ScholarWorks@GSU

Sources of Support and Family Quality of Life of Grandmothers Raising Grandchildren With and Without Disabilities

Authors	Kresak, Karen E
Citation	Kresak, Karen E. "Sources of Support and Family Quality of Life of Grandmothers Raising Grandchildren With and Without Disabilities." Dissertation, Georgia State University, 2012. https://doi.org/10.57709/2365633
DOI	https://doi.org/10.57709/2365633
Download date	2026-04-21 08:03:27
Link to Item	https://hdl.handle.net/20.500.14694/5973

ACCEPTANCE

This dissertation, SOURCES OF SUPPORT AND FAMILY QUALITY OF LIFE OF GRANDMOTHERS RAISING GRANDCHILDREN WITH AND WITHOUT DISABILITIES, by KAREN ELIZABETH KRESAK, was prepared under the direction of the candidate's Dissertation Advisory Committee. It is accepted by the committee members in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Education, Georgia State University.

The Dissertation Advisory Committee and the student's Department Chair, as representatives of the faculty, certify that this dissertation has met all standards of excellence and scholarship as determined by the faculty. The Dean of the College of Education concurs.

____
Peggy A. Gallagher, Ph.D.
Committee Chair

____
Catherine Cadenhead, Ph.D.
Committee Member

____
Susan R. Easterbrooks, Ed.D.
Committee Member

____
Susan J. Kelley, Ph.D.
Committee Member

____
Elizabeth A. Steed, Ph.D.
Committee Member

____
Date

____
Gwen Benson, Ph.D.
Interim Chair, Department of Educational Psychology and Special Education

____
R. W. Kamphaus, Ph.D.
Dean and Distinguished Research Professor
College of Education

AUTHOR'S STATEMENT

By presenting this dissertation as a partial fulfillment of the requirements for the advanced degree from Georgia State University, I agree that the library of Georgia State University shall make it available for inspection and circulation in accordance with its regulations governing materials of this type. I agree that permission to quote, to copy from, or to publish this dissertation may be granted by the professor under whose direction it was written, by the College of Education's director of graduate studies and research, or by me. Such quoting, copying, or publishing must be solely for scholarly purposes and will not involve potential gain. It is understood that any copying from or publication of this dissertation which involves potential financial gain will not be allowed without my written permission.

____

Karen Elizabeth Kresak

NOTICE TO BORROWERS

All dissertations deposited in the Georgia State University library must be used in accordance with the stipulations prescribed by the author in the preceding statement. The author of this dissertation is:

Karen Elizabeth Kresak
1559 Twin Courts Lane
Marietta, GA 30008

The director of this dissertation is:

Dr. Peggy Ahrenhold Gallagher
Department of Educational Psychology and Special Education
College of Education
Atlanta, GA 30303-3083

VITA

Karen Elizabeth Kresak

ADDRESS: 1559 Twin Courts Lane
Marietta, GA 30008

EDUCATION:

Ph.D. 2011	Georgia State University Education of Students with Exceptionalities
2003	Georgia State University Preschool Special Education Endorsement
M.Ed. 1990	Georgia State University School Psychometry
M. A. 1988	Assumption College Counseling Psychology
B. A. 1984	Georgia State University Psychology

PROFESSIONAL EXPERIENCE:

2003-Present	Preschool Special Education Teacher Marietta City Schools, Marietta, Georgia
1995-2003	Teacher EBD (Grades K-4) Marietta City Schools, Marietta, Georgia
1991-1995	Teacher SEBD (Grades K-5) Northwest Georgia Psychoeducational Program, Rome, Georgia

PRESENTATIONS AND PUBLICATIONS:

Kresak, K., & Gallagher, P. A. (2011, November). *Sources of support and family quality of life of grandmothers raising grandchildren: Lessons for teachers of students with disabilties*. Poster presented at Teacher Education Division Annual Conference, Austin, TX.

Kresak, K., & Gallagher, P. A. (2011, November). *Sources of support and family quality of life of grandmothers raising grandchildren.* Poster presented at Division for Early Childhood Annual International Conference, National Harbor, MD.

Gallagher, P. A., Kresak, K., & Rhodes, C. A. (2010). Perceived needs of grandmothers of children with disabilities. *Topics in Early Childhood Special Education, 30,* 56-64.

Kresak, K., & Gallagher, P. A. (2010, February). *Perceived needs of grandmothers of grandchildren with disabilities*. Poster presented at the biennial Conference on Research Innovations in Early Intervention (CRIEI), San Diego, CA.

Kresak, K. (2010, October). *Grandparents raising grandchildren: Who are they and what do they need?* Paper presented at Georgia Association for Young Children Annual Conference, Atlanta, GA.

Kresak, K., Gallagher, P. A., & Rhodes, C. A. (2009). Siblings of infants and toddlers with disabilities in early intervention. *Topics in Early Childhood Special Education, 29*, 143-154.

Kresak, K., & Coleman, M. B. (2008). Brothers and sisters: A special part of exceptional families (3rd ed.). [Review of the book]. *Physical Disabilities: Education and Related Services, 26*, 55-57.

Kresak, K. (2008). Playing to get smart. [Review of the book]. *IPA/USA Quarterly*. www.ipausa.org/IPAUSA2008Sum.pdf

Kresak, K., Rhodes, C. A., & Gallagher, P. A. (2008, March). *Grandparents of young children with special needs*. Paper presented at Institute for the Study of Disadvantage and Disability (ISDD) Break the Cycle II, Atlanta, GA.

Rhodes, C. A., Gallagher, P. A., & Kresak, K. (2008, October). *What do grandparents say? Understanding their needs and concerns as caregivers*. Poster presented at Division for Early Childhood Annual International Conference, Minneapolis, MN.

Rhodes, C. A., Gallagher, P. A., & Kresak, K. (2007, October). *Grandparents of young children with special needs*. Poster presented at Division for Early Childhood Annual International Conference, Niagara Falls, Ontario.

PROFESSIONAL SOCIETIES AND ORGANIZATIONS:

2004-Present Council for Exceptional Children (CEC)
2004-Present Division for Early Childhood (DEC)
2004-Present National Association of the Education of Young Children (NAEYC)
2004-Present Georgia Association for Young Children (GAYC)

ABSTRACT

SOURCES OF SUPPORT AND FAMILY QUALITY OF LIFE OF GRANDMOTHERS RAISING GRANDCHILDREN WITH AND WITHOUT DISABILITIES

by

Karen Kresak

Researchers have examined sources of support as well as family quality of life of parents raising children with disabilities (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Darling & Gallagher, 2004; Davis & Gavidia-Payne, 2009; Zuna, Turnbull, & Summers, 2009). Scant research on grandparents raising grandchildren with disabilities has been conducted; an examination of sources of support and family quality of life of grandparents raising grandchildren is lacking in the literature. This study examined the sources of support and quality of life of 50 grandmother-headed families, approximately half of whom were raising grandchildren with disabilities and approximately half of whom were raising grandchildren without disabilities. Comparative analyses revealed that there were significant differences between grandmothers raising grandchildren with and without disabilities in regard to sources of support and family quality of life. Informal support was significantly higher for grandmothers raising grandchildren without disabilities. In addition, grandmothers raising grandchildren without disabilities rated satisfaction with all aspects of family quality of life except parenting as significantly higher than grandmothers raising grandchildren with disabilities. Correlational analyses showed a moderate correlation between sources of support and family quality of life for both groups of grandmothers. While total informal social support was significantly correlated with satisfaction ratings of family quality of life for both groups of grandmothers, total formal support was significantly correlated with satisfaction ratings of family quality of life only for grandmothers raising grandchildren with disabilities. Hierarchical multiple regression analyses

were used to test the relationship among four predictor variables (age of grandmother, educational level of grandmother, age of grandchild, and presence of child disability) and two criterion variables (total score on sources of support rating and total score on family quality of life rating). Results showed that there was a significant relationship between presence of child disability and satisfaction ratings of family quality of life. No significant relationship was found between presence of child disability and sources of support.

SOURCES OF SUPPORT AND FAMILY QUALITY OF LIFE OF GRANDMOTHERS RAISING GRANDCHILDREN WITH AND WITHOUT DISABILITIES

by
Karen Elizabeth Kresak

A Dissertation

Presented in Partial Fulfillment of Requirements for the
Degree of
Doctor of Philosophy
in
Education of Students with Exceptionalities
in
the Department of Educational Psychology and Special Education
in
the College of Education
Georgia State University

Atlanta, Georgia
2011

Copyright by
Karen E. Kresak
2011

ACKNOWLEDGEMENTS

I want to express thanks to my family—
To my husband without whose love and support I could not have earned this degree.
To my children who motivated me to keep going by their sense of pride in my accomplishments.
To my dad for his constant encouragement and lifelong support of my dreams.

I am grateful to Dr. Peggy Gallagher, my advisor and committee chairperson, for her support and guidance throughout my program and this dissertation process. I truly appreciate the knowledge you have bestowed upon me and the opportunities you have given me.

I thank my committee members, Dr. Catherine Cadenhead, Dr. Susan Easterbrooks, Dr. Susan Kelley, and Dr. Elizabeth Steed. Your expertise and invaluable feedback have made this dissertation a successful research study.

I appreciate the grandparent support group leaders and coordinators of the Local AAAs for helping find grandmothers. I could not have done it without you.

Special thanks go to the grandmothers who took the time from their busy lives to meet with me and who talked to me about their experiences. I truly learned a lot from you.

