GRANDCHILDREN'S AUTISTIC SPECTRUM DISORDERS AND FAMILY FUNCTIONING AS PREDICTORS OF GRANDMOTHERS' STRENGTHS AND NEEDS

by

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Abstract

GRANDCHILDRENS' AUTISTIC SPECTRUM DISORDERS AND FAMILY FUNCTIONING AS PREDICTORS OF GRANDMOTHERS' STRENGTHS AND NEEDS

By

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Literature on intergenerational relationships clearly illustrates the importance of the grandparent role in the family. While much research has been done on the grandparent role when children are typically developing, little research has been done on the grandparent role when children have special needs. This study looked at grandmothers of children with ASD. The investigator collected data from 34 mother – grandmother dyads from children who were typically developing, 31 mother – grandmother dyads from families of children who were diagnosed with HFA/AS, and 19 mother – grandmother dyads from families of children who were diagnosed with AD. First, the study looked at consistency between mothers' and grandmothers' report of grandmothers' strengths and needs. Second, the study looked at the impact of grandchildren's ASD on grandmothers' strengths and needs. Finally, the study looked at the impact of family systems variables on grandmothers' strengths and needs. The study also looked at background variables that may impact grandmothers' strengths and needs. Results from the study partially supported the hypothesis that grandmothers will view circumstances as good as or better than mothers view circumstances. To a large extent there was agreement between

grandmothers' and mothers' reports of grandmothers' strengths and needs. Where there were significant differences, grandmothers' reports of grandmothers' strengths and needs were more favorable than mothers' reports of grandmothers' strengths and needs. Grandmothers reported more strengths and fewer needs than mothers reported. Results from this study strongly supported previous research showing that grandparents of children with special needs are different from grandparents of children with typical development in terms of their role and experience. Results showed that grandmothers of children with ASD have fewer reported strengths and more needs than grandmothers of children with typical development. Results partially supported the hypothesis that family functioning will be associated with greater strengths and decreased needs for grandmothers, indicating that these variables, when unbalanced, hinder inclusion of grandmothers' involvement and satisfaction. Directions for future research and implications for education are also discussed.

dedicated to

children with special needs and their grandparents

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CHAPTER I

Introduction

Grandparents

Grandparents play an important role in modern families, and yet little is known about the actual experience of grandparenting. Due to increased longevity and improved health, today's grandparents spend many more years together with their children and grandchildren. Modern grandparents are involved in today's family life for a longer period of time than ever before and grandparents are an important role in modern families. Grandparents are stronger, more physically fit, younger, and more active than in previous generations (Bumpass, 1990; Elder, 1994; Szinovacs, 1998; Uhlenberg, 1996). It is not surprising that researchers have become increasingly interested in the actual experience of grandparenting. Psychologists and sociologists have begun to examine the role of grandparents in today's families and have conducted research projects which are of importance to the present study.

Initial research involving grandparents focused on the relevance of the grandparent role in a society where the emphasis tended to be on nuclear family functioning as opposed to extended family functioning (Denham & Smith, 1989). The initial question asked by researchers was, whether grandparents bring to families a useful set of skills and abilities that enrich the lives of their children and grandchildren. An alternate possibility is that grandparents are entrenched in an older ideology that may hinder or harm grandchildren's development and the ability of parents to parent independently and effectively. In terms of the rights of grandparents the question is, would or should grandparents feel a sense of responsibility and obligation towards

grandchildren. The role of grandparent is not necessarily a voluntary relationship and could be perceived as an additional burden at a time of life replete with developmental challenges, such as aging, retiring, and loss of significant others.

Early research focused on function of the grandparent role, grandparent activities, and grandparent styles. Cherlin and Furstenberg (1986) enumerated several important grandparent functions. They found that grandparents often serve as the family role model. They serve as family watchdogs and were found to be sources of emotional and financial support during emergencies and times of stress. In many cases, grandparents serve as daily caregivers. They are often the family historians and provide for the family a practical connection to the past and an enrichment of the family's sense of identity (Cherlin & Furstenberg, 1986; Wood & Robertson, 1976).

More recently, research has focused on background variables, such as geographical distance, gender, and lineage. These variables have been shown to mediate grandparent-grandchild relationships (Denham & Smith, 1989; Somary & Stricker, 1998). Variables of interest include but are not limited to: grandparents' age/life stage of family (includes grandparents' and grandchildren's ages), grandparents' gender, grandparents' lineage (whether grandparent is related to grandchild through mother or father), grandchildren's disposition, and grandparent-parent affectional solidarity (relationship quality and history between parent and grandparent).

The research on background variables has helped to clarify important issues which may complicate how grandparents enact their role. The way in which background variables affect grandparent-grandchild relationships is critical because it illustrates the complexity of the grandparent role. The role of grandparent is not a unitary phenomenon

where all grandparents feel satisfied and successful. Research clearly indicates that there are predictable trends between background variables and how grandparents experience their role. Because this study focuses on the impact of disability and family functioning, it is important to measure background variables in order to control for their effects. Background variables are controlled for via targeted recruitment and selection criteria. In the present study the use of stringent selection criteria enables this researcher to have a limited sample size while still measuring the variables of interest. Selection criteria include control for grandparents' gender by limiting the current study solely to grandmothers. Geographical distance is controlled by recruiting grandmothers who lived within 50 miles of their participating grandmother. Age is controlled for by looking at families of children between the ages of 6 and 14. Several background variables which are possibly significant are measured but allowed to vary as part of this study. Data regarding these variables has been collected and reported as part of this research project.

One important perspective is a model proposed by Strom and Strom (1991) which posits that grandparenting is a developmental or learned perspective. Strom and Strom's (1991) theory emphasizes the potential for growth and development of grandparents as they enact their role in the family. Grandparenting is not seen as a prescribed or stagnant role. It is viewed as a developmental process that is malleable and subject to both positive and negative change. According to this perspective, grandparents are learners who have different profiles based on different backgrounds and circumstances. The developmental perspective of grandparenting suggests that grandparenting skills, roles, and experiences can be measured, taught, and developed (Strom & Strom, 1991).

Buki, Ma, Strom, and Strom (2003) offer a relevant example in their study of immigrant grandparents. The authors suggest that immigrant grandparents have unique strengths and needs, therefore, they and their families benefit from information and workshops that are tailored to their circumstances. The theory is that different circumstances generate unique grandparent profiles which include unique strengths and needs. If this is true of immigrant grandparents, it is surely true of the unique circumstances of grandparents of children with special needs. Strom and Strom's (1991) perspective of grandparenting applies to the current study because like the unique profile of immigrant grandparents the grandparents of children with special needs have a different profile from those in typical families. In order to explore the variable profiles that grandparents exhibit, Strom and Strom (1993) developed a measure of grandparents' strengths and needs. That measure is the Grandparent Strengths and Needs Inventory (GSNI).

The GSNI is based on Strom and Strom's (1991) theory of grandparent strengths and needs. It posits six constructs of grandparenting (satisfaction, success, teaching, frustration, difficulty, and information needs) representing two composites (strengths and needs). The GSNI is a valid and reliable instrument which objectively measures constructs of interest to this study. Previous research on grandparents has relied on unstructured interviews or shorter scales focusing on levels of involvement or types of support. The GSNI, in contrast, is a well-developed, empirically-validated scale focusing on the role and subjective experience of grandparents and not just their level of participation. For the purpose of this study the GSNI was used as a measure of grandmothers' strengths and needs and is the dependent variable of interest. The

grandmother group targeted for study is the group of grandmothers of children with special needs, specifically, autism spectrum disorders (ASD).

Previous research on intergenerational relationships suggests that older generations consistently take a more positive view of circumstances, a tendency known as the developmental stake in the literature on intergenerational relationships (Aquilino, 1999; Lynott & Roberts, 1997). Differences in perception may interfere with intergenerational solidarity. This finding has consequences in terms of research as reports from different generations may yield different information. This finding also has applications in practice as families may benefit from knowing that generations typically differ in how they assess situations. In the current study mothers' and grandmothers' reports were used in order to look at the agreement in their view of circumstances.

Grandparents of Children with Special Needs

Research indicates that parenting children with special needs places a variety of stressors on both the nuclear family and the extended family. Grandparents, as part of the extended family must adjust to the additional trauma. Research indicates that grandparents experience grief as well as additional worry as their role is impacted by the diagnosis of a disability (Vadasy, 1987; Vadasy, Fewell, & Meyer, 1986). Research indicates that in families with special needs children, grandparents often play an important role and have added responsibilities (Hornby & Ashworth, 1994; Schilmoeller & Baranowski, 1998). Researchers have indicated that grandparents rarely have access to adequate information and support (George, 1988; Vadasy, 1987). This is problematic because it confounds an already complicated relationship. Without resources

grandparents can struggle with adequacy issues and confusion regarding appropriate levels of involvement.

Mothers and fathers have reported that grandparents' acceptance of their grandchild's disability helps them in their own adjustment to that disability (Mirfin-Veitch & Bray, 1997; Mirfin-Veitch, Bray, & Watson, 1996). Research also has shown that grandparents are rated very high in parents' support networks and may be among the first people that parents will turn to when they are under duress (Findler, 2000). Hastings, Thomas, and Delwiche (2002) suggest that though grandparents can be a source of comfort and assistance, they can bring with that support some negative consequences. Adult children may have concerns regarding their parents' aging process, and their own relationships with their parents. The authors suggest that grandparents bring to the family a dynamic set of positive and negative issues. Consequently, as a group, they would benefit from additional information, strategies, and guidance as they negotiate their role in the family.

Research indicates that there are a unique set of background variables which impact grandparent-grandchild relationships when there is a child with a disability (Hastings, 1997). These include but are not limited to: shared view of disability (Harris, Handleman, & Palmer, 1985), shared view of grandparents' role (Mirfin-Veitch et al., 1996), time since diagnosis (Mosala & Ikonen - Mosala, 1985), and severity of diagnosis (Turnbull & Turnbull, 1990).

The current study attempts to add to the grandparent research literature as it relates to grandparents of children with special needs. This study looks at grandparents of

children with disabilities, specifically grandmothers of children with autism spectrum disorders (ASD).

Grandparents of Children with Autism Spectrum Disorders

Different disabilities pose different kinds and levels of stress for family members (Hodapp, 1999). For example, orthopedic impairments pose different challenges for families than challenges posed when the diagnosis is mental retardation. Autism spectrum disorders (ASD) are pervasive developmental disorders characterized by social deficits and communication impairment. Because of the chronic nature of ASD, the inclusion of grandparents in the treatment model offers children increased opportunities for social learning and parents increased opportunities for assistance. Interventions for children with ASD are often time consuming and they are most effective when implemented with multiple people across multiple situations. It is sensible to provide grandparents with the information and resources they need to become effective members of the treatment team.

Family Systems Theory: Family Systems Variables and Grandparents

Family systems theory attempts to explain ways families function and the purpose family systems serves in the individual lives of family members (Minuchin, 1974). Systems theory assumes that family functioning is both stable and dynamic. Functioning is stable in that it reflects the family's values, but it is dynamic in that it changes as a result of normal life-course development or in response to stressful life events. Change impacts the family system and feedback loops from the family system to the individual, and from the individual's response back to the family system. Family functioning is predictive of how family members experience normal developmental change, such as the birth of a child, and major life stressors, such as death in the family or a divorce.

The Circumplex Model of Martial and Family Systems developed by Olson, Sprenkle, and Russell (1979) is an application of family systems theory. The Circumplex Model describes family functioning by the utilization of three dimensions: cohesion, flexibility, and communication. Research has shown that these dimensions have optimal ranges that are associated with favorable outcomes for family members (Olson, 2000). The Circumplex Model constructs are measured using the Family Adaptability and Cohesion Evaluation Scale – Fourth Edition (FACES IV) package.

Flexibility is defined as the amount of change that occurs in a family (Olson, 2000). Flexibility is measured on a continuum from rigid to chaotic. The Circumplex Model posits that families functioning in the middle or balanced range of flexibility, between rigid and chaotic, will have more positive outcomes as measured by family members' experiences. Thus, this study predicts that families with balanced flexibility will have more positive outcomes for grandmothers (increased strengths, decreased needs). Alternately stated, unbalanced flexibility will be associated with more negative outcomes (decreased strengths, increased needs).

Cohesion is defined as the closeness between family members (Olson, 2000). Cohesion is measured on a continuum from enmeshed to disengaged. Like flexibility, midrange or balanced cohesion is optimal and associated with more positive outcomes for family members. Thus, this research predicts that families with balanced cohesion will have more positive outcomes for grandmothers (increased strengths, decreased needs). Alternately, unbalanced cohesion (enmeshed, disengaged) will be associated with more negative outcomes (decreased strength, increased needs).

Communication is defined as the act of making information, ideas, thoughts, and feelings known among members of a family unit (Olson, 2000). Communication is measured linearly with increased communication associated with better outcomes for family members. Thus, this study predicts that families with better communication will have more positive outcomes for grandmothers (increased strengths, decreased needs). Alternately, poor Communication will be associated with more negative outcomes (decreased strengths, increased needs) for grandmothers.

Research Questions

Based on the above discussion, this study proposes to answer the following research questions.

1. Do mothers and grandmothers agree on grandmothers' experiences?

2. Do the experiences of grandmothers with typically developing grandchildren differ from those of grandmothers with grandchildren with ASD in the areas of satisfaction, success, teaching, frustration, difficulties, and information needs?

3. Does nuclear family functioning impact on grandmothers' experiences?

Current Study

In the current study questionnaires were given to three groups: mothers and grandmothers of families of children with typical development, mothers and grandmothers of families of children with Autistic Disorder (AD), and mothers and grandmothers of families of children with High Functioning Autism (HFA)/Asperger's Syndrome (AS). The questionnaire packet for mothers included a parent form of the GSNI and the FACES-IV package. The questionnaire packet for grandmothers included the grandparent form of the GSNI. The FACES-IV package was not used with

grandparents as reporters. Questionnaires provided information on mothers' and grandmothers' report of grandmothers' strength and needs across the three groups (typical development, High Functioning Autism/Asperger's Syndrome, and Autistic Disorder) and the impact of family functioning on grandparents' strengths and needs. Missing data were handled with Multiple Imputation and the data were analyzed using Mixed Effects Modeling.

Results

Results from the study partially supported the hypothesis that grandmothers will view circumstances as good as or better than mothers view circumstances. To a large extent there was agreement between grandmothers' and mothers' reports of grandmothers' strengths and needs. Where there were significant differences, grandmothers' reports of grandmothers' strengths and needs were more favorable than mothers' reports of grandmothers' strengths and needs. Grandmothers reported more strengths and fewer needs than mothers reported.

Results from this study strongly supported previous research showing that grandparents of children with special needs are different from grandparents of children with typical development in terms of their role and experience. Results showed that grandmothers of children with ASD have fewer reported strengths and more needs than grandmothers of children with typical development.

Results partially supported the hypothesis that family functioning will be associated with greater strengths and decreased needs for grandmothers, indicating that these variables, when unbalanced, hinder inclusion of grandmothers' involvement and satisfaction.

CHAPTER II

Literature Review

This chapter is divided into five sections. The first section reviews research on grandparent demographics, dimensions of the grandparent role, grandparent styles, and background variables that impact grandparent-grandchild relationships. Strom and Strom's (1991) theory of grandparent development is also discussed. The second section provides a review of research on grandparents of children with disabilities. This section shows how grandparents' experiences can be affected in families where children have disabilities and how their role is different from that of grandparents of typically developing children. The next section is a review of basic information on autism spectrum disorders (ASD). The purpose of this section is to describe the specific nature of ASD, including High Functioning Autism (HFA), Asperger's Syndrome (AS), and Autism Disorder (AD) and to explain how ASD might impact on grandmothers' experiences. The fourth section is a review of the basic concepts of family systems theory and the Circumplex Model of Marital and Family Systems (Olson, 2000). In the fifth section the concept of developmental stake (Aquilino, 1999; Lynott & Roberts, 1997) is presented. Finally, a rationale for the current study is provided.

Research on Grandparents

Grandparent Demographics

Increased longevity and improved health means that today's grandparents and grandchildren pass through many more years together than in previous generations. Researchers studying longevity and grandparent relationships point to the unprecedented number of grandparents who see their grandchildren reach adolescence, young adulthood,

and middle age. The opportunity structure for grandparent-grandchild relationships has shifted in recent generations, and the picture of grandparents as being older, frail, and unavailable is no longer accurate. In fact there is a great deal of time between the onset of grandparenthood and the stage of being a frail grandparent, and during that time many grandparents play an important role in the family (Bumpass, 1990; Elder, 1994; Szinovacs, 1998; Uhlenberg, 1996).

According to Bengston and Haryootan (1994) the majority (56%) of adults who are over the age of 65 years have at least one grandchild. Looking at adults over the age of 65 with children, this number jumps from 56% to 94% (Roberto, 1990). These percentages translate to an estimated 50 million Americans who are grandparents today. That is a sizable subgroup of the population (Farkas & Hogan, 1994; Strom & Strom, 1990).

Researchers have determined that the median age of grandparents is 48, a finding that has been consistent throughout the 20th century (Sprey & Matthews, 1982). According to a national study by the American Association of Retired Persons (AARP) (AARP, 1999) that included 823 grandparents over the age of 50, nearly half of all grandparents first became grandparents during middle age. According to the AARP study, 48% of today's grandparents were less than 50 years of age when their first grandchild was born. Schwartz and Waldrop (1992) reported that one third of grandparents are less than 55 years of age, and one half of grandparents are less than 60 years of age, suggesting that many grandparents are young and probably involved in family life. In fact, individuals who are grandparents are likely to be working, raising children, and involved in multiple outside roles when they first become grandparents.

Sixty-six percent of grandparents live less than one hour away from their grandchildren (AARP, 1999). While it is true that families today are more spread out geographically than in previous generations, the majority of grandparents and grandchildren live near each other.

With regard to the frequency of contact between grandparents and grandchildren, according to the AARP study, the majority of grandparents (68%) see at least one grandchild on a regular basis (AARP, 1999). Eighty-two percent of grandparents have seen one of their grandchildren in the previous month and another 24% of grandparents said they see a grandchild once a month to once every few months. In addition to contact that is in person, 80% of grandparents contact a grandchild by telephone at least once every few weeks. A smaller number, 12%, reported using traditional mail at least once every few weeks. Fifty-five percent send regular mail at least once every few months.

Researchers have also looked at the percentage of grandparents with grandchildren living in their households. Szinovacs (1998) found that 10% of grandparents live with their grandchildren. The number of grandparents living with grandchildren in their households among minority groups is even higher, specifically, 26% of Black grandmothers and nearly 23% of Hispanic grandmothers live in households with grandchildren compared to 7% of White grandmothers and 4% of White grandfathers. Sometimes families move into grandparents' homes and, other times, grandparents move into the homes of their adult children.

Fuller-Thompson, Minkler, and Driver (1997) used data from a nationally representative sample of 2,095 grandmothers to study characteristics of grandmothers who have primary care of grandchildren. The data for this study came from the National

Survey of Families and Households (NSFH), which was carried out in 1987 and 1988 by Sweet, Bumpass, and Call (1988). Fuller-Thompson et al. (1997) estimated that 10.9% of grandparents assume custodial responsibility for at least one grandchild, for at least 6 months, at some point in their lives. Fifty-six percent of those grandparents assumed custody of a grandchild for a period of time that was more than three years. The authors found that African American grandparents, young grandparents, and grandparents with more than one grandchild were more likely to assume custody of grandchildren than were other groups.

Researchers examined the impact that assuming custody of grandchildren has on grandparents' well being (Bowers & Meyers, 1999; Crnic & Greenburg, 1990; Emick & Hayslip, 1999; Jendrek, 1994; Minkler & Roe, 1993; Pinson-Millburn, Fabian, Schlossberg, & Pyle, 1996; Solomon & Marx, 1995; Thomas, Sperry, & Yarbrough, 2000). These researchers found that custodial care of grandchildren by grandparents is associated with increased stress and decreased mental health for the grandparents, and that grandparents often lack needed support and guidance.

The impact of assuming custody of grandchildren on grandparents' wellbeing is greater when grandchildren have disabilities (Burnette, 2000; Daly & Glenwick, 2000). Burnette (2000) examined the impact of custody on grandparents when children have a disability and found that grandparents were more likely to suffer symptoms of depression. This is particularly important to consider since research also shows that the incidence of disability is higher among children who are in the custodial care of their grandparents (Hayslip, Henderson, Shore, & Lampert, 1998; Pruchno, 1999). Given these

findings, custodial grandparents of children with disabilities represent a group that would benefit from outside support.

Many grandparents provide childcare for their grandchildren on a regular basis without co-residence or custody. Grandparents provide childcare for several reasons. Often, their grandchildren's parents are working full-time, and they are needed to help with daycare. More now than in the past, grandparents may provide help because there are more single-parent homes and the cost of childcare is high. Thus, many families rely on grandparents' support in early childhood (Baydar & Brooks-Gunn, 1998; Bowers & Meyers, 1999).

Using the same data as Fuller-Thomas et al. (1997), Baydar and Brooks-Gunn (1998) conducted a study of grandmothers who help care for their grandchildren without being the primary caregiver. Using the data from the nationally representative sample of 2,095 grandmothers, they found that nearly half (43%) of today's grandmothers provide care for their grandchildren regularly. Grandmothers who are between 60 and 70, who have more adult grandchildren, who have younger adult children, who are married, who are highly educated, and who are in good health are more likely to provide care for their grandchildren.

Dimensions of the Grandparent Role

Silverstein and Bengston (1997) provide a framework for studying variables associated with the role of grandparenting. They suggested that the grandparent role is composed of three latent dimensions. The three dimensions are (a) role affinity, (b) opportunity structure, and (c) role function.

Role affinity refers to the societal construction of the grandparent role. It consists of the individual and societal beliefs and attitudes about grandparents' roles and responsibilities. The concept of role affinity is sometimes referred to as role meaning in the literature. Early researchers debated the relevance of the grandparent role (Denham & Smith, 1989; Kahana & Kahana, 1971; Kivinick, 1982; Neugarten & Weinstein, 1964; Robertson, 1977; Werner, Lowenstein, & Katz, 1998; Wilcoxin, 1987). More recent research focuses on the dynamic relationship between generations and validates the importance of the grandparent role in modern families (Kennedy, 1992a; Kennedy, 1992b). Current research is multifaceted taking into consideration the perspective of adult children, children, and grandparents. Research has suggested that being an involved and successful grandparent provides grandparents with a primary group reference, a group with which grandparents can identify (Wood & Robertson, 1976). Timberlake (1981) suggested that the grandparent role is important for grandparents' development as individuals and provides individuals with a way of expanding themselves socially and personally. The grandparent role fills a need for creativity, accomplishment, and competence, while adding structure and stability to individuals' lives. Kahana and Kahana (1971) suggested that being a grandparent anchors individuals in a social structure. That structure is subject to change and may slip away as one ages.

Gutmann (1994) suggested that being a grandparent has a compensatory effect for many grandparents, giving them the chance to parent again. The author suggests that this may be especially true for grandfathers who may have been too busy to be involved when their own children were young. The grandparent role may provide a final validation of life for grandparents allowing them to evaluate their own parenting by observing how

their offspring function as parents. For some, becoming a grandparent may be a sign of family success (Troll, 1985). Mead (1970) suggested that grandparents are symbols of change for the younger generation and that they add continuity between the past and the future through oral and written history. Strom and Strom (1991) suggest that grandchildren benefit when grandparents are capable and interested in providing safe and nurturing environments and that they admire adults who are able to provide those environments for them.

The second dimension identified by Silverstein and Bengston (1997) is "opportunity structure." The authors suggest that opportunity and availability are strong mediators of how grandparents enact their role. Research has shown an important variable that may impact grandparents' opportunity structure is grandparents' competing roles (AARP, 1999). Competing roles for grandparents include their responsibilities to other family members, community organizations, and their level of employment. It stands to reason that grandparents' opportunity to spend time with grandchildren would be affected by grandparents' competing roles and obligations. Burton and Bengston (1985) found that women who become grandmothers at a very young age have concerns when their role as grandmother conflicts with their other roles and obligations. Baydar and Brooks-Gunn (1998) found that having other roles often meant that grandmothers were more active in general, and also in their role as grandmothers.

The third dimension identified by Silverstein and Bengston (1997) is role function. This dimension refers to the concrete and observable behaviors that grandparents perform. Role function refers to grandparent functions, grandparent activities, and the myriad ways that individuals choose to be involved with their

grandchildren. The research on grandparents clearly points to a dynamic involvement between grandparents and grandchildren.

According to the AARP study (AARP, 1999), grandparents reported that they share many functions with parents. Some of the shared activities include teaching children values (83%), entertaining children (87%), and listening to their problems (77%). Grandparents in the AARP study (AARP, 1999) reported that certain child-rearing issues are solely within the parents' domain, for example, making decisions regarding discipline and education. In contrast, grandparents viewed certain child-rearing activities as more in the grandparents' domain. For example, grandparents identified the role of family historian and of spoiling children as more of the grandparents' role than the parents' (AARP, 1999). Grandparents have been described as the "family watch dog," because grandparents are often the backup support when things go wrong. For example, this may occur when grandparents assume custody of children when parents are unable to care for their children, or when grandparents provide daycare so parents can work.

Kivinick (1991) has examined the shared activities of grandparents and grandchildren. Reported activities include having grandchildren over for dinner (86%), going out to dinner (84%), watching an entertainment program on TV (76%), going shopping (75%), reading to grandchildren (75%), and exercising or playing sports with their grandchildren (53%).

