital and doctor stays, and chores.

Gardner, Scherman, Mobley and Brown (1994) interviewed 32 grandparents to assess their involvement with their grandchild with a disability. Grandchildren's ages ranged from 20 months to 13 years and the majority of grandchildren had spina bifida. Other disabilities named by grandparents were metabolic/chromosomal disorders, mental retardation, autism, and attention deficit disorder. Gardner et al. (1994) looked at involvement, roles, and functions of grandparents, and conducted interviews in five areas: beliefs of role as a grandparent, grandparent/grandchild relationships, specific functions as grandparents, impact of roles on grandparent/grandchild relationship, and help in adjustment for family. Grandparent roles were reported to include twice as much direct contact with the grandchild (games, going for walks,

love, encouragement, attention). Direct parent contact also was reported and included babysitting, respite, and financial help. Other roles were transportation to doctor's appointments, school, parties, etc., medical and therapeutic interventions, and diet. The majority of grandparents reported emotional support as the strongest area (love, affection, and encouragement). However, one-fifth of the grandparents felt ineffective in providing support. Half of the grandparents in the study felt no change in the grandparent/grandchild relationship relative to the disability, yet half did feel a change in expectations (lowered) for the grandchild. Some grandparents "expressed concern or frustration that the nature of their grandchild's disability created additional tensions and reduced their patience in interacting with their grandchild" (p. 189).

In summary, grandparents, and grandmothers in particular, are unique and important sources of social support to families with and without a child with a disability. Research generally finds that grandparents' support is the most common form of familial support next to spousal support (Green 2001). Grandmothers are perceived as more supportive than grandfathers (Trute, 2003). More specifically, maternal grandmothers are perceived to be more supportive than paternal grandmothers (Trute, 2003). While families are changing constantly, grandparents continue to be a valued source of extended family and intergenerational relationships. Studies of grandparents continues to be a growing area of research, especially with regard to the support they provide (Mitchell, 2007; Trute, 2003).

Rationale for Current Study

Research has clearly shown that families are systems with complex reciprocal interactions. Systems theory views the family as a complex, open, and dynamic set of individuals and interactions, organized by a hierarchy of power, subsystems, and sets of rules

that the family changes depending on their stage of development (Nichols & Schwartz, 2004; Walsh, 2002). Change increases the stress in the family system, and the family acts as a self-regulating system that attempts to maintain homeostasis (Ritvo & Glick, 2002; Walsh, 2002). Most families pass through the stages of the family life cycle with adaptive outcomes; yet, some experience unforeseen stress or off-time changes and have a much more difficult time maintaining homeostasis in their system (Britner et al., 2003; DeMarle & Le Roux, 2001). One stressor on the family system is the birth of a child with a disability.

It has been well documented that stress in a family with a child with a disability may be related to stage in the life cycle, perceptions of the child and the disability, and environmental factors. Experiences of stress may also change over time, based on changing demands as the child and parents age (Britner et. al, 2003). Family functioning within a system has been shown to be affected by having a child with a disability, specifically with regard to cohesion and flexibility.

Using the Double ABCX model (McCubbin & Patterson, 1983), it has been shown that when systems are stressed, there are factors that affect response to stress. For example, the impact of the child with a disability as a stressor (A) is moderated by parental resources (B), and parental cognitions (C), which results in an outcome of stress or some other indicator of adjustment (X).

Much research has been conducted on a critical component of parental resources, social support, in both emotional and instrumental forms. Studies show that the presence of supportive people, both professional and nonprofessional, correlates inversely with negative psychological and physical symptoms and disorders (Cutrona & Russell, 1990; Dunst et al., 1994; Hobfoll & Freedy, 1990). Studies also show that social support correlates positively with physical and

mental health, and moderates the effects of stressors on family functioning (Boyd, 2002; Salisbury, 1990). Overall, social support is a powerful coping resource for parents with a child with a disability (Kuster & Merkle, 2003).

Finally, grandparents, and grandmothers in particular, are unique and important sources of social support to families with and without a child with a disability. Research generally finds that grandparents' support is the most common form of familial support next to spousal support (Green 2001). Grandmothers are perceived as more supportive than grandfathers (Trute, 2003).

While a great deal of research has been conducted separately on the family system, family functioning, parenting stress, a child with a disability, and grandparent social support, very little research has examined the impact that grandmother social support provision has upon family flexibility, family cohesion, and parenting stress when there is a child with a disability in the family. This is an important area of research due to the growing number of children born with a disability each year and the increased amount of support the child and family requires (Mitchell, 2007).

The present study examined differences in grandmother support, parenting stress, and family functioning from the perspective of mothers and grandmothers. Assessments of parenting stress, support, and family functioning typically rely on parents' opinions, usually through checklists, and most studies have examined young children and adolescents. This practice gives an incomplete picture since mothers are the primary caregivers in most cases, both physically and mentally, and grandparents, as part of the extended family system, have been overlooked as members of a parenting dyad in family functioning. In addition, the disability in young children has been shown to be more challenging initially rather than later on in the life cycle. Thus, mother and grandmother ratings probably have shared qualities and unique differences regarding

their child/grandchild with a disability and the effects of the disability on the family. There has been little study of mother–grandmother agreement in perceptions of support provided to young children with special needs; this study attempted to examine support, stress, and functioning in families with a child with a disability.

This study addressed two primary questions concerning family functioning, stress, and use of support in a sample of 53 mother-grandmother dyads with a child with a disability and without a disability, during the young childhood period of 2 to 12 years of age using the Double ABCX Model. Children between the ages 2 and 12 were chosen as the age range for the current study because the age range falls in the "Parenting Young Children" stage of the family life cycle where there are similar challenges and goals. Infants and adolescents were excluded from the current study because they are in different life cycle stages and have dissimilar expected stressors. The proposed study asked the following research questions: 1) Do families with a child with a disability differ from non disability families with regard to grandmother support, family functioning, and parental stress? 2) What are the relationships among grandmother support, family functioning, and parental stress in families with a child with a disability?

Hypotheses

Hypothesis 1: There will be a positive relationship between grandmother support and family functioning, such that high levels of grandmother support are associated with balanced flexibility and balanced cohesion.

Hypothesis 2: Levels of grandmother support will be negatively correlated with levels of parenting stress, such that high rates of support will be associated with low levels of parenting stress.

Hypothesis 3: Support scores from the Child with a Disability group will be higher than the

support scores of the Child without a Disability group, such that levels of support by mother and grandmother of a child with a disability will be higher than levels of support by mother and grandmother of a child without a disability.

Hypothesis 4: Greater levels of emotional support than instrumental support will be found in both groups, such that higher levels of emotional support will be perceived by mothers and grandmothers in the Child with a Disability group and the Child without a Disability group.

Hypothesis 5: Family functioning scores from the Child with a Disability group will be lower than the family functioning scores of the Child without a Disability group, such that scores of flexibility and cohesion of mothers with a child with a disability will be lower than scores of flexibility and cohesion of mothers of a child without a disability.

Hypothesis 6: Parenting stress scores from the Child with a Disability group will be higher than parenting stress scores of the Child without a Disability group, such that parenting stress scores of mothers with a child with a disability will be higher than parenting stress scores of mothers with a child without a disability.

CHAPTER 3

Methodology

Participants

Participants were from a suburban county in a northeastern state. There are approximately 1.5 million residents in the suburban area, 6.1% of whom are under 5 years old and 24.2% of whom are under 18 years old. There are slightly more female than male residents (50.6% female), and the majority of residents are Caucasian/White (87%). Less than one fifth of the residents speak a language other than English (17.1%). The majority of residents have graduated from High School (86.2%), and 27.5% have a college degree. The average household income is about $83,000. Last, there are approximately 283,000 county residents who have a disability. No information was available on the exact number of residents under five years of age who have a disability.

Mothers and grandmothers of at least one child (ages 2 through 12 years) with a disability were asked to participate in the current study. Mothers and grandmothers of at least one child (ages 2 through 12 years) without a disability were also asked to participate in the current study, as a control group. The above participants who have a child with a disability comprised the "Child with a Disability" group. The above participants who have a child without a disability comprised the "Child without a Disability" group.

Participants were recruited via flyers hung at several libraries, schools, preschools, daycare centers, parent-child community programs (such as Gymboree), and pediatrician's offices (see Appendix A). In the flyer, mothers and grandmothers were asked to call the researcher directly to volunteer. A packet was then mailed to the participant that contained separate surveys for the mother and grandmother, including a consent form, a demographic

questionnaire, the Family Adaptability and Cohesion Evaluation Scale (4th Edition) (Olson, Gorall, & Tiesel, 2004), the Parenting Stress Index (3rd Edition) (Abidin, 1995), and the Social Support Scale (Dunst & Trivette, 1986). Participants returned the packets in preaddressed, postage-paid envelopes.

Fifty-three mother-grandmother dyads participated in this study. Twenty-two dyads were in the "Child with a Disability" group, and the remaining thirty-one dyads were in the "Child without a Disability" group. Five dyads were excluded because only the mother or grandmother completed the survey, but their counterpart did not. Only complete dyad information was used for the current study. Participants were dominant in both reading and speaking English.

Culturally, the participants represent the norms of the county, being predominantly Caucasian/White and from middle-class SES areas. However, the group also had a number of participants that were of African American/Black or Hispanic descent and from either upper middle class SES or low SES areas making the groups heterogeneous. The participants in the current study are also more diverse than those reported in the testing manuals used in this study, for example, the research sample of the Support Functions Scale consisted of only parents of preschool aged children with a disability, while the current study expanded the use of the Support Functions Scale to include parents of older children with and without a disability.