TABLE OF CONTENTS

		Page
List of Tables	……………………………………………………………………..	v

Chapter		
1	STATEMENT OF THE PROBLEM ……………………………..	1
	Introduction ……………………………………………………..	1
	Significance of the Problem …………………………………….....	2
	Research Questions ……………………………………………….....	5
	Research Question One ………………………………………..	5
	Research Question Two ……………………………………….	5
	Research Question Three ……………………………………...	5
	Research Question Four ……………………………………….	6
	Hypotheses ………………………………………………………….	6
	Hypothesis for Research Question One ……………………….	6
	Hypothesis for Research Question Two …………………….....	6
	Hypothesis for Research Question Three ……………………..	6
	Hypothesis for Research Question Four …………………….....	6
2	REVIEW OF THE LITERATURE ……………………………....	7
	Importance of Families ………………………………………..	7
	Theoretical Foundation ………………………………………..	8
	Custodial Care ………………………………………………....	9
	Characteristics of Custodial Grandparents …………………….	10
	Consequences of Custodial Grandparenting …………………..	13
	Characteristics of Grandchildren Raised by Grandparents …....	16
	Grandparents Raising Grandchildren with Disabilities ……….	17
	Sources of Support …………………………………………….	19
	Family Quality of Life ………………………………………....	23
	Summary …………………………………………………….....	26
3	METHODOLOGY ……………………...................................	28
	Statement and Operational Definitions of Independent Variables..	28
	Statement and Operational Definitions of Dependent Variables...	28
	Demographic Information..	33
	Research Design and Rationale..	34
	Participants..	34
	Recruitment..	35
	Implementation..	36
	Setting..	37
	Data Collection..	37

	Data Analyses	38
	Supports and Family Quality of Life Reported by Families	38
	Demographic Data	39
	Relationship Between Supports and Quality of Life	40
	Factors Predictive of Supports and Quality of Life	40
4	RESULTS	41
	Demographics	41
	Grandmother Characteristics	44
	Caregiver Situation	46
	Grandchildren Characteristics	47
	Disability of Grandchildren	49
	Results of Research Questions	49
	Research Question One	49
	Results of Question One	49
	Research Question Two	50
	Results of Question Two	50
	Research Question Three	52
	Results of Question Three	52
	Research Question Four	53
	Results of Question Four	54
5	DISCUSSION	57
	Conclusions	57
	Implications	61
	Limitations	64
	Suggestions for Future Research	67
References		71
Appendixes		93

LIST OF TABLES

Table		Page
1	Individual items of the Family Support Scale subcategories...........	30
2	Items included in each subscale domain of the Family Quality of Life scale..	32
3	T-test analysis of demographic data between grandmothers raising grandchildren with and without disabilities………………………...	42
4	Chi square analysis of demographic data between grandmothers raising grandchildren with and without disabilities………………...	42
5	Association between income and presence of disability..................	43
6	Association between gender of grandchild and presence of disability..	44
7	Characteristics of grandmothers raising grandchildren with and Without disabilities..	45
8	Characteristics of the caregiving situation.......................................	47
9	Disability categories and level of severity for grandchildren...........	48
10	Comparison of means for family support composite and subscales by presence of disability..	50
11	Comparison of means for family quality of life composite and subscales by presence of disability...	51
12	Correlations between sources of support and quality of life of grandmothers raising grandchildren with disabilities.......................	53
13	Correlations between sources of support and quality of life of grandmothers raising grandchildren without disabilities.................	54
14	Summary of the hierarchical regression analysis for variables predicting family quality of life...	55
15	Summary of the hierarchical regression analysis for variables predicting sources of support...	56

CHAPTER 1

STATEMENT OF THE PROBLEM

Introduction

Grandparents raising grandchildren is a growing phenomenon that affects 5.8 million children in the United States (U.S. Bureau of the Census, 2003). Presently, there are 1.3 million children living in grandparent-headed households with no biological parent present (U. S. Bureau of the Census, 2003). Additionally, one in ten grandparents will take on the role of primary caretaker to a grandchild for at least six months before the child is age 18 (Burnette, 1997; Silverstein & Vehvilainen, 2000). A majority of these grandchildren are with grandparents through informal arrangements among family members, which often results in limited or no institutional support as the grandparents may not have legal guardianship. Grandparents often have difficulty obtaining health insurance coverage, public financial assistance, and housing as well as gaining legal rights to make decisions regarding their grandchildren's education and medical care (Chalfie, 1994; Minkler & Roe, 1993; Minkler, Roe, & Price, 1992). Many of the grandchildren living with grandparents are at risk of having or have developmental, cognitive, neurological, behavioral, and/or emotional problems (Brown, Neikrug, & Brown, 2000; Dowdell, 1995; Pinson-Millburn, Fabian, Schlossberg, & Pyle, 1996; Shore & Hayslip, 1994; Smith & Palmieri, 2007; Whitley & Kelley, 2008). This may be due, for example, to their prenatal and/or early life experiences, which may have involved drug/alcohol exposure, neglect/abuse, poor nutrition, lack of preventive medical/dental care, and inconsistent and/or dangerous living conditions (Smith & Dannison, 2008).

Empirical evidence suggests that regardless of their racial status, grandparents raising grandchildren are negatively affected by their caregiving responsibilities in many areas including

social and economic well-being, psychological stress, and physical health (Burton, 1992; Dowdell, 1995; Kelley, 1993; Minkler & Roe, 1993). Kelley and colleagues (2000) found that fewer family resources, less social support, and poorer physical health were related to greater levels of psychological distress among grandmothers raising grandchildren. Likewise, studies of the long term effects of grandparent caregiving report high rates of depression, poor self-rated health and/or frequent presence of chronic health problems, especially among grandmothers (Burton, 1992; Dowdell, 1995; Minkler & Roe, 1993; Minkler, Fuller-Thomson, Miller, & Driver, 1997). Both grandparents and grandchildren may face significant problems with respect to emotional adjustment and activities of daily living when these families are formed, often because these new living arrangements are typically borne of extremely stressful circumstances (Edwards, 1998; Fuller-Thomson, Minkler, & Driver, 1997). Those grandparents raising grandchildren whom they perceive as having neurological, physical, emotional, or behavioral difficulties are the least likely to seek and receive counseling and/or medical services for themselves (Shore & Hayslip, 1994). The distress experienced by custodial grandparents can have a serious effect on parenting and child outcomes often resulting in negative grandparent and grandchild outcomes (Campbell & Miles, 2008).

Significance of the Problem

Researchers have determined the presence of two distinct groups of grandparent caregivers: (a) grandparents with difficulties that stem from the demands of the parenting role, and (b) grandparents with difficulties related to a grandchild with disabilities (Hayslip & Kaminski, 2005b). Grandparents raising grandchildren with developmental disabilities often face unique and ongoing challenges that can influence various aspects of family life (Guralnick, 1997; Kolomer, McCallion, & Overeynder, 2003; Lecavalier, Leone, & Wiltz, 2006; McKinney,

McGrew, & Nelson, 2003). The demands of assuming a parental role later in life are exacerbated by raising a grandchild who is experiencing physical, emotional, or behavioral difficulties (Grant, 2000; Hayslip, Shore, Henderson, & Lambert, 1998; Sands & Goldberg-Glen, 2000). The nature of the disability of the child can produce different challenges and stresses in relation to family lifestyles as well (Hastings, 2002; Hayes, 1996; Kraus, Seltzer, & Jacobson, 2005). Consequently, children with disabilities typically require more time and attention than children without disabilities (Hughes, 1999; Roach & Orsmond, 1999). The drain on grandparents' time and energy causes fatigue and makes them more vulnerable to stress, depression, and physical health problems. The persistence and strength of these negative effects can compromise positive coping and enjoyment of daily life (Bailey et al., 2006). How well a family copes with stress influences family functions, satisfaction, feelings of efficacy, and children's life outcomes (Zeitlin & Rosenblatt, 1985). While effective coping fosters family quality of life, ineffective coping with family-related stress impairs parenting skills (Fiedler, Simpson, & Clark, 2007).

In order to cope with the stress of raising grandchildren, especially those with disabilities, grandparents often rely upon social supports such as family and extra-familial resources, spiritual support, and formal support, which includes the use of community and professional resources (Seligman & Darling, 2007). Theoretically, social support is seen as the resource that buffers the relationship between caregiver stress and well-being (Crowther & Rodriguez, 2003). Grandparent caregivers consistently report the need for a support network of people who are experiencing circumstances that are similar to their own (Burton, 1992; Turbin, 1993). Gerard and colleagues (2006) found that grandparents dealing with numerous child health problems and frequent stressors related to common parenting tasks benefitted from receiving formal support, which reduced role-related stress and enhanced quality of life. Results also indicated that

grandparents responded positively to assistance in the form of support groups, health services, legal and social services, as well as to recreational programs for their grandchildren.

However, sources of both informal and formal support are often limited or unavailable. Studies of custodial grandparents have identified social isolation and inadequate social support networks as key problems for these grandparents (Hayslip & Kaminski, 2005a). Social networks and the social support they provide lessen stress, promote well-being, and enhance the use of coping strategies (Crnic, Friedrich, & Greenberg, 1983; McCubbin, et al., 1980), all of which increase a family's quality of life. The extent to which the emotional and psychological support needs of grandparents are addressed will influence the overall functioning of the grandchild and the family (Schalock & Alonso, 2002). Custodial grandparents will need greater support from family, friends, community services, and professionals from many disciplines to help them cope with the physical and emotional challenges of providing care to their grandchildren (Roberto & Qualls, 2003). Therefore, examining the mediating effects of social support on familial well-being or quality of life may help professionals in increasing sources of support for all grandparent caregivers.

Over the course of the last several decades, several researchers have focused their efforts on defining the rapidly growing population of grandparent-headed families (Fuller-Thomson & Minkler, 2000a, 2000b; Fuller-Thomson & Minkler, 2001; Hayslip et al., 1998; Pruchno, 1999) as well as examining the physical and emotional effects of raising grandchildren (Janicki, McCallion, Grant-Griffin, & Kolomer, 2000; Kelley, Yorker, & Whitley, 1997; Minkler & Roe, 1993; Minkler, Fuller-Thomson, Miller, & Driver, 2000; Sands & Goldberg-Glen, 1998, 2000; Silverstein & Vehvilainen, 2000). While much research has looked at grandparents raising grandchildren in general, little research has focused on grandparents raising grandchildren with

disabilities in particular (Emick & Hayslip, 1999; Force, Botsford, Pisano, & Holbert, 2000; Kolomer, McCallion, & Janicki, 2002). Because these grandchildren have, or are at risk of having, developmental delays which may interfere with family functioning and quality of life, there is a need to examine this unique group of grandparents.