The authors of the AARP study (AARP, 1999) also looked at conversations between grandparents and grandchildren. They found that many grandparents and grandchildren have open communication. The majority of the grandparents spoke to grandchildren about everyday issues, such as school (84%), morals and values (78%),

planning future visits (72%), and daily activities (72%). Many grandparents report speaking to grandchildren about more sensitive issues, for example, religion and spirituality (65%), cigarette smoking (47%), drinking or alcohol use (43%), illegal drugs such as marijuana or cocaine or drug use (45%), and sex (24%). While the majority of grandparents in the AARP study thought that grandchildren were more likely to discuss serious issues with their parents, there were grandparents who believed their grandchildren were as likely to talk to them about sensitive issues as they were to talk to their parents. Forty-four percent of grandparents reported that their grandchildren were as likely to speak to them about religion and about spirituality, as they were to speak to parents. Thirty-one percent reported that their grandchildren were equally likely to speak with them about drinking and alcohol use, and 30% said their grandchildren were equally likely to speak to them about drug use.

Grandparent Styles

A different approach to studying grandparent involvement that is popular among researchers has been to collect data from large samples of grandparents, identify groups or clusters of grandparents, and label them as reflecting different grandparent styles. This approach is helpful, since it illustrates categorical differences in the way grandparents enact their role. Recent attempts to categorize grandparents have used statistical techniques such as factor and cluster analysis, adding to the empirical validity of the grandparent styles identified.

Neugarten and Weinstein (1964) observed five grandparent styles among upper, middle, and lower class citizens aged 50 to 60. These included: formal type, fun seeker, surrogate, reservoir of family wisdom (authoritarian style), and distant figure

(intermittent). Robertson (1977) observed grandparents from a larger age range (40 years and over) and found four grandparent styles. These were: apportioned (balancing needs of child with needs of self), symbolic (emphasis on the sources of satisfaction in relationship), individualized (little regard for normative expectation, emphasis on satisfaction), and distant. Cherlin and Furstenerg (1986) identified three grandparent styles from a sample of 510 men and women: detached, active, and passive. They found that most of the grandparents fell into the active category. Active was subsequently divided into three categories: supportive, authoritative, and influential.

Baydar and Brooks-Gunn (1998) sought to develop a grandmother typology that was an improvement on previous typologies. They used the framework described above by Silverstein and Bengston (1997), using role affinity, opportunity structure variables, and role function variables, to identify grandparent styles. That research identified four grandmother styles: homemaker, young and connected, remote, and frail.

The typology research cited indicates that grandparents enact their role in families in a variety of ways. There is not a single prescribed way of being a grandparent. Grandparents make choices about activities and type or level of involvement. Research on grandparents' styles does not take into consideration that individual grandparents may change their style over time, in different circumstances, and with different grandchildren. The research is also unclear as to why grandparents adopt one style over another. More recent research has focused on mediating background variables that impact on grandparent-grandchild relationships (Forsyth, Roberts, & Robin, 1992; Uhlenberg & Hammil, 1998). By focusing on mediating variables a clearer picture emerges as to why grandparents make the choices they do in terms of activity and involvement.

Background Variables Impacting Grandparents' Role

Geographical distance. Geographical distance is a static variable that impacts grandparents' opportunities to be an active participant in their grandchildren's lives. There is a direct relationship between geographical distance and frequency of contact that is well documented in the literature (Cherlin & Furstenberg, 1986; Kennedy, 1992; Uhlenberg & Hammil, 1998). Geographical proximity between grandparents and grandchildren relates to frequency of contact between them, with more contact increasing the opportunities for grandchildren and grandparents to spend time together, developing strong intergenerational relationships. Silverstein and Marenco (2001) found that 87% of grandparents who live less than 10 miles from their grandchildren had weekly visits. Researchers suggest that the frequency of visits with grandchildren decreases significantly after the 50-mile range; others suggest that 25 miles is the key distance. Given that children have up to four grandparents, there is a good chance that they will have at least one grandparent living within an hour of their home (Kennedy, 1992).

It stands to reason that grandparents living far away will have different kinds of relationships with their grandchildren than those living in closer proximity. Distance does not preclude involvement. Grandparents who live far away are also involved and play an important role in the family. Phone contact, long visits, emotional support, and the psychological significance of grandparents in grandchildren's lives provide closeness in intergenerational relationships despite distance (Kennedy, 1992; Kornhaber & Woodward, 1981; Rossi & Rossi, 1990).

Grandparents' age/life stage of family. Grandparents' age, and more generally, the life cycle stage of the family affect the opportunities that grandparents have to form,

build, and maintain bonds with their grandchildren in a number of interesting ways (Burton, 1987; AARP, 1999; Silverstein & Long, 1998; Silverstein & Marenco, 2001; Szinovacs, 1998; Uhlenberg & Hammil, 1998). For example, in the AARP study (AARP, 1999), it was reported that grandparents who are between the ages of 60 and 69 visit with their grandchildren more than grandparents from any other age group. As an explanation, they posited that many grandparents retire between 65 and 69 years of age and have more time to visit family. They are less dependent on others for transportation and they are less likely to experience health-related problems than are grandparents who are older than 69.

Grandparents report changes in their relationship with grandchildren as the family gets older. Silverstein and Long (1998) questioned grandparents about their relationships with adult grandchildren. Grandparents reported that their contact with grandchildren and proximity to grandchildren decreased as they got older, but that the emotional salience of their role as grandparents increased. They authors suggested that increased emotional salience of the grandparent role occurred because being a grandparent was a source of identity for older grandparents. The authors further posited that early relationships between grandparents and grandchildren likely serve as a foundation for this valued symbolism later on in the family life cycle. Thompson, Clark, and Gunn (1985) questioned grandparents regarding their perceptions about the impact of aging on their role as grandparent. Older grandparents reported perceiving a change in their roles from being a provider to one who receives more than they are giving.

Grandchildren's age has been shown to affect the nature of grandparent-grandchild relationships (Baranowski, 1982; Boon & Brussoni, 1996; Clingempeel, Colyar, Brand, & Hetherington, 1992; Creasy & Kaliher, 1992; Creasy & Koblesky,

1991; Kahana & Kahana, 1970; Silverstein & Marenco, 2001). Grandparents of young grandchildren may act as caregivers and teachers, enjoying many shared activities (Silverstein & Marenco, 2001). As a grandchild approaches adolescence, the child's developmental task is typically to individuate, separating from the family of origin. At this point, grandparents need to construct new ways of being involved with their grandchildren. Research indicates that grandparents may feel less successful when grandchildren become teenagers and may need more information regarding their adolescent grandchildren (Strom & Strom, 1991). In adulthood there is a return to the grandparent-grandchild relationship (Langer, 1990). Hodgson (1992) looked at relationship quality between adult grandchildren and their grandparents. Results showed that that the majority of adult grandchildren maintain a high degree of contact with their grandparents. He suggested that after adolescence, grandchildren come back to their families, though they now have competing demands (e.g., their own families, careers). In one study of young adult grandchildren, the grandparent-grandchild relationship is described as less activity-based and more symbolic for the young adult (Crosnoe & Elder, 2002).

As the grandparent-grandchild dyad matures, both grandparent and grandchild have changing developmental needs, interests, time constraints, and priorities. As the grandparent-grandchild dyad ages, important variables shift allowing for growth or stress in the relationship. It is worth considering how the grandparent-grandchild relationship shifts in terms of how grandparents and grandchildren relate to one another, how they support one another, and what they mean to one another symbolically. It is important to

explore how to facilitate grandparent-grandchild relationships that are mutually beneficial across the family life cycle on practical levels, as well as emotional and symbolic levels.

Grandparents' gender. Research indicates that grandmothers appear to be more involved in grandchildren's lives than grandfathers; in fact, research in this area suggests some real differences in terms of expectations, satisfaction, and function between grandfathers and grandmothers (Kivett, 1985). Research indicates that grandmothers tend to take a more active role with their grandchildren; they tend to derive greater satisfaction from being a grandparent, and they tend to report closer relationships (Eisenberg, 1988; Silverstein & Marenco, 2001; Somary & Stricker, 1998; Uhlenberg & Hammil, 1998). Their greater involvement may lead to greater impact, and research supports the notion that grandmothers are at least perceived as having greater influence on the development of their grandchildren's values than grandfathers (Somary & Stricker, 1998). In contrast to grandmothers, research shows that grandfathers visit less frequently, have more distant relationships with their grandchildren, and have a more narrow view of the grandparent role (Barranti, 1985; Hartshorne & Manaster, 1982).

One explanation for the observed difference in involvement between grandmothers and grandfathers is the women as kin keeper theory (Eisenberg, 1988; Robertson, 1977). This is the concept that women traditionally rear the children and keep the family. According to the kin keeper theory, it is quite natural for grandmothers and grandfathers to have different kinds of relationships with their grandchildren. Indeed, grandmothers and grandfathers should not be expected to have the same kinds of relationships with their grandchildren.

On the other hand, the belief that grandfathers do not want or are not capable of having more involved relationships with grandchildren is a sometimes ill founded assumption. Baranowski (1990) suggested that grandfathers may derive greater satisfaction in their roles as grandparents because they missed out on much of the childrearing of their own children. For example, they may have been at work while their wives were raising children. He also suggested that grandfathers may not have the same skill sets in terms of communication, child rearing, and relationship building as grandmothers have. To this end, he posits that grandfathers are at a greater risk than grandmothers for becoming the forgotten grandparent, suggesting that some grandfathers may need more help than grandmothers in defining and fulfilling their role as grandparent.

Maternal lineage. Maternal grandmothers and grandfathers appear to have more involved relationships with grandchildren than paternal grandparents, and maternal grandmothers, in particular have the closest relationships (Cherlin & Furstenberg, 1986; Fisher, 1983; Hagestad, 1986; Kahana & Kahana, 1971; McGreal, 1986; Roberto & Stroes, 1992; Somary & Stricker, 1998; Uhlenberg & Hammil, 1998). Researchers have interpreted the greater closeness of maternal grandmothers with grandchildren as an extension of the strong bond between mothers and daughters (Cherlin & Furstendberg, 1986; Hoffman, 1979). They suggest that the bond between mothers and daughters leads to more contact and closer feelings between grandparents and grandchildren. Fischer (1983) suggested that the greater mother-daughter bond is a function of the daughter's transition to motherhood. The increased mother-daughter bonding around grandchildren may alienate other grandparents in the extended family.

Grandchildren's disposition. Research (Fingerman, 1998) indicates that grandchildren's disposition is a variable affecting grandparent-grandchild relationships. Fingerman (1998) found that grandparents construct unique relationships with each of their grandchildren depending on the individual grandchild's disposition. Grandparenting a difficult grandchild is associated with stress, worry and negative attributions about the grandchild's behavior. In contrast, grandparenting a grandchild with shared interests, attributes, and achievements is associated with considerable enjoyment, role satisfaction, and feelings of wellbeing for the grandparent. Grandchildren who are not emotionally salient, neither worrisome nor special, do not have a significant impact on grandparents' sense of overall wellbeing. This relates to the current research because while grandparents derive enjoyment from relationships with special needs grandchildren, they risk detachment when grandchildren have behavioral or dispositional problems. In these cases, grandparents' attributions regarding grandchildren's behaviors are seen as the mechanism that interferes with the relationship and the grandparents' sense of wellbeing.

Affectional solidarity. The quality of the relationship between parents and grandparents is referred to as affectional solidarity in the grandparent literature. This relationship between grandparent and adult children has been shown to mediate grandparent-grandchild relationships (Kivett, 1985; Mathews & Sprey, 1985; Uhlenberg & Hammil, 1998). Kivett (1985) suggests that adult children specify roles for grandparents by setting conditions and providing structure for the relationship, acting as "gatekeeper" for the grandparent-grandchild dyad. Cherlin and Furstenburg (1986) suggest grandparents may "selectively invest" in one or more grandchildren depending on their feelings of closeness with the children's parents. Whitbeck, Hoyt, and Huck

(1993) found that the affectional solidarity between grandparents and grandchildren's parents is associated with more frequent contact between grandparents and grandchildren.

Grandparent Development Theory

Strom and Strom (1991) have postulated a theory regarding grandparent development. The model they have outlined provides a developmental and learning perspective on grandparents emphasizing the importance of the role of grandparent within the family structure. The theory underscores the dynamic nature of the grandparent role within the family system. It points out that grandparents are always changing and that the role is not prescribed or stagnant in any way. The theory emphasizes the potential for growth and development as grandparents enact their role.

The theory looks at grandparents as individuals with unique profiles characterized by individual strengths and needs. The theory has a prescriptive component in that it recognizes that grandparents, like parents and children, may need emotional support and guidance based on individual needs and individual strengths. One goal of the grandparent development theory is to increase practitioner sensitivity to the developmental needs of grandparents. Another goal of the theory is inclusion. In understanding grandparents' strengths and needs and increasing sensitivity to those needs, grandparents are included and assisted in identifying appropriate degrees of participation in the family structure. With inclusion comes the need for education. Education provides grandparents with the information they need to be helpful, or at least to be informed regarding grandparenting issues. An important component of Strom and Strom's (1991) theory is the recognition of contributions made by grandparents. It is in recognizing the real contributions made by grandparents that adult children can fully utilize grandparents' experience and support.

Strom and Strom (1993) developed a measure of grandparents' strength and needs, the Grandparent Strengths and Needs Inventory (GSNI). The measure is available in three forms (grandchild, parent, and grandparent) and provides an assessment of grandparents' strengths and needs (also known as grandparents' potentials and concerns). The GSNI has been used extensively in practice and research and it is utilized in the current study.

Developmental Stake Theory

Another question of interest is whether grandmothers' and mothers' perceptions of circumstances are similar, or whether grandmothers and mothers differ in their estimation of events. Previous research on intergenerational relationships suggests that older generations consistently take a more positive view of circumstances a phenomenon known as developmental stake theory in the literature on intergenerational relationships (Aquilino, 1999; Lynott & Roberts, 1997). This phenomenon has implications for research and practice. The current study investigates differences in mothers' and grandmothers' perceptions of grandmothers' strengths and needs by collecting information from mother-grandmother dyads using parallel forms of the GSNI.

Summary Section: Research on Grandparents

In summary, the discussion above presents an overview of grandparent research, including: demographics, dimensions of the grandparent role, and research on grandparent styles. A review is provided of background variables that have been shown to impact grandparent functioning. This information is relevant as it shows which background variables need to be measured and controlled for in future research. This section provides an overview of Strom and Strom's (1991) theory of grandparent

development, along with a description of the GSNI, the measure the authors developed in order to assess grandparents' strengths and needs. Finally, this section discusses the developmental stake hypothesis which suggests that in intergenerational relationships, older generations take a more positive view on circumstances than younger generations.

The research cited above clearly shows that grandparents are involved in modern American family life. They are relevant and valued members of the family structure. How they choose to enact their role as grandparents varies and is based on individual characteristics and circumstances which are measurable and malleable. Greater understanding of the dynamic role of grandparents by family members and practitioners has the potential to enhance the functioning of multigenerational family systems. While much is known about grandparents of children with typical development, less is known about grandparents of children with disabilities. The next section is a review of the research that has been done on grandparents of children with disabilities.

Research on Grandparents of Children with Disabilities

Impact on Grandparents of Grandchildren's Disability

Research indicates that the concerns of grandparents of children with disabilities are different from the concerns of grandparents of typically developing children (Hastings, 1997). Research on children's disabilities and the family shows that the diagnosis of a disability is a stressor on the family system. Family members must cope with shock, grief, and loss. Like members of the immediate family, members of the extended family and grandparents specifically, have added concerns. George (1988) has suggested that grandparents experience the same shock and grief as parents when children are diagnosed with a disability. Unlike parents, grandparents rarely have access

to the kind of information and support provided to parents. Grandparents are unlikely to be included in the information loop or treatment plan. Vadasy (1987) emphasizes how grandparents may be doubly affected when children have disabilities as they have concerns for their adult children and for their grandchildren.

Scherman, Gardner, Brown, and Schutter (1995) conducted a study of 32 grandparents of children with Spina Bifida. The authors conducted telephone interviews with the grandparents. The grandchildren in this study were between the ages of 20 months and 13 years. The authors examined grandparents' perceptions of the impact of grandchildren's disabilities on the grandparents' daily life. Also studied was grandparents' long-term emotional impact from having a grandchild with a disability and the fears and concerns they had about their grandchild's future. Additionally, the authors explored grandparents' concerns regarding their adult children and the impact on those children of parenting a child with a disability.

With regard to impact of grandchildren's disabilities on grandparents' daily life, 39% of those interviewed said it made them spend more time at the hospital with children and grandchildren, 22% said the experience brought the family together, 17% said they were negatively affected because the experience caused sadness or devastation, 10% reported mixed emotions, and 9% were unaffected by the experience because they lived far away (greater than 200 miles).

Grandparents were asked about their general fears and concerns regarding their grandchildren in order to assess the long term emotional impact of the disability. The results of the survey indicated that 33% of those interviewed were concerned about their grandchildren's inability to live independently, 31% were concerned about their

grandchildren's ability to establish deep relationships, 15% were concerned about not knowing who would take care of their grandchildren when they became adults, 15% were concerned that their grandchildren's medical, physical, and mental status would deteriorate, and 6% were concerned about society's negative treatment of their grandchildren.

When grandparents were asked about their concerns and fears regarding their adult children, their grandchildren's parents, 53% were concerned about the mental and physical stress that the grandchildren's disability had on their adult children's marriage, 23% were concerned that their adult children would continue to have sufficient finances to care for their grandchildren, and 13% were concerned about whether their adult children could provide an environment in which their grandchildren could acquire independent living skills. Ten percent had concerns with no elaboration.

The Scherman et al. (1995) study serves to illuminate areas of possible concern when grandchildren have disabilities. Documenting this kind of information by surveying this subgroup of grandparents provides information for practitioners and researchers to use when formulating workshops, curricula, assessment tools, and interventions. The percentages of grandparents experiencing a particular worry, which is sometimes low, is important, but it is not so important as the range and seriousness of grandparents' concerns and the development of strategies for addressing those concerns.

Grandparents as Providers of Practical and Emotional Support

Grandparents of children with special needs have added responsibilities in the family compared to grandparents of children with typical development (Seligman, 1991; Turnbull & Turnbull, 1990). The research in this section looks at the type of support that

grandparents may provide in families when grandchildren have disabilities. Studies consistently suggest that grandparents provide both practical and emotional support to families of children with disabilities.

Mirfin-Veitch, Bray, and Watson (1996) conducted unstructured, face-to-face interviews with 12 parent-grandparent pairs. Subjects were known to each other and were recruited from a grandparenting workshop. Nine of the pairs consisted of mother-adult daughter dyads. The remaining 3 were male-female combinations. Grandchildren were under 15 years of age and had a range of intellectual and physical disabilities. Interviews were audio taped, transcribed, and participant diaries regarding frequency of contact were collected. Using the diaries, the researchers recorded the number, length, and reasons for contact between parents, grandparents, and grandchildren. The authors looked at parents' and grandparents' perceptions of support enacted by the grandparents. In most of the families, parents and grandparents had nearly identical assessments of grandparents' level of support, suggesting that grandparents and parents have a shared view of grandparents' level of involvement.

Results from the Mirfin-Veitch et al. (1996) indicate that 75% of the grandparents were "supportive" and 25% were "not supportive". Among the "supportive" dyads, babysitting, respite care, help with household chores, and financial assistance were ways the grandparents provided support. Parents in the supportive dyads reported that the immediate and easily accessible aspect of grandparents' practical assistance was particularly important and helpful to them.

In addition to practical support, the grandparents in this study provided emotional support. Among the 75% of grandparents regarded as belonging to a "supportive" dyad,

parents reported that grandparents' emotional support was as important as the practical support they offered. In these dyads, the grandparents' acceptance of the child's disability often helped the parents' own attitudes and feelings regarding their child's disability. In this way grandparents were important in parents' own coping. Parents also said that the grandparents' immediate acceptance of the child's disability was very meaningful for them. Parents in "supportive dyads" reported using grandparents as individuals to whom they could express their feelings.

Baranowski and Schilmoeller (1999) looked at the role of grandparents as support agents for the family system. They conducted a study with 105 mothers of children with severe and multiple disabilities who were recruited through United Cerebral Palsy (UCP). The disabilities that were reported included: developmental delays (22%), Cerebral Palsy (20%), communication or language problems (13%), attention deficit disorder (12%), mental retardation (10%), seizures (10%), disruptive behavior disorder (10%), Down's syndrome (7%), autism (6%), hearing impairment (5%), and physical anomalies (5%) (percentages add to more than 100 because some children had multiple disabilities). The age range of the children was not reported. The authors measured grandparent involvement using The Grandparent Involvement Scale (Baranowski & Schilmoeller, 1999). Examples of items from the scale are "this grandparent takes care of child", and "this grandparent loans or gives money". The scale also assessed mothers' perception of grandparents' overall helpfulness.

In terms of practical support, mothers from this sample reported that many grandparents take care of grandchildren, do things with grandchildren, provide respite care, know how to address the medical needs of grandchildren, and are comfortable and

helpful in working to increase grandchildren's skills. For example, one grandmother helped her grandson with his speech, and another grandparent helped work on the child's goals from therapy.

As in the work of Mirfin-Veitch et al. (1996), Baranowski and Schilmoeller (1999) found that grandparents provide emotional support as well as practical support within the family system. Parents from other studies reported that immediate acceptance and understanding regarding the grandchildren's disability was important for their own adjustment. Several mothers indicated that their child's grandparent accepted him or her regardless of how he or she behaved. One respondent wrote that grandparents' acceptance of the child was the most important thing that the grandparent did. When grandparents had difficulty accepting grandchildren's disabilities at the outset, mothers reported that these difficulties were an added challenge for them.

Hornby and Ashworth (1994) also conducted a study of grandparents' provision of practical and emotional support when grandchildren have a disability. Their sample consisted of 25 parents of children with severe learning disabilities. The children's disabilities included cerebral palsy, Down's syndrome, mental retardation, quadriplegia, and profound deafness, with many children having multiple disabilities. Using a questionnaire, the authors assessed levels of practical, emotional, and financial support provided by maternal and paternal grandparents. Also studied was parental satisfaction with grandparent support.

With regard to practical support, 11% of grandparents babysat once a week, 18% of grandparents babysat once a month, and 57% of grandparents never babysat. Thirteen percent of grandparents helped with errands once a week, 72% percent of grandparents

never did errands or shopping. Eight percent of grandparents helped out around the house once a week, and 78% of grandparents were assessed as never helping around the house. Sixteen percent of grandparents took their grandchild on an outing at least once every 2 weeks, however, the majority of grandparents never took their grandchild on outings. Six percent of grandparents took care of children in their own home overnight or on holiday, once a month or more, 72% of grandparents never provided such visits. Twenty percent of grandparents regularly or occasionally provided financial assistance, 63% never provided such assistance.

Some but not all of the grandparents in the Hornby and Ashworth (1994) study provided emotional support. Fifty-two percent of grandparents were assessed as being always understanding about their grandchild's disability, 13% were assessed as being never understanding, and 11% were assessed as being rarely understanding. Thirty-three percent of grandparents were considered to be always willing to listen to problems, 25% were occasionally willing to listen, and 25% were considered unwilling to discuss problems regarding their grandchild's disability.

With regard to parents' perception of grandparent support, 61% of grandparents were assessed as giving the exactly appropriate amount of support, while 22% were considered to have provided too little support, and 24% were considered to have added to parents' problems. These percentages are lower than the percentages reported in the Mirfin-Veitch et al. (1996) study where 75% of grandparents were regarded as supportive and 25% were regarded as unsupportive. This is may be due to the fact that the study participants in the Mirfin-Veitch et al. (1996) study were participating in a workshop for grandparents of children with disabilities and may have had higher levels of adjustment

and involvement. It is likely that the lower estimates of parent satisfaction with grandparent support that are cited in the Hornby and Ashworth (1994) study are more representative of the actual population.

Based on their results, Hornby and Ashworth (1994) suggest that when children have disabilities, grandparents' actual level of practical and emotional support is low. They suggest that many grandparents of children with disabilities do not know what to do with their special needs grandchildren and more work is needed to facilitate grandparent involvement when grandchildren have special needs.

The research reported in the three studies cited illustrates the type of activities that grandparents could potentially engage in with their special needs grandchildren. It is difficult to make a judgment about whether the level of involvement is high or low for this group. It is clear that support and involvement can occur and is valued. This information is helpful for grandparents and practitioners attempting to educate family members on how to increase engagement in the grandparent-grandchild dyad.

Impact on Parents' Stress of Grandparents' Support

While the type and range of support that grandparents provide to families when children have disabilities has been described, little research has examined the impact of grandparents' support on parents. When grandparents are knowledgeable and sensitive about the needs of children and families when there is a disability and accomplish quick adaptation to the new and unexpected circumstances of children's disabilities, the parents' stress is likely to decrease and the entire family system is likely to benefit. When grandparents are lacking information and support and unsure as to their role or appropriate degree of involvement, they may withdraw or be minimally involved. When

grandparents lack access to necessary support and information, the burden of communicating accurate information to grandparents regarding the disability and teaching strategies for successful experiences remains with the parent and is an added stress. While the research cited above shows how grandparents provide emotional and practical support, few studies have examined the actual impact of grandparents' support on parents' stress (Hastings, 1997).

Heller, Hseih, and Rowits (2000) conducted a study examining the impact of grandmothers' emotional support on the well-being of mothers when children have intellectual disabilities. The subjects included 120 mothers of children with moderate to profound intellectual disabilities living in the family homes. Surveys and interviews conducted in-home asked about characteristics of the child (age, level of intellectual disability, physical health, maladaptive behavior) and mother (age, minority status, and socio-economic status), support received other than from grandparents, grandparent support (instrumental and emotional), and maternal depression. The results of the Heller et al. (2000) study indicated that grandmothers' emotional support is a predictor of mothers' depression: that increased emotional support is associated with decreased maternal depression. The mother's age and physical health were also predictors of maternal depression.