Mothers' ages ranged from 22 years to 45 years, with a mean of 34.49 years. All mothers were the biological mothers of their children. Of the 53 dyads, 95.35% of the participants were from homes with two biological parents, and the remaining participants had single parent households. There was an average of 2.14 children in the home. Grandmothers' ages ranged from 47 years to 82 years, with a mean of 60.19 years. Of the 53 grandmothers, 79.07% were maternal grandmothers and 16.28% were paternal grandmothers. Grandmothers lived between 0

and 2,835 miles from mothers in the study, with a mean of 91.8 miles. Grandmothers reported having an average of 3.51 grandchildren. The target children reported on in the study were comprised of 52.83% boys and 47.16% girls. In the Child without a Disability group, 48.39% were boys and 51.61% were girls, and in the Child with a Disability group, 59.09% were boys and 40.91% were girls. Approximately 39.5% of the children were school-aged, and 60.5% were nonschool-aged.

Descriptive Analysis

The background questionnaire supplied information regarding each member of the dyads, including age, structure, number of children, age of target child, presence or absence of a disability, type of disability if present, education level of adult, income of household, and ethnicity. Group differences on these variables were examined using *t*-tests and chi-square statistics. In the "Child with a Disability" group, 22 dyads completed questionnaires. In the "Child without a Disability" group, 31 dyads completed questionnaires. While 200 dyads were sent questionnaires, 53 dyads completed the questionnaires, making the response rate 26.5%.

While several disability classifications were represented in the current study, the most common disability classification noted was Preschooler with a Disability (n = 5). Additional disabilities reported were: Attention Deficit Hyperactivity Disorder (n = 4), Speech and Language Impairment (n = 4), Learning Disability (n = 4), Down Syndrome (n = 2), Autism (n = 1), Mental Retardation (n = 1), and Multiple Disabilities (n = 1).

Age of Target Child, Mothers and Grandmothers

The target child for each dyad ranged in age from 2 years to 12 years old. Distributional summaries in Table 1 demonstrate similarities in the ages of corresponding mothers and grandmothers between the two groups. A series of *t*-tests revealed no significant differences

between groups for the age of mothers (t (53) = -.68, p = .66) and grandmothers (t (53) = 1.78, p = .43). However, significant differences were found between the ages of the target child between groups (t (53) = 2.86, p = .0001), wherein children in the Disability group were older than children in the Non-disability group.

Table 1

Ages of Mothers, Grandmothers, and Target Child by Group Status

	Child with a Disability Group (n = 22)			Child without a Disability Group (n = 31)		
Family Member	Mean	*SD*	Range	Mean	*SD*	Range
Mother's Age	34.09	6.59	22-45	34.77	4.65	28-45
Grandmother's Age	61.23	9.15	49-82	59.45	7.06	48-82
Target Child's Age	6.41	3.08	2-12	3.55	1.99	2-11

Demographic Variables: Education, Income, and Ethnicity

Education level, income range, and ethnicity of families were compared across the two groups. Table 2 summarizes frequency distributions for mothers' and grandmothers' highest level of education achieved. Based on the Fisher's exact test, no differences in educational level were found between the two groups (p > .05).

Table 2

Highest Level of Education Achieved for Mothers and Grandmothers by Group Status

	Mothers		Grandmothers	
Education Level	Child with a Disability Group (n = 22)	Child without a Disability Group (n = 31)	Child with a Disability Group (n = 22)	Child without a Disability Group (n = 31)
Some H.S.	2	0	0	1
High School	6	3	9	12
Some College	1	5	7	9
College	3	5	5	3
Advanced Degree	10	18	1	6
Fisher's exact test	p = .144		p = .376	

Table 3 shows that a majority of participating families identified themselves as White/Caucasian. The remaining families were identified as Black/African American or Other. No between-group differences were found based on the reports of ethnicity ($p > .05$).

Table 3

Ethnicity Identified by Mothers and Grandmothers by Group Status

	Mothers		Grandmothers	
Ethnicity	Child with a Disability Group (n = 22)	Child without a Disability Group (n = 31)	Child with a Disability Group (n = 22)	Child without a Disability Group (n = 31)
Black/African American	3	1	3	2
White/ Caucasian	18	28	18	29
Other	1	2	1	0
Fisher's exact test	p = .475		p = .246	

A majority of mothers reported an annual household income of over $100,000 and a majority of grandmothers an annual household income of $70,000 to $100,000 (see Table 4). No statistical differences in income were found in the income level of mothers ($p > .05$). However,

the distribution of income for grandmothers appears to be higher in the no disability group compared to the group with a disability (p = .052). This is consistent with research on low participation rates from families in lower SES ranges as reported by Galea & Tracy, (2007).

Table 4

Annual Income Identified by Mothers and Grandmothers by Group Status

	Mothers		Grandmothers	
Annual Income Level	Child with a Disability Group (n=22)	Child without a Disability Group (n=31)	Child with a Disability Group (n=22)	Child without a Disability Group (n=31)
<$10,000	3	0	5	2
$10,000-$30,000	3	2	1	3
$30,000-$50,000	3	2	3	4
$50,000-$70,000	2	3	0	8
$70,000-$100,000	4	6	6	9
>$100,000	7	18	7	5
Fisher's exact test	p = .182		p = .052	

In summary, descriptive analyses revealed that families in the Child with a Disability and the Child without a Disability groups were comparable on most family demographic variables, such as mother age, grandmother age, ethnicity, and highest level of education. Differences were observed on target child age and yearly income.

Instruments

Mothers in this study completed the Background Questionnaire, the Family Adaptability and Cohesion Evaluation Scales (4th Edition) (Olson, Gorall, & Tiesel, 2004), the Support Functions Scale (Dunst & Trivette, 1986), and the Parenting Stress Index (3rd Edition) (Abidin, 1995). Grandmothers completed only the Background Questionnaire and the Support Functions

Scale.

The Background Questionnaire

The Background Information for Mothers (see Appendix C) asked for information about each of the following characteristics: maternal age, marital status, family structure, number of children, target child's age, target child's gender, presence of disability in child, type of disability, maternal education, family income, urban/suburban/rural area, and ethnicity/race. The Background Information for Grandmothers (see Appendix H) asked for information on the following characteristics: grandmother age, marital status, family structure, number of grandchildren, target grandchild's age, target grandchild's gender, presence of disability in child, type of disability, grandmother education, family income, urban/suburban/rural area, and ethnicity/race.

The Family Adaptability and Cohesion Evaluation Scales, 4th Edition

The Family Adaptability and Cohesion Evaluation Scales, 4th Edition (FACES IV) (Olson, Gorall, & Tiesel, 2004) were used to assess the cohesion and flexibility of members in a family based on Olson's Circumplex Model of family functioning (see Appendix D). Six scales are included: Balanced Cohesion, Balanced Flexibility, Disengaged Cohesion, Enmeshed Cohesion, Rigid Flexibility, and Chaotic Flexibility. Each scale has seven items making the entire assessment form 42-items long. A profile is then provided which can be used to plot the scales.

All scales have very good levels of reliability and validity. Reliabilities of the six FACES IV scales are as follows: Disengaged = .87, Enmeshed = .77, Rigid = .83, Chaotic = .85, Balanced Cohesion = .89, Balanced Flexibility = .80. Alpha reliability analysis was also run for the validation scales and ranged from .91 to .93.

Validity studies comparing the FACES IV to similar measures, such as the Self-Report Family Inventory, Family Satisfaction Scale, and the Family Assessment Device, showed that scales designed to measure balanced cohesion and flexibility had large positive correlations with validity scales (range = .89 to .99), while the scales designed to measure the low extreme of cohesion and the high extreme of flexibility had large negative correlations with the validation scales (range = -.67 to -.93) (Craddock, 2001; Franklin, Streeter, & Springer, 2001).

The FACES-IV is scored by converting sums of scores for the six scales and supporting subscales into percentiles. Balanced levels of Cohesion range from 16% to 85%, while the extremes (0-15% and 86-100%) are considered unbalanced. Flexibility ranges also vary from 16% to 85%, and the extremes are considered unbalanced.

All six converted scales provided in the FACES IV were used to assess range of family functioning in both the "Child with a Disability" group and the "Child without a Disability" group. Total converted scores were also compared for the groups. Ratio scores were used to compare the relative amount of balanced versus unbalanced characteristics between the two groups. Raw scores were not used for analyses, and only percentiles were used for comparison purposes.

The Support Functions Scale

The Support Functions Scale (Dunst & Trivette, 1986), a self-report measure, was used to determine the types of help needed as per mother's report (see Appendix F) and assistance provided as per grandmother's report (see Appendix I). The extended version was used for the current study, which includes 20 items (compared to the 12-item short-form). Mothers were asked to rate their need for financial, emotional, instrumental, and informational support on a five-point scale ranging from never (1) to quite often (5). Grandmothers were asked to rate their

provision of financial, emotional, instrumental, and informational support on the same five-point scale. Information was grouped into two subscales for the current study, Emotional and Instrumental.

Research on the development of the Support Functions Scale showed reliability to be moderate to high. In particular, internal consistency reliability (Cronbach's alpha) was .87; split-half reliability (using the Spearman-Brown formula) was .88; test-retest reliability (1-month interval) was .91. In validity studies conducted by the authors (Dunst & Trivette, 1986), the Total score (20-item scale) was found to be the best predictor in validity studies. Concurrent validity was assessed by comparing the above scale to the other measures of family well-being, personal well-being, and time demand on respondent (Dunst & Trivette, 1986; McCubbin & Patterson, 1983; Trivette & Dunst, 1992). Family well-being (correlation = .27) and personal well-being (correlation = .33) were significantly related to support. While financial support was significantly related to family well-being (correlation = .27), emotional support (correlation = .17), and instrumental support (correlation = .29) were significantly related to personal well-being.

The Support Functions Scale was scored by summing the total of all endorsed items, with a range from 0-100. High scores are associated with high levels of support needed or provided, while low scores are associated with a lack of support needed or provided. The total score was used to compare mother's need for support to grandmother's provision of support, and the relationships between the mother's need for support and grandmother's provision of support was compared between the "Child with a Disability" and "Child without a Disability" group. In addition, several items were used to assess emotional support (items 1, 4, 6, 8, 10, 13, 14, 16, and

18) while others were used to assess instrumental support (items 2, 3, 5, 7, 9, 11, 12, 15, 17, 19, and 20).