Research Questions

This study investigated the sources of support and satisfaction ratings of family quality of life for grandmothers raising grandchildren with and without disabilities. The study also examined the potential impact of four family characteristics: (a) age of grandmother, (b) educational level of grandmother, (c) age of grandchild, and (d) presence of child disability on sources of support and family quality of life.

Research Question One

What sources of supports are reported by grandmothers raising grandchildren with disabilities compared to grandmothers raising grandchildren without disabilities?

Research Question Two

What satisfaction ratings of family quality of life are reported by grandmothers raising grandchildren with disabilities compared to grandmothers raising grandchildren without disabilities?

Research Question Three

Are grandmothers raising grandchildren with disabilities different from grandmothers raising grandchildren without disabilities with respect to various types of support and family quality of life?

Research Question Four

What factors predict family supports and quality of life of grandmothers raising grandchildren with disabilities compared to grandmothers raising grandchildren without disabilities?

Hypotheses

Hypothesis for Research Question One

It is hypothesized that the support from various sources (family members, neighbors, community organizations, and service providers) would be the same for grandmothers raising grandchildren with and without disabilities.

Hypothesis for Research Question Two

It is hypothesized that the satisfaction ratings of family quality of life would be the same for grandmothers raising grandchildren with and without disabilities.

Hypothesis for Research Question Three

It is hypothesized that supports and family quality of life are not inter-correlated.

Hypothesis for Research Question Four

It is hypothesized that there are no predictive factors, individually or in combination, that are correlated with supports and family quality of life.

CHAPTER 2

REVIEW OF THE LITERATURE

Importance of Families

The family is regarded as the primary and most powerful system to which a person belongs (Seligman & Darling, 2007). The family is composed of several different subsystems that reciprocally influence one another (Stoneman & Brody, 1984). These subsystems include the spouse/partner subsystem, the sibling subsystem, and/or the parent-child subsystem. Changes in any one subsystem are assumed to influence other family subsystems (Bronfenbrenner, 1979; Turnbull & Turnbull, 2005; Whitechurch & Constantine, 1993). The needs and experiences of all members can affect the other members of the family. For example, the family affects the development of the child and the child influences family functioning (Bronfenbrenner, 1979), especially if that child has a disability. This ecological model focuses on the interaction between the family and the environment with the primary assumption being that the individual and the environment are inseparable and must be considered jointly (Bronfenbrenner, 1979; Hartman & Laird, 1987).

The traditional family constellation has gradually changed over the years. No longer is the “traditional” family considered the norm. Factors such as economic hardship, divorce, teenage pregnancy, child abuse and neglect, and substance abuse have changed the makeup of the family. Family composition has taken many forms: single parents, same gender parents, grandparent(s) with adult child and grandchild, and grandparents with grandchildren. No matter the makeup, family has been defined as “two or more people who regard themselves as a family and who carry out functions that families typically perform” (Turnbull, Turnbull, Erwin, & Soodak, 2006, p.7). Grandparent-headed households have joined the list of contemporary family

units. Custodial grandparenting also has assumed a variety of forms: co-parenting with an adult child, acting as sole custodial parent, or dual parenting with a spouse (Hayslip & Kaminski, 2008). A disproportionate number of grandparent-headed families are raising grandchildren with learning, behavioral, and/or developmental disabilities because of the prenatal and/or postnatal experiences of the grandchildren, which could include drug exposure, abuse/neglect, and inadequate care (Brown & Boyce-Mathis, 2000; Silverstein & Vehvilainen, 2000). These second-time parents play a central role in determining the developmental outcomes of the children in their care, whether the children have disabilities or not (Hayslip & Kaminski, 2008).

Theoretical Foundation

This study is based upon the theoretical foundation of family systems theory (Bronfenbrenner, 1979; Turnbull & Turnbull, 2005). Family systems theory recognizes the interrelatedness of family members and the importance of acknowledging the needs of all family members (Brown, Nolan, & Davies, 2001; Carpenter, 1997; Dunst, Trivette, & Johanson, 1994; Turnbull, Blue-Banning, Turbiville, & Park, 1999). Family systems theory is rooted in the ecological theory of Uri Bronfenbrenner (1979). Bronfenbrenner proposed that a child's life should be conceptualized as occurring across an ecological system which includes micro and macro subsystems that simultaneously affect a child's ongoing development. He noted that the family and the home are the primary contexts in which development occurs and that these primary contexts affect the child's progress in other settings. From this perspective, individuals can best be understood within the context of the family.

The family systems model builds upon a systems framework. Each component of the framework affects the other components either positively or negatively. Components of the framework include the following: family characteristics (factors describing a family), family

interaction (ongoing process of family relationships responsive to individual and family needs), family function (tasks performed by the family to meet individual and collective needs of its members), and family life cycle (developmental and non-developmental changes that families pass through) (Turnbull et al., 2006). The purpose of the family systems model is to understand how the beliefs, behaviors, characteristics, and functioning of family members influence the lives and decision making of other members (Goldenberg & Goldenberg, 1990; Minuchin, 1974; Turnbull & Turnbull, 1990). The focus then becomes the whole family rather than an individual with the goal being to identify and build on family strengths. In light of this, professionals need to clearly understand the unique circumstances of custodial grandparents and their grandchildren in order to assist families in promoting continued growth and enrichment of the family (Racicot, 2003).

Custodial Care

Grandparents assume full-time custodial care of their grandchildren for a multitude of reasons. Usually it occurs in the context of some family trauma and can be a highly stressful process (Jendrek, 1994; Minkler & Roe, 1993; Shore & Hayslip, 1994). Researchers have identified maternal substance abuse and the resulting child maltreatment as the primary reason grandparents assume responsibility of parenting their grandchildren (Burton, 1992; Dowdell, 1995; Jendrek, 1994; Kelley, 1993; Minkler & Roe, 1993; Minkler et al., 1992; Pruchno, 1999). Other contributing factors include: (a) parental death (Fuller-Thompson & Minkler, 2000a; Pruchno, 1999); (b) incarceration of the biological mother (Dowdell, 1995; Fuller-Thompson & Minkler, 2000a; Kelley, 1993; Pruchno, 1999); (c) mental illness of a parent (Dowdell, 1995; Kelley, 1993); (d) abandonment (Pruchno, 1999); and (e) teen pregnancy (Hayslip & Kaminski, 2005a; Pinson-Millburn et al., 1996).

The assumption of care can be unanticipated and involuntary, often resulting from unforeseen circumstances. The custodial relationship may be permanent (e.g., through the death of a parent) or temporary depending upon the circumstances of assuming care (Burnette, 1999; Minkler & Roe, 1993). Despite the possibility of indefinite custody, many of the grandparents assume responsibility for the grandchildren because they believe they are the only person who can keep the child out of the public foster care system (Cox, 2000; Goodman & Silverstein, 2002) or they believe they can provide better care than the parent (Hayslip & Kaminski, 2005a). Grandparents also may feel compelled by moral or religious beliefs to assume care (Burton, 1992). In addition, grandparents offer to care for their grandchildren in order to help their own adult children in times of crisis (Hayslip et al., 1998). The common thread among grandparent caregivers appears to be the commitment to the well-being of their grandchildren (Erhle & Day, 1994; Jendrek, 1994; Minkler & Roe, 1993).

Characteristics of Custodial Grandparents

Custodial grandparents or grandparent caregivers are adults who have primary responsibility for their grandchildren younger than 18 years of age on a full-time basis (Hayslip & Kaminski, 2005b; Shore & Hayslip, 1994; U. S. Bureau of the Census, 2003). According to the Pew Research Center (2010) analysis of the U. S. Census Bureau data, approximately 2.9 million grandparents have primary responsibility for their grandchildren. Of these grandparents, 840,000 (or 39%) have been caring for their grandchildren for five or more years (U. S. Bureau of the Census, 2003). Forty-nine percent of children being raised by grandparents also live with a single parent (Pew Research Center, 2010). However, for forty-three percent of children being raised by grandparents, there is no parent in the household (Pew Research Center, 2010). These "skipped generation" family units, where grandchildren and grandparents live together with

neither parent present, have become the most rapidly increasing living arrangement among contemporary families (Bryson & Casper, 1999; Fuller-Thompson & Minkler, 2000a).

Custodial grandparenting appears to have no ethnic or socioeconomic boundaries. All groups have been impacted by the assumption of the parenting role. In examining grandparent-headed households by ethnicity/race, 54% are Caucasian, 31% are African American, and 11% are Hispanic/Latino (U.S. Bureau of the Census, 2005-2007). Proportionally, grandparent caregivers are over-represented within African American (4.3%) and Latino (2.9%) households when compared to Caucasian (1%) households (Fuller-Thompson & Minkler, 2000a; Minkler et al., 1992; U. S. Bureau of the Census, 2001b). In a national study, Minkler and Fuller-Thompson (1999) found that African Americans had 83% higher odds of being grandparent caregivers than other ethnic groups. Likewise, additional researchers found that almost 30% of African American grandmothers and 14% of African American grandfathers reported being the primary caregiver for a grandchild for at least six months (Szinovacz, 1998) compared to 10.9% of all grandparents (Fuller-Thompson et al., 1997). However, there has been a 19% increase in the number of Caucasian grandparents caring for their grandchildren over the last decade (Pew Research Center, 2010).