Research suggests some difference between mothers and fathers in terms of the type of support they find helpful. Weisbren (1980) conducted a study looking at the relationship between grandparents' provision of practical support and parents' stress when children have a developmental disability. The authors found that fathers in families where grandparents provide practical support report less stress than fathers in families

without grandparents' practical support. Grandparents' provision of practical support was not associated with less stress for mothers. Hastings, Thomas, & Delwiche (2002) suggest that mothers' level of stress may be affected by emotional support rather than practical support.

Hastings et al. (2002) conducted an empirical study to explore the impact of grandparent support on mothers and fathers. The impact of both support and conflict from grandparents on parents' stress was also studied. This is interesting in light of the research cited above showing that grandparents can be both a source of support and an added burden. Hastings et al. (2002) sample consisted of 61 parents of children with Downs' syndrome (34 mothers and 27 fathers) who completed questionnaires. The questionnaires had three sections. The first section regarded demographic information. The second section contained the Friedrich Short Form of the Questionnaire on Resources and Stress (QRS) with an amended depression sub-scale. The three subscales in this section were a pessimism scale, a depression scale, and a family and parent problems scale. The third section of the questionnaire looked at grandparents' support and grandparents' conflict. Grandparents' support was assessed with 4 questions and grandparents' conflict was assessed with two questions. The mothers and fathers in the study assessed support and conflict with all four grandparents. Support and conflict scores from each of the four grandparents were averaged so that mothers and fathers had mean scores for grandparent support and grandparent conflict.

Hastings et al. (2002) found that mothers and fathers agreed in their estimation of grandparent support and conflict. Grandparents' support was related to pessimism, support and lack of conflict was associated with lower depression and fewer family

problems. The authors interpreted their findings to mean that an individual grandparent can be a source of support and conflict simultaneously. This study provides empirical evidence that grandparent support improves parent stress, but it allows for grandparent conflict to coexist. This suggests that family members, including members of the extended family, are often in flux, bringing both positive and negative elements to the situation. Research indicates that all members of the family would benefit from counseling, information, and support as they sort out their roles and feelings (Hastings et al., 2002).

Green (2001) conducted a qualitative study examining the impact of grandparents' support on parents' emotional adjustment. Data were drawn from a survey and follow-up interviews. In general, the results showed that grandparents' support was associated with decreased parents' stress in that parents who received grandparents' support were regarded as having a positive outlook, high energy, and an ability to cope with the difficulties associated with children's disabilities.

Several additional themes emerged from the Green (2001) study. The findings showed that parents who receive help from grandparents also sought out and accepted help from a greater number of other outside sources. One explanation for this is that the successful, helping relationship between parents and grandparents provides parents with an internal working model for developing those kinds of relationships with others. Interview information from the Green (2001) study revealed the importance of direct participation between grandparents and grandchildren, and how direct participation has a positive effect on parents' stress. The study showed that grandparents' direct participation with grandchildren led grandparents to feelings of pride in grandchildren and that direct

involvement normalized relationships by helping grandparents to get to know their grandchild on a personal, one-to-one basis. Without direct participation, parents needed to manage the information given to grandparents and needed to mediate the grandchild-grandparent relationship. Communicating information about children's disabilities and mediating the grandparent-grandchild relationship was an added stress for parents. This suggests that support in the form of direct participation rather than indirect participation may have a positive impact on parents' stress.

Grandparent involvement was also associated with negative consequences and conflict for parents. The Green (2001) interviews revealed that parents may have concerns for their grandparents and feel stressed when grandparents are highly supportive. Grandparents may be reluctant to ask for help out of fear that parents are already overburdened by the demands of their children's disability. The grandparent-adult child relationship is reciprocal in nature, so that increased involvement brings increased responsibility for both parties.

The research cited above shows that grandparent involvement does have an impact on mothers' and fathers' wellbeing. The type of support (practical versus emotional, direct versus indirect) mediates the relationship between grandparents' support an parents' stress with mothers responding to emotional support and fathers responding to practical support and direct support being better than indirect support. Support and conflict are not mutually exclusive (support does not indicate the lack of conflict) and support that comes with conflict is still helpful and better than absence of support.

Relative Position of Grandparents in Parents' Social Support Network

Grandparents may be among the first people that parents turn to when children have a disability. In the study by Mirfin-Veitch et al. (1996) "supportive" parents reported that they were more comfortable approaching grandparents than they were approaching friends. When grandparents are involved and supportive, parents may be more likely to approach grandparents for help than they are to approach other people.

Findler (2000) conducted a study of 47 mothers of children with cerebral palsy and 43 mothers of children without a disability in order to determine the relative position of grandparents within the social support network of mothers when children have special needs. Mothers were interviewed in their homes regarding their social support network and their satisfaction with social support. The author used a measure of social support network a measure of satisfaction with social support. The author looked at the position of grandparents within the hierarchy of the family social support network. Results from the Findler (2000) study indicate that grandparents are ranked highly by mothers as providers of social support. All four grandparents are ranked within the top eight people in parents' social support network. No differences were found in the size of the family or friends network of the research group and the typical group. This was in contrast to previous research showing that families of children with disabilities tend to have smaller family and friend networks than families of children with typical development (Kazak & Marvin, 1984).

Background Variables Impacting Grandparents' Role

Grandparents' gender/ maternal lineage. With regard to grandparents' gender, Seligman et al. (1997) examined the perceptions of mothers (n = 42) of children with

disabilities regarding the amount of practical and emotional support offered by their children's grandmothers and grandfathers. Grandmothers were perceived to be more supportive than grandfathers. The maternal grandmothers were perceived to be more supportive than paternal grandmothers, and maternal grandparents were more supportive than paternal grandparents. In terms of differences among the grandparents, Baranowski and Schilmoeller (1999) found that maternal grandmothers, in particular, were seen by mothers as people who would listen, provide emotional support, and would be encouraging. Grandfathers tended to provide more practical than emotional support, such as financial assistance and caretaking.

Turnbull and Turnbull (1990) suggested that mothers may seek out help from their own mothers when children have disabilities because of the stress they are experiencing and the difficulties associated with children's disabilities. They warn that other grandparents and other family members may feel alienated when mothers rely on their own mothers exclusively. In terms of grandparents' relative position within the mothers' support network, Findler (2000) found that maternal grandmothers were often listed first in mothers' support network, before other grandparents and often before husbands.

Affectional solidarity. Affectional solidarity refers to the present day relationship quality between grandparents and adult children. In disability families, a problematic relationship between grandparents and their adult children can seriously hinder grandparent-grandchild relationships at a time when the family system needs to function most effectively.

Mirfin-Veitch et al. (1996) found that a problematic relationship history between grandparents and adult children undermined grandparents' provision of support. Parents with low affectional solidarity and consequently low levels of grandparent support reported feeling deprived of a valuable source of support. In some cases parents were angry and felt that grandparents were not fulfilling their expected role in the family. When affectional solidarity was low, parents regarded grandparents as too distant or too involved, disengaged or interfering. When affectional solidarity is low it may be particularly important to address conflict and help parents and grandparents to define their expectations and roles. Baranowski and Schilmoeller (1999) and Schilmoeller and Baranowski (1998) reported empirical studies with larger samples that also provided evidence that affectional solidarity is a significant predictor of grandparents' overall helpfulness and involvement.

Time since diagnosis. One variable that appears to be related to grandparents' effectiveness when children have disabilities is time since diagnosis (Mosala & Ikonen - Mosala, 1985; Schilmoeller & Baranowski, 1998; Seligman et al., 1997). In a survey of seventy families by Schilmoeller and Baranowski (1998), the authors found that grandparents were experiencing fewer negative feelings and more positive feelings at the time of study than at the time they first learned of their grandchild's disability.

Mosala & Ikonen - Mosala (1985) conducted a study looking at grandparents' emotional response to grandchildren's disabilities over time. They found that grandparents go through an adjustment process that resembles parents' adjustment process. After an initial period of shock, devastation, loss, and role confusion, many grandparents develop coping skills and are able to be involved and satisfied with their

role. The authors noted that even grandparents who adjust well may have lasting concerns about their grandchildren with disabilities.

In the Mosala & Ikonen - Mosala (1985) study, grandmothers reported that the level and type of involvement changed as time passed since diagnosis. Grandparents from the study who were "supportive" reported that the type and level of support they offered was very high in the beginning, but decreased as the family adjusted and as the grandchildren grew older. This result is corroborated by results from Heller et al. (2000) study described above. In the Heller et al. (2000) study, grandparents of younger children provided more practical support than grandparents of older children, suggesting a shift in grandparents' provision of support as time since diagnosis increases and as grandchildren age.

Shared view of grandparents' role. There is preliminary support for an argument that grandparents' and parents' share a view of grandparents' role. In addition to a shared view of grandchildren's disabilities, a shared view of the grandparents' role may be an important variable. Mirfin-Veitch et al. (1996) found that variables that affect grandparent involvement include grandparents' fears about interfering, grandparents' concerns about being too involved and grandparents' fears of not knowing how to interact when grandchildren have special needs. It stands to reason that in families where there is a shared view of the grandparents' role between parents and grandparents, grandparents will be more satisfied with their role, feel more successful, and feel less frustrated. What a grandparent's role should be is likely to vary from family to family. What seems to be important is that parents and grandparents have their roles clearly defined. Families with special needs grandchildren may have a more difficult time in

defining roles and communicating needs. Those families are likely to benefit from counseling and support groups.

Type of disability. The type of disability, which includes the severity of disability and treatment issues, may influence grandparents' functioning. Hodapp (1999) found that the effects of children's disabilities on family members vary substantially depending on the nature of the disability. Turnbull and Turnbull (1990) explain how the type and severity of disability influence family's response to the disability. When children have disabilities with medical complications, families often need to coordinate medical appointments, emergency care plans, and respite care with caretakers who are knowledgeable about their children's medical needs. When children have behavior problems it is important for caretakers and educators to understand the causes of the problematic behavior and to understand how to respond. Turnbull and Turnbull (1990) show how different disabilities pose different challenges.

S*ummary Section: Grandparents of Children with Disabilities.*

This section on research of grandparents of children with disabilities provided an overview of the research on how grandchildren's disabilities impact the extended family system, including: the emotional impact of grandchildren's disabilities on grandparents, grandparents as providers of emotional and practical support, the impact of grandparent support on parents' stress, and the position of grandparents in the parents' social support network. Background variables which mediate the grandparent-grandchild dyad when children have a disability were discussed. While research has looked at grandparents of children with disabilities in general, less is known about grandparents of children with ASD.

Grandparents of Children with Autism Spectrum Disorders (ASD)

Basic Concepts Associated with ASD

There are several diagnostic terms used by health care professionals when referring to autism spectrum disorders. They include Autistic Disorder (AD), Asperger's Syndrome (AS), Pervasive Developmental Disorder (PDD), Pervasive Developmental Disorder –Not Otherwise Specified (PDD-NOS). Autism spectrum disorders are pervasive developmental delays that are characterized by social deficits, communication impairments, and unusual behavior patterns. The diagnostic criteria of Autistic Disorder (AD) and Asperger's Syndrome (AS) as defined by the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (1994) fourth edition (DSM-IV) are listed in Appendix A. Characteristics include impairments in nonverbal behaviors, failure to develop peer relationships, lack of spontaneity, and lack of social and emotional reciprocity. Behavior, interests, and activities are restricted, repetitive, and stereotypical. Atypical behavior patterns are often manifested by preoccupation with restricted interests, inflexible adherence to nonfunctional routines or rituals, repetitive motor mannerisms, and sometimes preoccupation with parts or objects.

In terms of differential diagnosis for Asperger's Syndrome (AS), in AS there is no clinically significant delays in cognitive development or in the development of self help skills. While Asperger's Syndrome (AS) is not characterized by general delay in language, communication is impaired. Individuals with AS demonstrate language that is within the normal range, but very often is characterized by deviations from what is typical of speech/language development. In contrast, individuals with Autistic Disorder

(AD) have delayed fundamental language skills and in many cases do not develop speech at all. When the diagnosis is AD, cognitive and adaptive functioning is also impaired.

The key social features of autism spectrum disorders (ASD) are described in detail by Beebe and Risi (2003). Social difficulties include poor use of nonverbal communication, lack of social or emotional reciprocity, poor use of time and space in social interactions, limited social play and recreational skills, and poorly developed social relationships.

Twachtman-Cullen (1998) provided a review of the deviant communication patterns typically observed in ASD. These include differences in paralinguistic aspects of speech such as atypical prosody, rhythm, and timing. Children with ASD may exhibit atypical, nonverbal communication including unusual gestures, inappropriate facial expressions, and poor eye contact. Another feature of communication discussed by Twachtman-Cullen (1998) is echolalic speech; individuals with ASD may echo whole phrases or sentences from television and use them inappropriately in everyday situations. Children with ASD commonly have difficulty with nonliteral communication such as processing figures of speech and understanding analogies. Individuals with ASD have deficits with abstract language and concepts and can be concrete in their use of language. Children with ASD may have difficulty in everyday conversation, including difficulty determining the appropriate quantity and quality of details needed to communicate an idea.

In addition to having social pragmatic and communication deficits, individuals with ASD are often cognitively and behaviorally rigid. They rely on routine, have difficulties with unexpected change, and are stressed and disorganized by transitions.

Individuals with Autistic Disorder may display behavioral inflexibility through simple repetitive motor mannerisms, like hand flapping. Individuals with Asperger's Syndrome (AS) have more complex and more cognitively sophisticated stereotypical behavior (Howlin, 1999). These behaviors may include rituals and fixation on restricted areas of interest. While behaviors seem to reflect advanced cognitive skills and abilities they are rarely adaptive in terms of everyday functioning (Beebe & Risi, 2003).

Several core deficits have been proposed as explanations for the developmental delays of ASD. One hypothesis suggests that children with ASD have deficits in their theory of mind, or their ability to infer and integrate the mental states of others (Howlin, Baron-Cohen, & Hadwin, 1999). It has been suggested that children with ASD have poorly developed executive functioning (Ozonoff, 1997). The literature also suggests that ASD children may have poorly developed sensory integration and difficulties with central coherence (Frith, 1989). Stereotypical and rigid behavior may be related to deficits in mental flexibility (Ozonoff, 1997). It has been suggested that rigid and repetitive behaviors serve to reduce anxiety (Tantam, 2000). Psychoanalytic theories of the development of ASD are not supported by research. Most researchers agree that ASD is a neurodevelopmental disorder with a genetic component (Tsai, 1999).

Impact of ASD on Family Members

Turnbull and Turnbull (1990) and Hodapp (1999) have suggested that different disabilities pose different kinds of challenges for family members. Trigonaki (2002) looked specifically at the needs of parents of children with autism and found that these parents have specific needs that are different from parents of children with typical development and from parents of children with other disabilities. Midence and O'Neill

(1999) discuss the invisible nature of ASD and parents' need to explain their children's behavior to others as a developmental delay and not as an emotional disturbance. This differentiation is sometimes difficult for parents to negotiate. Grandparents as part of the extended family experience the same difficulties often with less information and training. Margetts, Lecouteur, and Croom (2006) discusses the particular anguish that families experience because the cause of ASD is unknown. Not having a known cause can make the diagnosis difficult to understand for parents and grandparents. Symptoms of ASD can be exhausting and chronic for family members (Sivberg, 2002). In addition to the core symptoms related to communication and socialization, other maladaptive symptoms such as hyperactivity, explosive behaviors, aggression, and self injurious behavior complicate the situation. Management of these symptoms presents unique challenges for parents and families of children with ASD.

Special Concerns Raised by Grandparents of Children with ASD

Margetts et al. (2006) conducted a qualitative study of grandparents' concerns when children have ASD. Study participants were six grandparents of children with autism. Three themes emerged from grandparent interview data. They were (a) parental bond (described grandparents' protective bond towards grandchild and adult child), (b) striving for answers (described grandparents' need to search for meaning and information), (c) keeping family intact (described grandparents' need to hold the family together). The authors suggest that more research is needed on grandparents' concerns in order to formulate a family-centered, multidisciplinary approach to assessment and treatment of ASD.

Harris et al. (1985) conducted and empirical study looking at independent variables that might mediate grandparent involvement when children have ASD. The authors looked at 19 families of children with autism. The sample consisted of 19 mothers, 14 fathers, 15 maternal grandmothers, 11 maternal grandfathers, 10 paternal grandmothers, and 7 paternal grandfathers of 19 autistic children. For each of the 19 autistic children, multiple family members completed a questionnaire describing their view of the special needs child, the impact of the special needs child on parents, and the relationship between parents and grandparents. The authors found that a shared view between grandparents and parents regarding grandchildren's ASD led to greater provision of support by grandparents and greater visitation. More research of this type is needed to illuminate variables that mediate grandparent involvement when children have ASD. The current research project looks at family functioning as a mediating variable of grandparents experience when children have ASD.

Parent and Grandparent Training when Children have ASD

Research has been conducted on the effectiveness of parent training via workshops (Johnson, Handen, Butter, et al., 2007; Sivberg, 2002). Insights provided by that research can be used when developing grandparent workshops. Given the unique challenges posed by a diagnosis of ASD, as well as, the chronic and complicated nature of the disorder, grandparents need information if they are to be effective members of the treatment team. Johnson et al. (2007) determined that in terms of parent training, parents of children with ASD have different needs from parents of children with other disabilities and different needs from parents of typically developing children. Johnson et al. (2007) developed a model for parent training which teaches parents to observe antecedent and

consequent behavior using a “prevention antecedent management” format. Emphasis in parent training was on identifying the function of a child’s behavior. Parents were taught to recognize disruptive behavior as a vehicle through which a child influences the behavior of others. Parents were taught to reinforce more appropriate communicative behavior. The training includes instruction in communication, play, social skills, and the appropriate use of positive reinforcement and extinction. These techniques are used to manipulate the environment so that a child’s ASD can be accommodated. By providing greater predictability in the child’s environment, disruptive behavior associated with children’s incomplete comprehension of daily events decreases. Johnson et al. (2007) conclude that more research is needed to empirically validate parent training manuals. In addition to a lack of empirically validated parent training manuals, there are no training manuals designed specifically for grandparents. In terms of future research, current parent training needs to be validated and training specific to grandparents needs to be developed (Johnson et al., 2007).

Appropriate Levels of Grandparent Involvement when Children have ASD

The appropriate level involvement for grandparents of children with ASD depends on the individual characteristics of the grandparent and the family. The ideal as described by Margetts et al. (2006) is a family that experiences a “culture of participation”. Grandparents should be recognized as a capable source of support to parents at first assessment and as part of the treatment plan in terms of intervention. As effective members of the treatment team, grandparents need both information and training. The clinical team needs to support grandparents as advocates for their

grandchildren and the whole family so that the clinical team can implement family centered children's services that include the extended family.

Summary Section: Grandparents of Children with ASD

This section provides a review of the basic concepts of ASD. ASD are on a spectrum in terms of severity and impact children's social and communication skills. The impact of ASD on family members is discussed. It is often difficult for family members to arrive at a shared view of diagnosis and treatment because the cause of ASD is unknown and because of the invisible nature of ASD. ASD is a chronic disorder, as such, a system wide treatment plan that include multiple family members across multiple settings are needed. Grandparents are a potential resource to be included in the treatment team. Research is also presented that has looked at specific concerns raised by grandparents of children with ASD. Finally, research on parent and grandparent training and the appropriate level of grandparent involvement is presented.

Family Systems Theory

Family Systems Perspective when Children have Special Needs

In the last two decades, there has been a major paradigm shift towards systems theory in how professionals deal with parents and families of children with exceptionalities. Turnbull and Turnbull (1990) provide a historical perspective of the role of family and parents in the education of exceptional children. They discuss a paradigm shift in which parents were initially viewed as a source of their child's disability to a modern model where parents are seen as decision makers and collaborators. Professionals' interest has shifted from focusing solely on the needs of the child with a disability to focusing on the needs of the mother-child dyad and also the needs of other

caretakers and family members. Assessment and intervention includes a response from the practitioner to the general family needs and the needs of individual family members. There has been a broadening of focus in assessment and treatment to include family members as well as resources outside the family such as school, community, and the extended family. Turnbull and Turnbull (1990) suggest that the best way to view families when children have a disability is to use a family systems approach. The family systems approach works because knowledge of a family's unique characteristics can inform professionals of families' strengths, needs, and priorities. Knowledge about family systems helps professionals determine which family members are potential resources in which context (Turnbull & Turnbull, 1990).

Impact on Family Systems

A major question in studying disability and the family is how the system is affected by the child's disability (Hornby & Seligman, 1991). The management needs of children with disabilities can be extensive and costly, requiring shifts in roles and responsibilities for individual family members. Having a family member with a disability can mean numerous medical appointments, visits to the hospital, clinics, and participation in support groups (Hornby & Seligman, 1991). Management needs can include anything from hands-on physical care, to arranging and coordinating schedules of family members for professional visits. In addition, children's disabilities impact families' financial resources. Financial burdens include medical expenses and in many cases the costs of respite care. Family members' roles and relationships need to be responsive to these concrete demands (Turnbull & Turnbull, 1990). Changing family structure may be temporary, while others may be more permanent in nature. In any case, the family needs

to cope with disability by sharing roles and responsibilities associated with children's special needs (Hornby & Seligman, 1991).

Primary caregivers often have added responsibilities with regard to children's social and emotional development. Primary caregivers may be responsible for helping siblings and extended family members develop relationships with the special needs child. Additionally, primary caregivers may need to help children develop friendships with their peers. Primary caregivers may scaffold for the family system the psychological impact of children's disabilities. Individual family members' feelings need to be acknowledged, expressed, and addressed. Family members' questions regarding the cause of a disability, concerns about the affected child's future and the family members' future must be processed by the family system.

In addition to changes within the family system, social networks outside of the family are affected (Kazak & Marvin, 1984). Changes in the social network have to do with increased isolation and/or a need to be associated with other families who are experiencing similar challenges (Findler, 2000). The need to network with other families in an attempt to share information is real and often times a burden to already existing social networks within and outside of the family system. When primary caregivers have difficulty supporting the social and emotional challenges of the family members, family relationships may be challenged and the family is at risk for role confusion.

When children have special needs family tasks range from conceptualizing the disability, to constructing social networks, communicating information, to managing the child's disability in terms of health and education and future planning. These tasks are made difficult when external supports are not adequate. Family members can quickly

become discouraged when stigmatizing attitudes create additional burdens or when major family dysfunction exists (Hornby & Seligman, 1991). Turnbull and Turnbull (1990) make an excellent point when they call attention to the research showing the many positive contributions made by children with exceptionality to families. The authors point out that the child's disability is not necessarily the stressor as much as the family's response to the disability.

Understanding Family Systems

Turnbull and Turnbull (1990) provide a framework for understanding and collaborating with families that emphasizes the expansive, interactive, and changing qualities of family systems. The model consists of four dimensions. Those dimensions are family characteristics, family life cycle, family interactions, and family functions.

Basic family characteristics refers to variables such as family size, form, cultural background, social economic status, geographic region, nature of exceptionality, and personal characteristics of individuals within the family unit. Characteristics could also include family members' health and coping styles and generally any characteristic which affects a family's response to a member's disability. A family's characteristics can be either a resource or an obstacle in terms of how a family responds to a child's special needs (Turnbull & Turnbull, 1990).

Family life cycle refers to the fact that the needs of family members change over time. Different developmental stages pose different challenges and are characterized by different dynamics. An assessment of the family life cycle includes assessment and sensitivity to the developmental needs of all members.

Family interactions refer to relationships within the family such as marital, sibling, parental, and extended family relationships. Relationships are subsystems and the family unit is a whole entity with relationships as component parts. The behavior of one component influences the behavior of another. Other family systems theorists have referred to the mutual influence within a system as circular causality (Nichols & Schwartz, 2007). Circular causality suggests that problems are sustained by an ongoing series of actions and reactions with little emphasis on initial causes. Family subsystems are separated by boundaries. Turnbull and Turnbull (1990) state that boundaries may be open or closed. Boundaries exist between family members and with individuals outside of the family. When boundaries are open information, suggestions, and requests are shared. When boundaries are closed there is an absence of collaboration.

According to Turnbull and Turnbull (1990), families exist to meet the individual and collective needs of their members. Family functions refer to the tasks that the family performs to meet those needs. Turnbull and Turnbull (1990) introduce eight categories of family functioning. They are affection, self esteem, spiritual needs, economics, daily care, socialization, recreation, and education. In family systems theory these could also be referred to as family outputs. In considering family functions it is critical to remember that the categories of family functioning influence each other and are impacted by a child with special needs. Family functioning is also dependent on family members' skills and abilities and their motivation at any given time (Turnbull & Turnbull, 1990).

Subsystems and Boundaries

In addition to family functioning, the concept of subsystems is helpful when understanding families. Turnbull and Turnbull (1990) identify four relevant subsystems

within family systems. They are the parent subsystem, the marital subsystem, the sibling subsystem, and the extended family subsystem. Family subsystems are separated by boundaries and those boundaries may be open or closed. Boundaries exist within subsystems and between subsystems, for example there is a boundary between siblings and there is a boundary between the marital subsystem and the extended family subsystem. When the boundary between the parent subsystem and the extended family subsystem is open, grandparents may take on parenting responsibilities. When that boundary is closed, a suggestion from grandparents regarding child rearing may be perceived by parents as interfering and unwelcome.

Circumplex Model of Marital and Family Systems

Introduction to the Circumplex Model. The Circumplex Model of Marital and Family Systems developed by Olson et al. (1979) is an application of family systems theory and a useful way of studying family functioning (see Appendix B for diagram of model). The model applies to both marital systems and family systems and it is the model used in the current study. Research supports the use of the Circumplex Model to describe family dynamics (Olson, 2000). Model constructs are well defined and valid and reliable instruments have been developed to measure important family constructs. The Circumplex Model focuses on subsystems within families by addressing three central dimensions: (a) family cohesion, (b) family flexibility, and (c) family communication.