Parenting Stress Index

The Parenting Stress Index (3rd Edition) (Abidin, 1995) was used to assess perceived levels and types of stressors involved in raising a child (see Appendix E). It is a 120-item self-report that measures stress in two categories, Child Domain and Parent Domain. The Child Domain has 47 items that examine adaptability, demandingness, mood, distractibility/hyperactivity, acceptability of child to parent, and child's reinforcement of parent. The Parent Domain has 54 items that include measures of depression, attachment to child, social isolation, sense of competence in the parenting role, relationship with spouse/parenting partner, role restrictions, and parental health. Both the Child Domain and Parent Domain are rated on a 5-point Likert scale. A third category, Life Stress, has 19-items which are rated yes or no for their presence.

Internal consistency reliability is satisfactory: the Child Domain reliability is .90, Parent Domain reliability is .93, and the reliability for the Total Score is .95. Subscale reliability ranges from .70-.83 for the Child Domain and .70-.84 for the Parent Domain. Test-retest reliabilities on the Total Score over 1-3 months is .96 and over one year is .65.

The PSI has strong validity. In a study using the PSI, alpha for the total parent domain ranged from .83 to .86 and from .80 to .84 for the total child domain (Benzies, Harrison & Magill-Evans, 2004).

The PSI is scored by converting sums of scores for the 13 measures above into percentiles. In addition, sums of Domain scores are calculated for the Child and Parent areas, and are converted into percentiles. A Total Score is the sum of the Child Domain and Parent

Domain scores, and the sum is converted into a percentile. Last, the Life Stress score is a sum of 19 items and the sum is converted into a percentile. High scores are associated with higher levels of stress, and low scores are associated with lower levels of stress.

The Total Score was used to compare overall levels of stress between the "Child with a Disability" group and the "Child without a Disability" group. The Parent Domain score was used to compare the levels of stress experienced internally by mothers in the "Child with a Disability" group to the mothers in the "Child without a Disability" group. The Child Domain score was used to compare the stressors the mothers experience related to their child's characteristics in both the "Child with a Disability" and "Child without a Disability" groups. In addition, all subscale scores were used to compare differences in flexibility, demandingness, mood, distractibility/hyperactivity, acceptability of child to parent, child's reinforcement of parent, maternal depression, maternal attachment to child, maternal social isolation, maternal sense of competence in the parenting role, maternal relationship with spouse/parenting partner, maternal role restrictions, and maternal health for both groups.

For the current study, coefficients of reliabilities were calculated to be .94 for the Parenting Stress Index, .68 for the Family Adaptability and Cohesion Evaluation Scale-IV, and .92 for the Support Functions Scale.

Procedure

Both mothers and grandmothers were recruited via flyers hung at several libraries, schools, preschools, daycares, parent-child community programs (such as Gymboree), and pediatrician's offices in suburban areas of Suffolk County, New York (see Appendix A). In the flyer, mothers and grandmothers were asked to call the researcher directly to volunteer for the current study.

A packet was then mailed to the participant that contained two more packets, one for the mother and one for the grandmother. For both the "Child with a Disability" group and the comparison group, mothers were given a letter of consent and an overview of the current study (see Appendix B). The mothers were then asked to complete a demographic questionnaire (see Appendix C), the FACES-IV (see Appendix D), the Parenting Stress Index (see Appendix E), and the Social Support Scale (see Appendix F). Each mother was also asked to solicit a grandmother in the family, and was given a packet of information to give to the grandmothers. For both groups, grandmothers were given a letter of consent and an overview of the current study (see Appendix G). The grandmothers were then asked to complete a demographic questionnaire (see Appendix H) and the Social Support Scale (see Appendix I). Participants were instructed that the packets were to be completed independent of one another.

Once complete, participants were asked to return the packet in a preaddressed, postage-paid envelope. Each mother who returned a completed packet was mailed a $20.00 gift card to a popular local store (such as Target), and each grandmother who returned a completed packet was mailed a $10.00 gift card to the same store. Mothers were provided with a greater incentive due to the lengthier packet of questionnaires required for the current study.

Chapter IV

Results

This results section provides a summary of the statistical findings of the current study, including the research design, overall group differences, and hypothesis testing for each separate hypothesis.

Hypothesis Testing

Research Design

The research design is a quasi-experimental static-group comparison design. The presence of a disability and level of grandmother support serve as independent variables, and family functioning (flexibility and cohesion), social support, and parenting stress serve as dependent variables. Mother/grandmother dyads with a child with a disability are compared on the above measures to a control group of mother/grandmother dyads with a child without a disability.

Data Analysis

Statistical analyses for testing the hypotheses included Bivariate Pearson correlations, independent sample *t*-tests, ANOVA and MANOVA. Table 5 provides the means and standard deviations of mothers' responses on the Parenting Stress Index. Results showed significant differences between groups on the total stress rated, parent stress score, and child stress score, with higher means in the Child with a Disability Group. Similar scores were found between groups with regard to life stress scores.

Table 5

Means and Standard Deviations of Mothers' Responses on the PSI

	Child with a Disability Group (n = 22)			Child without a Disability Group (n = 31)		
PSI Score	Mean	*SD*	Range	Mean	*SD*	Range
Total Score	61.23	32.61	12-99	26.00	21.53	1-82
Parent Score	53.00	31.37	8-99	28.71	22.52	3-75
Child Score	68.23	32.22	7-99	28.32	21.66	2-85
Life Score	48.68	36.05	1-99	40.36	31.83	1-99

Note. PSI = Parenting Stress Index. Scores are percentiles, and higher scores indicate greater levels of stress.

Table 6 provides the means and standard deviations of mothers' responses on the Family Adaptability and Cohesion Evaluation Scales. Mothers in the Child with a Disability Group had mean Cohesion scores in the "very connected" range, and mothers in the Child without a Disability Group had mean Cohesion scores in the "connected" range. Both groups of mothers had mean Flexibility scores in the "somewhat flexible" range.

Table 6

Means and Standard Deviations of Mothers' Responses on the FACES-IV by Group Status

	Child with a Disability Group (n = 22)			Child without a Disability Group (n = 31)		
FACES Scale	Mean	*SD*	Range	Mean	*SD*	Range
Balanced Cohesion	69.91	25.36	20-95	65.07	28.68	10-95
Balanced Flexibility	35.23	18.55	10-70	31.23	17.78	10-83

Note. FACES-IV = Family Adaptability and Cohesion Evaluation Scales (4th Edition). FACES Balanced Cohesion scores (percentiles): 86-100=enmeshed, 66-85= very connected, 36-65=connected, 16-35= somewhat connected, and 0-15= disengaged. FACES Balanced Flexibility scores: 86-100=chaotic, 66-85 =very flexible, 36-65= flexible, 16-35= somewhat flexible, and 0-15 = rigid. Midrange scores (percentiles between 16 and 85) indicated more balanced cohesiveness and flexibility.

Table 7 provides the means and standard deviations of mothers' and grandmothers'

responses on the Support Functions Scale. Similar scores were found between groups amongst both mothers' and grandmothers' scores.

Table 7

Means and Standard Deviations of Mothers' and Grandmothers Responses on the Support Functions Scale by Group Status

	Child with a Disability Group (n = 22)			Child without a Disability Group (n = 31)		
	Mean	*SD*	Range	Mean	*SD*	Range
Mother	54.50	11.50	34-79	52.81	19.29	30-98
Grandmother	61.18	16.03	33-93	57.71	13.99	37-83

Note. Scores are summed raw scores, and higher sums indicate higher levels of support received by mothers and provided by grandmothers.

Hypothesis 1: There will be a positive relationship between grandmother support and family functioning, such that high levels of grandmother support are associated with high levels of balanced cohesion and balanced flexibility.

Bi-variate correlations compared mother support scale total, grandmother support scale total, and mother family functioning ratings. Table 8 provides information on these variables. A statistically significant coefficient was found between the Balanced Flexibility scale of the FACES-IV and grandmother Support Functions Scale total ($r = .297$, $p = 0.05$). All remaining correlations were not statistically significant.

Hypothesis 1 was partially supported. Grandmother overall support was associated with family flexibility, but not with cohesion.

Table 8

Pearson Correlations Between FACES-IV Total Scores and Support Scale Totals (with 95% Confidence Intervals)

	Mother Support Total	Grandmother Support Total
Mother FACES Total	.164 (-.123; .426)	-.015 (-.295; .267)
Grandmother FACES Total	.103 (-.373; .184)	.297 (.017; .534)*

Note. FACES = Family Adaptability and Cohesion Evaluation Scales.
* Significant at 0.05 level (two tailed)

Hypothesis 2: Levels of grandmother support will be negatively correlated with levels of parenting stress, such that high rates of support will be associated with low levels of parenting stress.

Bi-variate correlations compared support scale totals and parenting stress ratings. Table 9 provides information on these variables. A statistically significant coefficient was found between the Grandmothers's Support Functions Scale total score and the Parenting Stress Index (PSI) Life Stress total ($r = .317$, $p = 0.05$). All remaining variables were not statistically significant.

Hypothesis 2 was partially supported. Grandmother overall support was inversely related with Life stress, but not with parenting stress, child stress, or overall stress.

Table 9

Pearson Correlations between Support Scale Totals and PSI Totals (with 95% Confidence Intervals)

	Mother Support Total	Grandmother Support Total
PSI Total Score	.13 (-.15; .40)	.13 (-.16; .39)
PSI Parent Score	.19 (-.09; .45)	.13 (-.16; .39)
PSI Child Score	.06 (-.22; .34)	.11 (-.18; .38)
PSI Life Score	.12 (-.17; .39)	.32 (.04; .55)*

Note. PSI = Parenting Stress Index.
* Significant at 0.05 level (two tailed)

Hypothesis 3: Support scores from the Child with a Disability group will be higher than the support scores of the Child without a Disability group, such that levels of support by mother and grandmother of a child with a disability will be higher than levels of support by mother and grandmother of a child without a disability.

Multiple Analysis of Variance (MANOVA) was performed to address this question. The two outcome variables were Support Functions Scale Total Score, reported by mothers and grandmothers. The predictor was the child disability status with two levels (disability and no disability). The summary statistics for those two groups are provided in Table 10. No statistical differences were found between the groups on the two outcome variables ($p > .05$).