Income issues. Many grandparent-headed households live at or below the poverty level. According to the U. S. Bureau of the Census (2001a), the percentage of grandparent caregivers living below the poverty level (19%) is greater than that for other types of families with children (14%). Fuller-Thompson and colleagues (1997) found that grandparent caregivers are 60% more likely to live in poverty than grandparents not raising grandchildren with grandmother-headed households being the most impoverished. Two-thirds of those children living in grandmother-only headed households are living in poverty (Bryson & Casper, 1999). Burton (1992) found that

over 78% of grandparent caregivers reported facing financial hardships while 52% reported not having resources to meet the needs arising out of caregiving. Likewise, Kelley (1993) found that 56% of grandparents studied reported financial difficulty related to child-rearing.

Work issues. Employment issues often arise when grandparents begin raising their grandchildren. Grandparents who are employed may have to give up working outside the home in order to raise their grandchildren, thus losing much needed income and putting their own future economic well-being at risk (Hayslip & Goldberg-Glen, 2000; Musil, Schrader, & Mutikani, 2000). For retired grandparents, whose income is already limited, the lack of adequate assistance from government agencies and the increased expenditures force many to either draw from their retirement or savings accounts, cash in life insurance policies, or return to the work force (Beverly, 1995; Burton, 1992; Minkler & Roe, 1993). Providing for the family becomes even more difficult with multiple caregiving demands (Beverly, 1998) or when there are grandchildren with disabilities within the family. In addition, lack of financial stability may compound other difficulties faced by these families (Hayslip & Goldberg-Glen, 2000).

Gender and age of grandparents. The majority (63%) of all grandparent families are headed by grandmothers (Burnette, 1997; Dressel & Barnhill, 1994; Simmons & Dye, 2003; U. S. Bureau of the Census, 2003). In analyzing data from the National Survey of Families and Households (NSFH), Fuller-Thompson and colleagues (1997) found that 77% of the grandparents were grandmothers. Similarly, in a nationally representative longitudinal study, Fuller-Thompson and Minkler (2000b) found that more than three-quarters (77%) of all caregiving grandparents were women. The ages of custodial grandparents have been reported to range between 35 and over 80 years with the average age being in the mid 50's (Beverly, 1995; Fuller-Thompson & Minkler, 2000a; Minkler & Roe, 1993; Woodworth, 1996). However, nearly

20% of custodial grandparents are over the age of 65 (Fuller-Thompson & Minkler, 2000a; U. S. Bureau of the Census, 2003).

Consequences of Custodial Grandparenting

Positive consequences. Despite the difficulties of assuming care of their grandchildren, grandparents report positive aspects of taking on this parental role. Grandparents receive pleasure from their close relationship with their grandchildren (Ehrle & Day, 1994; Hayslip & Kaminski, 2005b) and feel intrinsically rewarded to care for a child (Giarrusso, Silverstein, & Feng, 2000). Caregiving can provide a meaningful new role for the grandparent leading to the grandparent feeling more useful and productive (Emick & Hayslip, 1996, 1999). Grandparents feel good that they are able simultaneously to help their adult child and their grandchild (Burton, 1992). The caregiving role may afford grandmothers a second chance at successful parenting (Ehrle & Day, 1994; Gatti & Musatti, 1999). These grandmothers believe that they can learn from previous experiences and improve upon past negative parenting behaviors. Merriwether-deVries and colleagues (1996) reported the rewards of custodial grandparenting, which included the ability to nurture family legacies and traditions through the lives of their grandchildren and the receipt of unconditional love and supportive companionship of the child. In a study by Minkler and Roe (1993), grandmothers stated that the positive aspects of custodial grandparenting included knowing their grandchildren were safe and given a better chance to succeed. Grandmothers also were relieved and grateful at having the chance to do something positive for the family.

Negative consequences. One of the main disadvantages of raising grandchildren is the risk of illness and/or disability for the caregiver. The normal declines in health related to aging may be exacerbated by the daily activities of caring for a child (Hayslip & Hicks Patrick, 2006).

Chronic health conditions such as arthritis and heart disease may affect the grandparent's ability to perform those tasks associated with caregiving (Cox, 2003). Longitudinal data from the Health and Retirement Study (HRS) revealed that custodial grandparents were 80% more likely to report physical health problems and a decline in physical health over the previous year than were traditional grandparents (Hayslip, Temple, Shore, & Henderson, 2006). Minkler and Roe (1993) also found that 39% of grandparent caregivers reported deteriorating health after beginning to care for their grandchildren. However, grandparents often will deny their own health problems for fear of having their grandchildren removed from their care.

Another disadvantage of custodial caregiving is the risk of mental health problems resulting from the stresses of the caretaking role, aging, illness, socioeconomic status, and the grandchild's health (Burton, 1992; Kelley et al., 1997). Grandparents experience symptoms of anxiety, but the most common concern is heightened symptoms of depression (Sands & Goldberg-Glen, 1998). Studies have shown that grandparents raising grandchildren have higher than expected rates of depression (DeToledo & Brown, 1995; Musil, 1998). Results from a national study showed that grandparent caregivers have close to twice the rates of depression of other grandparents (25.1% vs. 14.5%; Minkler et al., 1997). Caring for grandchildren with developmental or other disabilities may increase the risk for symptoms of depression. In a study of inner-city African American grandparents caring for at least one child with a developmental disability, Janicki and colleagues (2000) found that more than 50% of grandparents reported elevated symptoms of depression on the Center for Epidemiologic Studies Depression Scale (CES-D). Burnette (2000) found similarly high rates of depressive symptoms among inner city Latino grandparents of children with disabilities.

In addition to depression, grandparent caregivers may express various other feelings and emotions in regards to assuming custodial care. Feelings of shame, guilt, and anxiety over their own child's drug addiction, incarceration, or death due to AIDS are fairly common (Roe, Minkler, Saunders, & Thompson, 1996; Waldrop & Weber, 2001). Feelings of anger and resentment are also common as a result of assuming this unexpected and unwanted role (Minkler & Roe, 1993; Waldrop & Weber, 2001). Some grandparents may experience guilt when they cannot spend quality time with their other noncustodial grandchildren (Emick & Hayslip, 1996). Many experience grief over the various losses that have placed them in the caregiving role, especially the loss of their own child (Baird, 2003; Pinson-Millburn et al., 1996). As grandparents age, they must deal with the fear for their grandchild's well-being should they become unable to provide care due to physical or mental incapacitation or if they should die (Bullock, 2004; Pinson-Millburn et al., 1996; Shore & Hayslip, 1994).

Relationships with other family members and friends are affected when assuming care of grandchildren. In general, grandparents raising grandchildren have fewer and lower quality relationships than their peers who are not raising grandchildren (Solomon & Marx, 2000). Minkler, Roe, and Price (1992) found that grandmothers' marital relationships were negatively affected by the assumption of the caregiver role. Jendrek (1993) found that declines in marital satisfaction were four times more likely among grandparent caregivers than in two comparison groups of noncustodial grandparents. Decreased socialization with friends as a consequence of grandparent caregiving has also been observed (Burton, 1992; Jendrek, 1993, 1994; Minkler & Roe, 1993; Minkler, Roe, & Robertson-Berkeley, 1994). Shore and Hayslip (1990) found that almost 40% of custodial grandparents felt isolated from friends due to becoming caregivers. Feeling socially isolated was especially prominent if grandparents did not have any friends who

were currently raising children (Bullock, 2004; Dowdell, 1995; Kelley et al., 1997; Minkler & Roe, 1993; Strom & Strom, 2000). As a consequence of raising grandchildren, custodial grandparents no longer “fit” into their traditional peer group or into the parent peer group of their grandchildren’s peers (Beverly, 1998). In addition, the everyday tasks of childrearing prevent them from engaging in activities they once enjoyed or plans they had for this stage of their lives (Jendrek, 1994). Feelings of isolation are compounded when grandparents must raise grandchildren with disabilities. Children with behavioral, developmental, and/or physical disabilities often require specialized health care. Often, grandparents have no friends or family members who will provide assistance or respite care for these children with disabilities. The absence of regular and dependable respite has been reported as a major concern for grandparents who are isolated or who are facing the most demanding caregiving concerns (Burton, 1992; Minkler et al., 1992).

Characteristics of Grandchildren Raised by Grandparents

Custodial grandchildren often have or are at risk of having physical, behavioral, and/or emotional problems stemming from circumstances that occurred prior to the grandparents assuming care. These circumstances include abuse or neglect by the biological parent, substance abuse by a parent, poor nutrition, insufficient cognitive stimulation in the early years, poverty, and inadequate health care (Ghuman, Weist, & Shafer, 1999; Janicki et al., 2000; Landry-Meyer, 1999; Smith & Palmieri, 2007; Williamson, Softas-Nall, & Miller, 2003). Children raised by grandparents experience higher levels of behavioral and emotional problems when compared to children living with their biological parents (Smith & Dannison, 2008). Silverstein and Vehvilainen (2000) found that 42% of the grandchildren in their study had special needs, including learning disabilities, ADHD, depression or developmental delays.

In a large-scale investigation of children in kinship care, Dubowitz and colleagues (1994) found that 26% of children exhibited severe behavior problems, 30% received special education services, and 66% experienced two or more medical problems simultaneously including asthma, anemia, dental and vision problems, and stunted physical growth. Whitley and Kelley (2008) completed developmental screenings on young grandchildren of grandparents participating in an interdisciplinary intervention program. Those children with "suspect scores" on the screening instrument were given a full evaluation. Results of the study showed that nearly one-third of grandchildren had a diagnosis of fetal alcohol syndrome and another one-third of grandchildren had unspecified developmental delay. Hayslip and colleagues (1998) examined the impact of raising grandchildren on custodial grandparents and found that about half of their sample of custodial grandparents reported caring for a grandchild with at least mild behavioral, emotional, school-related, or neurological problems. The disabilities and/or delays exhibited by custodial grandchildren often result in challenges for the grandparents who are striving to maintain family structure and function as effective caregivers (Smith & Dannison, 2002).