Cohesion. Olson (2000) defines family cohesion as the bonding and closeness that couple and family members have with one another. The author states that cohesion focuses on how systems balance separateness with togetherness and loyalty with independence. Examples of the specific traits that are measured by the family cohesion

dimension include emotional bonding, boundaries, coalitions, friendships, decision-making, interests, and reactions (Olson, 2000).

According to the Circumplex Model (Olson, 2000) cohesion is measured along a continuum with five levels. The three middle levels are considered balanced or adaptive and the two extreme levels are considered unbalanced or maladaptive. The five levels of cohesion are: disengaged/disconnected (extremely low score on the cohesion scale), somewhat connected (low to moderate score on the cohesion scale), connected (moderate score on the cohesion scale), very connected (moderate to high score on the cohesion scale), and enmeshed/overly connected (extremely high score on the cohesion scale). Balanced levels are somewhat connected, connected, and very connected. Unbalanced levels are disengaged/disconnected, and enmeshed/overly connected.

An unbalanced family system is described as disengaged/disconnected. That family system is characterized by extreme emotional separateness. In theses family systems, there is little involvement among family members and there is a great deal of personal separateness and independence. Individuals function autonomously and have separate interests and priorities. Members are unable or unwilling to seek support from one another or to engage in mutual problem solving. Disconnected families function independently, are separate, lack closeness, and do not accept responsibility for each other's well-being (Olson, 2000).

A second type of unbalanced family system is the enmeshed/overly-connected family. In this family system there are extreme levels of emotional closeness and unquestioning loyalty. Individual members are codependent and highly reactive. Family members do not respect personal space and there is little separation between members.

The energy of individual members is focused almost exclusively within the family circle with few friends or interests outside the family. Enmeshed family systems consist of members who are overly connected with too much togetherness, too much closeness, and high dependency needs (Olson, 2000).

Families that are balanced in cohesion are bonded emotionally with each other while still maintaining an acceptable level of independence. They have mastered the skill of being close while still maintaining independent identities. Individual family systems' functioning falls between the two extremes of high enmeshment and high disengagement (Olson, 2000; Turnbull & Turnbull, 1990).

Flexibility. Olson (2000) defines flexibility as the amount of change in a family's leadership, roles, and relationships. The authors state that a family's flexibility indicates how the system balances stability with change. Flexibility measures leadership, role shifts, discipline, and adaptability in the context of change and stress. Specific traits related to flexibility include control and discipline (leadership), negotiation styles, roles, and relationship rules.

According to the Circumplex Model, Flexibility is measured on a continuum with five levels (Olson, 2000). The three middle levels are considered balanced and the two extreme levels are considered unbalanced. The five levels of flexibility are: rigid/inflexible (extremely low score on the flexibility scale), somewhat flexible (low to moderate score on the flexibility scale), flexible (moderate score on the flexibility scale), very flexible (moderate to high score on the flexibility scale), and chaotic/overly flexible (extremely high scale on the flexibility scale). Balanced levels are somewhat flexible,

flexible, and very flexible. Unbalanced levels are rigid/inflexible, and chaotic/overly flexible.

An unbalanced family system in terms of the flexibility dimensions is rigid/inflexible. That family type is characterized by one individual who takes charge and is highly controlling. Rigid inflexible family systems engage in limited negotiations with most decisions imposed by one individual. Roles are strictly defined and leadership and titles do not change. The family is characterized by rigid relationships which are unbalanced and inflexible. Leadership is authoritarian, strict discipline is maintained and change is poorly tolerated. One individual family member takes charge and is highly controlling. There tends to be limited negotiation with most decisions imposed by the leader. Roles are strictly defined and titles do not change. Rigid relationships are unbalanced and inflexible, and are characterized by too little change, authoritarian leadership, roles that seldom change, and strict discipline (Olson, 2000; Turnbull & Turnbull, 1990).

A second type of unbalanced family system functioning is the chaotic/overly flexible family. In this family system roles are unclear and shift from individual to individual. Leadership is limited and erratic. Decisions are impulsive. There is a lack of planning and there is endless negotiating (Olson, 2000; Turnbull & Turnbull, 1990).

By contrast, families that are somewhat flexible, flexible, and very flexible are considered balanced in terms of this flexibility. Families that are balanced on the flexibility dimension change when necessary, share leadership, share roles, and have democratic discipline (Olson, 2000; Turnbull & Turnbull, 1990).

Communication. The third dimension of the Circumplex Model is communication. Communication can be conceptualized as a facilitating dimension. Good communication facilitates cohesion and flexibility. Indicators of good family communication include listening skills (empathy and attentive listening), speaking skills (speaking for oneself and not for others), self disclosure (sharing feelings about oneself and the relationship), clarity, continuity tracking (staying on topic), and respect and regard (affective aspects of communication).

Communication is measured on a continuum from good communication to poor communication. Several studies investigating communication have found that systems that are balanced on cohesion and flexibility tend to have very good communication (Olson, 2000).

Satisfaction. The authors of the Circumplex Model have included a fourth component to consider when analyzing family functioning, that is family satisfaction. Olson (2000) suggests that there are circumstances when extreme functioning in terms of cohesion of flexibility may be adaptive for family members. Olson (2000) offers several examples of stressful life events which may lead to families experiencing unbalanced family functioning as adaptive (e.g., death of a family member, the diagnosis of a disability or birth of a child with a disability, chronic illness, divorce, etc.). In addition, Olson (2000) suggests that there may be differences among cultures in terms what are adaptive levels of cohesion and flexibility. For example, it may be true that enmeshed functioning is adaptive among minority cultures in a given community. If a family is characterized by unbalanced functioning, but report high levels of family satisfaction, it means that extreme or unbalanced functioning is adaptive for that particular family.

Basic hypotheses using the Circumplex Model. The Circumplex Model purports specific relationships between the central dimensions (i.e., cohesion, flexibility, and communication) and optimal family functioning. The model shows that there are curvilinear relationships between cohesion and flexibility with optimal family functioning, and that there is a linear relationship between communication and optimal family functioning, such that, midrange scores on the cohesion and flexibility scales plus high range scores on the communication scale are associated with optimal family functioning. In contrast, having extreme high or low range scores on the cohesion and flexibility scales and low range scores on the communication scales are associated with problems in family functioning (Olson, 2000). The principal hypothesis derived from the Circumplex Model is that Balanced type families are more effective across the family life cycle than unbalanced types (Olson, 2000). Thus, research hypotheses should predict that in response to normal developmental change or in response to major life stressors, family members with balanced cohesion and flexibility scores and better communication scores will have higher scores on a variety of outcome measures. In the current study, it is expected that grandmothers from families with optimal family functioning will have the best outcomes in terms of their strengths and needs, when children are typically developing and especially when children have special needs.

Family Systems Variables and Children with Disabilities

Turnbull and Turnbull (1990) discuss how disengagement can be problematic within family systems and when children have disabilities. In a disengaged, unbalanced system there are low degrees of cohesion. Unbalanced family systems are characterized by under involvement, few shared interests, few shared relationships, and excessive

privacy. This is ineffective for family members and particularly for children with special needs because low degrees of cohesion isolate family members from emotional support and loyalty of other family members (Turnbull & Turnbull, 1990). The exceptional child can be left without supportive family interactions, and can be isolated without the assistance needed to develop independence.

Turnbull and Turnbull (1990) also discuss how enmeshment within or between subsystems can be problematic for family members and when children have disabilities. In enmeshed family systems, it is possible for a parent and child with special needs to become overly dependent on each other and exclude other family subsystems. For example, a mother who has primary care of a severely physically disabled child may be overly responsive to that child's needs to the exclusion of the other children's needs or to the exclusion of the marital relationship. When enmeshment occurs with the parent-child subsystem, there is a potential problem for the child who is thwarted in his or her attempts for independence and for the mother who may not pursue her own personal goals.

Family systems which are unbalanced on the dimension of flexibility are problematic in terms of meeting the needs of individual family members. This style of functioning is particularly ineffective in families with special needs children. Rigid/inflexible families are less likely to adapt to the increased demands of an exceptional child. They are less likely to share responsibilities or to shift roles easily. The person who is in charge in rigid/inflexible families may overpower and alienate other family members, reducing their ability to contribute to the family system or share new ideas.

Families that are chaotic are not good for family members or children with disabilities either. In chaotic families, which demonstrate a low degree of control and structure, follow through on needed responsibilities is problematic. Family members may not be able to take responsibility, set goals, and make reliable commitments. Without a defined family leader, roles are unclear, goals are not likely to be set, and expectations may not be met (Turnbull & Turnbull, 1990).

Family Systems Variables and Grandparents

There is very little research that has looked at the impact of family systems variables, cohesion, flexibility, and communication, on grandparents' involvement. Turnbull and Turnbull (1990) suggest that there is greater grandparent involvement in family systems when family functioning is balanced and they cite the need for research in this area. This may be especially true when grandchildren have special needs. Hastings et al. (2002) looked at families of children with disabilities and found that good communication in the nuclear family is an important variable influencing grandparent involvement. In a study by Trute (2003) of 70 parents of children with developmental disabilities, the authors looked at family functioning and grandparent involvement. The results were inconclusive and more research was suggested to examine the relationship between family functioning and grandparent involvement.

Summary Section: Family Systems Theory

This section provides a review of family systems concepts relevant to the current study. There has been a shift in perspective among mental health providers from focusing solely on the child with a disability to focusing on the needs of the entire family system (Hornby & Seligman, 1991). In order to assist the entire family when children

have a disability, greater understanding of how disabilities in children can impact family members and how families function is needed (Turnbull & Turnbull, 1990). The Circumplex Model of Marital and Family Systems (Olson et al., 1979, 2007) provides a framework for looking at several important aspects of family functioning that include cohesion, flexibility, communication, and family satisfaction. The basic hypothesis of the Circumplex Model is that families with balanced cohesion, balanced flexibility, and good communication will have better outcomes for family members. Alternately stated, unbalanced cohesion, unbalanced flexibility, and poor communication are associated with worse outcomes for family members. Family members' satisfaction with their families level of functioning is measured because sometimes unbalanced functioning is adaptive for families (e.g., enmeshment may be adaptive when there is chronic illness in the family). Turnbull and Turnbull (1990) discuss how families that are characterized by unbalanced functioning often do not meet the needs of children with disabilities. Less is known about the impact of family functioning on grandparent involvement. The current study addresses this gap in the literature.

Rationale for Current Study

This current study examined similarities in reports between grandmothers and mothers. Second, this study examined the impact of grandchildren's autistic spectrum disorders (ASD) on grandmothers' strengths and needs and how the experiences of grandmothers with typically developing grandchildren may differ from those of grandmothers of grandchildren with ASD. Finally, the current study examined family functioning as a predictor of grandmothers' experiences.

Much of the research on grandparents of children (Hastings, 1997; Sandler & Warren, 1998) focuses on mothers' perceptions of grandparents' involvement, rather than grandmothers' own report. In order to enhance the quality of this research, grandmothers were used as respondents in addition to mothers. Previous research on intergenerational relationships suggests that older generations consistently take a more positive view of circumstances (Aquilino, 1999; Lynott & Roberts, 1997). It is possible that mothers' reports will be slightly more negative than grandmothers' reports. Although parallel forms of the GSNI for parents and grandparents are available, previous research using the measure has not looked at agreement between parents' and grandparents' responses within a family. By using mothers and grandmothers as respondents, it was possible to see whether or not mothers and grandmothers share a view of grandmothers' strengths and needs.

The research that has been done on the impact of disability on grandparents suggests that grandparents of children with disabilities have added concerns and additional responsibilities (Baranowski & Schilmoeller, 1999; Gardner et al., 1994; Scherman et al., 1995). Grandparents may be a resource in the family or an added burden in the family, or both (Hastings, 1997; Seligman, 1991). Research indicates that it is often the case that grandparents are among the first people that parents will turn to when children have disabilities (Findler, 2001), and parents often state that grandparents' acceptance of their grandchild's condition helps in their own healing (Mirfin-Veitch et al., 1996). In addition, there are several background variables, some of which are unique to families of children with disabilities, and some of which are similar to grandparents of typically developing children (e.g., child's age, lineage, grandparents' gender, time since

diagnosis, severity of disability, age of child, perspectives on disability) that have been shown to impact grandparents' experience and role when children have a disability (Glasberg & Harris, 1997; Hornby & Ashworth, 1994; Katz & Kessel, 2002; Mirfin-Veitch et al., 1996). Research involving autism spectrum disorders has shown concerns specific to grandparents of children in that disability group.

The research that has been carried out with grandparents of children with disabilities has several methodological weaknesses that are addressed in the current study. Methodological issues include: small, non representative samples; lack of comparison groups of grandparents of children with typical development; use of parent's report rather than grandparent's report; qualitative rather than quantitative studies, using semi-structured interviews rather than valid and reliable instruments; and lack of controls for confounding background variables such as grandparents' gender, geographical distance, grandchildren's disability, and grandchildren's age.

In an attempt to address these methodological issues, this researcher selected grandmothers and mothers of children with a specific disability, autism spectrum disorders (ASD). In so doing, parents' gender, grandparents' gender, and grandchildren's type of disability were controlled. In addition, grandmothers were selected who live within 50 miles of their grandchild and grandmothers and mothers of children between the ages of 6 and 14 years were selected, thus geographical distance and grandchildren's age were also controlled. The current study used a large enough sample to detect a significant effect and used reliable instruments of grandparent self-reported role and experiences rather than relying on a structured interview with small groups of grandmothers or parent's report of grandparent's experiences. Grandmothers and mothers

completed the Grandparent Strengths and Needs Inventory (GSNI) to measure grandmothers' role and experiences.

The current study examined family functioning as a predictor of grandmothers' involvement. Using the Circumplex Model of Marital and Family Systems (Olson et al., 1979), it was expected that as family functioning approached optimal levels, outcomes for grandmothers would be more favorable. Family functioning was measured using the Family Adaptability and Cohesion Evaluation Scales Fourth Edition (FACES IV), completed by mothers. While the relationship between family systems variables and grandmothers' involvement has not been tested, there is some evidence supporting family functioning, (e.g., communication), as a mediator of grandparents' involvement and satisfaction when children have a disability (Hastings et al., 2002; Trute, 2003). Thus, the current study addresses a gap in the literature by looking at the impact of family functioning on grandmothers using a comprehensive measure and a sample of typically developing families as well as families with a disability. The current study extends the research supporting the validity of the Circumplex Model by showing how family functioning relates to grandmother outcomes.

Based on the above discussion, this study addresses three research questions.

1. Do mothers' and grandmothers agree on grandmothers' experiences?

2. Do the experiences of grandmothers with typically developing grandchildren differ from those of grandmothers with grandchildren with ASD in the areas of satisfaction, success, teaching frustration, difficulties, and information needs?

3. Does nuclear family functioning impact on grandmothers' experiences?

CHAPTER III

Methodology

This chapter describes the methodology of this study that will examine consistency between mothers' report and grandmothers' report of grandmothers' strengths and needs, the impact of grandchildren's ASD on grandmothers' strengths and needs, and the impact of family system's variables on grandmothers' strengths and needs.

Participants

A total of 152 grandmothers and mothers participated in this study. Cohen (1992) suggests a sample size of 67 to detect a medium effect at the $p < .05$ significance level and a sample size of 52 to detect a small effect when conducting multiple regression equations with two predictor variables. Therefore, the recruitment goal was to collect from 34 dyads containing children with ASD and 34 dyads containing children with typical development (136 mothers and grandmothers). The following selection criteria were established to minimize variation external to the study questions: (a) child's age within the range of 6-14 years; (b) driving distance between grandmother and grandchild of less than 50 miles.

The final sample consisted of 84 grandmother/mother dyads, some of which (n = 68 dyads) were fully observed and some of which were partially observed (n = 16), (mother alone or grandmother alone completed a questionnaire). The actual sample was divided into three groups. The control group consisting of dyads of grandmothers and mothers of typically developing children contained 30 fully observed dyads and 4 partially observed dyads (N = 68, 34 dyads). The High Functioning Autism/Asperger's (HFA/AS) group consisted of 27.5 fully observed dyads, and 4 partially observed dyads

(*N* = 63, 3.5 dyads). The Autistic Disorder (AD) group consisted of 10.5 fully observed dyads and 8 partially observed dyads (*N* = 37, 18.5 dyads). Therefore in the total sample, there were a total of 78 fully observed dyads (30 + 27.5 +10.5 = 68) and 16 partially observed dyads (4 + 4 + 8 = 16). Of the 16 partially observed dyads, 10 were completed by mothers alone and 6 were completed by grandmothers alone.

Table 1 presents the background characteristics of the sample. The sample consisted of mothers and grandmothers who were mostly caucasion and living within 50 miles of each other. The majority of the grandchildren were between 6 and 14 years of age and the majority of the grandmothers were maternal grandmothers.

Looking at the means, standard deviations, and ranges for each of these variables shows that the groups (typical development, HFA/AS, AD) were largely the same on most of the background variables including race, religion, grandmothers' age, and grandmothers' level of education. The only exceptions to this were grandchildren's gender and lineage. Sixty one percent of the typical group were female (39% male), 22% of the HFA/AS group were female (78% male), and 8% of the AD group were female (92% male). Thus there were more males in the ASD groups. Slight differences were observed between the groups in terms of grandmothers' lineage. Ninety-four percent of grandmothers in the typical group were related to their grandchild through their daughter, compared to 89% in the HFA/AS group, and 76% in the AD group. Thus there were more paternal grandmothers in the ASD groups. The effects of grandchildren's gender and grandmothers' lineage on the dependent variable were accounted for by including these variables in the final models.

Table 1

Sample Numbers, Means, Standard Deviations, and Ranges for Demographic Variables by Diagnosis (N = 168, 84 dyads)

	Typical (*N* = 68, 34 dyads)				HFA/AS (*N* = 62, 31dyads)				AD (*N* = 38, 19dyads)			
	N	M	SD	Range	*N*	M	SD	Range	*N*	M	SD	Range
						Children						
Gender	34	0.61	0.49	0 - 1	32	0.22	0.42	0-1	19	0.08	0.27	0 - 1
Age	34	9.63	2.85		32	10.26	2.94		19	9.44	3.66	
Time	34	0.00	0.00		28	5.18	2.70		16	7.25	3.33	
						Grandmothers						
Age	34	67.28	7.47		31	68.62	7.43		19	65.83	10.13	
Marital [a]	34	2.24	1.68	1 – 5	29	2.36	1.67	1 – 5	16	2.68	1.91	1 - 5
Lineage[b]	34	0.94	0.24	0 - 1	31	0.89	0.31	0 - 1	19	0.76	0.43	0 - 1
Geo. Dist	34	3.00	0.80	1 - 6	31	3.27	0.91	1 - 6	19	3.19	1.16	1 - 6
Caregiv[c]	34	2.46	0.73	1 - 4	31	2.22	0.73	1 - 4	19	2.03	0.67	1 - 4
# gchild	34	4.81	2.13		31	3.95	2.41		19	4.93	2.47	
Emplo [d]	34	1.76	1.03	1 – 4	31	1.83	0.95	1 - 4	19	2.03	1.17	1 - 4
Religion[e]	31	1.68	1.00	1 – 5	29	1.81	1.02	1 – 5	14	1.74	0.97	1 - 5
Race[f]	32	1.00	0.00	1 - 5	30	1.05	0.38	1 – 5	16	1.00	0.00	1 - 5
Income[g]	34	5.27	1.38	1 - 6	31	5.08	1.31	1 - 6	19	5.54	1.34	1 - 6
Education[h]	34	4.62	2.04	1 - 7	31	4.92	1.66	1 - 7	19	4.88	1.95	1 – 7
Health [i]	34	1.88	0.62	1 - 4	31	1.81	0.73	1 – 4	19	1.62	0.63	1 - 4
Time [j]	34	3.26	0.76		31	3.02	0.86		19	2.99	1.01	
						Mothers						
Age	34	37.61	10.91		31	39.18	11.09		19	33.55	15.84	
Mari[a]	34	1.32	0.83	1 - 5	31	1.06	0.35	1 – 5	19	1.22	0.62	1 - 5
Educa[h]	34	6.23	1.23	1 - 7	31	5.91	1.09	1 - 7	19	5.97	0.82	1 - 7

Table 1 (*continued)*

	Typical (*N* = 68, 34 dyads)				HFA/AS (*N* = 62, 31dyads)				AD (*N* = 38, 19dyads)			
	N	M	SD	Range	*N*	M	SD	Range	*N*	M	SD	Range
					Mothers *(continued)*							
Race[f]	33	1.06	0.34	1 - 5	29	1.14	0.72	1 - 5	16	0.94	0.25	1 -5
Inco[i]	34	5.81	1.24	1 - 6	31	5.83	0.50	1 - 6	19	5.45	1.13	1 - 6
#children	34	2.49	0.62		31	2.08	1.03		19	2.40	0.66	

[a]Gender: 0 = *male,* 1 = *female.* [b]Marital status: 1 = *married,* 2 = *separated*, 3 = *divorced,* 4 = *never married*, 5 = *widowed*. [c]Lineage: 0 = *paternal,* 1 = *maternal.* [d]Geographical distance: 1 = we live together, 2 = *less than a mile,* 3 = *1 to 24 miles*, 4 = *25 to 199 miles*, 5 = *200 to 1,000 miles*. 6 = *more than 1,000 miles*. [e]Caregiving: 1 = *daily,* 2 = *often*, 3 = *seldom,* 4 = *never*. [f]Employment status: 1 = *retired,* 2 = *working part time,* 3 = *working full time,* 4 = *unemployed.* [g]Religion: 1 = *Christianity,* 2 = *Islam,* 3 = *Judaism,* 4 = *other.* [h]Race: 1 = *White,* 2 = *Black*, 3 = *Hispanic*, 4 = *Asian*, 5 = other. [i]Income: 1 = *under $9,999,* 2 = *$10,000* to *$19,999,* 3 = *$20,000 to $29,999,* 4 = *$30,000 to $39,999,* 5 = *$40,000 to $49,999,* 6 = *over $50,000.* [j]Education: 1 = *8th grade or less,* 2 = *some school,* 3 = *high school diploma,* 4 = *vocational training,* 5 = *some college,* 6 = *college degree,* 7 = *graduate degree.* [k]Health status: 1 = *excellent,* 2 = *good,* 3 = *fair,* 4 = *poor.* [l]Time Spent: 1 = *less than one hour,* 2 = *1 to 5 hours*, 3 = *5 to 10 hours,* 4 = *more than 10 hours.*

Measures

Grandparent Strengths and Needs Inventory (GSNI)

Strom and Strom (1993) developed a comprehensive measure of grandparent development called Grandparent Strengths and Needs Inventory (GSNI, see Appendixes C and D). The purpose of the GSNI is to help grandparents recognize their strengths, also conceptualized as potentials, and identify areas in which they may need further growth, conceptualized as needs or concerns. The GSNI is designed to measure grandparents'

potentials and concerns with regard to individual grandchildren, as they are prompted in the front of the measure to identify the grandchild whom they are thinking of as they answer the questions. The GSNI also has background information questions that were used for this study. The measure includes parallel forms for grandparents, parents, and grandchildren. Different forms allow for different reports of the same construct (i.e., mothers', grandmothers', and grandchildren's perception of grandparents' areas of potential and concern). In this study, complementary forms allow for the comparison of mothers' and grandmothers' perspectives on grandmothers' behavior.

The GSNI measures grandparent behavior with 60 Likert-type items divided into six subscales of 10 items each. The six subscales emphasize different aspects of grandparent development. They are: success, satisfaction, teaching, difficulty, frustration, and information needs. Three of the GSNI subscales (satisfaction, success, and teaching) are combined into a composite score of grandparents' potentials. The remaining subscales (difficulties, frustration, and information needs) can be combined into a composite score of grandparents' concerns.

The satisfaction scale measures aspects of being a grandparent that are pleasing and satisfying. According to the authors, grandparents and grandchildren typically strive to build relationships that are mutually satisfying, despite the fact that their needs are continually changing as a result of normal developmental growth and unexpected stressful events (e.g., death in the family, divorce, disability). The satisfaction scale was designed to reveal grandparent's current role satisfaction with regard to a specific grandchild.

The success scale reflects the ways in which grandparents successfully perform their roles. The authors state that grandparents need to feel capable of providing as nurturing and stimulating environment, or else they may withdraw from grandparent responsibilities. Furthermore, the authors suggest that grandchildren admire adults who help them grow, adapt, and feel capable. In many ways the success scale is a measure of grandparents' feeling of self efficacy in their role as grandparent. The success scale reveals grandparent's feelings of success and competence at fulfilling their role with individual grandchildren.

The teaching scale assesses the extent to which grandparents teach the kinds of lessons that grandparents are often expected to provide. This scale was designed to measure the extent to which grandparents assist parents in teaching and reinforcing the lessons that parents teach on a regular basis. This scale is interesting because it is assesses direct participation between grandparents and a specific grandchild.

The difficulty scale reflects the problems encountered by grandparents as they attempt to fulfill their obligations to the family and grandchildren as grandparents. Given that grandparents encounter different types of problems at different developmental levels, and that their experience is always changing, the scale reveals the difficulties that a grandparent is currently facing.

The frustration scale is designed to reveal behaviors of grandchildren that are upsetting to grandparents. Thus, the frustration scale focuses on grandchildren's abilities and behaviors and the frustration scale focuses on grandparent's own abilities and behaviors.

The information needs scale measures things grandparents need to know about grandchildren. The authors contend that grandparents, who are informed about the abilities, feelings, values, choices, and problems of grandchildren and of their parents, are more likely to be involved in a way that is adaptive for all. This scale reveals the kinds of information that grandparents feel they need to know in order to function effectively.