Table 10

Means and Standard Deviations of Support Functions Scale Totals by Group Status

Support Functions Total Score	Child with a Disability Group (n = 22)		Child without a Disability Group (n = 31)	
	M	*SD*	*M*	*SD*
Mother	54.50	11.50	52.81	19.29
Grandmother	61.18	16.03	57.71	13.99

Note. Scores are summed raw scores, and higher sums indicate higher levels of support received by mothers and provided by grandmothers.

The value of the Hotteling-Lawley test was estimated to be .017, and the overall F statistics (2, 51) = .424 with the corresponding p value of .657. Therefore, Hypothesis 3 was not supported.

Hypothesis 4: Greater levels of emotional support than instrumental support will be found in both groups, such that higher levels of emotional support will be perceived by mothers and grandmothers in the Child with a Disability group and the Child without a Disability group.

MANOVA was performed to test whether there were differences between the Child with a Disability and the Child without a Disability groups on any of the four outcome variables: Emotional Support based on mother and grandmother reports on the Support Functions Scale and Instrumental Support based on mother and grandmother reports on the same scale. As seen in Table 11, no differences were found.

Table 11

Means and Standard Deviations of Types of Support on the Support Functions Scale by Group Status

Support Functions Scale Scores	Child with a Disability Group (n = 22)		Child without a Disability Group (n = 31)	
	M	*SD*	*M*	*SD*
Mother Emotional	28.73	9.85	27.29	6.73
Mother Instrumental	34.41	7.69	32.48	8.40
Grandmother Emotional	25.77	6.87	25.61	10.59
Grandmother Instrumental	27.77	9.79	25.23	8.09

Note. Scores are summed raw scores, and higher sums indicate higher levels of support received by mothers and provided by grandmothers.

The value of the Hotteling-Lawley test was estimated to be .032, and the overall F statistic (4, 49) was .384 with the corresponding p value of .819. Therefore, Hypothesis 4 was not supported.

Hypothesis 5: Family functioning scores from the Child with a Disability group will be lower than the family functioning scores of the Child without a Disability group, such that scores of flexibility and cohesion of mothers with a child with a disability will be lower than scores of flexibility and cohesion of mothers of a child without a disability.

A MANOVA analysis was performed to test whether there were differences between the Child with a Disability group and the Child without a Disability group on the FACES-IV measure of flexibility and cohesion. Table 12 shows that no differences were found ($p > .05$).

Table 12

Means and Standard Deviations of FACES-IV by Group Status

	Child with a Disability Group (n = 22)		Child without a Disability Group (n = 31)	
FACES Scores	*M*	*SD*	*M*	*SD*
Balanced Flexibility	35.23	18.55	31.22	17.78
Balanced Cohesion	68.91	25.36	65.07	28.68

Note. FACES-IV = Family Adaptability and Cohesion Evaluation Scales (4th Edition). FACES Balanced Cohesion scores (percentiles): 86-100=enmeshed, 66-85= very connected, 36-65=connected, 16-35= somewhat connected, and 0-15= disengaged. FACES Balanced Flexibility scores: 86-100=chaotic, 66-85 =very flexible, 36-65= flexible, 16-35= somewhat flexible, and 0-15 = rigid. Midrange scores (percentiles between 16 and 85) indicated more balanced cohesiveness and flexibility.

The value of the Hotteling-Lawley test was estimated to be .014, and the overall *F* statistic (2, 51) was .351 with the corresponding *p* value of .706. Therefore, Hypothesis 5 was not supported.

Hypothesis 6: Parenting stress scores from the Child with a Disability group will be higher than parenting stress scores of the Child without a Disability group, such that parenting stress scores of mothers with a child with a disability will be higher than parenting stress scores of mothers with a child without a disability.

A MANOVA was run to investigate whether there were differences in stress levels between the Child with a Disability group and the Child without a Disability group. The overall Hotteling-Lawley test was found to be significant, F (4, 49) = 7.326, $p < .001$. Specifically, the differences were found in the following indicators of stress: Total, Parent, and Child. Table 13 shows the specific *F* values for each individual outcome variable. Therefore, Hypothesis 6 was supported.

Table 13

Means, Standard Deviations and ANOVAS of PSI Totals by Group Status

	Child with a Disability Group (n = 22)		Child without a Disability Group (n = 31)		ANOVA F test
PSI Scores	*M*	*SD*	*M*	*SD*	
Total	61.23	32.61	26.00	21.53	F = 22.47 (p < .001)*
Parent	53.00	31.37	28.71	22.51	F = 10.79 (p = .002)*
Child	68.23	32.22	28.32	21.66	F = 29.13 (p <.001)*
Life	48.68	36.05	40.36	31.83	F = 0 .79 (p = .379)

Note. PSI = Parenting Stress Index. Scores are percentiles, and higher scores indicate greater levels of stress.
* = significant

An overall Multiple Analysis of Variance (MANOVA) compared the groups on all variables of interest: Total Support, Flexibility, Cohesion, Total Stress, Parent Stress, Child Stress, and Life Stress. The overall Pillai test yielded the value of 0.438, which was significant at the alpha level of .01 (F (10, 43) = 3.2663), demonstrating a presence of group differences on at least one of the outcomes.

Table 14

Means and Standard Deviations of FACES Scales by Group Status

	Child with a Disability Group (n = 22)		Child without a Disability Group (n = 31)	
FACES Scale	*M*	*SD*	*M*	*SD*
Balanced Cohesion	70.10	25.10	65.69	28.59
Balanced Flexibility	33.60	17.91	28.56	18.61
Communication	62.55	25.41	65.52	26.02
Satisfaction	54.14	26.16	55.16	27.58

Note. FACES-IV = Family Adaptability and Cohesion Evaluation Scales (4th Edition). FACES Balanced Cohesion scores (percentiles): 86-100=enmeshed, 66-85= very connected, 36-65=connected, 16-35= somewhat connected, and 0-15= disengaged. FACES Balanced Flexibility scores: 86-100=chaotic, 66-85 =very flexible, 36-65= flexible, 16-35= somewhat flexible, and 0-15 = rigid. Midrange scores (percentiles between 16 and 85) indicated more balanced cohesiveness and flexibility.
* = significant

An overall Multiple Analysis of Variance (MANOVA) compared the groups on four dimensions of the Family Adaptability and Cohesion Evaluation Scale (4th Ed.). The value of the Pillai test was estimated to be 0.054. The overall F statistics (4, 49) = 0.684 with the corresponding p value of 0.607. Thus, no differences exist on any of the four outcomes.

Individual group comparisons were further pursued to find out specific variables that were different between the two groups. Results of individual analyses of variance (ANOVAS) are summarized in Table 15.

Table 15

Results of Individual Group Comparisons (ANOVAS) for Support, Cohesion, Flexibility and Stress

	F Statistics (df = 1, 52)	*p* value
SFS Mother Emotional Support	0.35	.556
SFS Grandmother Emotional Support	0.17	.684
SFS Mother Instrumental Support	0.01	.921
SFS Grandmother Instrumental Support	1.07	.306
FACES Balanced Cohesion	0.25	.616
FACES Balanced Flexibility	0.63	.432
PSI Total	10.79	<.001*
PSI Parent	10.79	.002*
PSI Child	29.13	<.001*
PSI Life	0.79	.379

Note. SFS = Support Functions Scale; FACES = Family Adaptability and Cohesion Evaluation Scale (4th Ed.); PSI = Parenting Stress Index.
* = significant

As shown earlier, only the scores on the Parenting Stress Index for Total Stress, Parent Stress, and Child Stress were found to be significant between the Child with a Disability and Child without a Disability groups. In sum, grandmother support was positively correlated with mother's balanced flexibility and negatively correlated with mother's life stress, and total stress, parent stress and child stress were found to be higher in families with a child with a disability; however, support was not found to be significantly different between families with a child with and without a disability, types of support were not found to be significantly different between groups, overall family functioning was not found to be significantly different between groups.

Chapter V

Discussion

This study investigated the influence of grandmother support on family functioning and parenting stress in families with a child with and without a disability. It was hypothesized that families with a child with a disability would have more unbalanced levels of family functioning, greater stress, and require more support than families with a child without a disability. Families in both groups in the current study showed similar levels of flexibility, cohesion, and support. However, the two groups differed in their levels of parenting stress.

Parenting Stress

Stress has been found to be higher in families with a child with a disability than in families with a child without a disability (Smith, Oliver, & Innocenti, 2001). It was expected that stress involving parenting dynamics, child dynamics, and major life events would be greater for families with a child with a disability than for families with a child without a disability. There were group differences in ratings of total stress, parent stress, and child stress. Overall stress ratings for families with a child with a disability were, indeed, higher than total stress ratings for families with a child without a disability in the current study, in part due to both increased parent stress and child stress.

Parent stress, as measured by the Parenting Stress Index (3rd Edition) (Abidin, 1995), assessed feelings of depression in parent, attachment to child, feelings of social isolation, a sense of competence in the parenting role, the relationship with spouse/parenting partner, perceived role restrictions, and parental physical health. It has been well established that having a child with a disability impacts parent mental health, including feelings of guilt, anxiety, depression, loneliness, and helplessness, particularly in mothers (Murray & Greenberg, 2001, 2006;

Samrinki, 1997; Sen & Yurtsever, 2007; Tröster, 2001). Marital strain has also been reported to be higher in families with a child with a disability (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Oelofsen & Richardson, 2006). The research reported in the current study supports the findings from other studies that there is increased interpersonal and intrapersonal stress and strain related to raising a child with a disability, regardless of the disability.

For example, it has been established that families with a child with a disability may experience financial adjustments (Parish & Cloud, 2006; Sen & Yurtsever, 2007), such as changes in medical insurance, child care, professional services, equipment, transportation, and work disruptions, depending on the severity and type of disability. Research also shows that families with a child with a disability are at greater risk of living in poverty when compared to families with a child without a disability (Parish & Cloud, 2006). More families with a child with a disability in the current study reported their annual income to be less than $10,000 than did families with a child without a disability. This certainly adds to the stressors of raising any child, but exacerbates the financial impact a child with a disability has on the family.