Grandparents Raising Grandchildren with Disabilities

Grandparents raising grandchildren with disabilities often face unique challenges. The demands of assuming custodial care are exacerbated by raising a grandchild with physical, emotional, or behavioral difficulties or delays (Emick & Hayslip, 1999; Hayslip et al., 1998). Custodial grandparents are at greater risk for depression (Burnette, 2000; Fuller-Thompson et al., 1997; Janicki et al., 2000) and experience more stress (Force et al., 2000; Grant, 2000), especially if they are dealing simultaneously with their own health issues (Burton, 1992) and the pressures of raising their grandchildren. Because caring for a child with disabilities requires additional time and attention, grandparents' feelings of burden and strain often are intensified

(Bowers & Myers, 1999; Hayslip et al., 1998; Sands & Goldberg-Glen, 2000). However, grandparents may underreport levels of emotional distress for fear of being viewed as incapable of raising grandchildren (Force et al., 2000; Janicki, et al., 2000).

Hayslip and colleagues (1998) examined the impact of raising grandchildren with physical, emotional, or behavioral problems on custodial grandparents. Results showed that custodial grandparents had higher levels of personal distress than their peers raising grandchildren without significant problems. In a similar study, Emick and Hayslip (1999) found that grandparents raising grandchildren with neurological, physical, emotional, or behavioral problems exhibited the most distress, the most disruption of roles, and the most deteriorated grandparent-grandchild relationships. Researchers also report that custodial grandparents of grandchildren with mental retardation/developmental delay experience greater stress than their peers whose grandchildren do not have mental retardation/developmental delay (McCallion, Janicki, Grant-Griffin, & Kolomer, 2000). Additional research documents increased depressive symptomatology among grandparent caregivers to grandchildren with mental retardation/developmental delay (Janicki et al., 2000).

Evidence suggests that grandparent caregivers of children with disabilities experience both the same and heightened needs as other grandparent caregivers (McCallion, Janicki, & Kolomer, 2004). In a study involving grandparent families with and without children with disabilities, McCallion and colleagues (2000) found that grandparents caring for a child with a disability received less social support than did other family caregivers. Grandparents also reported experiencing higher levels of role strain, financial strain, and life disruption than either custodial grandparents raising grandchildren without problems or traditional grandparents (Emick & Hayslip, 1999). Findings from a study examining the perceived needs of grandmothers

of children with disabilities confirmed that grandmothers had unique needs including informational needs, respite needs, and needs for strategies to deal with issues related to their grandchild's disability (Gallagher, Kresak, & Rhodes, 2010).

Sources of Support

Families need both formal and informal resources and support in order to handle the day-to-day activities of family life. Often, social support is found to be a mediator of stress in parents (Crnic & Greenberg, 1990; Hayslip & Hicks Patrick, 2006). By assuming the parental role, grandparents may find themselves isolated as a result of their new responsibilities. Established support networks may be disrupted due to the assumption of the parental role, thus making grandparents vulnerable to stress (Cox, 2003; Minkler et al., 1994). The number, age, and gender of grandchildren as well as any behavioral and/or health problems the grandchildren have may increase the need for social support (Hayslip & Hicks Patrick, 2006). Whitley and colleagues (2001) found that without support to help with daily routines, grandmothers may have difficulty in meeting the physical demands of parenting on a long-term basis. Consequently, inadequate social support and social isolation can affect the physical and mental health of custodial grandparents, as well as their parenting ability due to increased psychological distress (Emick & Hayslip, 1999, Fuller-Thompson & Minkler, 2000b; Kelley, Whitley, Sipe, & Yorker, 2000; Solomon & Marx, 2000), placing custodial grandparents at risk for depression (Musil, 1998) and lowered self-esteem (Giarrusso, Silverstein et al., 2000).

On the other hand, adequate social support can mitigate the effects of the numerous stressors custodial grandparents face (Giarrusso, Feng, Silverstein, & Marenco, 2000; Hayslip & Shore, 2000; Kolomer et al., 2003; Landry-Meyer, 1999). Through collaborative efforts, grandparents and professionals can efficiently locate and manage the varied resources, supports,

and services required by the family which would likely improve the family's quality of life (Dunst & Bruder, 2002). Researchers have found that increased levels of emotional (e.g., friendships, empathy) and instrumental (e.g., respite, child care) support have been associated with less depression, less parental role strain, and better self-rated health among custodial grandmothers (Emick & Hayslip, 1999; Musil & Ahn, 1997). Emick and Hayslip (1999) found that well-being was related to overall social support from one's children and from one's friends whereas more effective parental coping was associated with support from relatives. In a similar study, Hayslip and colleagues (1998) found that among grandparents raising grandchildren with neurological, physical, emotional, or behavioral problems, more overall social support and more support provided by grandparents' own children were associated with increased tolerance of a grandchild's disruptive or irritating behavior.

Sources of support can be thought of as varying along a continuum beginning with the family and moving outward and progressively more distant from individual family members (Bronfenbrenner, 1979). Social support often is differentiated as either "formal" or "informal". Formal support is described as professionally delivered, specific social services which are available to custodial grandparents in order to meet their instrumental or emotional needs (Musil et al., 2000). Informal support often comes from family, friends, neighbors, or church organizations and includes both instrumental and emotional support. Both types of social support refer to individuals having or feeling a sense of assistance (Landry-Meyer, Gerard, & Guzell, 2005).

Often, accessing formal and informal support is difficult for custodial grandparents. Many grandparents may not have access to social services which are currently available to them. Minkler and colleagues (1993) identified lack of transportation and suitable child care as two

barriers to accessing community interventions among grandparent caregivers. Hayslip and Shore (2000) discovered that many grandparents do not use formal services because they lack awareness of available services, lack time or transportation, cannot afford the expense of such help, or require more specialized services. Even if grandparents are aware of available services, they may avoid seeking assistance due to the stigma associated with the reasons for becoming custodial grandparents in the first place (Fuller-Thompson & Minkler, 2000a; Porterfield, Dressel, & Barnhill, 2000) or for fear of being perceived as incompetent caregivers (Gerard, Landry-Meyer, & Roe, 2006).

When grandparents assume caregiving responsibilities, there are changes in their informal social supports, which can affect the support they receive. A large social network does not necessarily guarantee that grandparents will receive assistance or support. Burton (1992) found that 97% of the grandparents and great grandparents in her study did not receive consistent and reliable support from family members. Grandparents often report losing friends when they take on the parenting role because their friends are no longer raising children of their own (Wohl, Lahner, & Jooste, 2003). Finding support and friendship among active parents may be difficult due to the age difference between custodial grandparents and traditional parents who are often much younger. Barrera (1986) noted that some stressful events elicit shunning responses from family and friends. A highly demanding or troubled grandchild might lead some friends or family members to avoid the grandparent. Likewise, grandparents who experience high amounts of daily parenting hassles may rely too heavily on particular friends or family, thus exhausting their resources (Gerard et al., 2006).

Where a family resides can influence the support and services they receive. Grandparents in rural areas may encounter unmet needs due to few available resources, ill-equipped social

service agencies, transportation concerns, and geographic isolation (Cohen & Pyle, 2000; Cuellar & Butts, 1999). Grandparents in rural areas may experience more social isolation than grandparents in urban areas due to the remote geography and the greater physical distance between neighboring families (Roberto, Richter, Bottenberg, & MacCormack, 1992). However, in their study examining the needs and supports of caregivers of young children with disabilities, Darling and Gallagher (2004) found evidence to the contrary. Urban caregivers reported receiving less overall support and feeling more isolated than their rural counterparts, despite living in a more densely populated area. Even though it may be assumed that grandparents living in urban areas may have more access to supports, this may not always be the case.

In addition to formal and informal support, the perception of social support plays an important role in how grandparents handle the stressors of raising grandchildren. Perceived social support is defined as an individual's appraisal of the availability and adequacy of one's social support network (Gerard et al., 2006; Landry-Meyer et al., 2005). Research has documented that the nature and amount of perceived support from both formal and informal sources correlate highly with successful coping (Crnic, Greenberg, & Slough, 1986; Dunst, Trivette, & Deal, 1994). Musil (1998) found that greater perceived support was associated with less depression in custodial grandparents. On a similar note, Giarrusso, Feng, and colleagues (2000) found that greater perceived support lessened the negative effect of stress on the self-esteem among custodial grandparents. However, grandparents' estimates of the support they receive from others or from formal social services agencies may differ from the actual degree of support offered (Kolomer et al., 2003; Landry-Meyer, 1999). Few grandparents perceive themselves as receiving reliable support from families and friends necessary to fulfill their familial obligations even though they may be part of a large informal network (Burton, 1992;

Minkler & Roe, 1993). Appraisals of low social support from significant others can undermine grandparents' well-being, especially when paired with the demands of their grandchildren's problems and the everyday hassles of caregiving (Kolomer et al., 2003).

Research has shown that social support has direct, mediational, and moderating influences on the behavior and development of children with disabilities (Bruder, 2000). Informal support, in particular, has shown the strongest relationship to both family and child outcomes. However, grandparents caring for a child with a disability report receiving less support than either custodial grandparents raising children without problems or grandparents who are not raising grandchildren, thus placing the families at risk for negative outcomes (Baker, 2000; Emick & Hayslip, 1999; McCallion et al., 2000; Shore & Hayslip, 1994). It may be expected then that family supports and services will have an impact on general family well-being (Mannan, Summers, Turnbull, & Poston, 2006). King and colleagues (1999) have noted that the presence of social support was a predictor of parental well-being as characterized by less depression and stress in families of children with disabilities. Likewise, Davis and Gavidia-Payne (2009) found that support from family and friends enhances the emotional well-being of families of children with disabilities.

Family Quality of Life

Families of children with disabilities are often confronted with ongoing challenges that can impact various aspects of family life (Guralnick, 1997; Lecavalier et al., 2006; Werner et al., 2009). These challenges have been associated with increased feelings of burden, stress, depressive symptoms, and lower levels of family well-being (Baker et al., 2003). Researchers have expressed an interest in a more global construct to reflect family well-being, namely family quality of life (Bailey et al., 1998; Brown et al., 2006; Brown et al., 2000; Poston et al., 2003).