Raw scores for each scale range from 10 to 40. In addition, the potentials score and the concerns score can be calculated, with a maximum score of 120. Response choices for all questions on the GSNI are “Always”, “Often”, “Seldom”, and “Never”. Within the Potentials composite “Always” is scored with 4 points and “Never” is scored with 1 point. Within the concerns composite “Always” is score with 1 point and “Never” is scored with 4 points. Thus, higher scores on the potentials subscales or composite indicate more potential and higher scores on concerns subscales indicate fewer concerns. Thus, on the GSNI, higher scores are always better with this approach and a score above 75 is considered favorable. For the current research, however, the scoring procedure for the concerns composite was amended slightly, such that, among the concerns subscales “Always” receives 4 points and “Never” receives 1 point. This was done in order to maintain consistency in the response format as the questionnaire involved many questions. Thus, for the current research higher potentials scores indicate greater potential, and higher concerns scores indicate greater concerns. Thus for the current research higher scores are not always better; it is preferable to have high potentials scores and low concerns scores. Given that a cutoff score of 75 on the potentials and concerns composites is normally considered as favorable, then, in the current study, a score that is greater than 75 for potentials and less than 75 for concerns would be favorable.

The construct validity of GSNI was supported by factor analysis. Collinsworth, Strom, Strom, and Young (1991) conducted a study with responses from 2,012 inventories completed by grandparents, parents and children to determine whether the underlying structure of the instrument fit the hypothesized dimensions suggested by the position of 60 items on six subscales.

The reliability of the GSNI was established with a sample of 98 grandparents, each responding to the instrument twice with a six-week interval between administrations. Internal consistency estimates of .93 and .93, respectively, were obtained for the potentials scale and .88 and .92 for the concerns scale. Subscale alphas were also in the favorable range (.82 to .93). Test-retest correlations range from .70 to .85. Item analysis led to the revision of one item based on low item to total correlation (Strom, Strom, Collinsworth, & Young, 1991). Reliability was assessed again during an intervention program with 760 grandparents, parents, and grandchild respondents. Alpha coefficients from .90 to .93 were obtained for each subpopulation on their pre-test, 12 weeks later on the post-test and 12 weeks thereafter on a delayed post test administration (Strom et al., 1991). Similar alpha coefficients were calculated in a comparative study of 408 grandparents and 470 grandchildren, representing two generations drawn from White and Black families (Strom et al., 1991). The potentials and concerns indexes for these four subpopulations ranged from .91 to .95. In this study scores on the 6 subscale measures were used each with a range of 10 to 40 points.

The FACES IV Package

The FACES IV package (see Appendix E) consists of three components: (1) the Family Adaptability and Cohesion Evaluation Scales – Fourth edition (FACES IV), (2)

the Family Communication Scale (FCS), and (3) the Family Satisfaction Scale (FSS) (Olson, Gorall, & Tiesel, 2007). The FACES IV contains a demographic profile sheet, which was used to collect background information. The Family Assessment Package can be completed by one or more family members.

The first component, the FACES IV, is a questionnaire instrument with 42 Likert-type items. It has been designed to measure two of the central components of the Circumplex Model of Marital and Family Systems (Olson et al., 1979), which are Cohesion and Flexibility. The Circumplex Model is depicted in Figure 1. Both components of the Circumplex Model are conceptualized along a continuum with the optimal range of family functioning being the middle, and with family functioning at the extreme ends of the continuum being less favorable. The curvilinear relationship that exists between family Cohesion and Flexibility and favorable outcomes for family members is more difficult to measure than variables with linear relationships to family outcomes. In the FACES IV, the authors address this difficulty by measuring parts of the low, middle, and high ends of the cohesion and flexibility continuum using separate scales. The use of separate scales to measure the full range of the cohesion and flexibility dimensions is a development in the FACES IV compared to previous versions of the measure, which have been criticized for inadequately assessing the low and high ends of the cohesion and flexibility continua (Olson et al., 2000). The balanced scales measure the middle range of the cohesion continuum and flexibility continuum and the unbalanced scales measure the extreme ends of the cohesion continuum and flexibility continuum.

Cohesion is defined as the emotional closeness among family members (Olson, 2000). The author lists emotional bonding, boundaries, coalitions, time, space, friends,

decision making, interests and reactions as traits that have to do with cohesion. The cohesion continuum ranges from unbalanced and disengaged to unbalanced and enmeshed. Specifically, the balanced cohesion scale consists of 7 items (i.e., items # 1, 7, 13, 19, 25, 31, 37) designed to measure the extent to which a family is functioning in the middle range of the Cohesion dimension, indicating a balance between separateness and togetherness. Examples of items on the balanced cohesion scale are: "Family members are involved in each other's lives," "Family members feel very close to each other", and "Family members are supportive of each other during difficult times." Families scoring high on the balanced cohesion scale are labeled *Very Connected*, families scoring in the middle are labeled *Connected*, and families scoring low on this scale are labeled *Somewhat Connected*. When interpreting the balanced cohesion scale a linear relationship between high scores and favorable outcomes is expected.

The extreme, maladaptive ends of the cohesion continuum are measured with the unbalanced disengaged scale and the unbalance enmeshed scale. The unbalanced disengaged scale is composed of 7 items (i.e., items # 3, 9, 15, 21, 27, 33, 39) that are designed to measure the extent to which family members are disconnected from one another emotionally. Examples of items on the unbalanced disengaged scale include: "We get along better with people outside our family than inside," "Family members seem to avoid contact with each other when at home", and "Family members feel closer to people outside the family than to other family members." The Unbalanced Enmeshed scale is composed of 7 items (i.e., items # 4, 10, 16, 22, 28, 34, and 40) that measure the extent to which family members rely too heavily on one another. Items from the unbalanced enmeshed scale include: "We spend too much time together," "Family

members feel pressured to spend most free time together," "Family members are too dependent on each other." When interpreting the unbalanced cohesion scales an inverse, but linear relationship with favorable family outcomes is expected.

Flexibility is defined as the capacity for change in a family's leadership, roles, and relationships (Olson, 2000). The balanced flexibility scale is designed to measure the extent to which a family is functioning well, or in the middle range of flexibility. Specific family traits that are related to balanced flexibility are leadership style such as control and discipline, negotiation styles, role relationships, and relationship rules. Like cohesion, flexibility is measured along a continuum, with flexibility ranging from unbalanced and chaotic to unbalanced and rigid. The balanced flexibility scale consists of 7 items designed to measure the extent to which family members balance consistency with the need to change with the changing needs of the family system. For example, items include: "Our family tries new ways of dealing with family's problems", "The parents check with the children before making important decisions in this family," and "Children have a say in their discipline." Families scoring high on this scale are labeled *Very Flexible*, and families scoring low are labeled *Somewhat Flexible*, and families in the middle are labeled *Flexible*. When interpreting the balanced flexibility scale, direct and linear relationships between high scores on the balanced flexibility scale and positive outcomes are expected.

The extreme ends of the flexibility continuum are measured with the unbalanced chaotic scale, and the unbalanced rigid scale. The Unbalanced rigid scale is composed of 7 items (i.e., items # 5, 11, 17, 23, 29, 35, 41) and measures the extent to which family members resist changing roles, relationships and rules. Examples of items include:

"There are strict consequences for breaking the rules in our family," "There are severe consequences when a family member does something wrong," and "This family has a rule for almost every possible situation." The unbalanced chaotic scale consists of 7 items (i.e., items # 6, 12, 18, 24, 30, 36, 42) and is a measure of the family's lack of leadership, rules, and organization. Examples of items from the unbalanced chaotic scale include: "We never seem to get organized in our family," "We need more rules in our family," and "Things do not get done in our family." When interpreting the unbalanced flexibility scales, an inverse, but linear relationship with family outcomes is expected.

The FACES IV package includes an answer sheet and an EXCEL program to facilitate tracking and scoring of subjects' responses. The EXCEL program takes each item response and sums them for each of the 6 scales measuring the full range of cohesion and flexibility. Raw scores for each scale are converted to percentile scores using the percentile conversion chart. A cohesion ratio score, a flexibility ratio score, and a total ratio score can also be calculated and used as a composite. The formulas for the ratio scores are a ratio of balanced to unbalanced scores for each dimension and for the measure overall.

Cohesion Ratio = Balanced Cohesion / (Disengaged + Enmeshed/2)

Flexibility Ratio = Balanced Flexibility / (Rigid + Chaotic/2)

Total Ratio = Balanced Cohesion + Balanced Flexibility / (Disengaged + Enmeshed + Chaotic + Rigid/2)

The lower the ratio score, the more unbalanced the system, conversely, the higher the ratio score, the more balanced the system. Ratio scores are useful composites, however, the balanced to unbalanced ratios do not provide information about the source

of the Unbalanced functioning. Specifically, if a family has a low cohesion ratio score, it will be unclear whether they endorsed items on the unbalanced disengaged scale or on the unbalanced enmeshed scale, and if a family has a low flexibility ratio score, it will be unclear whether they endorsed items on the unbalanced rigid scale or on the unbalanced chaotic scale.

Psychometric data on the FACES IV supports its use. Olson, Gorall, &Tiesel (2007) conducted a reliability and validity study for the FACES IV. The authors used a convenience snowball sample from the metropolitan area. One hundred and twenty four students were recruited and encouraged to get family friends, and anyone they knew to participate. By this method the 124 students yielded 487 respondents. Using data from this study, concurrent and discriminate validity was established through comparison with 3 widely used family assessment instruments (i.e., Self Report Family Inventory, Family Assessment Device, and the Family Satisfaction Scale). Correlations between the FACES IV scales and the validation scales were relatively high with the "Balanced" scales highly correlated with the validation scales (range = .63 to .88) and the "Unbalanced" scales negatively correlated with the validation scales ranging from -.58 to -.82 (range excludes Enmeshed scale and the Rigid scale). An alpha reliability analysis was conducted to examine the internal consistency of the six scales. Results of the Alpha reliability analysis of the six FACES IV scales are as follows: Disengaged = .87, Enmeshed = .77, Rigid = .83, Chaos = .85, Balanced Cohesion =.89, Balanced Flexibility = .80.

The Family Communication Scale (FCS) is the second of the FACES IV package. Family communication is defined as the act of making information, ideas, thoughts, and feelings known among members of a family unit. Family communication is a linear

variable and ranges from poor to very effective (Olson & Barnes, 2004). The FCS consists of 10 Likert-type items and is scored by adding the responses so that the sum will be between 10 and 50. Raw scores can be interpreted as follows: scores of 40-50 suggest that family has very good family communication; scores of 35-39 suggest that family generally has good family communication; scores of 25-34 suggest that family has some good aspects in communication, but also some areas could improve; and scores of 10-24 suggest that family needs to talk more with each other about how to improve communication. The Family Communication Scale is based on the Parent and Adolescent Communication Scale (PACS), a widely used measure in family research with established validity (Barnes & Olson, 1985). The authors collected information on the scale's reliability using a national sample of 1,841 individuals and found the internal consistency reliability of the scale is .88.

The Family Satisfaction Scale (FSS) is the third component of the FACES IV package. The FSS is a 10 item, Likert-type scale that is designed to assess family member's satisfaction with the other dimensions of the family assessment package, that is, communication, cohesion, and flexibility levels. The FSS has been used extensively in research, most frequently in conjunction with one of the FACES instruments (Olson et al., 2007). There is also good evidence for reliability. Based on a sample of 1,253 family members, the 10 item family satisfaction scale has an alpha reliability of .92 (Olson, 1995). Based on a sample of 1,253 family members, the mean score for the scale is 33.4 and standard deviation is 7.5. When scoring the Family Satisfaction Scale, the raw scores will be between 10 and 50. Scores are interpreted as follows: scores of 40-50 suggest that family members are very happy about their family, scores of 35-39 suggest that family

members are generally happy about their family; scores of 25-34 suggest that family members are somewhat happy about their family; scores of 10-24 suggest that family members are unhappy about their family. The FACES IV was developed and normed for members of the immediate family and not extended family members like grandparents; research has not been done on grandparents as reporters of family functioning.

Diagnosis: Typically developing, High Functioning Autism (HFA)/Asperger's Syndrome (AS), Autistic Disorder (AD)

During recruitment, mothers and grandmothers were asked if their grandchild or child was diagnosed with ASD or was typically developing. Surveys for mothers and grandmothers of children with ASD contained a question asking for child's specific diagnosis (High Functioning Autism/Asperger's Syndrome, Autistic Disorder, other) and time since diagnosis. Surveys for grandmothers and mothers contained a question asking for any other diagnoses (e.g., attention deficit disorder, mental retardation, visual Impairment, hearing impairment, orthopedic impairment).

Background Measures

The GSNI and the FACES IV contain questions about background information pertaining to grandchildren, grandparents, and parents. Grandchildren's background variables were grandchildren's age, gender, disability, and time since diagnosis. Grandparents' variables were grandparents' age, geographical distance from grandchildren's home, race, religion, marital status, employment status, education level, income level, time spent with grandchildren per month, and frequency of care-giving. Parents' variables were parents' age, race, religion, marital status, employment status, education level, and income. This information was used to describe

the sample accurately. When these variables had significant variance indicating that they might be significant predictor variables of the dependent variables, they were added to the models as control variable. See Table 1 for how these variables were coded and for means, percentages and ranges.

Procedure

Dyads, each containing a grandmother and mother of a child with ASD, and dyads, each containing a grandmother and mother of a typically developing child (see above for additional selection criteria), were recruited via an email announcement (see Appendix F). The recipients of this announcement were members of a national listserv that is maintained by an organization that supports and advocates for families of children with ASD. The announcement stated the purpose of the study, gave eligibility criteria for participation, and provided contact information with the name, telephone number, and University affiliation of the principal investigator. Both types of dyads (grandmother and mothers of children with ASD/grandmothers and mothers of children who are typically developing) were recruited with this announcement

When mothers or grandmothers contacted the principal investigator to say that they were interested in or willing to be in the study, the principal investigator explained the details of the study further and inquired whether the family contained a child with ASD or a typically developing child. If the family had a child with ASD, they were placed in the research group. If the family had a typically developing child and did not have a child with ASD, they were placed in the comparison group. The principal investigator then shared that one of the research goals was to collect information from mother/grandmother dyads (pairs of mothers and grandmothers from the same family).

To that end, grandmothers were asked if their grandchild's mother would be interested in also completing a survey. Mothers were asked if their child's grandmother (paternal or maternal) would be interested in also completing a survey. In most cases, mothers and grandmothers put the principal investigator in contact with the other part of the dyad. Mothers and grandmothers who felt that the other member of the dyad would not have the time or interest in participating in the study were nevertheless invited to complete a questionnaire. Although not specifically targeted, dyads containing a mother and a grandmother of a child older than 14 years or younger than 6 years, and dyads containing a grandmother who lived more than 50 miles from the study child expressed interest in completing surveys; they too were allowed to complete questionnaires.

Research subjects were given a choice to have the survey instrument packages sent to one address (e.g., the mother's or the grandmother's home address) or separately to the mothers' and grandmothers' respective homes. Research subjects were also given the option of meeting with the principal investigator and completing the surveys in person.

The grandmothers' packet included the consent form (see Appendix G), and the appropriate version of the *Grandparent Strengths and Needs Inventory (GSNI)*. The mothers' packet included the same consent form, the *Family Adaptability and Cohesion Evaluation Scale Package (FACES IV Package),* and the appropriate version (see below) of the *Grandparent Strengths and Needs Inventory-Parent Form (GSNI-P).*

In the parent form of the GSNI (adapted by the principal investigator), for both the research group and the comparison group, mothers were instructed to think of a specific grandmother, the grandmother that then got the parallel form of the GSNI, and

this grandmother's relationship to the study child. In the grandparent form of the GSNI (also adapted by the principal investigator), for both the research group and the comparison group, grandmothers were instructed to think about their relationship with a specific grandchild as they completed the survey. If the study child had ASD, grandmothers and mothers reported on the grandmothers' relationship with the child. In addition, if the study child had ASD, mothers and grandmothers answered questions about the child's current specific diagnosis within the autistic spectrum, as well as, how much time had elapsed since diagnosis. If the study child did not have ASD, mothers and grandmothers were asked if the child had been diagnosed with another disability, and if so, they were asked for the child's diagnosis.

Grandmothers and mothers returned completed surveys in the pre-stamped and pre-addressed envelope provided. All identifying information was kept separate from the responses. The principal investigator scored surveys and maintained results in a computer database. Original protocols were held in a locked file cabinet at the home of principal investigator.

Research Hypotheses

Research suggests that experiences of grandparents with ASD grandchildren may be different from experiences of grandparents with typically developing grandchildren. Also, family functioning may play a role in grandparents' experiences. In order to answer the proposed research questions the following hypotheses were proposed.

The first research question is, whether or not mothers and grandmothers agree about grandmothers' experiences. Previous research suggests that when older persons and younger persons are asked to rate the same situation, older generations consistently have

a more positive outlook than younger generations, a tendency known as generational stake. Therefore, we expect grandmothers' report of her own strengths and needs be as good as or better than mothers' report of grandmothers' strengths and needs.

HO1: Reporter Effect

(a) Grandmothers' report of her strengths and needs as reported by the six scales on the GSNI will be as good as or better than mothers' report of grandmothers' strengths and needs (as measured by Grandparent Satisfaction, Grandparent Success, Grandparent Teaching, Grandparent Frustration, Grandparent Difficulty, and Grandparent Information Needs scales of the GSNI) (Strom et al., 1993).

The second research question is whether or not the experiences of grandparents with typical developing grandchildren differ from grandparents of grandchildren with ASD. We should expect based on research that because grandchildren's disability is a stressor on the family, grandmothers' potentials will go down and grandmothers' concerns will go up with severity of ASD Diagnosis.

HO2: Diagnosis

(a) With increased severity of autism diagnosis (typically developing, HFA/AS, AD), grandmothers will be less satisfied with their role as a grandmother (as measured by the Grandparent Satisfaction scale of the GSNI) (Strom et al., 1993).

(b) With increased severity of autism diagnosis (typically developing, HFA/AS, AD), grandmothers will feel less successful in their role as a grandmother (as measured by the Grandparent Success scale of the GSNI) (Strom et al., 1993).

(c) With increased severity of autism diagnosis (typically developing, HFA/AS, AD), grandmothers will be less likely to mentor their grandchild (as measured by the Grandparent Teaching scale of the GSNI) (Strom et al., 1993).

(d) With increased severity of autism diagnosis (typically developing, HFA/AS, AD), grandmothers will have less tolerance for their grandchild's behavior (as measured by the Grandparent Frustration scale of the GSNI) (Strom et al., 1993).

(e) With increased severity of autism diagnosis (typically developing, HFA/AS, AD), grandmothers will feel their role is more challenging (as measured by the Grandparent Difficulties scale of the GSNI) (Strom et al., 1993).

(f) With increased severity of autism diagnosis (typically developing, HFA/AS, AD), grandmothers will need more information about their grandchild's development (as measured by the Grandparent Information Needs scale of the GSNI) (Strom et al., 1993).

The third research question is whether family functioning impacts on grandmothers' experiences. Research suggests that optimal levels of cohesion, flexibility, communication, and satisfaction will be associated with better outcomes for grandmothers (Turnbull & Turnbull, 1990). In other words, balanced cohesion, balanced flexibility, high levels of communication and high levels of satisfaction will be associated with increased grandmothers' strengths and decreased grandmothers' needs. Conversely, suboptimal levels of family functioning are expected to lead to decreased strength and increased needs. In other words, unbalanced cohesion, unbalanced flexibility, low levels of communication, and low family satisfaction will be associated with decreased grandmothers' strengths and increased grandmothers' needs.

HO3: Family Functioning, Cohesion

(a) As family cohesion (as measured by the Unbalanced Enmeshed scale, the Unbalanced Disengaged scale, and the Balanced Cohesion scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be more satisfied with their role as a grandmother (as measured by the Grandparent Satisfaction scale of the GSNI) (Strom et al., 1993).

(b) As family cohesion (as measured by the Unbalanced Enmeshed scale, the Unbalanced Disengaged scale, and the Balanced Cohesion scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be feel more successful in their role as a grandmother (as measured by the Grandparent Success scale of the GSNI) (Strom et al., 1993).

(c) As family cohesion (as measured by the Unbalanced Enmeshed scale, the Unbalanced Disengaged scale, and the Balanced Cohesion scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be more likely to mentor their grandchild (as measured by the Grandparent Teaching scale of the GSNI) (Strom et al., 1993).

(d) As family cohesion (as measured by the Unbalanced Enmeshed scale, the Unbalanced Disengaged scale, and the Balanced Cohesion scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will have more tolerance for their grandchild's behavior (as measured by the Grandparent Frustration scale of the GSNI) (Strom et al., 1993).

(e) As family cohesion (as measured by the Unbalanced Enmeshed scale, the Unbalanced Disengaged scale, and the Balanced Cohesion scale of the FACES

IV) (Olson et al., 2007) approaches optimal levels, grandmothers will see their role as less challenging (as measured by the Grandparent Difficulties scale of the GSNI) (Strom et al., 1993).

(f) As family cohesion (as measured by the Unbalanced Enmeshed scale, the Unbalanced Disengaged scale, and the Balanced Cohesion scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will less likely to need more information about their grandchild's development (as measured by the Grandparent Information Needs scale of the GSNI) (Strom et al., 1993).

HO3: Family Functioning, Flexibility

(a) As family flexibility (as measured by the Unbalanced Rigid scale, the Unbalanced Chaotic scale, and the Flexibility scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be more satisfied with their role as a grandmother (as measured by the Grandparent Satisfaction scale of the GSNI) (Strom et al., 1993).

(b) As family flexibility (as measured by the Unbalanced Rigid scale, the Unbalanced Chaotic scale, and the Flexibility scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be feel more successful in their role as a grandmother (as measured by the Grandparent Success scale of the GSNI) (Strom et al., 1993).

(c) As family flexibility (as measured by the Unbalanced Rigid scale, the Unbalanced Chaotic scale, and the Flexibility scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be more likely to mentor their

grandchild (as measured by the Grandparent Teaching scale of the GSNI) (Strom et al., 1993).

(d) As family flexibility (as measured by the Unbalanced Rigid scale, the Unbalanced Chaotic scale, and the Flexibility scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will have more tolerance for their grandchild's behavior (as measured by the Grandparent Frustration scale of the GSNI) (Strom et al., 1993).

(e) As family flexibility (as measured by the Unbalanced Rigid scale, the Unbalanced Chaotic scale, and the Flexibility scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will see their role as less challenging (as measured by the Grandparent Difficulties scale of the GSNI) (Strom et al., 1993).

(f) As family flexibility (as measured by the Unbalanced Rigid scale, the Unbalanced Chaotic scale, and the Flexibility scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be less likely to need more information about their grandchild's development (as measured by the Grandparent Information Needs scale of the GSNI) (Strom et al., 1993).

HO3: Family Functioning, Communication

(a) As family communication (as measured by the Communication scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be more satisfied with their role as a grandmother (as measured by the Grandparent Satisfaction scale of the GSNI) (Strom et al., 1993).

(b) As family communication (as measured by the Communication scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be

feel more successful in their role as a grandmother (as measured by the Grandparent Success scale of the GSNI) (Strom et al., 1993).

(c) As family communication (as measured by the Communication scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be more likely to mentor their grandchild (as measured by the Grandparent Teaching scale of the GSNI) (Strom et al., 1993).

(d) As family communication (as measured by the Communication scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will have more tolerance for their grandchild's behavior (as measured by the Grandparent Frustration scale of the GSNI) (Strom et al., 1993).

(e) As family communication (as measured by the Communication scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will see their role as less challenging (as measured by the Grandparent Difficulty scale of the GSNI) (Strom et al., 1993).

(f) As family communication (as measured by the Communication scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will less likely to need more information about their grandchild's development (as measured by the Grandparent Information Needs scale of the GSNI) (Strom et al., 1993).

HO3: Family Functioning, Family Satisfaction

(a) As family satisfaction (as measured by the Family Satisfaction scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be

more satisfied with their role as a grandmother (as measured by the Grandparent Satisfaction scale of the GSNI) (Strom et al., 1993).

(b) As family satisfaction (as measured by the Family Satisfaction scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be feel more successful in their role as a grandmother (as measured by the Grandparent Success scale of the GSNI) (Strom et al., 1993).

(c) As family satisfaction (as measured by the Family Satisfaction scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will be more likely to mentor their grandchild (as measured by the Grandparent Teaching scale of the GSNI) (Strom et al., 1993).

(d) As family satisfaction (as measured by the Family Satisfaction scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will have more tolerance for their grandchild's behavior (as measured by the Grandparent Frustration scale of the GSNI) (Strom et al., 1993).

(e) As family satisfaction (as measured by the Family Satisfaction scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will see their role as less challenging (as measured by the Grandparent Difficulty scale of the GSNI) (Strom et al., 1993).

(f) As family satisfaction (as measured by the Family Satisfaction scale of the FACES IV) (Olson et al., 2007) approaches optimal levels, grandmothers will less likely to need more information about their grandchild's development (as measured by the Grandparent Information Needs scale of the GSNI) (Strom et al., 1993).

CHAPTER IV

Results

The purpose of this chapter is to explain the results of the current study. First the data analysis procedures are described, including how the database was structured for dyadic analysis, how missing data were handled, and what statistical analyses were used. Next the results of the study are presented.

Data Analyses

Structuring Data for Dyadic Analysis

In order to study these hypotheses, data were collected from dyads containing a grandmother and a mother. Each mother provided information regarding her immediate family's nuclear family functioning and her perspective of a specific grandmothers' behavior. Each grandmother provided a corresponding self-report of her own behavior. Observations between each mother and grandmother are not independent and as such they need to be treated as nested data with the unit of observation being the dyad (Kenny, Kashy, & Cook, 2006).