Child stress, was also found to be significantly different between groups. Child stress, as measured by the Parenting Stress Index (3rd Edition) (Abidin, 1995), examined parent perceptions of how adaptable, demanding, moody, distractible, hyperactive, reinforcing, and acceptable the child is to the parent. A child with a disability may display more challenging and externalizing behaviors and greater needs which give rise to perceived stress related to the child.

Benson (2006) found that another persistent source of stress for many parents with a child with a disability is dealing with behavioral challenges that may exist. Behavioral challenges associated with the disability can cause great stress on a family, depending on the severity and type of disability. Parents' marital stress and/or individual internal stress may be intensified by

the presence of a disability, yet have been present prior to the child's birth. For example, a child with a disability may have difficulty communicating and therefore use physical actions to express himself or herself. While the child may grow increasingly frustrated over not being understood, it may be equally challenging and frustrating for the parents to understand their child and meet his or her needs. This difficulty in reciprocal communication and in meeting each other's needs could then add stress to a family system.

Stress is cushioned by support from any source (Benson, 2006; Trute, Worthington, & Hiebert-Murphy, 2008). In the current study, it was expected that support would alleviate stress related to parent issues, child behaviors and temperament, and major life events. Grandmother support was associated with reducing stress for major life events, but not with parent or child stress. Short-term stress linked to major life events may be buffered by additional emotional and instrumental support from grandmothers or anyone. Yet, day-to-day, long-term hassles and stressors seem less influenced by grandmother support. Perhaps a heightened need for help brings on an intense level of support in the forms of caregiving, financial resources, distribution of responsibilities, and emotional support, but long-term support is less noticeable as it becomes a part of the everyday family system. Or it may be that grandmother support is more accepted by mother in times of great family stress on a short-term level. Mothers may really want support from grandmother or other family member when a crisis in the home arises, but may not be open to ongoing support from grandmother at other times.

Support from grandmothers is generally more emotional in nature (Trute, 2003). In the situation in which child is diagnosed or classified with a disability, grandmother support may come in the forms of listening, loving both parent(s) and child unconditionally, being a shoulder to cry on, and staying positive. Emotional support is impactful, yet difficult to identify in its

subtle and enduring nature. More often instrumental support is recognized because it is more short-term and tangible in nature. For example, in the case of a child who requires a hospitalization, a grandmother's instrumental support may involve transportation to and from the hospital, caring for siblings, providing meals for the family, aiding in household duties, and relaying information to extended family members. The current study showed that emotional and instrumental support were relatively equally represented, and it may be due to the ever-changing needs of the family.

The findings of the current study also support McCubbin and Patterson's (1983) Double ABCX model of stress and coping. In their model, an interaction among: (A) the stressor, (B) coping resources, and (C) the family definition of the stressor, leads to (X) the family system's sense of crisis. In the current study, the stressor (A) was the presence of a disability in a child in the family. Coping resources (B) for the families varied, but grandmother support was assessed in each family using the Support Functions Scale. The family definition of the stressor (C) was assessed using the Parenting Stress Index which investigated mother's perceptions of parent stress, child stress, life stress and overall stress. Lastly, the family system's sense of crisis (X) or family functioning was assessed using the Family Adaptability and Cohesion Evaluation Scales.

Support

Research shows that social support can impact family functioning (Dunst, Trivette, & Hamby, 1994; Holahan & Moos, 1985). In the current study, it was expected that high levels of grandmother support would be associated with high levels of balanced flexibility and cohesion. Grandmother overall support for both groups was found to be related to mothers' perceptions of family flexibility. This means that the family's harmony or balance in its flexibility, leadership, role shifts, and discipline were associated with overall ratings of support by grandmothers. It

seems that the provision of support from grandmother enhances a family's ability to cope with change internal to a family system, such as changes in roles or responsibilities.

Grandmothers may impact a family in a variety of ways. For example: aiding in the upkeep of the house, caring for the grandchildren, being a friend, helping with day-to-day activities, such as homework and preparing for the day, and in carrying over therapeutic interventions (Seligman, Goodwin, Paschal, Applegate & Lehman, 1997). In many ways, the grandmother greatly supports the family by acting as a third parent.

However, much of the support provided depends on factors such as proximity of the grandmother to the nuclear family, desire for help from the nuclear family, severity of need of the grandchild with a disability, health of the grandmother and her spouse, and relationship of grandmother to the nuclear family before grandchildren were born, to name a few. Families may be negatively impacted by grandmothers as well, if the grandmother is inaccessible physically or emotionally, or is involved but judgmental in any way. The current finding, that grandmother support positively impacts flexibility, may be a function of the relationship and availability of the grandmother to the nuclear family.

While grandmother support and family flexibility were positively related, grandmother support was not found to be related to cohesion or closeness, loyalty, and interdependence in the current sample. It may be that grandmother support could relieve some responsibilities and buffer change in a family; however, closeness and loyalty between a couple and in a family may not be receptive to outside influences.

The research shows that support tends also to be higher in families with a child with a disability than in families with a child without a disability (Boyd, 2002; Dunst, Trivette, & Cross, 1986; Tröster, 2001). The current study results indicated no differences in support levels.

While trends supporting the hypothesis were noted, a significant difference was not found. It is possible that grandmothers and mothers in the current study perceived their amount of support relative to the needs of the home. For example, in a family with high need for support, the support was also high; families in less stressful homes had less need for support, and therefore received less support. Both types of households require support, but the outcome may be the same. The addition of support, no matter how much or what kind, made the two groups function in similar ways making differences undetectable in the sample size of the current study.

Emotional support and instrumental support are beneficial to both families with a child with a disability and families with a child without a disability. Emotional support in the forms of active listening, empathy, nonjudgment, and love may be more easily provided by some grandmothers than instrumental support in the forms of childcare, chores, errands, and financial help. It was expected that more emotional support would be provided and perceived than instrumental support. However, no differences in types of support were found in the current study. This could be interpreted to mean that both emotional and instrumental support are relatively equally provided and perceived, and it did not depend on the presence of a disability in the child in the family.

Family Functioning

Results indicate that no differences in family functioning were found between groups. Balanced cohesion and balanced flexibility scores were similar in both families with and without a child with a disability. Family functioning was assessed in both group using the Family Adaptability and Cohesion Evaluation Scales, 4th Edition (FACES IV) (Olson, Gorall, & Tiesel, 2004). Family flexibility and family cohesion were expected to be less balanced in families with a child with a disability than in families with a child without a disability. Family flexibility in

both the Child with a Disability group and the Child without a Disability group ranged from "rigid" to "very flexible". Thus, both types of families showed similar degrees of emotional flexibility.

Family cohesion in the Child with a Disability group ranged from "somewhat connected" to "enmeshed" and the cohesion in the Child without a Disability group ranged from "disengaged" to "enmeshed". Families with a child with a disability rated themselves less disengaged than did families with a child without a disability.

Prior research shows that a child with a disability can impact and change a family system (Fish, 2002; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Murray & Greenberg, 2001; Parish & Cloud, 2006; Sarimski, 1997; Sen & Yurtsever, 2007; Trachtenberg & Batshaw, 1997), and marital strain has been found to be greater in families with a child with a disability (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006), which would lead to less balanced cohesion. Also, prior research indicates that parents of children with a disability report lower togetherness than parents of children without a disability (Oelofsen & Richardson, 2006). It may be that unforeseen stressors of raising a child with a disability aggravate preexisting stress in a couple, or the parents focus more on their child with a disability and his or her needs than the needs of their own relationship making the foundation of their family fragile.

It was expected that flexibility and cohesion in a family with a child with a disability would be lower than the flexibility and cohesion in a family with a child without a disability. Contrary to research cited above, the current sample showed no differences in flexibility or cohesion between groups. However, the current sample supports research that shows that having a child with a disability does not unavoidably lead to poor family functioning (DeMarle & Le Roux, 2001). The difference between research cited above and the current study may be due to

differences in sample size, perceptions of the family by mothers versus other family members in comparable research, or unique qualities about the current sample.

Sample Characteristics

The current study focused on families with a child between the ages of two and twelve years based on the Family Life Cycle (Carter & McGoldrick, 1999). Stage three of the Family Life Cycle involves parents of young children. While the age range was represented in the current study, the results were skewed between groups. Younger children were more often found in the Child without a Disability group, and older children were more often found in the Child with a Disability group. This may be due to the age of identification of a disability's presence or time of classification. Children who were in the younger cohort may have not yet been identified as having a disability present, whereas the school aged children were identified. This finding is important because it may indicate that raising preschool age children may inherently bring differences in parenting stress, child stress, overall family stress, family functioning, need for support, and types of support needed than school aged children. Without separating the groups by age, it is unclear if the disability impacts the stress, functioning, and support of a family or if the presence of a disability impacts the family, or both. No differences were found in mother's ages between groups or in grandmother's ages between groups, despite having a younger or older child or grandchild.

Educational Implications

The findings of this study could have an impact on the type of services that are provided to family members of children with and without disabilities, especially as they relate to extended family members. The inclusion of social support as an indirect service may also be considered when helping families with children with a disability.

While the present data represent only the views of mothers and grandmothers, they provide an interesting dyadic perspective of the effect of support on different types of families. Given this perspective, family stress clearly is impacted by the presence of a disability or stressful child demands, and interventions related to stress could and should incorporate grandmothers as a source of support in a multigenerational intervention. However, the implication of a grandmother as a link in a chain of support also has to address the limitations that one person can provide. Historically, grandmothers act as third and/or surrogate parents, particularly in high-need families, providing both extensive emotional and instrumental help. Yet, when the grandmother takes on the parenting responsibilities she also likely endures a considerable amount of stress. The grandmother then has to look outward for support, causing a broadening of the support system.

Therefore, when considering grandmothers as supports for mothers and their families, one must consider support for grandmother as well. Community center programs, school-based programs, senior center support or links through local libraries may be helpful resources to grandmothers.