Family quality of life has been defined as “conditions where the family’s needs are met, and family members enjoy their life together as a family and have a chance to do things which are important to them” (Park et al., 2003; p. 368). Family quality of life extends beyond the individual with a disability and encompasses the needs of all family members, as well as the strengths of the family unit (Smith-Bird & Turnbull, 2005; Zuna, Turnbull, et al., 2009). An important point to make, however, is that there is no standard family quality of life. The family decides what “quality” means to them (Park, Turnbull, & Turnbull, 2002). By enhancing their quality of life, families of children with disabilities may more nearly function as other families who have typically developing children. It has been noted that families that function well and have meaningful quality of life are seen as a social resource, including families of children with disabilities (Werner et al., 2009). Based on a national survey exploring valued outcomes, Dunst and Bruder (2002) reported that family satisfaction and improved family quality of life were the most valued outcomes as determined by practitioners and parents. Therefore, leaders in the disability field have called for family quality of life as a valued outcome of policies and services (Bailey et al., 1998, Dunst & Bruder, 2002; Turnbull, Brown, & Turnbull, 2004).

Family quality of life studies have attempted to explore how various domains of life are impacted when there is a child with a disability (Brown et al., 2006). In addition, these studies have examined the perceptions of the family members about family life in general. Researchers have begun to focus on the impact of family characteristics on quality of life (Scorgie, Wilgosh, & McDonald, 1998; Wang et al., 2004). For example, family income has been shown to influence home environment and emotional well-being of all family members (Park et al., 2002; Yau & Li-Tang, 1999). Scorgie and colleagues (1998) conducted a meta-analysis with 25 studies focusing on stress and coping in families of children with disabilities. Results showed

that those families with higher incomes tended to report greater emotional well-being and parenting satisfaction. Likewise, Wang and colleagues (2004) found that maternal satisfaction ratings of family quality of life increased as a function of family income. Turnbull, Summers, Lee, and Kyzar (2007) reviewed studies of family outcomes of families with a child with disabilities and concluded that lower socioeconomic status of families predicted lower family well-being, adaptation, and family functioning. Turnbull and Turnbull (2005) pointed out that families with higher socioeconomic status have more resources available to deal with issues related to their child's disabilities.

The severity of a child's disability and the presence of behavior problems also have been shown to be associated with lower levels of family well-being (Baker et al., 2003; Floyd & Gallagher, 1997; Hastings, Daley, Burns, & Beck, 2006; Zuna, Summers, Turnbull, Hu, & Xu, 2009). In a study examining parental satisfaction, Wang and colleagues (2004) found that severity of disability was negatively associated with satisfaction ratings of family quality of life for both fathers and mothers. Satisfaction with family quality of life decreased as a function of the severity of the child's disability. Challenging behaviors have been associated with feelings of stress and depression in parents of children with disabilities. Research has shown that higher levels of depression and stress are negatively associated with family quality of life as well (Baker et al., 2003; Zuna, Summers et al., 2009). Because custodial grandparents are at risk for both stress and depression and are more likely to be raising a child with a disability, it is important that custodial grandparents and their families receive the supports they need in order to improve their quality of life.

Providing family support and delivering services using the family-centered approach are established core concepts of disability policy and practice (Turnbull, Beegle, & Stowe, 2001).

Family supports and services should be targeted on ameliorating negative and strengthening positive impacts of raising a child with disabilities (Summers et al., 2005). The emphasis on quality of life is highly consistent with the commitment to family-centered services. King and colleagues (1999) found that a higher level of family-centered support was predictive of greater satisfaction with services, less stress, and better overall well-being. Similarly, in a study of families of children with intellectual disabilities, these families regarded supportive and respectful care as vital in improving their quality of life (Knox, Parmenter, Atkinson, & Yazbeck, 2000). Ultimately, a positive family quality of life should be a desired outcome of policies and services (Bailey et al., 1998). By examining family quality of life, professionals may be better able to identify possible challenges which families face, especially grandparents raising grandchildren, and the supports necessary for them to have true quality of life (Purcell, Turnbull, & Jackson, 2006).

Summary

Families have a powerful impact on their children’s development. As the definition of a family continues to expand to include others besides biological parents, researchers and practitioners must broaden their views of what constitutes a family as well. This broadened view must include grandparents as primary caregivers of children with, and without, disabilities. Since grandparent caregiving has been linked to negative outcomes such as decreased peer-network interaction and social isolation, depression, and lowered life satisfaction (Burton, 1992; Fuller-Thomson & Minkler, 2000b; Kelley et al., 2000), it is important to identify social support resources that may facilitate positive development among grandparent caregivers (Landry-Meyer et al., 2005). Families who do not have the necessary resources and supports may not be able to adequately rear healthy, competent children (Hobbs et al., 1984). Parents who are experiencing

heightened well-being are more likely to interact with their children in positive and supportive ways (Dunst & Trivette, 1988), which has positive effects on child and family outcomes. Heightened well-being is often the result of having the supports and resources necessary to carry out childrearing responsibilities. A family's social networks can provide these supports and resources and are an essential component for positive adaptation in the family system (Dunst, 2000; Ylven, Bjorck-Akesson, & Granlund, 2006). Therefore, the availability of adequate social support may be an important factor in contributing to the success of grandparent-headed households (Hayslip, King, & Jooste, 2008). As more grandparents assume the parental role, they will need greater support from community services, educators, practitioners, and clinicians to assist them in providing for their grandchildren and to help them cope with the physical and emotional challenges brought on by an altered family life (Roberto & Qualls, 2003). Understanding the specific social support needs of grandparents raising grandchildren will be particularly important for the development of public policy advocating for grandparent caregivers and their grandchildren (King, Hayslip, & Kaminski, 2006).

CHAPTER 3

METHODOLOGY

This study investigated the sources of support and satisfaction ratings of family quality of life for fifty grandmothers, approximately half of whom were raising grandchildren with disabilities and approximately half of whom were raising grandchildren without disabilities. The study also examined the potential impact of four family characteristics: (a) age of grandmother, (b) educational level of grandmother, (c) age of grandchild, and (d) presence of child disability on sources of support and family quality of life.

Statement and Operational Definitions of Independent Variables

There were four independent or predictor variables in this study. Two of the predictor variables were characteristic of the grandmother: (a) age of grandmother, and (b) educational level of grandmother. For the purposes of this study, grandmother referred to a grandmother or great grandmother who was raising one or more grandchildren. Two predictor variables were characteristic of the grandchild: (a) age of grandchild, and (b) presence or absence of child disability. A child with a disability was defined as an individual who currently received services under Public Law 108-446, the Individuals with Disabilities Education Improvement Act of 2004 (IDEA 2004), Americans with Disabilities Act (ADA, 1990), or Section 504 of the Rehabilitation Act (1973) and had an Individualized Education Plan (IEP) or 504 Plan.

Statement and Operational Definitions of Dependent Variables

There were two dependent or criterion variables examined in this study: (a) family sources of support, and (b) family quality of life. Family support was measured by the Family Support Scale (FSS; Dunst, Jenkins, & Trivette, 1986). The Family Support Scale (FSS) is a 19-item self-report measure that assesses the helpfulness of sources of support to families raising a

young child with disabilities or who is at risk for poor developmental outcomes (Dunst, Jenkins, & Trivette, 1984; Dunst, Trivette, & Deal, 1988). The original version of the Family Support Scale contained eighteen items (Dunst et al., 1984). The newer version, which contains nineteen items, added “neighbors” to the list of people or groups that are helpful to families raising young children (Dunst et al., 1988). The Family Support Scale is comprised of five major sources of support which include: (a) Kinship Support, (b) Spouse/Partner Support, (c) Informal Support, (d) Programs/Organizations, and (e) Professional Services (See Table 1). Ratings are on a five point Likert scale ranging from Not At All Helpful (1) to Extremely Helpful (5). The four informal sources of support subcategories are combined to obtain the Informal Social Support Score. The sum of the Professional Services subcategory is the Formal Support Score. The Total Family Support Scale score is obtained by summing the Informal Social Support score and the Formal Support score. Higher scores on both the subscales and the total scale are reflective of increased social support. Because this instrument was designed for parents of children with developmental disabilities, two wording changes were made so that items addressed grandparent caregivers rather than parents. The researcher provided the author of the FSS with a copy of the abstract and was given written permission to use the FSS with grandparents.

Reliability and validity for the 18-item Family Support Scale were assessed in a sample of diverse families of young children with disabilities or who were at risk for poor developmental outcomes (Dunst et al., 1984). Internal consistency reliability for the FSS was .77, split-half reliability was .77, and test-retest reliability was .75 (Dunst et al., 1984). Internal consistency reliability for the FSS subscales were Kinship (.56), Spouse/Partner Support (.67), Informal Support (.72), Programs/Organizations (.53), and Professional Services (.56). The author stated that internal consistency reliability for the 19-item version of the FSS was exactly

Table 1

Individual Items of the Family Support Scale Subcategories

Sources of Support
Kinship
My parents
My relatives or kin
Spouse/partner
My spouse or partner
My spouse or partner's parents
My spouse or partner's relatives or kin
Informal support
My friends
My spouse or partner's friends
My own children
Neighbors
Other grandparents
Church members/minister
Programs/organizations
Coworkers
Grandparent group members
Social groups/clubs
School/daycare
Professional service
Family/child's physician
Early intervention program
Professional helpers
Professional agencies

Note. Family Support Scale: Reliability and Validity (8614) provided courtesy of the Winterberry Press, www.WBPress.

the same as the internal consistency reliability of the 18-item version (C. Dunst, personal communication, October 26, 2011). In the present study, internal consistency reliability was calculated for the Family Support Scale using Cronbach's alpha. Internal consistency reliability was .79 for the total scale. Alphas for the four individual subscales were Kinship (.36),

Spouse/Partner Support (.63), Informal Support (.74), Programs/Organizations (.49), and Professional Services (.55).