Kenny et al. (2006) provide guidelines for structuring the database and analyzing data that are collected from dyads. Following these guidelines, a database was created such that the responses of each mother and each grandmother were entered separately. When mothers were the sole respondent on measure, as was the case for the FACES IV, these responses were assumed to be a property of the dyad and entered for both mother and grandmother. Each grandmother/mother dyad was assigned an identification number, allowing the dyad to be the unit of analysis. For further elaboration on structuring the

database for dyadic analysis and for identifying types of variables that are best suited for dyadic analysis, the reader is referred to Kenny et al. (2006).

Missing Data

Missing data tend to be a problem in social science research. In this data set, data were missing because individual mothers and grandmothers did not answer every question and because several dyads (n = 16) were partially observed (either grandmother or mother failed to return a completed questionnaire).

A decision about how to handle missing data should be based on the type of missing data. Data can be missing for several reasons: Missing Completely At Random (MCAR), Missing At Random (MAR), and Missing Not At Random (MNAR) (Collins et al., 2001). Some examples of MCAR occur when people skip pages or questions unintentionally, or forget to return surveys. When data are MAR, there is a rational reason for missingness that can be identified and measured. For example, grandmothers of nonverbal grandchildren with autism may find some items do not apply to their situation and leave them blank; in this case, level of disability would be a measurable cause of missingness. When data are MNAR, the missingness of information relates to an unobserved and unmeasured variable.

As stated above, a missing data strategy should be based on the kind of missingness present; however, it is often hard to know what kind of missingness holds in a particular data set. For example, in the current data set, it is unclear whether dyads are partially observed because of MCAR or MAR. Collins et al. (2001) suggest that when the type of missingness is unknown, then it is preferable to assume that data are MAR. Under this condition, as well as when sample sizes are small (as in the current study), modern,

inclusive strategies such as multiple imputation procedures (MI) and maximum likelihood (ML) estimates are better than traditional approaches (Collins et al, 2001). When samples are small or when data are MAR rather than MCAR, exclusive strategies (e.g., listwise deletion) or traditional strategies (e.g., mean substitution) produce biased estimates, distorted statistical power, and invalid conclusions (Collins et al., 2001). Given that we do not know what kind of missingness are present, and given that the sample is small so that we want to preserve cases, an inclusive approach such as multiple imputation is preferred.

In multiple imputation, values for missing data are estimated according to repeated analyses of imputed data sets (data sets with missing values estimated based on partially observed data; Collins et al., 2001). In this study, 20 such data sets were created (this is generally considered a sufficient number of imputations to arrive at reliable estimates). The 20 data sets are effectively stacked on top of each other in what is now considered the imputed database (N = 168 x 20 = 3,360; Dyad N = 84 x 20 = 1,680). Finally, data analyses are carried out across all 20 data sets.

While the MI approach to handling missing data is useful, it is not as definitive as it would be if one had a single, complete data set. Rather, a range of analyses are conducted on the incomplete data sets and the answers are pooled to end up with an effect estimate with the least amount of error. For further elucidation on choosing and carrying out missing data strategies, please see Acock (2005) and Collins et al. (2001). The multiple imputation did a good job recovering the information and the relative efficiencies were all above .95. In this case, it was preferable to use multiple imputation than to use another missing data procedure, because multiple imputation enabled this

researcher to preserve partially observed cases, whether they were partially observed because mother or grandmother did not reply, or because mother or grandmother stated that a question did not apply, or because mother or grandmother left an answer blank.

Mixed Effects Modeling

The imputed dataset (*N*=3,360, Dyad *N* = 1,680) was analyzed using mixed effects modeling (PROC MIXED) using SAS software. Several background variables were included in the models to control for their effects. These variables were number of grandchildren, time spent together, grandchildren's gender, lineage of grandmother, and grandmothers' age. Grandchildren's age, geographical distance between grandmothers and grandchildren, and time since diagnosis were excluded from the current analysis. Grandchildren's age and geographical distance were excluded because these were selection criteria variables and so they varied very little.Time since diagnosis was excluded because it is a variable that cannot be measured for the typical development group. Time since diagnosis varied only slightly because it is associated with grandchildren's age, which was a selection criteria variable.

Prior to running this procedure, the independent or predictor variables were centered and standardized to simplify interpretation of the beta weights; categorical predictor variables with greater than two categories (e.g., number of grandchildren) were centered and continuous predictor variables (e.g., cohesion) were standardized. The dependent variables (e.g., grandmothers' satisfaction, grandmothers' success) were not centered or standardized.

Because this was a dyadic analysis and because we were interested in studying the effect of reporter, it was necessary to fit two models, the null model and the full model

for each dependent variable (the six scores on the GSNI). The null model included only the dyad indicator, while the full model included all covariates (grandmothers' number of grandchildren, amount of time grandmothers spend with study child, study child's gender, and grandmother's age), and the eight predictor variables (diagnosis as well as the FACES IV package scales: balanced cohesion, unbalanced enmeshed, unbalanced disengaged, balanced flexibility, unbalanced rigid, unbalanced chaotic, communication, and satisfaction).

With mixed models there are two levels of variation. The first level is the level where individual variation occurs and the second level is the level of the dyad. There are two kinds of variables that correspond to these two levels, for individual level variables values vary within and between the dyad and for dyad level variables, values vary only between dyads. Age is an example of an individual level variable. Examples of dyad level variables are diagnosis and each of the family systems' variables; mother and grandmother in a dyad have the same value on these variables. One reason for using mixed models is that it allows us to analyze data from dyads where the dependent variable will be an average of the dyad. As researchers are interested in how much of the variation in the dependent variable is explained by individual level predictors and how much is explained by family level predictors. In order to make optimal use of mixed models it is useful to have individual level variables and dyad level (group level) variables in the model.

The intraclass correlation (see Table 2), is defined as a proportion of the between dyad variance to total variance (between and within). In considering the ICC, the null model was used as a baseline with the full model used as a comparison. Across all

dependent variables, the full model ICC is lower than the null model ICC, meaning that the proportion of between dyad to total variance (between plus within) of the full model is lower than the proportion of between dyad to total variance of the null model. This shows that the predictor variables are explaining at least some of the between dyad variation. The full model ICC is showing what proportion of the variance between dyads is left unexplained after the predictors have done their work. In the case of Satisfaction, the null model (ICC = .60) and the full model (ICC = .44), shows that the full model is accounting for some but not all of the between dyad variance. See Table 2 for values on each of the dependent variable. The level 2 model is always bigger than level 1 because it is easier to make predictions about dyads than individuals. R^2 in the .30s is standard for social science research.

Level 1 R^2 and Level 2 R^2 gives a comparison of the fitted model (the full model) with null. Level 1 R^2 tells how much of the level 1 variance is explained by the model, and Level 2 R2 tells how much level 2 variance is explained by the model. R2 comparing the full model to the null model at level 1 and then at level 2.

For ease of interpretation of the main study variable (i.e., diagnosis), Effect Sizes (ES) were calculated for the effect of diagnosis on grandmothers' strengths and needs (see Table 3). Effect sizes for family systems variables were not calculated because family systems variables were standardized.

Table 2

Summary R^2 Information

Variable	Level 2 Variance Full	Level 1 Variance Full	Level 2 Variance Null	Level 1 Variance Null		ICC Full	ICC Null	Level 1 R^2	Level 2 R^2
Difficulty	3.69	15.20	12.79	15.52	-	0.20	0.45	0.33	0.45
Frustration	8.18	8.36	12.67	8.90	-	0.49	0.59	0.23	0.28
Infoneeds	9.89	27.52	26.47	28.99	-	0.26	0.48	0.33	0.42
Satisfaction	6.68	8.62	13.90	9.41	-	0.44	0.60	0.34	0.41
Success	2.50	18.90	4.24	20.73	-	0.12	0.17	0.14	0.18
Teaching	8.69	23.46	13.60	27.69	-	0.27	0.33	0.22	0.26

Results

Background Variables Effects

The results of the mixed effects models can be viewed in Table 3. With regard to time spent, the variable in this study measuring amount of time spent between grandmother and grandchild, was a significant predictor ($B = 1.88$, $p < .01$) of grandmothers' satisfaction, a measure of grandmothers' good feelings about her role as grandparent, indicating that for every 1 category shift in time spent together, there is a 1.88 point increase in grandmothers' satisfaction. Time spent was also a significant predictor ($B = 1.20$, $p < .05$) of grandmothers' success, a measure of grandmother's feeling good about her ability in her role as grandmother, indicating that for every 1 category shift in time spent there is a 1.20 point increase in grandmothers' success. With regard to grandmothers' needs, time spent was a significant predictor ($B = -1.32$, $p < .05$) of grandmothers' difficulty, a measure of the extent to which grandmothers experience their role as difficult, such that for every 1 category shift in time spent there is a 1.32 point decrease in grandmothers' difficulty.

Previous research also suggests that grandmothers with more grandchildren may have more strengths and fewer needs as they have more experience. This hypothesis was also supported in the current research. Specifically with regard to a decrease in grandmothers' needs; grandmothers' number of grandchildren was a significant predictor (B = -.70, p < .05) of grandmothers' frustration, indicating that for every increase in the number of grandchildren, there is a -0.7 point decrease in grandmothers' frustration.

Table 3

Mixed Effects Model Results by GSNI Scales (Imputed n = 168 x 20 = 3360; Imputed Dyad n = 84 x 20 = 1680 Dyads)

Parameter	β	*SE*	*Pr* > |*t*|
	Satisfaction		
Intercept	35.54	1.40	<.0001
Number of grandchildren (c)	0.12	0.28	0.67
Time spent (c)	1.88***	0.53	0.00
Reporter	-0.54	0.51	0.29
Child's gender	0.91	0.91	0.32
Lineage	-0.52	1.59	0.74
Grandmother's age (s)	0.00	0.51	0.99
Diagnosis	-2.11***	0.59	0.00
Communication (s)	-0.74	0.78	0.34
Cohesion (s)	-0.32	0.80	0.69
Flexibility (s)	0.38	0.55	0.49
Disengaged (s)	0.21	0.75	0.78
Enmeshed (s)	1.24**	0.48	0.01
Rigid (s)	0.58	0.49	0.24
Chaotic (s)	-1.15^	0.62	0.07
Family Satisfaction (s)	0.78	0.94	0.41

****p<.001, **p<.01, *p<.05, ^p<.10*

Table 3 *(continued)*

Parameter	β	*SE*	*Pr* > |*t*|
		Success	
Intercept	35.81	1.52	<.0001
Number of grandchildren (c)	-0.21	0.26	0.41
Time spent (c)	1.20*	0.53	0.03
Reporter	-1.65*	0.71	0.02
Child's gender	0.34	0.89	0.71
Lineage	-0.54	1.59	0.74
Grandmother's age (s)	-0.35	0.48	0.47
Diagnosis	-0.92	0.67	0.17
Communication (s)	-0.95	0.80	0.24
Cohesion (s)	0.83	0.67	0.22
Flexibility (s)	-0.54	0.62	0.39
Disengaged (s)	0.52	0.67	0.44
Enmeshed (s)	1.12**	0.43	0.01
Rigid (s)	0.08	0.47	0.86
Chaotic (s)	-0.82	0.59	0.17
Family satisfaction (s)	1.36	0.85	0.11
		Teaching	
Intercept	35.65	1.85	<.0001
Number of grandchildren (c)	-0.41	0.33	0.21
Time spent (c)	2.06***	0.67	0.00

****p<.001, **p<.01, *p<.05, ^p<.10*

Table 3 *(continued)*

Parameter	β	*SE*	*Pr* > |*t*|
	Teaching *(continued)*		
Reporter	-2.47***	0.83	0.00
Child's gender	0.38	1.27	0.77
Lineage	-0.92	2.04	0.65
Grandmother's age (s)	-0.01	0.63	0.99
Diagnosis	-1.77^	0.93	0.06
Communication (s)	-2.53*	1.07	0.02
Cohesion (s)	0.15	1.02	0.88
Flexibility (s)	0.57	0.81	0.48
Disengaged (s)	-0.01	0.89	0.99
Enmeshed (s)	1.37^	0.71	0.06
Rigid (s)	0.98	0.65	0.13
Chaotic (s)	-0.96	0.90	0.29
Family satisfaction (s)	2.23*	1.13	0.05
	Frustration		
Intercept	18.44	1.61	<.0001
Number of grandchildren (c)	-0.70**	0.26	0.01
Time spent (c)	0.16	0.56	0.77
Reporter	0.27	0.54	0.63
Child's gender	-1.78	1.08	0.10
Lineage	-2.01	1.56	0.20
Grandmother's age (s)	0.24	0.45	0.59

****p<.001, **p<.01, *p<.05, ^p<.10*

Table 3 *(continued)*

Parameter	β	*SE*	*Pr* > |*t*|
	Frustration *(continued)*		
Diagnosis	-0.27	0.64	0.67
Communication (s)	-1.55*	0.77	0.04
Cohesion (s)	0.39	0.74	0.60
Flexibility (s)	0.05	0.47	0.91
Disengaged (s)	-0.92	0.63	0.15
Enmeshed (s)	-1.08^	0.60	0.07
Rigid (s)	0.82	0.50	0.10
Chaotic (s)	1.26*	0.58	0.03
Family satisfaction (s)	-0.07	0.73	0.93
	Difficulty		
Intercept	13.85	1.74	<.0001
Number of grandchildren	0.18	0.24	0.45
Time spent (c)	-1.32*	0.55	0.02
Reporter	0.49	0.71	0.49
Child's gender	-0.44	0.92	0.63
Lineage	1.43	1.50	0.34
Grandmother's age (s)	0.29	0.44	0.52
Diagnosis	2.54***	0.59	<.0001
Communication (s)	0.35	0.71	0.62
Cohesion (s)	-0.02	0.71	0.98

****p<.001, **p<.01, *p<.05, ^p<.10*

Table 3 *(continued)*

Parameter	β	*SE*	*Pr* > |*t*|
	Difficulty *(continued)*		
Flexibility (s)	0.15	0.59	0.79
Disengaged (s)	1.08^	0.60	0.07
Enmeshed (s)	-1.68***	0.48	0.00
Rigid (s)	0.51	0.45	0.26
Chaotic (s)	1.14^	0.60	0.06
Family satisfaction (s)	-0.65	0.76	0.39
	Information Needs		
Intercept	18.85	2.27	<.0001
Number of grandchildren (c)	0.11	0.31	0.71
Time spent (c)	-1.09	0.87	0.22
Reporter	-1.18	0.91	0.20
Child's gender	-1.87	1.36	0.17
Lineage	1.44	2.10	0.50
Grandmother's age (s)	-0.26	0.62	0.67
Diagnosis	1.63*	0.85	0.05
Communication (s)	-1.76	1.09	0.11
Cohesion (s)	0.23	1.13	0.84
Flexibility (s)	0.98	0.76	0.20
Disengaged (s)	0.04	0.96	0.97
Enmeshed (s)	-1.06	0.81	0.19

****p<.001, **p<.01, *p<.05, ^p<.10*

Table 3 *(continued)*

Parameter	β	*SE*	*Pr* > |*t*|
	Information Needs *(continued)*		
Rigid (s)	-0.10	0.70	0.89
Chaotic (s)	2.34***	0.72	0.00
Family satisfaction (s)	-1.03	1.27	0.42

****p<.001, **p<.01, *p<.05, ^p<.10*

Reporter Effect

Previous research suggests that mothers' reports will be as good as or worse than grandmothers' report (Aquilino, 1999; Lynott & Roberts, 1997). The tendency for the older generation to provide more favorable, optimistic reports than younger generations, when reporting on the same phenomenon, is well documented in the literature. In order to test the hypothesis that mothers' report and grandmothers' report will differ, the reporter effect (0 = *grandmother report*, 1 = *mother report*) was used (see Table 3). The reporter effect is a summary of the dyad level deviation score between grandmothers' report and mothers' report of each of the dependent variable scales. In the current study, the deviation between mothers' report and grandmothers' report was significant for the grandmothers' success scale and the grandmothers' teaching scale. Specifically, reporter was a significant predictor (B = -1.65, $p < .05$) of grandmothers' success, indicating that for every 1 category shift in reporter (from grandmothers' report to mothers' report) there is 1.65 decrease in grandmothers' success. Reporter was a significant predictor (B = -2.47, $p < .05$) for grandmothers' teaching, indicating that for every 1 category shift in

reporter (0=grandmothers' report, 1=mother report), there is a 2.47 point decrease in grandmothers' teaching. In both findings, mothers' report is less favorable than grandmothers' report. The effect of reporter was not significant for the remaining several scales including grandmothers' satisfaction, grandmothers' difficulty, grandmothers' frustration, and grandmothers' information needs, indicating that mothers' reports and grandmothers' reports of grandmother behavior is often similar.

Diagnosis Effect

Previous research shows that disabilities are stressors on the family (Hornby & Seligman, 1991), and so it is expected that with increased severity of disability grandmothers' strengths will decrease and grandmothers' needs will increase.

Sample size, average values, standard deviations and effect sizes for each of the dependent variables (grandmothers' satisfaction, grandmothers' success, grandmothers' teaching, grandmothers' difficulties, grandmothers' frustration, and grandmothers' information needs) by diagnosic category (typical development, HFA/AS, AD) are listed in Table 4. Although the effect of diagnosis on family systems variables was not a research question, the sample size, average values, and standard deviations for each of the family systems variables by diagnostic category are listed in Table 5. Effect sizes for family systems variables were not determined because family systems variables were standardized.

The effect of diagnosis (0 = *typical*, 1 = *HFA/AS*, 2 = *AD*) on each of the dependent variables (as reported by an average of mothers' report and grandmothers' report) was examined by the mixed models (see Table 3). Specifically, diagnosis was a significant predictor of grandmothers' satisfaction (B = -2.11, $p < .05$), indicating that for

every 1 category shift in diagnosis (0 = *typical*, 1 = *HFA/AS*, 2 = *AD*), there is a 2.11 point decline in grandmothers' satisfaction. This is a significant effect given that there are 3 categories in the diagnosis variable. For a 2 category shift, from typical development to Autistic Disorder, a 4.22 point decline is predicted. Diagnosis was a significant predictor of grandmothers' teaching (B = -1.77, p < .05), indicating that for every 1 category shift in diagnosis (0 = typical, 1 = HFA/AS, 2 = AD), there is a 1.77 point decline in grandmothers' teaching, for a 2 category shift to Autistic Disorder a 3.54 decline is predicted. With regard to the association between grandchildren's diagnosis and increases in grandmothers' needs, diagnosis was a significant predictor of grandmothers' difficulty (B = 2.54, p < .01), indicating that for every 1 category shift in diagnosis there is a 2.54 point increase in grandmothers' difficulty, for every 2 category shift there is a 5.08 point increase. Diagnosis was a significant predictor of grandmothers' information needs (B = 1.63, p < .05) indicating for every 1 category shift in diagnosis (0 = *typical*, 1 = *HFA/AS*, 2 = *AD)*, there is a 1.63 point increase in grandmothers' information needs, for every 2 category shifts a 3.26 point increase. No differences were found between the groups with regard to grandmothers' success or grandmothers' frustration, indicating that diagnosis does not explain the variance in grandmothers' success or frustration over and above the control variables.

Table 4

Sample Numbers, Means, Standard Deviations, and Effect Sizes for GSNI Scales by Diagnosis (*N* = 168, 84 *Dyads)*

	Typical (*N* = 68, 34 dyads)			HFA/AS (*N* = 62, 31 dyads)			Autism (*N* = 38, 19 dyads)			
	N	*M*	*SD*	*N*	*M*	*SD*	*N*	*M*	*SD*	*ES*
Satisfaction	68	35.36	3.24	62	33.06	4.39	38	30.30	6.00	4.41
Success	68	34.93	4.53	62	33.55	4.68	38	32.47	5.81	3.89
Teaching	68	33.64	5.41	62	32.37	5.77	38	29.65	8.11	5.36
Difficulty	68	14.87	4.34	62	18.15	4.93	38	20.28	5.54	3.94
Frustration	68	14.78	3.98	62	17.88	4.90	38	14.93	4.16	5.06
Info Needs	68	16.25	5.60	62	24.04	7.10	38	20.82	7.25	6.30

Table 5

Sample Numbers, Means, and Standard Deviations of FACES IV Scales by Diagnosis (N=168, 84 Dyads)

	Typical (N=68, 34 dyads)			HFA/AS (N=62, 31 dyads)			Autistic Disorder (N=38, 19 dyads)		
	N	*M*	*SD*	*N*	*M*	*SD*	*N*	*M*	*SD*
Cohesion	68	29.88	4.88	62	27.98	4.67	38	29.68	4.69
Flexibility	68	20.95	4.02	62	21.52	4.06	38	23.31	4.08
Disengaged	68	9.10	3.28	62	10.01	2.93	38	9.67	2.92
Enmeshed	68	9.67	4.02	62	10.80	4.16	38	10.71	4.96
Rigid	68	14.56	4.34	62	14.72	5.06	38	13.37	5.22
Chaotic	68	10.88	3.99	62	13.00	4.44	38	11.51	3.54
Communic	68	39.52	7.48	62	36.77	7.06	38	38.07	7.18
Famsat	68	38.12	7.68	62	33.56	8.20	38	37.50	8.15

Family Functioning Effect

Previous research indicates that as family systems' variables (cohesion, flexibility, communication, and satisfaction) approach optimal levels (midrange for cohesion, midrange for flexibility, high range for communication, and high range for satisfaction), outcomes for family members, including extended family members, will increase (Turnbull & Turnbull, 1990). Thus, it was predicted that as family functioning variables approach optimal levels, grandmothers' strengths will increase and grandmothers needs' as measured by the GSNI will decrease. This hypothesis was partially supported by the current results (see Table 3).

The family cohesion dimension was measured with 3 scales, the unbalanced enmeshed scale, the unbalanced disengaged scale, and the balanced cohesion scale. The balanced cohesion scale was not a significant predictor of grandmothers' strengths and/or needs, indicating that balanced cohesiveness between family members was not related to grandmothers' strengths or needs.

The unbalanced enmeshed scale, a measure of excessive closeness among family members, was a significant predictor ($B = 1.24$, $p < .01$) of grandmothers' satisfaction. The positive beta weight reported here indicates that for every 1 standard deviation shift in unbalanced enmeshment there is a 1.24 standard deviation increase in grandmothers' satisfaction. The similar relationship was found between unbalanced enmeshed scores and grandmothers' success ($B = 1.12$, $p < .01$). This positive Beta weight indicates that for every 1 standard deviation shift in unbalanced enmeshment, there is a 1.12 increase in grandmothers' success. Unbalanced enmeshed scores were a near significant predictor ($B = 1.37$, $p = .06$) of grandmothers' teaching, indicating that if true, then given a bigger

sample size, then for every 1 standard deviation shift in enmeshment (4.32 points) there is a 1.37 increase in grandmothers' teaching. High scores on the unbalanced enmeshed scale were also predictive of decreased grandmothers' difficulty. Enmeshed was a significant predictor (B = -1.68, $p < .05$) of grandmothers' difficulty, indicating that for every 1 standard deviation shift in enmeshment (4.32 points) there is a 1.68 decrease in grandmothers' difficulty. Excessive enmeshment was a near significant predictor in an unexpected direction (B = -1.08, $p = .07$) for grandmothers' frustration, indicating that if true given a bigger sample size, then for every 1 standard deviation shift in enmeshment (4.32 points) there is a 1.08 decrease in grandmothers' frustration. High scores on the unbalanced enmeshed scores are theoretically not optimal and therefore these results were surprising. Here unbalanced enmeshment is associated or nearly associated with increased strengths (satisfaction, success, and teaching) and decreased needs (difficulty, frustration) for grandmothers.

The unbalanced disengaged scale a measure of excessive alienation among family members, was a near significant predictor (B = 1.08, $p = .07$) of grandmothers' difficulty, indicating that if true for every 1 standard deviation shift in disengaged (3.10 points) there is a 1.08 point increase in grandmothers' difficulty.

The family flexibility dimension is measured with three scales, the unbalanced chaotic scale, the unbalanced rigid scale, and the balanced flexibility scale. As with the balanced cohesion scale, the balanced flexibility scale was not a significant predictor of grandmothers' strengths or needs, indicating that balanced cohesiveness between family members is not related to grandmothers' strengths or needs.

The unbalanced chaotic scale, a measure indicating too much flexibility in a family system was a significant predictor ($B = 1.26$, $p < 05$) of grandmothers' frustration, indicating that for every 1 standard deviation shift in family chaos (4.18 points) there is a 1.26 increase in grandmothers' frustration. The unbalanced chaotic scale was a significant predictor ($B = 2.34$, $p < .01$) of grandmothers' information needs, indicating that for every 1 standard deviation shift in family chaos (4.18 points) there is a 2.34 point increase in grandmothers' information needs. In addition, unbalanced chaotic was a nearly significant predictor of grandmothers' satisfaction ($B = -1.15$, $p = .07$). For every 1 standard deviation shift in family chaos, there is a 1.15 standard deviation decrease in grandmothers' satisfaction.

The unbalanced rigid scale was a near significant predictor ($B = .82$, $p = .10$) for grandmothers' frustration in the expected direction, indicating that if true given a larger sample, then for every 1 standard deviation shift in rigid (4.84 points) there is a .82 point increase in grandmothers' frustration.

Good communication was a significant predictor ($B = -1.55$, $p < .05$) of grandmothers' frustration in the expected direction, indicating that for every 1 standard deviation shift in communication (7.35 points), there is a 1.55 decrease in grandmothers' frustration. Communication was a near significant predictor of grandmothers' information needs ($B = -1.76$, $p = .11$), indicating that for every 1 standard deviation shift in communication (7.35 points), there is a 1.76 decrease in grandmothers' information needs. Good communication was significant predictor of teaching in an unexpected direction ($B = -2.53$, $p < .05$), indicating a 2.53 decrease in grandmothers' teaching among families with high communication.