Schools can also offer workshops to parents, grandparents, and other family members separately and/or together to address the needs of the family from a school-based perspective. This may entail providing one-time information sessions about disability facts, school programs, community resources, and sources of respite. Other workshops may be ongoing to address concerns that come up on a day-to-day basis, and offer a chance to connect to other multigenerational families who have similar stressors.

From another viewpoint, many agencies provide conferences and workshops for ongoing professional development or for families to gain exposure to a great deal of information in an

efficient manner. As a conference or workshop topic, multigenerational support for families with a child with a disability, specific to the disability, would be a way to extend support beyond the nuclear family. Indeed, a grandparent panel discussion would offer tremendous valuable insight into the impact a child with a disability can have on a family system.

Other sources of support and resources for families may also include local libraries, senior centers, play groups, formal organizations such as the Autism Society of America, Down Syndrome Association, Families Together in New York State, Family Voices of New York, Family Village, National Dissemination Center for Children with Disabilities, or Parent to Parent of New York State.

Further research in several areas is warranted based on the current study. Although economic, ethnic, and educational differences were not found in this research, a larger and more diverse sample is needed to determine if such differences exist. A major finding of this study involved the differences in age groups. This implies that there may be differences within the one stage of the Life Span Development perspective, wherein parenting younger children is somehow more stressful than parenting older children, especially when a disability is present. In order to investigate this avenue further, more research is needed on a preschool population separately from the school aged population. Moreover, school aged children may have distinctly different impacts on family functioning and parenting stress depending on their grade level, which leads to further areas of exploration.

While the research on grandparents continues to need expansion, very little research has focused solely on grandfathers' perceptions and roles in families with children with disabilities. Perhaps a father-grandfather dyadic study would be an interesting extension of the current study, as fathers and grandfathers are often overlooked as a unit.

In applying the current results to the field of School Psychology, one could include an assessment of family stress and support or resources available in the evaluation process, which would better link assessment to intervention. For example, upon initial evaluation, an assessment of the types of, and access to, support and resources for the family would help in tailoring the intervention recommendations to the family and the community.

Limitations of Study

Several limitations of the study are recognized. The volunteer nature of the sample makes it difficult to determine the population it represents and how those who choose not to participate may be different from those who do. Another limitation is the reliance on self-report measures. Self-report is appropriate for many of the variables that involve individual perception. However, it would be beneficial to use a more objective measure, particularly related to support, that includes frequency during the week or number of hours as a more quantitative measure of support.

The total number of mothers and grandmothers participating was modest. The sample size and difference between sample sizes of groups may not have revealed the relationships between all variables measured. A larger sample size for both groups may have provided not only more information, but, perhaps, more significant results.

While the current study focused on one stage of the family life cycle, the age range was difficult to use for direct comparison purposes, especially given the undiagnosed nature of many preschool aged children. It could very well be that some of the current participants in the younger range (2-5) had a disability that was not yet recognized which impacts the results when comparing disabled and nondisabled youth.

Both groups tended to be rather homogeneous, and the impact of stress, support, family

functioning, and disability across cultures and ethnicities would be an interesting avenue for future research. While the current study did not investigate severity of disability in relation to family functioning, support, and stress, it would also be an opportunity for exploration.

A major limitation on the generalizability of this study is that the results reflect the perceptions of mother and grandmother only. It would be a more broad and inclusive view of the family system if siblings, fathers, and grandfathers were invited to participate. In all, a full picture of the family would have to include more viewpoints of all family members.

Conclusion

This study examined the relationship between grandparent support, family functioning, and parental stress on families with children with and without disabilities. Families are viewed as an ever-changing complex system with reciprocal interactions. One possible stressor on the family system is the birth of a child with a disability. Parenting stress levels seem to fluctuate in the family system over time depending on the age of the child with a disability, developmental stage, and demands of the age and stage. Studies show that social support, specifically that from grandmothers, can buffer some of the stress related to parenting a child with a disability (Kuster & Merkle, 2003; Mitchell, 2007; Trute, 2003).

In this study the experience of parenting stress, child stress, and overall stress was higher in families with a child with a disability, and grandmother support was associated with reduced life stress and enhanced family flexibility; however, grandmother support was not found to enhance family cohesion, or diminish parenting stress, child stress, or overall stress experienced by mothers. Grandparents are important members of most families and can be important influences in the lives of their children and grandchildren.

Appendix A

Flyer

ATTENTION
MOTHERS and GRANDMOTHERS:

Do you have a child or grandchild (aged 2 to 12 years old)?

Are you interested in participating in a research study looking at your views on:

parenting stress?
family support?
family functioning?
and family togetherness?

Do you want to earn a **$10 or $20 gift card** for your participation?

I am interested in finding out about mothers' and grandmothers' views on types of support, family functioning, and parenting stress related to raising a child. Due to the increasing number of families with young children, I believe that it is important to consider how extended family members assist in reducing the stress involved in parenting and in increasing the way a family functions together.

If you volunteer, you will be asked to complete a packet of questionnaires regarding the above topics. Every mother will receive a $20 gift card and every grandmother will receive a $10.00 gift card for each packet completed.

Please call (631) 335-2760 if you are interested.

If you have any questions or concerns, please feel free to call me at (631) 335-2760.

Thank you very much for your time!
Natasha Tumbarello
Doctoral Student
C.U.N.Y Graduate Center

Appendix B

CONSENT FORM FOR MOTHERS

My name is Natasha Tumbarello and I am a student in the Educational Psychology Ph.D. program at the Graduate Center of the City University of New York (CUNY), and Principal Investigator of this project, entitled "The Effect of Grandmother Support on Family Functioning and Parenting Stress." This is a research study that compares families with a child with a disability to families with a child without a disability with respect to grandmother support, family flexibility, family togetherness, and parenting stress. The study is expected to provide information that will be useful when providing support to families and students in school environments.

I would like you to complete a packet of questionnaires. Specifically, I would like you to fill out a one page demographic questionnaire, a one-page questionnaire on social support, a seven-page questionnaire on parenting stress, and a two-page questionnaire on family functioning. The questionnaires will take approximately forty-five minutes to complete. Once completed, I would like you to place all materials in the enclosed self-addressed stamped envelope and mail the packet to me. In exchange for your completed packet, I will give you a $20.00 gift card to thank you for your participation. Your participation is completely voluntary. You can stop at anytime, and access to professional services at the site where you attained this packet will not be adversely affected by a decision not to participate.

I would also like you to ask a grandmother in your family to complete a similar packet of questionnaires. If you choose to participate, please give the packet marked "GRANDMOTHER" to any grandmother of your child. Inside she will find two of the same questionnaires that you have; the demographic questionnaire and the social support questionnaire. Consent forms and directions for the grandmother in your family are included in her packet. In exchange for her participation, she will also be given a $10.00 gift card.

Please do not discuss your results with anyone. All information gathered will be kept strictly confidential, and will be stored in a locked file cabinet to which only I will have access. At any time you can refuse to answer any questions or choose to no longer participate. There are minimal risks involved in this study, which may include answering uncomfortable questions. The benefit of your participation includes adding to the generalized knowledge of support for parents, particularly for those with a child with a disability. There will be approximately fifty participants taking part in this study. I may publish the results of the current study, but names of people or any identifying characteristics will not be used in any of the publications. If you would like a copy of the study, please provide me with your address and I will send you a copy in the future. I will file your address separately in a locked file cabinet and destroy it once the results of the study are sent. If you have any questions about the research, you can contact me at (631) 335-2760 or natgregory@hotmail.com, or my advisor, Dr. Marian Fish at (212) 817-7000 or mfish@gc.cuny.edu. If you have questions about your rights as a participant in this study, you can contact Kay Powell, IRB Administrator at the Graduate Center/City University of New York, (212) 817-7525 or kpowell@gc.cuny.edu.

Thank you for your participation in the study.
Natasha Tumbarello, M.A.

I agree to participate in the above study:

_____ _____

Participant's Signature Date Investigator's Signature Date

Appendix C

Background Information for Mothers

Name _____
Address _____
Your Age _____
Date _____

Family Member Completing This Survey:
_____ Mother (biological) _____ Stepmother
_____ Other (describe: _____)

Family Structure:
_____ Two Parents (biological) _____ Two Parents (adoptive)
_____ Two Parents (stepfamily) _____ One Parent
_____ Other (describe: _____)

Children in Family:
Gender _____ Age _____ Disability if any _____
Gender _____ Age _____ Disability if any _____
Gender _____ Age _____ Disability if any _____
Gender _____ Age _____ Disability if any _____
Gender _____ Age _____ Disability if any _____
Gender _____ Age _____ Disability if any _____

Please place a star next to the child who you are completing the surveys on today.

Your Education Level:
_____ Some High School _____ Competed High School
_____ Some College _____ Completed College
_____ Advanced Degree (describe: _____)

Your Household Income Level:
_____ Less than $10,000 per year _____ $10,000 - $30,000 per year
_____ $30,000 - $50,000 per year _____ $50,000 - $70,000 per year
_____ $70,000 - $100,000 per year _____ over $100,000 per year

Your Ethnic Background:
_____ Asian American _____ Black/African American
_____ Hawaiian or Pacific Islander _____ Hispanic/Latino
_____ Native American _____ White/Caucasian
_____ Other (describe: _____)

Appendix D

FACES IV Questionnaire

Directions: Fill in the corresponding number in the space provided.