The second dependent variable was family quality of life, which was measured by the Beach Center Family Quality of Life Scale (Beach Center on Disability, 2006; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Summers et al., 2005). The Family Quality of Life Scale (FQOL Scale) assesses families' perceptions of their satisfaction with different domains of family quality of life. The FQOL Scale is a 25-item self-report questionnaire that can be used with families of children of varying ages, disability types, and severity. The Family Quality of Life Scale is comprised of five subscales which include: (a) Family Interaction, (b) Parenting, (c) Emotional Well-being, (d) Physical/Material Well-being, and (e) Disability-Related Support (See Table 2). This questionnaire is rated on a five point Likert scale with each item being rated on satisfaction, ranging from (1) Very Dissatisfied to (5) Very Satisfied. For the current study, only families raising children with disabilities completed the Disability-Related Support subscale. For families with children without disabilities, a slightly revised version of the FQOL Scale was used. Zuna, Selig, and colleagues (2009) revised the scale by removing the disability-related items (questions 22-25) to use with families with typical children. The revised FQOL Scale included 21 nondisability-related items across the four domains. The FQOL Total score is obtained by summing the subscales. Individual subscale scores are obtained by calculating the mean for each of the five subscales. Higher scores on both the subscales and the total scale are reflective of greater satisfaction ratings of family quality of life.

High convergent validity, internal consistency, and test-retest reliability have been demonstrated by this scale in families of children with and without disabilities (Beach Center on Disability, 2006; Poston et al., 2003; Zuna, Turnbull et al., 2009). Zuna, Selig, Summers, and

Table 2

Items Included in Each Subscale Domain of the Family Quality of Life Scale

Subscales
Family interaction
My family enjoys spending time together.
My family members talk openly with each other.
My family solves problems together.
My family members support each other to accomplish goals.
My family members show that they love and care for each other.
My family is able to handle life's ups and downs.
Parenting
Family members help the children learn to be independent.
Family members help the children with schoolwork and activities.
Family members teach the children how to get along with others.
Adults in my family teach the children to make good decisions.
Adults in my family know other people in the children's lives (i.e., friends, teachers).
Adults in my family have time to take care of the individual needs of every child.
Emotional well-being
My family has the support we need to relieve stress.
My family members have friends or others who provide support.
My family members have some time to pursue their own interests.
My family has outside help available to us to take care of special needs of all family members.
Physical/material well-being
My family members have transportation to get to the places they need to be.
My family gets medical care when needed.
My family has a way to take care of our expenses.
My family gets dental care when needed.
My family feels safe at home, work, school, and in our neighborhood.
Disability-related support
My family member with a disability has support to accomplish goals at school or at workplace.
My family member with a disability has support to accomplish goals at home.
My family member with a disability has support to make friends.
My family has good relationships with the service providers who provide services and support to our family member with a disability.

Note. From "Assessing family outcomes: Psychometric evaluation of the beach center quality of life scale," by L. Hoffman, J. Marquis, D. Poston, J. A. Summers, & A. Turnbull, 2006, *Journal of Marriage and Family, 68, p. 1083. Copyright (2006) by Wiley & Sons, Inc.*

Turnbull (2009) found that Cronbach's alpha for the overall FQOL Scale was excellent (.92), which is similar to Cronbach's alpha for the disability-only sample (.88) that was previously reported by Hoffman and colleagues (2006). In addition, alphas for the four individual subscales were in the acceptable range (.75 to .85) and were also similar to the range of consistency indices reported by Hoffman et al. (.74 to .90), thus demonstrating that families of children without disabilities perceive the FQOL construct in a similar fashion as families of children with disabilities. The four subscales, excluding the Disability-Related Support subscale, of the FQOL Scale were analyzed when comparing families raising children with disabilities and those raising children without disabilities. In the present study, internal consistency reliability was calculated for the overall FQOL Scale as well as for the five individual subscales. Cronbach's alpha for the overall FQOL Scale was .93 and alphas for the five individual subscales ranged from .77 to .88.

Demographic Information

Grandmothers completed a demographic questionnaire, which included county of residence, age of grandmother, educational level of grandmother, race/ethnicity, marital status, presence of another adult in the home, helpfulness of other adult in the home, work status, household income, length of time as primary caregiver, number of grandchildren living in the home, ages and gender of grandchildren, and whether grandchildren have special needs. Only grandmothers raising grandchildren with disabilities completed the part of the demographic questionnaire regarding the grandchild's disability (using common terminology) and severity of disability. Grandchildren who were reported by grandmothers to have more than one disability category were recorded as having "multiple" disabilities.

Research Design and Rationale

This research was designed to examine responses of participants from two groups. The groups included grandmothers raising grandchildren with disabilities and grandmothers raising grandchildren without disabilities. Equivalent representation was ensured by targeting the specific participants for each group. Recruitment continued until the number of participants had reached 50 total participants, with 26 participants in the grandmothers raising grandchildren with disabilities group and 24 participants in the grandmothers raising grandchildren without disabilities group.

The dependent variables were examined using quantitative measures. Family support was measured and reported in terms of the overall helpfulness of support as well as the helpfulness of informal social support, the helpfulness of formal support, and the mean of each of the five subscales of support. Family quality of life was measured and reported using the summation of the satisfaction ratings for the overall FQOL Scale and the mean satisfaction ratings for each of the five subscales.

Participants

Participants in the study were English-speaking grandmothers raising at least one grandchild (with or without a disability) and who considered themselves to be the primary caregiver. Grandmothers did not have to have formal legal custody of their grandchild but the grandchild's biological parents had to be absent from the household. Grandchildren had to be between the ages of three and twelve years. Grandchildren with disabilities had to be currently receiving services under the Individuals with Disabilities Educational Improvement Act (IDEA, 2004), Americans with Disabilities Act (ADA, 1990), or Section 504 of the Rehabilitation Act (1973) and have an Individualized Education Plan (IEP) or 504 Plan. Children receiving only

speech-language services through their IEP were excluded from the study. If grandmothers were raising a child with a disability and a child without a disability, the family was placed in the grandmothers raising a child with a disability group. If grandmothers were raising more than one child with a disability, the oldest child with a disability meeting the age requirement was chosen as the participant child.

Recruitment

Primary recruitment methods included contacting the directors of three public agencies that focus on aging by phone and/or email. The public agencies that were contacted served thirty-five counties in the northwest sector of a southern state. The researcher also contacted the lead representative for the Head Start collaborative for the state, as well as statewide agencies, which serve children with disabilities. Representatives from each agency were asked about the number of families served in their programs, the possible number of grandparent families who might participate in the study and their preferences about distributing the packets which included informational flyers describing the research study. The representatives served as liaisons for the researcher to contact potential participants.

Families were told that the researcher wanted to examine their family sources of support and their family quality of life. Families contacted by agency representatives were provided with a “permission to contact” form which was used to obtain the signature of the potential participants. Researcher contact was based on the receipt of a signed “permission to contact” form thereby assuring that families not wishing to participate remained anonymous. Signatures on the form indicated that families were willing to be contacted for possible participation in the study.

Implementation

Grandmother caregivers recruited by agencies were contacted by email or phone after permission to contact was obtained. The researcher asked the potential participants to respond to the following questions:

1. Are you the primary caregiver of a grandchild between the ages of 3 and 12 years?
2. Does your grandchild have a disability? Who determined that your grandchild has a disability? Does your grandchild have an IEP or 504 Plan? What services does your grandchild receive from the school system?

If participants answered “no” to question number one, they were thanked for their interest, then told they did not qualify to participate, as the research was seeking participants who were the primary caregiver of at least one grandchild between the ages of three and twelve. Only two potential participants were excluded from participating in the study because at least one of their grandchildren was not between the ages of three and twelve. If participants answered “yes” to question number one and continued to agree to participate, the researcher set up an appointment by asking the participant to indicate where and when would be most convenient for them and then agreed to that time and place. If participants answered “no” to question number two, they were placed in the grandmothers raising grandchildren without disabilities group. If participants answered “yes” to the question “Does your grandchild have a disability,” they were asked who determined and/or diagnosed the disability and what services, if any, their grandchild received at school. Upon verification with the grandmothers that at least one of their grandchildren had a disability, they were placed in the grandmothers raising grandchildren with disabilities group.

Setting

Data were collected with respect to each family's scheduling preferences. Upon initial contact, the researcher offered to accommodate personal preference for meeting times and places. Meetings were scheduled for either day or evening times depending on the schedule of the families. Meeting places included the participant's home, public libraries, local restaurants, and conference rooms in local senior centers. The researcher accommodated whatever reasonable request was made by the participant for meeting time and place. The researcher set individual times for meetings over a twelve month period.

Data Collection

Data were collected during one individual session with each participant, with the researcher administering the instruments and ensuring that each participant had a similar experience. Instruments were read aloud in order to account for any issues of low literacy with clarifications as necessary. The order of the instruments was alternated in order to prevent an order effect. Participants were given a short introduction and overview of the purpose of the research study. After the introduction, the researcher read aloud the consent form to the participant. The participant was then asked to sign the consent form agreeing to participate in the research study and data collection began. The researcher maintained possession of the packet and marked all responses for the participants except their signature. The packet included (1) the consent form, (2) a demographic data sheet, (3) Family Support Scale, (4) Family Quality of Life Scale, and (5) a sheet containing a brief thank you and the researcher's contact information. The total time committed to data collection was kept to a minimum for the participants. The total time for completion of the scales was no more than 30 minutes. The process was rehearsed prior to the actual data collection. Pilot sessions with two grandmothers were conducted in order to

fine-tune the process of administering the scales and to verify the time needed to complete the instruments. Based on the pilot sessions, modifications were made to the administration of the Family Quality of Life Scale. Both grandmothers in the pilot study had questions regarding what constituted a “family.” The definition of “family” was taken from the instructions of the FQOL Scale, typed on an 8 ½ x 11” paper, and laminated. The definition was then read to grandmothers in the study prior to the implementation of the FQOL Scale.