Family satisfaction, a family systems variable indicating mother's satisfaction with her own nuclear family's level of functioning, was a significant predictor (B = 2.23, p = .05) of grandmothers' teaching, indicating that for every 1 standard deviation shift in mothers' satisfaction with her family's level of family functioning, there is a 2.23 point increase in grandmothers' teaching, a measure of which grandmother plays a role as teacher in the family.

Results from the study partially supported the hypothesis that grandmothers will view circumstances as good as or better than mothers view circumstances. To a large extent there was agreement between grandmothers' and mothers' reports of grandmothers' strengths and needs. Where there were significant differences, grandmothers' reports of grandmothers' strengths and needs were more favorable than mothers' reports of grandmothers' strengths and needs. Grandmothers reported more strengths and fewer needs than mothers reported.

Results from this study strongly supported previous research showing that grandparents of children with special needs are different from grandparents of children with typical development in terms of their role and experience. Results showed that grandmothers of children with ASD have fewer reported strengths and more needs than grandmothers of children with typical development.

Results partially supported the hypothesis that family functioning will be associated with greater strengths and decreased needs for grandmothers, indicating that these variables, when unbalanced, hinder inclusion of grandmothers' involvement and satisfaction.

CHAPTER V

Discussion

This chapter is a discussion of the results obtained in the course of this research. The chapter is divided into six sections. The first three sections correspond directly to the basic research questions proposed in the study including the reported effect, the diagnosis effect, and the family functioning effect. The fourth section is a discussion of the strengths and limitations of the study and the fifth section provides the educational implication of the study. The final section suggests future research directions.

Reporter Effect

A basic question addressed in this research was, whether mothers' report and grandmothers' report of grandmothers' strengths and needs are consistent with one another. Previous research using the GSNI has not focused on agreement among family members using this measure. Research on intergenerational relationships has shown that older generations systematically report things more favorably than younger generations. This tendency is known as developmental stake in the literature on intergenerational relationships (Aquilino, 1999; Lynott & Roberts, 1997). Based on this literature the hypotheses for the current study stated that grandmothers' reports of circumstances would be more favorable than mothers' reports.

Results from this study partially supported this hypothesis. On the grandmothers' success scale and on the grandmothers' teaching scale of the GSNI, there were significant effects of reporter, indicating that grandmothers' report and mothers' report of grandmothers' teaching and grandmothers' success were significantly different. In both models, the difference was in the expected direction according to developmental stake

theory with mothers' reports being less optimistic and less favorable than grandmothers' reports. On a practical level, this means that grandmothers' self report on the GSNI and mothers' report are not interchangeable. Many of the studies reviewed in the process of doing this research rely exclusively on mothers' report of grandmothers' role and experience. The current findings suggest that mothers' and grandmothers' reports vary and do not always agree. Relying on either report exclusively provides an incomplete picture and both mothers' report and grandmothers' report should be included in research conducted. In terms of practice, reporter effect may indicate a real difference in point of view between mother and grandmother of grandmothers' strengths and needs. That difference is subject to interpretation and should be reviewed. Reporter effect may occur in other family relationships as well and is a variable that can be researched and explored by practitioners. Different beliefs and perspective regarding role, strengths, and needs can be incorporated in the assessment and treatment design when working with families either in psychotherapy or support workshops.

Diagnosis Effect

Research shows that grandchildren's disabilities impact on grandparents (Hastings, 1997; Turnbull & Turnbull, 1990). The hypothesis for the current study states that grandmothers' strengths would decrease and that their needs would increase when grandchildren have a diagnosis of ASD. In each of the models where ASD was significant, autism had double the impact as HFA/AS, showing that the severity of a grandchild's disability impacts on grandmothers' role and experience as was suggested by Hodapp (1999).

Grandmothers of children with a diagnosis of ASD reported lower satisfaction scores on the GSNI. One explanation associated with this finding is that the grandmothers of children with disabilities are indeed not having a rewarding experience and that lower satisfaction is a reflection of the stress of interacting with a special needs child. A second possibility is that lower satisfaction scores are a function of the measurement instrument. Perhaps grandmothers' satisfaction when children have disabilities is fundamentally different, made up of different kinds of experiences, compared to grandmothers' satisfaction when children are typically developing. If that is the case, grandmothers' satisfaction in the ASD groups may not have been adequately tapped by the measure used. Either explanation supports the hypothesis that the experiences of the two groups are different.

Grandmothers of children with a diagnosis of ASD had lower teaching scores on the GSNI, indicating that they spend less time in teaching roles compared to grandmothers of typically developing children. The teaching scale of the GSNI measures involvement with grandchildren by assessing a number of concrete behaviors that occur between grandparents and grandchildren such as modeling manners, teaching values, teaching how to negotiate relationships, and teaching how to set goals. This scale is important because it measures direct participation between grandparents and grandchildren. Mothers have reported that direct participation between grandparents and grandchildren adds to the relationship quality between grandparents and grandchildren, is pivotal in reducing the stress associated with parenting a child with special needs, and normalizes family relationships (Green, 2001). One explanation for the lower teaching scores among grandmothers of children with ASD is that the learning needs of children

with ASD are different from the learning needs of typically developing children. Grandmothers may not have the skill set to function as teachers to children with special needs. Information regarding the learning needs of typically developing children is more accessible than is information regarding the learning needs of children with specific disabilities.

Grandmothers of children with a diagnosis of ASD had greater difficulty than grandmothers of typically developing children. Difficulties reported by grandmothers on the GSNI suggested a compromised ability to enter into a collaborative relationship with their adult children and their grandchildren. Grandmothers reported difficulty with giving advice, maintaining conversation, collaborating, and thinking innovatively about their roles. The items endorsed by these grandmothers suggest difficulty in role definition, reaching optimal levels of collaboration and achieving appropriate levels of involvement.

Grandmothers of children with a diagnosis of ASD had greater information needs regarding their grandchildren's school, grandchildren's emotional state, grandchildren's friendships, and the developmentally appropriate choices available to grandchildren than grandmothers of children with typical development. One explanation for this is that while the developmental tasks of special needs children mirror those of typical children, they are categorically different in terms of how those tasks are achieved. Differences exist in many areas including the type of classroom, peer group interactions, access to recreation, and transition planning. Those differences make the information needs of grandmothers of children with special needs greater and more complex.

There are several reasons why the differences in strengths (satisfaction, teaching) and needs (difficulties, information needs) among grandmothers of children with ASD that were identified in this research are important to study. First, when professionals address difficulties associated with differences in grandmothers' strengths and needs, grandmothers' adjustment to their grandchild's disability is facilitated. Research indicates that when grandparents make a good adjustment to grandchildren's disability, that adjustment is mirrored in better adjustment for all family members. Second, research shows that grandparents can be a valued resource when children have a disability or an added burden (Hastings, 1997; Seligman & Darling, 2007). When professionals address grandmothers' difficulties, the likelihood that grandmothers' will function in a supportive way is increased. Third, it is important to address grandmothers' strengths and needs because grandchildren with ASD benefit from interventions which include multiple family members. By addressing grandmothers' needs and developing grandmothers' strengths, it is more likely that they will be effective members of the treatment plan.

Family Functioning Effect

This study looked at the impact of family systems variables on grandmothers' strengths and needs. The Circumplex Model of Marital and Family Systems (Olson et al., 1979) suggests that family systems variables predict outcomes for individual family members, such as grandmothers. Specifically, as family functioning approaches balanced or optimal levels, outcomes for individual family members improve. As family functioning approaches the extreme or unbalanced levels, outcomes for individual family members will be compromised (Olson et al., 2000). The hypothesis for the current study is that as family functioning approaches optimal levels, grandmothers' strengths will

increase and grandmothers' needs will decrease. Results of the current study partially supported this hypothesis.

Neither scale measuring balanced Functioning (cohesion scale, flexibility scale), was significant in any of the models; however, several of the scales measuring unbalanced or not optimal functioning were significant. Families characterized by enmeshed functioning, measured by the FACES IV, were associated with grandmothers experiencing greater satisfaction, success, and teaching and fewer information needs, as measured by the GSNI. Olson (2000) suggested that enmeshed family functioning is adaptive when families encounter stressors, such as a disability, death, unemployment, economic hardship, or immigration. The current research suggests that enmeshed family functioning may be adaptive for extended family members in certain circumstances specifically when a child with special needs is part of the family system. One explanation for these findings is that enmeshment, which is characterized by close family relationships, togetherness, and mutual problem solving, may increase opportunities and expectations for grandparent involvement (Turnbull & Turnbull, 1990).

Families characterized by disengaged functioning, measured by the FACES IV, were associated with grandmothers experiencing greater difficulty, measured by the GSNI. Difficulties included grandmothers' compromised ability to enter the family system through activities such as advice giving, mutual conversations, spending time together, and working collaboratively. Turnbull and Turnbull (1990) suggested that disengaged families often do not meet the needs of children with disabilities. This study supports the notion that disengaged family functioning may not meet the needs of

grandmothers either. One explanation for this finding is that disengaged families are characterized by distant relationships and extreme emotional separateness to the exclusion of mutual problem solving. In a disengaged family system there may be no expectation for grandmother involvement, and the grandparent role is likely to be marginalized.

Families characterized by chaotic functioning, as measured by the FACES IV, were associated with grandmothers experiencing decreased satisfaction (enjoyment of grandparenting activities), increased frustration (unhappiness with aspects of grandchildren's behavior), and increased information needs (need for information relating to grandchildren's social, emotional, and developmental needs), as measured by the GSNI. Chaotic family functioning is characterized by constant and ineffective negotiations, diffusion of responsibility, and failure to set or achieve goals. In chaotic families, there is no appointed leader and very few routines (Olson, 2000). Chaotic functioning results in the abandonment of individual family members' needs (Turnbull & Turnbull, 1990). This research indicates that Grandmothers as part of the extended family system may experience greater difficulties and increased frustration in chaotic family systems. Given the chaotic family systems propensity towards disorganization it is not surprising that grandmothers in these systems express the need for increased information.

Families characterized by good communication as measured by the FACES IV were associated with grandmothers experiencing decreased frustration and increased information needs. Good communication was also associated with decreased teaching, an unexpected result.

Families characterized by high satisfaction with current functioning were associated with grandmothers' involvement. This suggests that grandmothers' direct participation with grandchildren may increase mothers' satisfaction and lends support to the hypothesis that grandparent involvement decreased mothers' stress.

The family functioning results reported here give partial empirical support to the hypotheses that unbalanced family functioning is associated with worse outcomes for family members, by looking at the affect of family systems variables on grandmothers. Family systems variables are process variables and so they are amenable to change in psychotherapy and support groups. Addressing family functioning in these venues may have benefits on all three generational levels, the grandchildren, the parents, and the grandparents. More research is needed that looks at the interaction effect of a diagnosis of ASD in grandchildren and family systems' variables to see, whether family systems variables affects grandmothers' strengths and needs in general, or in general and especially when grandchildren have special needs, like ASD.

Strengths and Limitations of Current Study

A strength associated with this study is the use of a comparison group of grandmothers and mothers of typically developing children. The study results showed empirically that grandmothers of children with ASD have different experiences in terms of their strengths and needs compared to grandmothers of typically developing children. Second, the current study used valid, reliable and comprehensive measures to explore constructs. Previous research has relied to a large extent on qualitative methods and small samples. Third, by collecting information from dyads containing a grandmother and a mother, this research assessed family functioning from the mothers' perspective and

grandmothers' strengths and needs from the perspective of both mother and grandmother. The current study tested the consistency between mothers' and grandmothers' reports on the GSNI. This was done in an attempt to add to the research literature on developmental stake (Aquilino, 1999; Lynott & Roberts, 1997). Finally, the use of Multiple Imputation to handle missing data enabled this researcher to save a significant number of cases that were partially observed, adding valuable data that would have otherwise been lost.

There are several ways this study could be improved. If the sample size were increased, the researcher could test for an interaction effect between family systems variables and diagnosis. For example with regard to the finding that families characterized by disengaged family functioning have grandmothers with more difficulties, it is not as yet clear whether disengagement is problematic for grandmothers in all groups or only very problematic for grandmothers in the disability groups. Secondly, more in depth measures tapping issues that are specific to disability grandparents may have added more information to the current study. For example, measures which ask specific questions of parents and grandparents in terms of practical coping strategies and their emotional response to stress would have added useful information regarding the disability families. In the universe of questions that can be asked of parents and grandparents, there are some that apply to typically developing children and do not apply to severely disabled, nonverbal children.

Selection bias is a problem in research utilizing questionnaires because the people who respond to questionnaires may differ in meaningful ways from people who do not return questionnaires or from people who do not want to participate in a study at all. In this study, participants may represent a group of grandparents that is more motivated than

the actual population of grandparents to whom results are generalized. Also, this researcher collected information from dyads containing a family's mother and grandmother. Mothers and grandmothers with poor relationships may have opted out of this study. Mothers and grandmothers with problematic relationships, or problematic family functioning may have been reluctant to participate in the study. Thus, the results may not be representative of individuals or families who are in crisis.

Educational Implications

The appropriate level of involvement for grandparents of children with ASD will depend on the characteristics of the family; however the ideal is described by Margetts (2006) as a culture of participation. Grandparents should be regarded as a potential major support to parents at first assessment and part of the treatment plan in terms of interventions. As part of the treatment team they should receive information and training. In the best case scenario, grandparents have the potential to act as advocates for grandchildren and as supports for the whole family. They should be supported by the clinical team in these endeavors. If grandparents are going to be part of the treatment team, training materials need to be developed to educate them regarding their roles and responsibilities. This is particularly true when grandchildren have a diagnosis of ASD because of the unique set of skills and abilities necessary to address the chronic and invisible nature of the disorder.

Professionals are faced with the challenge of discovering and developing grandparents' strengths as a potential resource. Additionally, professionals are challenged to explore stressors grandparents may present as they function within the family system. The clinical team working with families needs to assess the availability of

grandparents in the extended family system and need to suggest ways in which grandparents can be included in systemic interventions for children with ASD. Possible recommendations include support groups for grandparents, education regarding ASD, and specific strategies for dealing with their adult children and their grandchildren. Research supports that defining and expanding grandparent roles is helpful for families struggling to cope with major life stressors specifically a diagnosis of ASD. When the clinical team is educated regarding the research associated with grandparents of children with disabilities, they are better able to design workshops and interventions that are tailored to the needs of this group.

Implications and Future Research

Future research should be more quantitative in nature in an effort to differentiate themes specific to various disabilities. An interesting permutation of the research would be to explore the grandparent role as it changes through the life cycle. For example, what is the impact at diagnosis, what is the impact as the child begins school, and what is the impact as the child transitions to adulthood. The current study focused on grandmothers in order to control for the effect of grandparents' gender, however, the role and experience of grandfathers could be explored. Another interesting area of research could tap in to the effect of grandparent involvement on other family members such as mothers, fathers, and siblings. Instruments need to be developed that assess variables that are specific to families of children with disabilities. For example, instruments might be developed to measure grandparents' understanding of the special education process. Instruments that measure the effectiveness of grandparents support curriculum and

workshops are needed. The clinical team needs to use research based interventions in creating a culture of collaboration that includes grandparents as part of the treatment plan.

The research presented here adds to an already growing number of studies focusing on intergenerational relationships and the grandparent role. The study provides empirical support of previous research on developmental stake theory because grandmothers' view was as good or better than mothers' view of grandmothers' strengths and needs. The study findings provide empirical evidence for differences between grandmothers of children with ASD and grandmothers of children with typical development in terms of grandmothers' strengths and needs. This finding directly suggests that when children have ASD, grandmothers need support and information that is tailored to fit their circumstances. Second, this study provided empirical evidence that family systems variables impact grandmothers' strengths and needs. These findings add to to the research on family systems showing that family functioning affects family members' well-being in predictable ways. In addition to impacting members of the immediate family, this study shows that nuclear family functioning impacts extended family members' well-being.

Appendix A

DSM-IV CRITERIA

Diagnostic Criteria for Autistic Disorder is:

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
    a. Qualitative impairment in social interaction, as manifested by at least two of the following:
        i. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
        ii. Failure to develop peer relationships appropriate to developmental level
        iii. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
        iv. Lack of social or emotional reciprocity
    b. Qualitative impairments in communication as manifested by at least one of the following
        i. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
        ii. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
        iii. Stereotyped and repetitive use of language or idiosyncratic language
        iv. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
    c. restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
        i. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
        ii. apparently inflexible adherence to specific, nonfunctional routine or rituals
        iii. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
        iv. persistent preoccupation with parts of objects.

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to ge3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

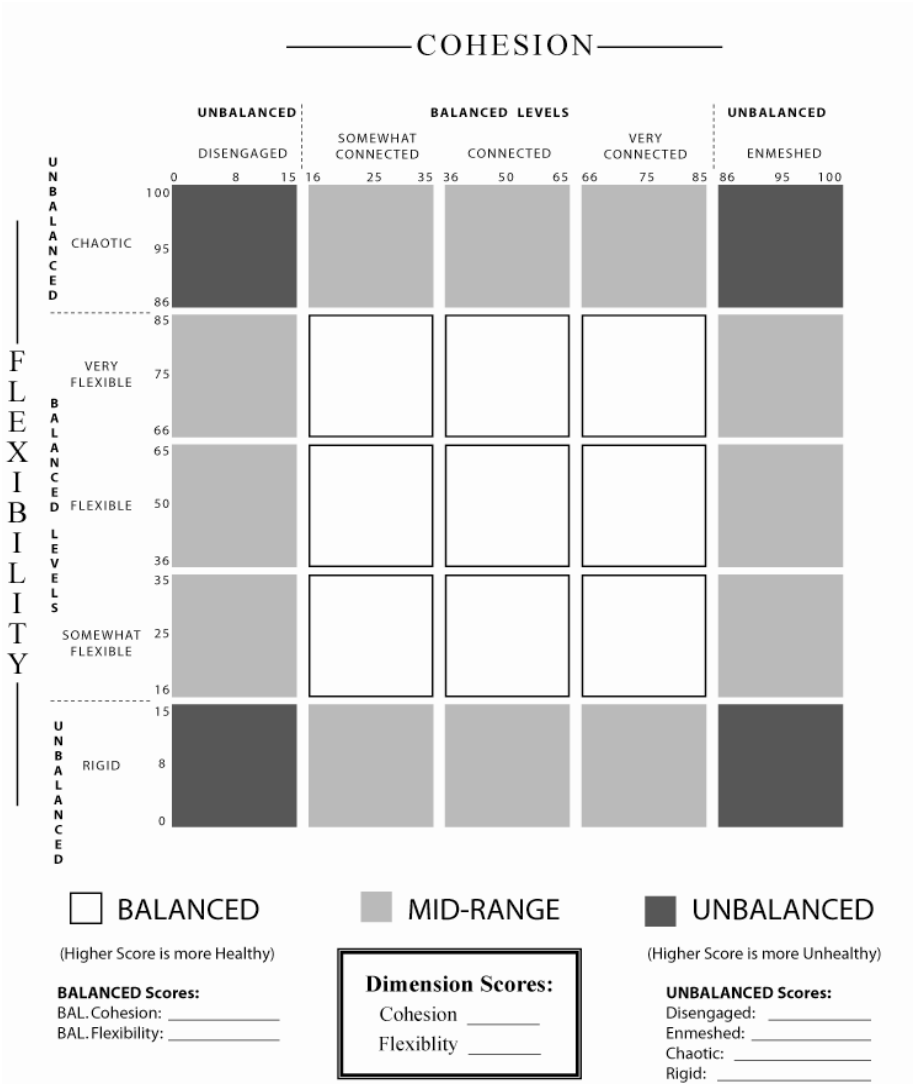
C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Diagnostic criteria for Asperger's Syndrome is:

A. Qualitative impairment in social interaction, as manifested by at least two of the following:
    a. marked impairment in the use of multiples nonverbal behaviors such as eye to eye gaze, facial expression, body postures, and gestures to regulate social interaction
    b. failure to develop peer relationship appropriate to developmental level
    c. lack of spontaneous seeking to share enjoyment, interest, or achievements with other people (e.g. by lack of showing or pointing out objects of interest to other people)
    d. lack of social or emotional reciprocity.
B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following.
    a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
    b. apparently inflexible adherence to specific, nonfunctional routines or rituals.
    c. stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
    d. persistent preoccupation with parts or objects.
C. The disturbance causes clinically significant impairment in social occupational, or other important areas of functioning.
D. There is no clinically significant general delay in language (e.g. single words used by age 2 years, communicative phrases used by age 3 years).
E. There is no clinically significant delay in cognitive development or in development of age-appropriate self-help skills, adaptive behavior (other than social interaction), and curiosity about the environment in childhood.
F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

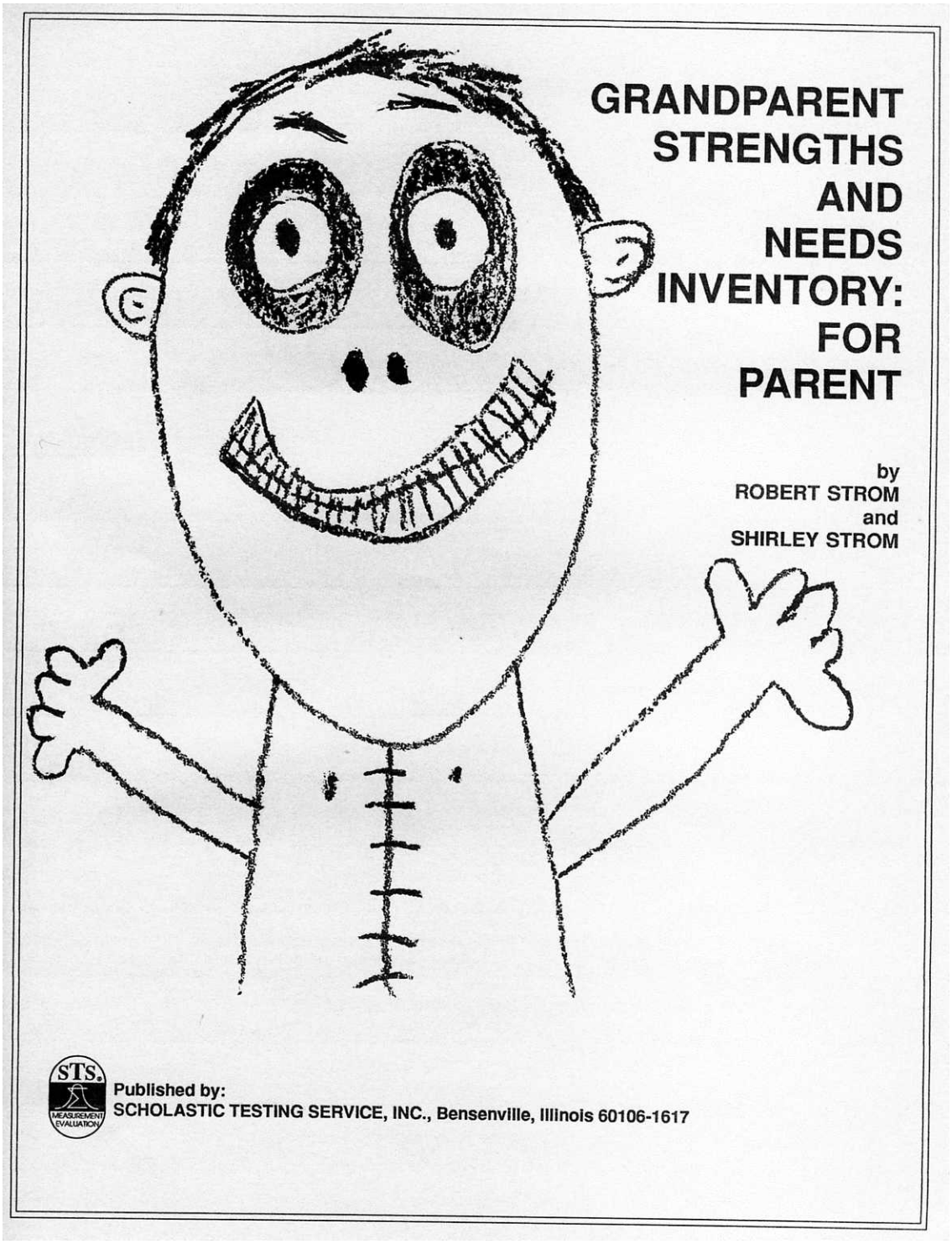
Appendix B

CIRCUMPLEX MODEL OF MARITAL AND FAMILY SYSTEMS



Appendix C

GRANDPARENTS STRENGTHS AND NEEDS INVENTORY – PARENT FORM



Portrait by Paris Strom, Age 6.

Published by:
SCHOLASTIC TESTING SERVICE, INC.
Bensenville, Illinois 60106-1617
Printed in the United States of America.

Please answer the following questions by checking the correct response.