1	2	3	4	5
DOES NOT describe our family at all	**SLIGHTLY describes our family**	**SOMEWHAT describes our family**	**GENERALLY describes our family**	**VERY WELL describes our family**

1. Family members are involved in each others lives. _____
2. Our family tries new ways of dealing with problems. _____
3. We get along better with people outside our family than inside. _____
4. We spend too much time together. _____
5. There are strict consequences for breaking the rules in our family. _____
6. We never seem to get organized in our family. _____
7. Family members feel very close to each other. _____
8. The parents check with the children before making important decisions. _____
9. Family members seem to avoid contact with each other when at home. _____
10. Family members feel pressured to spend most free time together. _____
11. There are severe consequences when a family member does something wrong. _____
12. We need more rules in our family. _____
13. Family members are supportive of each other during difficult times. _____
14. Children have a say in their discipline. _____
15. Family members feel closer to people outside the family than to other family members. _____
16. Family members are too dependent on each other. _____
17. This family has a rule for almost every possible situation. _____
18. Things do not get done in our family. _____
19. Family members consult other family members on personal decisions. _____
20. In solving problems, the children's suggestions are followed. _____
21. Family members are on their own when there is a problem to be solved. _____
22. Family members have little need for friends outside the family. _____
23. It is difficult to get a rule changed in our family. _____
24. It is unclear who is responsible for things (chores, activities) in our family. _____
25. Family members like to spend some of their free time with each other. _____
26. We shift household responsibilities from person to person. _____
27. This family doesn't do things together. _____
28. We feel too connected to each other. _____
29. Once a task is assigned to a member, there is little chance of changing it. _____
30. There is no leadership in this family. _____
31. Although family members have individual interests, they still participate in family activities. _____
32. Family members make the rules together. _____
33. Family members rarely depend on each other. _____
34. We resent family members doing things outside the family. _____

1	2	3	4	5
DOES NOT describe our family at all	**SLIGHTLY describes our family**	**SOMEWHAT describes our family**	**GENERALLY describes our family**	**VERY WELL describes our family**

35. It is important to follow the rules in our family. _____
36. No one in this family seems to be able to keep track of what their duties are. _____
37. This family has a good balance of separateness and closeness. _____
38. When problems arise, we compromise. _____
39. Family members know very little about the friends of other family members. _____
40. Family members feel guilty if they want to spend time away from the family. _____
41. Family members feel they have to go along with what the family decides to do. _____
42. It is hard to know who the leader is in the family. _____
43. Family members are satisfied with how they communicate with each other. _____
44. Family members are very good listeners. _____
45. Family members express affection to each other. _____
46. Family members are able to ask each other for what they want. _____
47. Family members can calmly discuss problems with each other. _____
48. Family members discuss their ideas and beliefs with each other. _____
49. When family members ask questions of each other, they get honest answers. _____
50. Family members try to understand each other's feelings. _____
51. When angry, family members seldom say negative things about each other. _____
52. Family members express their true feelings to each other. _____

1	2	3	4	5
Very Dissatisfied	**Somewhat Dissatisfied**	**Generally Satisfied**	**Very Satisfied**	**Extremely Satisfied**

53. The degree of closeness between family members. _____
54. My family's ability to cope with stress. _____
55. My family's ability to be flexible. _____
56. My family's ability to share positive experiences. _____
57. The quality of communication between family members. _____
58. My family's ability to resolve conflicts. _____
59. The amount of time we spend together as a family. _____
60. The way problems are discusses. _____
61. The fairness of criticism in my family. _____
62. Family members concern for each other. _____

THANK YOU FOR YOUR COOPERATION!

Appendix E

PSI Questionnaire

Directions: Consider your child (aged 2 to 12 years old) and fill in the corresponding number in the space provided.

SA	A	NS	D	SD
STRONGLY AGREE with the statement.	**AGREE with the statement.**	**NOT SURE.**	**DISAGREE with the statement.**	**STRONGLY DISAGREE with the statement.**

1. When my child wants something, my child usually keeps trying to get it. _____
2. My child is so active that it exhausts me. _____
3. My child appears disorganized and is easily distracted. _____
4. Compared to most, my child has more difficulty concentrating and paying attention. _____
5. My child will often stay occupied with a toy for more than 10 minutes. _____
6. My child wanders away much more than I expected. _____
7. My child is much more active than I expected. _____
8. My child squirms and kicks a great deal when being dressed or bathed. _____
9. My child can be easily distracted from wanting something. _____
10. My child rarely does things for me that make me feel good. _____
11. Most times I feel that my child likes me and wants to be close to me. _____
12. Sometimes I feel my child doesn't like me and doesn't want to be close to me. _____
13. My child smiles at me much less than I expected. _____
14. When I do things for my child, I get the feeling that my efforts are not appreciated very much. _____

For statement 15, choose a response from choices 1 to 4 below:

15. Which statement best describes your child? _____
    1. almost always likes to play with me
    2. sometimes likes to play with me
    3. usually doesn't like to play with me
    4. almost never likes to play with me

For statement 16, choose a response from choices 1 to 5 below:

16. My child cries and fusses _____
    1. much less than I expected.
    2. less than I expected.
    3. about as much as I expected.
    4. much more than I expected.
    5. it seems almost constant.

SA	A	NS	D	SD
STRONGLY AGREE with the statement.	**AGREE with the statement.**	**NOT SURE.**	**DISAGREE with the statement.**	**STRONGLY DISAGREE with the statement.**

17. My child seems to cry or fuss more often than most children. _____
18. When playing, my child doesn't often giggle or laugh. _____
19. My child generally wakes up in a bad mood. _____
20. I feel that my child is very moody and easily upset. _____
21. My child looks a little different than I expected and it bothers me at times. _____
22. In some areas, my child seems to have forgotten past learnings and has gone back to doing things characteristic of younger children. _____
23. My child doesn't seem to learn as quickly as most children. _____
24. My child doesn't seem to smile as much as most children. _____
25. My child does a few things which bother me a great deal. _____
26. My child is not able to do as much as I expected. _____
27. My child does not like to be cuddled or touched very much. _____
28. When my child came home from the hospital, I had doubtful feelings about my ability to handle being a parent. _____
29. Being a parent is harder than I thought it would be. _____
30. I feel capable and on top of things when I am caring for my child. _____
31. Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house. _____
32. My child reacts very strongly when something happens that my child doesn't like. _____
33. Leaving my child with a babysitter is usually a problem. _____
34. My child gets upset easily over the smallest thing. _____
35. My child easily notices and overreacts to loud sounds and bright lights. _____
36. My child's sleeping or eating schedule was much harder to establish than I expected. _____
37. My child usually avoids a new toy for a while before beginning to play with it. _____
38. It takes a long time and it is very hard for my child to get used to new things. _____
39. My child doesn't seem comfortable when meetings strangers. _____

For statement 40, choose from choices 1 to 4 below:

40. When upset, my child is: _____
    1. easy to calm down.
    2. harder to calm down than I expected.
    3. very difficult to calm down.
    4. nothing I do helps to calm my child.

For statement 41, choose from choices 1 to 5 below:

41. I have found that getting my child to do something or stop doing something is: _____
    1. much harder than I expected.
    2. somewhat harder than I expected.
    3. about as hard as I expected.
    4. somewhat easier than I expected.
    5. much easier than I expected.

For statement 42, choose from choices 1 to 5 below:

42. Think carefully and count the number of things which your child does that bothers you. For example, dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. _____
    1. 1-3
    2. 4-5
    3. 6-7
    4. 8-9
    5. 10+

For statement 43, choose from choices 1 to 5 below:

43. When my child cries, it usually lasts: _____
    1. less than 2 minutes
    2. 2-5 minutes
    3. 5-10 minutes
    4. 10-15 minutes
    5. more than 15 minutes

SA	A	NS	D	SD
STRONGLY AGREE with the statement.	**AGREE with the statement.**	**NOT SURE.**	**DISAGREE with the statement.**	**STRONGLY DISAGREE with the statement.**

44. There are some things that my child does that really bother me a lot. _____
45. My child has had more health problems than I expected. _____
46. As my child has grown older and become more independent, I find myself more worried that my child will get hurt or into trouble. _____
47. My child turn out to be more of a problem than I had expected. _____
48. My child seems to be much harder to care for than most. _____
49. My child is always hanging on me. _____
50. My child makes more demands on me than most children. _____
51. I can't make decisions without help. _____
52. I have had many more problems raising children than I expected. _____
53. I enjoy being a parent. _____
54. I feel that I am successful most of the time when I try to get my child to do or not do something. _____

SA	A	NS	D	SD
STRONGLY AGREE with the statement.	**AGREE with the statement.**	**NOT SURE.**	**DISAGREE with the statement.**	**STRONGLY DISAGREE with the statement.**

55. Since I brought my last child home from the hospital, I find that I am not able to take care of this child as well as I thought I could. I need help. _____

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

For statement 57, choose from choices 1 to 5 below:

57. When I think about myself as a parent I believe: _____
    1. I can handle anything that happens.
    2. I can handle most things pretty well.
    3. sometimes I have doubts, but find that I handle most things without any problems.
    4. I have some doubts about being able to handle things.
    5. I don't think I handle things very well at all.

For statement 58, choose from choices 1 to 5 below:

58. I feel that I am: _____
    1. a very good parent.
    2. a better than average parent.
    3. an average parent.
    4. a person who has some trouble being a parent.
    5. not very good at being a parent.

For questions 59 and 60, choose from choices 1 to 5 below:

59. What were the highest levels in school or college the following completed?
    Mother: _____
    1. 1^{st} to 8^{th} grade
    2. 9^{th} to 12^{th} grade
    3. vocational or some college
    4. college graduate
    5. graduate or professional school

60. Father _____
    1. 1^{st} to 8^{th} grade
    2. 9^{th} to 12^{th} grade
    3. vocational or some college
    4. college graduate
    5. graduate or professional school

For question 61, choose from choices 1 to 5 below:

61. How easy is it for you to understand what your child wants or needs? _____
    1. very easy
    2. easy
    3. somewhat difficult
    4. it is very hard
    5. I usually can't figure out what the problem is

SA	A	NS	D	SD
STRONGLY AGREE with the statement.	**AGREE with the statement.**	**NOT SURE.**	**DISAGREE with the statement.**	**STRONGLY DISAGREE with the statement.**

62. It takes a long time for parents to develop close, warm feelings for their children. _____
63. I expected to have close and warmer feelings for my child than I do and this bothers me. _____
64. Sometimes my child does things that bother me just to be mean. _____
65. When I was young, I never felt comfortable holding or taking care of children. _____
66. My child knows I am his or her parent and wants me more than other people. _____
67. The number of children that I have now is too many. _____
68. Most of my life is spent doing things for my child. _____
69. I find myself giving up more of my life to meet my children's needs than I ever expected. _____
70. I feel trapped by my responsibilities as a parent. _____
71. I often feel that my child's needs control my life. _____
72. Since having this child, I have been unable to do new and different things. _____
73. Since having this child, I feel that I am almost never able to do things that I like to do. _____
74. It is hard to find a place in our home where I can go to be by myself. _____
75. When I think about the kind of person I am, I often feel guilty or bad about myself. _____
76. I am unhappy with the last purchase of clothing I made for myself. _____
77. When my child misbehaves or fusses too much, I feel responsible, as if I didn't do something right. _____
78. I feel every time my child does something wrong, it is really my fault. _____
79. I often feel guilty about the way I feel toward my child. _____
80. There are quite a few things that bother me about my life. _____
81. I felt sadder and more depressed than I expected after leaving the hospital with my baby. _____
82. I wind up feeling guilty when I get angry at my child and this bothers me. _____
83. After my child had been home from the hospital for about a month, I noticed that I was feeling more sad and depressed than I had expected. _____

SA	A	NS	D	SD
STRONGLY AGREE with the statement.	**AGREE with the statement.**	**NOT SURE.**	**DISAGREE with the statement.**	**STRONGLY DISAGREE with the statement.**

84. Since having my child, my spouse has not given me as much help and support as I expected. _____
85. Having a child has caused more problems than I expected in my relationship with my spouse. _____
86. Since having a child, my spouse and I don't do as many things together. _____
87. Since having a child, my spouse and I don't spend as much time together as a family as I had expected. _____
88. Since having my last child, I have had less interest in sex. _____
89. Having a child seems to have increased the number of problems we have with in-laws and relatives. _____
90. Having children has been much more expensive than I had expected. _____
91. I feel alone and without friends. _____
92. When I go to a party, I usually expect not to enjoy myself. _____
93. I am not as interested in people as I used to be. _____
94. I often have the feeling that other people my own age don't particularly like my company. _____
95. When I run into a problem taking care of my children, I have a lot of people to whom I can talk to get help or advice. _____
96. Since having children, I have a lot fewer chances to see my friends and to make new friends. _____
97. During the past six months, I have been sicker than usual or have had more aches and pains than I normally do. _____
98. Physically, I feel good most of the time. _____
99. Having a child has caused changes in the way I sleep. _____
100. I don't enjoy things as I used to. _____

For statement 101, choose from choices 1 to 4 below:

101. Since I've had my child: _____
    1. I have been sick a great deal.
    2. I haven't felt as good.
    3. I haven't noticed any changes in my health.
    4. I have been healthier.

For statements 102 to 120, choose from choices Y for "Yes" and N for "No."

During the last 12 months, have any of the following events occurred in your immediate family?

102. Divorce _____
103. Marital reconciliation _____
104. Marriage _____
105. Separation _____
106. Pregnancy _____
107. Other relative moved into household _____
108. Income increased substantially (20% or more) _____
109. Went deeply into debt _____
110. Moved to new location _____
111. Promotion at work _____
112. Income decreased substantially _____
113. Alcohol or drug problem _____
114. Death of close family friend _____
115. Began new job _____
116. Entered new school _____
117. Trouble with superiors at work _____
118. Trouble with teachers at school _____
119. Legal problems _____
120. Death of immediate family member _____

THANK YOU FOR YOUR COOPERATION!

Appendix F

Support Functions Scale

(Extended Version)

Instructions: Please circle the response that best describes to what extent you have or feel a need for any of the following types of help or assistance.

	Never	Once In A While	Some-times	Often	Quite Often
1. Someone to talk to about things that worry you.	1	2	3	4	5
2. Someone to provide money for food, clothes, and other things.	1	2	3	4	5
3. Someone to care for your child on a regular basis.	1	2	3	4	5
4. Someone to talk to about problems when raising your child.	1	2	3	4	5
5. Someone to help you get services for your child.	1	2	3	4	5
6. Someone to encourage you when you are down.	1	2	3	4	5
7. Someone to fix things around the house.	1	2	3	4	5
8. Someone to talk to who has had similar experiences.	1	2	3	4	5
9. Someone to do things with your child.	1	2	3	4	5
10. Someone whom you can depend on.	1	2	3	4	5
11. Someone to hassle with agencies and businesses when you can't.	1	2	3	4	5
12. Someone to lend you money.	1	2	3	4	5
13. Someone who accepts your child regardless of how (s)he acts.	1	2	3	4	5
14. Someone to relax or joke with.	1	2	3	4	5
15. Someone to help with household chores.	1	2	3	4	5
16. Someone who keeps you going when things seem hard.	1	2	3	4	5
17. Someone to care for your child in emergencies or when you must go out.	1	2	3	4	5
18. Someone to talk to when you need advice.	1	2	3	4	5
19. Someone to provide you or your child(ren) transportation.	1	2	3	4	5
20. Someone who tells you about services for your child or family.	1	2	3	4	5

Appendix G

CONSENT FORM FOR GRANDMOTHERS

My name is Natasha Tumbarello and I am a student in the Educational Psychology Ph.D. program at the Graduate Center of the City University of New York (CUNY), and Principal Investigator of this project, entitled "The Effect of Grandmother Support on Family Functioning and Parenting Stress." This is a research study that compares families with a child with a disability to families with a child without a disability with respect to grandmother support, family flexibility, family togetherness, and parenting stress. The study is expected to provide information that will be useful when providing support to families and students in school environments.

I would like you to complete a packet of questionnaires. Specifically, I would like you to fill out a one page demographic questionnaire and a one-page questionnaire on social support. The questionnaires will take approximately ten minutes to complete. Once completed, I would like you to place all materials in the enclosed self-addressed stamped envelope and mail the packet to me. In exchange for your completed packet, I will give you a $10.00 gift card to thank you for your participation. Your participation is completely voluntary. You can stop at anytime, and access to professional services at the site where you attained this packet will not be adversely affected by a decision not to participate.

Please do not discuss your results with anyone. All information gathered will be kept strictly confidential, and will be stored in a locked file cabinet to which only I will have access. At any time you can refuse to answer any questions or choose to no longer participate. There are minimal risks involved in this study, which may include answering uncomfortable questions. The benefit of your participation includes adding to the generalized knowledge of support for parents, particularly for those with a child with a disability. There will be approximately fifty participants taking part in this study. I may publish the results of the current study, but names of people or any identifying characteristics will not be used in any of the publications. If you would like a copy of the study, please provide me with your address and I will send you a copy in the future. I will file your address separately in a locked file cabinet and destroy it once the results of the study are sent.

If you have any questions about the research, you can contact me at (631) 335-2760 or natgregory@hotmail.com, or my advisor, Dr. Marian Fish at (212) 817-7000 or mfish@gc.cuny.edu. If you have questions about your rights as a participant in this study, you can contact Kay Powell, IRB Administrator at the Graduate Center/City University of New York, (212) 817-7525 or kpowell@gc.cuny.edu.

Thank you for your participation in the study.

Natasha Tumbarello, M.A.

I agree to participate in the above study:

_____ _____

Participant's Signature Date Investigator's Signature Date

Appendix H

Background Information for Grandmothers

Name _____
Address _____
Your Age _____
Date _____

Family Member Completing This Survey:
_____ Maternal Grandmother _____ Paternal Grandmother
_____ Other (describe: _____)

Your Family Structure:
_____ Two Grandparents (biological) _____ Two Grandparents (stepfamily)
_____ One Grandparent
_____ Other (describe: _____)

Grandchildren in Family:
Gender _____ Age _____ Disability if any _____
Gender _____ Age _____ Disability if any _____
Gender _____ Age _____ Disability if any _____
Gender _____ Age _____ Disability if any _____
Gender _____ Age _____ Disability if any _____
Gender _____ Age _____ Disability if any _____

Please place a star next to the child who you are completing the surveys on today.

Your Education Level:
_____ Some High School _____ Competed High School
_____ Some College _____ Completed College
_____ Advanced Degree (describe: _____)

Your Household Income Level:
_____ Less than $10,000 per year _____ $10,000 - $30,000 per year
_____ $30,000 - $50,000 per year _____ $50,000 - $70,000 per year
_____ $70,000 - $100,000 per year _____ over $100,000 per year

Your Ethnic Background:
_____ Asian American _____ Black/African American
_____ Hawaiian or Pacific Islander _____ Hispanic/Latino
_____ Native American _____ White/Caucasian
_____ Other (describe: _____)

Appendix I

Support Functions Scale

(Extended Version)

Instructions: Please circle the response that best describes to what extent you give any of the following types of help or assistance to your daughter or daughter-in-law.

	Never	Once In A While	Some-times	Often	Quite Often
1. Someone to talk to about things that worry her.	1	2	3	4	5
2. Someone to provide money for food, clothes, and other things.	1	2	3	4	5
3. Someone to care for her child on a regular basis.	1	2	3	4	5
4. Someone to talk to about problems when raising her child.	1	2	3	4	5
5. Someone to help her get services for her child.	1	2	3	4	5
6. Someone to encourage her when she is down.	1	2	3	4	5
7. Someone to fix things around the house.	1	2	3	4	5
8. Someone to talk to who has had similar experiences.	1	2	3	4	5
9. Someone to do things with her child.	1	2	3	4	5
10. Someone whom she can depend on.	1	2	3	4	5
11. Someone to hassle with agencies and businesses when she can't.	1	2	3	4	5
12. Someone to lend her money.	1	2	3	4	5
13. Someone who accepts her child regardless of how (s)he acts.	1	2	3	4	5
14. Someone to relax or joke with.	1	2	3	4	5
15. Someone to help with household chores.	1	2	3	4	5
16. Someone who keeps her going when things seem hard.	1	2	3	4	5
17. Someone to care for her child in emergencies or when she must go out.	1	2	3	4	5
18. Someone to talk to when she needs advice.	1	2	3	4	5
19. Someone to provide her or her child(ren) transportation.	1	2	3	4	5
20. Someone who tells her about services for her child or family.	1	2	3	4	5

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