(5) What is the sex of my child?
(1) ____ male
(2) ____ female

(6,7) What is the age of my child?
_____ years

(8) What is my marital status?
(1) ____ married
(2) ____ separated
(3) ____ divorced
(4) ____ never married
(5) ____ widowed

(9) The grandparent I am thinking about is
(1) ____ my parent
(2) ____ the parent of my spouse

(10) How far do I live from this grandparent's house?
(1) ____ we live together
(2) ____ less than a mile
(3) ____ 1 to 24 miles
(4) ____ 25 to 199 miles
(5) ____ 200 to 1,000 miles
(6) ____ more than 1,000 miles

(11) What is the sex of this grandparent?
(1) ____ male
(2) ____ female

(12,13) How old is this grandparent?
_____ years

(14) What is the marital status of this grandparent?
(1) ____ married
(2) ____ separated
(3) ____ divorced
(4) ____ never married
(5) ____ widowed

(15) How much time does this grandparent spend with my child each month?
(1) ____ less than one hour
(2) ____ 1 to 5 hours
(3) ____ 5 to 10 hours
(4) ____ more than 10 hours

(16) What is the employment status of this grandparent?
(1) ____ retired
(2) ____ working part time
(3) ____ working full time
(4) ____ unemployed

(17) What is the religion of this grandparent?
(1) ____ Christianity
(2) ____ Islam
(3) ____ Judaism
(4) ____ other

(18) How often does this grandparent take care of this grandchild?
(1) ____ daily
(2) ____ often
(3) ____ seldom
(4) ____ never

(19) What is my race?
(1) ____ White
(2) ____ Black
(3) ____ Hispanic
(4) ____ Asian
(5) ____ other

(20) What is my annual household income?
(1) ____ under $9,999
(2) ____ $10,000 to $19,999
(3) ____ $20,000 to $29,999
(4) ____ $30,000 to $39,999
(5) ____ $40,000 to $49,999
(6) ____ over $50,000

(21) What is my highest level completed in school?
(1) ____ 8th grade or less
(2) ____ some high school
(3) ____ high school diploma
(4) ____ vocational training
(5) ____ some college
(6) ____ college degree
(7) ____ graduate degree

(22) What is my sex?
(1) ____ male
(2) ____ female

(23,24) What is my age?
_____ years

DIRECTIONS: This is a survey of your feelings about the family members identified above. For each item, circle the answer that tells best how you feel.

Grandparent Satisfaction—Some things about being a grandparent are satisfying. How often does your parent like these things?

1. My parent likes my [redacted]child to share feelings.	Always	Often	Seldom	Never
2. My parent likes how much time I spend with my child.	Always	Often	Seldom	Never
3. My parent likes the way my child helps at home with household tasks.	Always	Often	Seldom	Never
4. My parent likes my child's outlook on life.	Always	Often	Seldom	Never
5. My parent likes it when my child asks for advice.	Always	Often	Seldom	Never
6. My parent likes the way my child spends free time.	Always	Often	Seldom	Never
7. My parent likes the way my child stays in touch.	Always	Often	Seldom	Never
8. My parent likes to take part in activities my child enjoys.	Always	Often	Seldom	Never
9. My parent likes my child's willingness to offer help.	Always	Often	Seldom	Never
10. My parent likes how well my child does in school.	Always	Often	Seldom	Never

Grandparent Success—There are a number of things grandparents do well. How often is your parent good at these things?

11. My parent is good at listening to my child.	Always	Often	Seldom	Never
12. My parent is good at seeing the positive side of situations.	Always	Often	Seldom	Never
13. My parent is good at learning from my child.	Always	Often	Seldom	Never
14. My parent is good at sharing feelings with my child.	Always	Often	Seldom	Never
15. My parent is good at having an influence on my child.	Always	Often	Seldom	Never
16. My parent is good at reinforcing my goals as a parent.	Always	Often	Seldom	Never
17. My parent is good at respecting my child's opinions.	Always	Often	Seldom	Never
18. My parent is good at staying in touch with my child.	Always	Often	Seldom	Never
19. My parent is good at accepting help from my child.	Always	Often	Seldom	Never
20. My parent is good at learning from me.	Always	Often	Seldom	Never

Grandparent Teaching—The role of grandparent includes teaching. How often does your parent try to teach your child these things?

21. My parent tries to teach my child to care about other people's feelings.	Always	Often	Seldom	Never
22. My parent tries to teach my child what to expect of a grandparent.	Always	Often	Seldom	Never
23. My parent tries to teach my child about religion by being a good example.	Always	Often	Seldom	Never
24. My parent tries to teach my child good manners.	Always	Often	Seldom	Never
25. My parent tries to teach my child a sense of right and wrong.	Always	Often	Seldom	Never
26. My parent tries to teach my child the need for learning throughout life.	Always	Often	Seldom	Never
27. My parent tries to teach my child our family history and traditions.	Always	Often	Seldom	Never
28. My parent tries to teach my child how to plan and set goals.	Always	Often	Seldom	Never
29. My parent tries to teach my child how to handle arguments.	Always	Often	Seldom	Never
30. My parent tries to teach my child what is expected of a grandchild.	Always	Often	Seldom	Never

Grandparent Difficulty—Being a grandparent can be difficult at times. How often does your parent find these things difficult?

31. It is difficult for my parent to accept my child's values.	Always	Often	Seldom	Never
32. It is difficult for my parent to offer advice to me.	Always	Often	Seldom	Never
33. It is difficult for my parent to admit to my child the things he or she doesn't know.	Always	Often	Seldom	Never
34. It is difficult for my parent to keep a conversation going with my child.	Always	Often	Seldom	Never
35. It is difficult for my parent to give advice to my child.	Always	Often	Seldom	Never
36. It is difficult for my parent to talk with my child about certain issues.	Always	Often	Seldom	Never
37. It is difficult for my parent to find time to be with my child.	Always	Often	Seldom	Never
38. It is difficult for my parent to look at things in new ways.	Always	Often	Seldom	Never
39. It is difficult for my parent to get along with me.	Always	Often	Seldom	Never
40. It is difficult for my parent to get along with my child.	Always	Often	Seldom	Never

Grandparent Frustration—The behavior of family members can be frustrating to grandparents. How often is your parent frustrated by these things?

41. My parent is frustrated by my child's television habits.	Always	Often	Seldom	Never
42. My parent is frustrated by how my child treats me.	Always	Often	Seldom	Never
43. My parent is frustrated by how he or she is treated by my child.	Always	Often	Seldom	Never
44. My parent is frustrated by my child's manners.	Always	Often	Seldom	Never
45. My parent is frustrated by my child's sense of right and wrong.	Always	Often	Seldom	Never
46. My parent is frustrated by my child's listening habits.	Always	Often	Seldom	Never
47. My parent is frustrated by the discipline my child receives at home.	Always	Often	Seldom	Never
48. My parent is frustrated whenever he or she argues with my child.	Always	Often	Seldom	Never
49. My parent is frustrated by how I am raising my child.	Always	Often	Seldom	Never
50. My parent is frustrated by my child's choice of friends.	Always	Often	Seldom	Never

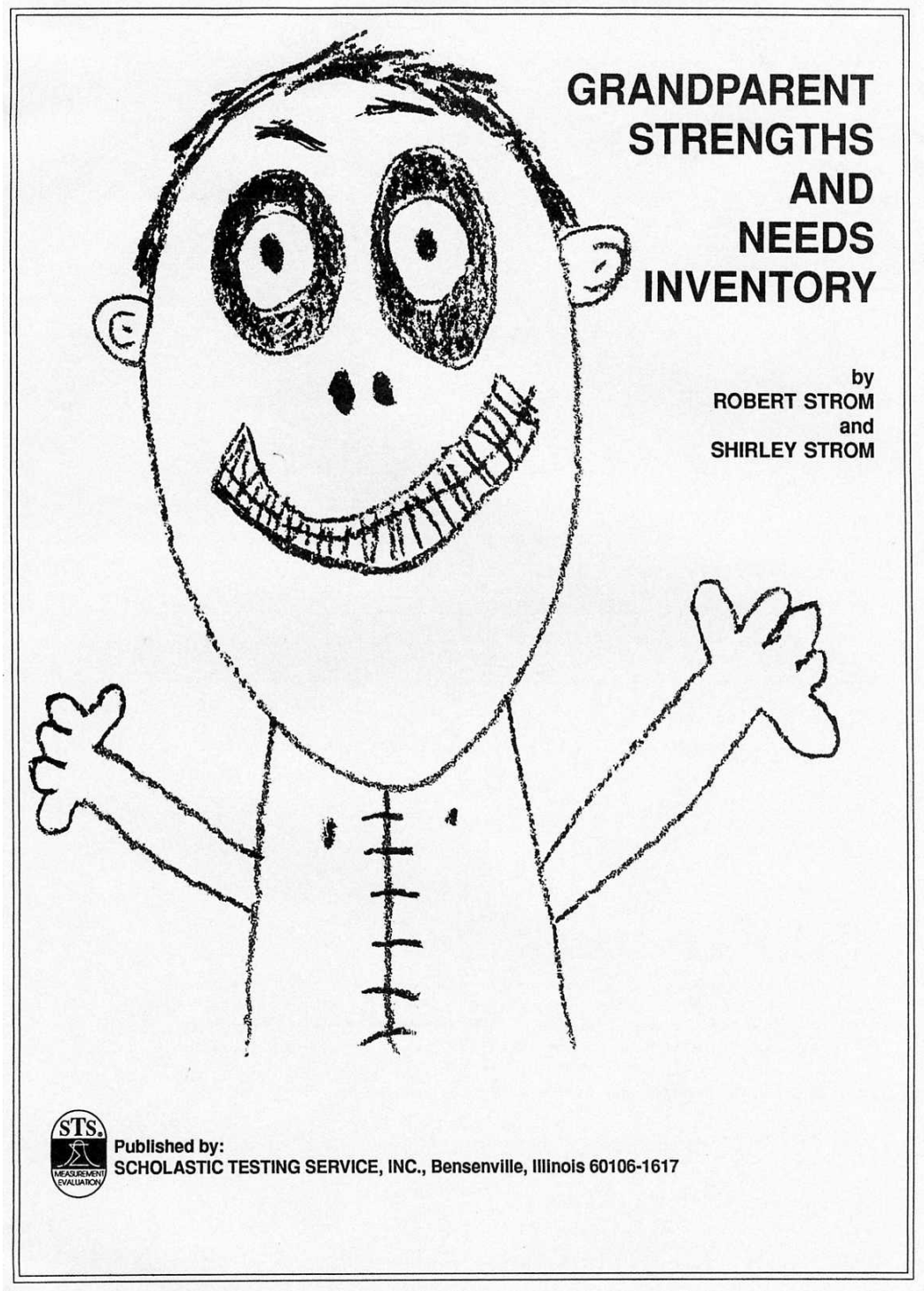
Grandparent Information Needs—There may be some things grandparents need more information about. How often does your parent need more information about these things?

51. My parent needs more information about the school experience of my child.	Always	Often	Seldom	Never
52. My parent needs more information about the fears and worries of my child.	Always	Often	Seldom	Never
53. My parent needs more information about the goals my child has chosen.	Always	Often	Seldom	Never
54. My parent needs more information about the stress my child has to manage.	Always	Often	Seldom	Never
55. My parent needs more information about the way my child is being raised.	Always	Often	Seldom	Never
56. My parent needs more information about the self-esteem of my child.	Always	Often	Seldom	Never
57. My parent needs more information about the attitudes of my child's age group.	Always	Often	Seldom	Never
58. My parent needs more information about the friendships of my child.	Always	Often	Seldom	Never
59. My parent needs more information about the difficult choices my child has to make at this age.	Always	Often	Seldom	Never
60. My parent needs more information about how to share ideas with my child as they watch television.	Always	Often	Seldom	Never

61. If there is anything else you would like to tell about the strengths and needs of your parent, please write it in this space.

Appendix D

GRANDPARENT STRENGTHS AND NEEDS INVENTORY



Portrait by Paris Strom, Age 6.

Published by:
SCHOLASTIC TESTING SERVICE, INC.
Bensenville, Illinois 60106-1617
Printed in the United States of America.

Please answer the following questions by checking the correct response.

(5) What is the sex of my grandchild?
(1) ____ male
(2) ____ female

(6,7) What is the age of my grandchild?
_____ years

(8) What is the marital status of my grandchild's parents?
(1) ____ married
(2) ____ separated
(3) ____ divorced
(4) ____ never married
(5) ____ widowed

(9) How am I related to this grandchild?
(1) ____ through my son
(2) ____ through my daughter

(10) How far do I live from this grandchild's house?
(1) ____ we live together
(2) ____ less than a mile
(3) ____ 1 to 24 miles
(4) ____ 25 to 199 miles
(5) ____ 200 to 1,000 miles
(6) ____ more than 1,000 miles

(11) What is my sex?
(1) ____ male
(2) ____ female

(12,13) What is my age?
_____ years

(14) What is my marital status?
(1) ____ married
(2) ____ separated
(3) ____ divorced
(4) ____ never married
(5) ____ widowed

(15) How much time do I spend with this grandchild each month?
(1) ____ less than one hour
(2) ____ 1 to 5 hours
(3) ____ 5 to 10 hours
(4) ____ more than 10 hours

(16) What is my employment status?
(1) ____ retired
(2) ____ working part time
(3) ____ working full time
(4) ____ unemployed

(17) What is my religion?
(1) ____ Christianity
(2) ____ Islam
(3) ____ Judaism
(4) ____ other

(18) How often do I take care of this grandchild?
(1) ____ daily
(2) ____ often
(3) ____ seldom
(4) ____ never

(19) What is my race?
(1) ____ White
(2) ____ Black
(3) ____ Hispanic
(4) ____ Asian
(5) ____ other

(20) What is my annual household income?
(1) ____ under $9,999
(2) ____ $10,000 to $19,999
(3) ____ $20,000 to $29,999
(4) ____ $30,000 to $39,999
(5) ____ $40,000 to $49,999
(6) ____ over $50,000

(21) What is my highest level completed in school?
(1) ____ 8th grade or less
(2) ____ some high school
(3) ____ high school diploma
(4) ____ vocational training
(5) ____ some college
(6) ____ college degree
(7) ____ graduate degree

(22) What is my state of health?
(1) ____ excellent
(2) ____ good
(3) ____ fair
(4) ____ poor

(23,24) How many grandchildren do I have?
_____ grandchildren

DIRECTIONS: This is a survey of your feelings about the family members identified above. For each item, circle the answer that tells best how you feel.

Grandparent Satisfaction—Some things about being a grandparent are satisfying. How often do you like these things?

1. I like my grandchild to share feelings with me.	Always	Often	Seldom	Never
2. I like how much time my son or daughter spends with my grandchild.	Always	Often	Seldom	Never
3. I like the way my grandchild helps at home with household tasks.	Always	Often	Seldom	Never
4. I like my grandchild's outlook on life.	Always	Often	Seldom	Never
5. I like it when my grandchild asks me for advice.	Always	Often	Seldom	Never
6. I like the way my grandchild spends free time.	Always	Often	Seldom	Never
7. I like the way my grandchild stays in touch with me.	Always	Often	Seldom	Never
8. I like to take part in activities my grandchild enjoys.	Always	Often	Seldom	Never
9. I like the willingness of my grandchild to help me.	Always	Often	Seldom	Never
10. I like how well my grandchild does in school.	Always	Often	Seldom	Never

Grandparent Success—There are a number of things grandparents do well. How often are you good at these things?

11. I am good at listening to my grandchild.	Always	Often	Seldom	Never
12. I am good at seeing the positive side of situations.	Always	Often	Seldom	Never
13. I am good at learning from my grandchild.	Always	Often	Seldom	Never
14. I am good at telling my grandchild how I feel.	Always	Often	Seldom	Never
15. I am good at having an influence on my grandchild.	Always	Often	Seldom	Never
16. I am good at reinforcing the parenting goals of my son or daughter.	Always	Often	Seldom	Never
17. I am good at respecting my grandchild's opinions.	Always	Often	Seldom	Never
18. I am good at staying in touch with my grandchild.	Always	Often	Seldom	Never
19. I am good at accepting help from my grandchild.	Always	Often	Seldom	Never
20. I am good at learning from my son or daughter.	Always	Often	Seldom	Never

Grandparent Teaching—The role of grandparents includes teaching. How often do you try to teach your grandchild these things?

21. I try to teach my grandchild to care about other people's feelings.	Always	Often	Seldom	Never
22. I try to teach my grandchild what can be expected of me.	Always	Often	Seldom	Never
23. I try to teach my grandchild about religion by being a good example.	Always	Often	Seldom	Never
24. I try to teach my grandchild good manners.	Always	Often	Seldom	Never
25. I try to teach my grandchild a sense of right and wrong.	Always	Often	Seldom	Never
26. I try to teach my grandchild the need for learning throughout life.	Always	Often	Seldom	Never
27. I try to teach my grandchild our family history and traditions.	Always	Often	Seldom	Never
28. I try to teach my grandchild how to plan and set goals.	Always	Often	Seldom	Never
29. I try to teach my grandchild how to handle arguments.	Always	Often	Seldom	Never
30. I try to teach my grandchild what I expect of him or her.	Always	Often	Seldom	Never

Grandparent Difficulty—Being a grandparent can be difficult at times. How often do you find these things difficult?

31. It is difficult for me to accept my grandchild's values.	Always	Often	Seldom	Never
32. It is difficult for me to offer advice to my son or daughter.	Always	Often	Seldom	Never
33. It is difficult for me to admit to my grandchild the things I don't know.	Always	Often	Seldom	Never
34. It is difficult for me to keep a conversation going with my grandchild.	Always	Often	Seldom	Never
35. It is difficult for me to give advice to my grandchild.	Always	Often	Seldom	Never
36. It is difficult for me to talk with my grandchild about certain issues.	Always	Often	Seldom	Never
37. It is difficult for me to find time to be with my grandchild.	Always	Often	Seldom	Never
38. It is difficult for me to look at things in new ways.	Always	Often	Seldom	Never
39. It is difficult for me to get along with my son or daughter.	Always	Often	Seldom	Never
40. It is difficult for me to get along with my grandchild.	Always	Often	Seldom	Never

Grandparent Frustration—The behavior of family members can be frustrating to grandparents. How often are you frustrated by these things?

41. I am frustrated by my grandchild's television habits.	Always	Often	Seldom	Never
42. I am frustrated by how my grandchild treats my son or daughter.	Always	Often	Seldom	Never
43. I am frustrated by how my grandchild treats me.	Always	Often	Seldom	Never
44. I am frustrated by my grandchild's manners.	Always	Often	Seldom	Never
45. I am frustrated by my grandchild's sense of right and wrong.	Always	Often	Seldom	Never
46. I am frustrated by my grandchild's listening habits.	Always	Often	Seldom	Never
47. I am frustrated by the discipline my grandchild receives at home.	Always	Often	Seldom	Never
48. I am frustrated when my grandchild argues with me.	Always	Often	Seldom	Never
49. I am frustrated by how my grandchild is being brought up at home.	Always	Often	Seldom	Never
50. I am frustrated by my grandchild's choice of friends.	Always	Often	Seldom	Never

Grandparent Information Needs—There may be some things grandparents need more information about. How often do you need more information about these things?

51. I need more information about the school experience of my grandchild.	Always	Often	Seldom	Never
52. I need more information about the fears and worries of my grandchild.	Always	Often	Seldom	Never
53. I need more information about the goals that my grandchild has chosen.	Always	Often	Seldom	Never
54. I need more information about the stress my grandchild has to manage.	Always	Often	Seldom	Never
55. I need more information about the way my grandchild is being raised.	Always	Often	Seldom	Never
56. I need more information about the self-esteem of my grandchild.	Always	Often	Seldom	Never
57. I need more information about the attitudes of my grandchild's age group.	Always	Often	Seldom	Never
58. I need more information about the friendships of my grandchild.	Always	Often	Seldom	Never
59. I need more information about the difficult choices my grandchild has to make at this age.	Always	Often	Seldom	Never
60. I need more information about how to share ideas with my grandchild as we watch television.	Always	Often	Seldom	Never

61. If there is anything else you would like to tell about your strengths and needs as a grandparent, please write it in this space.

Appendix E

FACES IV Package

FACES IV Questionnaire

Directions to Family Members:

1. All family members over the age 12 can complete FACES IV.
2. Family members should complete the instrument independently, not consulting or discussing their responses until they have been completed.
*3. Fill in the corresponding **number** in the space on the provided answer sheet.*

1	2	3	4	5
DOES NOT describes 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.**

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

31. Although family members have individual interests, they still participant 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.
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 this 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. Your family's ability to cope with stress.
55. Your family's ability to be flexible.
56. Your family's ability to share positive experiences.
57. The quality of communication between family members.
58. Your family's ability to resolve conflicts.
59. The amount of time you spend together as a family.
60. The way problems are discussed.
61. The fairness of criticism in your family.
62. Family members concern for each other.

Thank you for Your Cooperation!

FACES IV Package: Answer Sheet

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. ____ 7. ____ 13. ____ 19. ____ 25. ____ 31. ____ 37. ____ A.____
2. ____ 8. ____ 14. ____ 20. ____ 26. ____ 32. ____ 38. ____ B.____
3. ____ 9. ____ 15. ____ 21. ____ 27. ____ 33. ____ 39. ____ C.____
4. ____ 10. ____ 16. ____ 22. ____ 28. ____ 34. ____ 40. ____ D.____
5. ____ 11. ____ 17. ____ 23. ____ 29. ____ 35. ____ 41. ____ E.____
6. ____ 12. ____ 18. ____ 24. ____ 30. ____ 36. ____ 42. ____ F.____

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

43. ____ 44. ____ 45. ____ 46. ____ 47. ____ 48. ____ 49. ____ 50. ____
51. ____ 52. ____

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

53. ____ 54. ____ 55. ____ 56. ____ 57. ____ 58. ____ 59. ____ 60. ____
61. ____ 62. ____

Thank You for Your Cooperation!

FACES IV Package: Background Information

Subject ID (4 digit) _____ **Age:** ____ **Sex:** M: __ F:__ **Date:** _____

Education:

(a)___ Some High School (b) ___ Completed High School
(c) ___ Some college (d)___ Completed College (e)___ Advanced Degree

Income: (If relevant)

(a) ___ Less than $10,000 (b)___ $10-20,000 (c) ___ $20-30,000
(d)___ $30-40,000 (e)___ $40-50,000 (f) ___ $50-60,000
(g)___ $60-80,000 (h)___ $80-100,000 (i) ___ $100,000 or more

Ethnic Background: (check all that apply)

(a)___ Asian American (d) ___ Hispanic/Latino (g) ___ White/Caucasian
(b)___ Black/African American (e) ___ Mixed Race
(c)___ Hawaiian or Pac. Islander (f) ___ Native American

Current relationship status:

(a)___ Single, never married (e) ___ Married, not first marriage
(b)___ Single, divorced (f) ___ Life-partnership
(c)___ Single, widowed (g) ___ Living together
(d)___ Married, first marriage (h) ___ Separated

Current living arrangement:

(a)___ Alone (d)___ With Others
(b)___ With Parents (e)___ With Children
(c)___ With Partner (f)___ With Partner and Children

<u>Use Current Family: If no current Family, use Family of Origin</u>

Family Structure: (a) ____ Two parents (biological) (c) ___ Two Parent (same sex)
(b) ____ Two parents (step family) (d) ___ One Parent
(c) ____ Two parents (adoptive)

Family Member: (a)___ Father (c)___ First Child (e)___ Third Child
(b)___ Mother (d)___ Second Child (f)___ Fourth or Older Child

Number of Children in Family: (a) ____ None (b) ____ One (c) ___ Two (d) ____ Three
(e) ____ Four (f) ____ Five (g) Six or more

Appendix F

RESEARCH ANNOUNCEMENT

Grandmothers and Mothers Needed to Participate in Dissertation Research

A research study is being conducted to examine the roles and experience of grandmothers and mothers of children with autism contrasted with children with no disability. Grandparents of children with disabilities have added concerns and responsibilities, but rarely have access to adequate support and information, leading to confusion as to their appropriate role and degree of participation. This is unfortunate because grandparent involvement has been shown to reduce parents' stress, to expand and enrich the social worlds of autistic children, and to add dimension and meaning to grandparents' own lives.

The study uses questionnaires for grandmothers and mothers that take 20 to 30 minutes to complete. The questionnaires are mailed to you. All information gathered will be kept strictly confidential and will be stored in a locked file cabinet, to which only I, and my advisor, will have access. At any time you can refuse to answer any questions or withdraw from the study. Your participation in this study will add to our understanding of the role and experience of grandmothers today in families of children with disabilities, as well as the families of children with typical development.

If you are the mother or grandmother of a child between the ages of 6 and 14 who has been diagnosed with autism or Aspergers' disorder, or if you are the mother or grandmother of a child between the ages of 6 and 14 who has no disability, and you would like to participate in this dissertation research, please contact Alison Sullivan at (516)662 - 3769 or by email at absulli@aol.com

Appendix G

MOTHER/GRANDMOTHER CONSENT FORM

Ph.D. Program in Educational Psychology

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

CONSENT FORM

My name is Alison Sullivan, 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 the Principal Investigator of the project, entitled, "Grandchildren's Autism and Family Functioning as Predictors of Grandmothers' Role and Experience."

This is a research study on grandmothers and mothers of children with Autism Spectrum Disorder (ASD). Grandmothers and mothers of children with no disability will also be in this study.

If you are a grandmother, the questionnaire packet should take approximately 20 minutes to complete. If you are a mother, the questionnaire should take approximately 30 minutes to complete.

All information gathered will be kept strictly confidential and will be stored in a locked file cabinet, to which only I, and my advisor, will have access. At any time you can refuse to answer any questions or with from the study without penalty.

There are no known risks involved in this study. However, completing the questionnaire may raise concerns for you because the questions are about family involvement. Therefore, I have enclosed a list of counseling agencies and referrals for you to contact in case you have questions or concerns after participating in this study.

The benefit of your participation in this study is that it will add to our understanding of grandmothers' roles, contributions, and experiences in today's families, in general, and when children have a disability.

I may publish the results of the 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.

If you have any questions about this research, you can contact me at 516-662-3769 or absulli@aol.com, or my advisor Marian Fish at 212-817-8290 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, the Graduate Center/City University of New York, 212-817-7525, kpowell@gc.cuny.edu.

Thank you for considering participating in this study. If you wish to participate, then sign the consent statement below. I have enclosed a copy of this form for your records.

CONSENT STATEMENT: I have read and understood the information above. I consent to take part in the grandmothers' role and experience study.

SIGNATURE: _____

If you would like a copy of the study when it is done, provide your mailing address here (Circle one): Yes No

If yes, provide your mailing address here:

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