The researcher read each item on the demographic data sheet and marked the verbal responses of the participants on the sheet. After the demographic data sheet was completed, the researcher read each item on the FSS and FQOL Scale and marked the verbal responses of the participants on the scale. For the Family Support Scale, a verbal response with the label such as “not at all helpful, generally helpful, very helpful” or the corresponding Likert number was accepted. For the Family Quality of Life Scale, a verbal response with the label such as “very dissatisfied, neither satisfied nor dissatisfied, very satisfied” or the corresponding Likert number was accepted. A laminated card with the labels and corresponding Likert numbers for both scales (one scale on each side) was available for grandmothers to reference. After completion of the data collection, participants were thanked for their time and participation. Participants received a small compensation (a ten dollar gift card) for completing the scales. The researcher shared her contact information, indicating that in case they had follow-up questions, she could be contacted.

Data Analyses

Supports and family quality of life reported by families

Participants’ responses on the Family Support Scale (FSS) were calculated into subscale scores by taking the mean of the items’ ratings. Each of the five subscales within the FSS was added together in order to obtain an FSS Total score. Unadjusted scores for the four informal

sources of support subcategories were summed to obtain the Informal Social Support score. The unadjusted score for the professional services subcategory was the Formal Support Score. Participants' responses on the Family Quality of Life Scale (FQOL) were calculated into subscale scores by taking the mean of the items' ratings. Each of the five subscales within the FQOL scale were added together in order to obtain an FQOL Total score for families raising grandchildren with disabilities. In addition, the four subscales, excluding the Disability-Related Support subscale, were added together in order to obtain an FQOL Total score for comparison to the grandparents raising grandchildren without disabilities group. Each of the four subscales within the modified FQOL scale was added together in order to obtain an FQOL Total score for families raising grandchildren without disabilities. Directions for scoring the FSS and FQOL were provided by the respective authors.

Demographic data

Descriptive statistics were used to determine the measures of central tendency and variance of the demographic characteristics. T-tests were performed to determine if significant differences existed between ages of grandmothers, ages of grandchildren, number of grandchildren, and length of time as caregiver. Data were further analyzed using Chi Square Test of Association to determine if significant differences in demographics existed between grandmothers raising grandchildren with disabilities and grandmothers raising grandchildren without disabilities. T-tests were performed using the means of the subscales of the Family Support Scale as well as the mean of the total Family Support Scale score to determine if significant differences existed between grandmothers raising grandchildren with disabilities and grandmothers raising grandchildren without disabilities in regards to sources of support. T-tests were performed using the means of the subscales of the Family Quality of Life Scale as well as

the mean of the total Family Quality of Life Scale score to determine if significant differences existed between grandmothers raising grandchildren and grandmothers raising grandchildren without disabilities in regards to family quality of life.

Relationship between supports and quality of life

An inter-correlational matrix was computed in which Family Support Scale and Family Quality of Life Scale subscales and total scores were compared. Separate matrices were generated for grandmothers raising grandchildren with disabilities and grandmothers raising grandchildren without disabilities to determine if perceived support and reported quality of life were associated with each other while controlling for presence of child disability.

Factors predictive of supports and quality of life

A hierarchical multiple regression was performed between total score on sources of support as the dependent variable and age of grandmother, educational level of grandmother, age of child, and presence of child disability as the independent variables. A hierarchical multiple regression was performed between total score on family quality of life rating as the dependent variable and age of grandmother, educational level of grandmother, age of child, and presence of child disability as the independent variables. The analyses were performed using SPSS Regression and SPSS Explore for evaluation of assumptions. The standardized regression coefficients (β), R^2, R^2 change, and F were examined to determine significance at the 95% confidence limits. Regression analyses were used to assess the relationships among the variables and to predict a continuous dependent variable from a number of independent variables. Multiple regression analysis can establish that a set of independent variables explains a proportion of the variance in a dependent variable at a significant level and can establish the relative predictive importance of the independent variable (Tabachnick & Fidell, 2007).

CHAPTER 4

RESULTS

Demographics

The participant pool for this study included 50 grandmothers raising grandchildren with and without disabilities. Twenty-six (or 52%) grandmothers were raising at least one child with a disability and twenty-four (or 48%) grandmothers were raising grandchildren without disabilities. Two grandmothers were raising more than one child with a disability. Collectively, grandmothers were raising 86 grandchildren ranging in age from 2 years to 21 years of age. The number of grandchildren living in each household was between one and five children. T-tests revealed no significant differences between grandmothers raising grandchildren with and without disabilities in regards to age of grandmothers, age of grandchildren, number of grandchildren, or length of time as caregiver (See Table 3). However, two significant differences in demographics were found between grandmothers raising grandchildren with disabilities and grandmothers raising grandchildren without disabilities regarding income and gender of grandchild. Analysis by Chi Square Test of Association, χ^2 (5, N = 50) = 14.61, p = .012, showed a significant association between presence of child disability and income of grandmothers (See Table 4). The majority of grandmothers raising grandchildren with disabilities had household incomes either less than $15,000 (n = 12 or 24%) or greater than $50,000 (n = 7 or 14%). The majority of grandmothers raising grandchildren without disabilities had household incomes between $15,000 and $50,000 (See Table 5). Analysis by Chi Square Test of Association, χ^2 (1, N = 50) = 6.61, p = .010, showed a significant association between presence of child disability and gender of grandchild (See Table 4). More of the grandchildren with disabilities were male. Specifics of the analysis are presented in Table 6.

Table 3

T-test Analysis of Demographic Data Between Grandmothers Raising Grandchildren With and Without Disabilities

Demographic	*t*	*p*
Age of grandmother	-1.831	.073
Age of grandchildren	.131	.896
Number of grandchildren	.243	.809
Length as caregiver	-.412	.682

Table 4

Chi Square Analysis of Demographic Data Between Grandmothers Raising Grandchildren With and Without Disabilities

Demographic	χ^2	*p*
Education level	4.85	.901
Race/Ethnicity	3.53	.474
Marital status	6.56	.087
Another adult present	0.32	.571
Work status	0.42	.382
Income	14.61	.012*
Gender of grandchild	6.61	.010*
County of residence	17.33	.067

Note. $*p < .05$

Table 5

Association Between Income and Presence of Disability

			Have Disability	
			Yes	No
Income	< $15.000	Count	12	2
		% Within Group	85.7	14.3
		% of Total	24.0	4.0
	$15,001-20,000	Count	4	9
		% Within Group	30.8	69.2
		% of Total	8.0	18.0
	$20,001-30,000	Count	1	5
		% Within Group	16.7	83.3
		% of Total	2.0	10.0
	$30,001-40,000	Count	1	2
		% Within Group	33.3	66.7
		% of Total	2.0	4.0
	$40,001-50,000	Count	1	3
		% Within Group	25.0	75.0
		% of Total	2.0	6.0
	> $50,000	Count	7	3
		% Within Group	70.0	30.0
		% of Total	14.0	6.0
Total		Count	26	24
		% Within Group	52.0	48.0
		% of Total	52.0	48.0

Table 6

Association Between Gender of Grandchild and Presence of Disability

			Have Disability	
			Yes	No
Gender	Male	Count	21	11
		% Within Group	65.6	34.4
		% of Total	42.0	22.0
	Female	Count	5	13
		% Within Group	27.8	72.2
		% of Total	10.0	26.0
Total		Count	26	24
		% Within Group	52.0	48.0
		% of Total	52.0	48.0

Grandmother Characteristics

Grandmothers ranged in age from 39 to 85 years of age with a mean age of 60.16 years (SD = 9.84). The mean age for grandmothers raising grandchildren with disabilities was 57.8 (SD = 8.18) and the mean age for grandmothers raising grandchildren without disabilities was 62.8 (SD = 10.96). Sixty-four percent (n = 32) were African American, thirty percent (n = 15) were Caucasian, two percent (n = 1) were Hispanic, two percent (n = 1) were Multiracial, and two percent (n = 1) were Other (unspecified). Specific demographic data of the grandmothers are presented in Table 7.

Table 7

Characteristics of Grandmothers Raising Grandchildren With and Without Disabilities

	Disability				No Disability				Total			
Characteristic	n	%	M	SD	n	%	M	SD	n	%	M	SD
Age			57.8	8.18			62.8	10.96			60.16	9.84
Marital status												
Married	13	50.0			9	37.5			22	44.0		
Widowed	3	11.5			6	25.0			9	18.0		
Divorced	4	15.4			8	33.3			12	24.0		
Single/never married	6	23.1			1	4.2			7	14.0		
Education level												
5th-11th grade	4	15.2			3	12.5			7	14.0		
High school graduate	11	42.3			8	33.3			19	38.0		
Some college	7	26.9			10	41.6			17	34.0		
College graduate	1	3.9			1	4.2			2	4.0		
Some graduate school	1	3.9			0	0.0			1	2.0		
Graduate degree	2	7.8			2	8.4			8	4.0		
Race/ethnicity												
African American	16	61.6			16	66.6			32	64.0		
Caucasian	9	34.6			6	25.0			15	30.0		
Hispanic	0	0.0			1	4.2			1	2.0		
Multiracial	0	0.0			1	4.2			1	2.0		
Other	1	3.8			0	0.0			1	2.0		
Work status												
Full-time	3	11.5			3	12.5			6	12.0		
Part-time	3	11.5			5	20.8			8	16.0		
Retired	7	26.9			8	33.4			15	30.0		
Full-time homemaker	5	19.3			6	25.0			11	22.0		
Other	8	30.8			2	8.3			10	20.0		
Income												
Less than $15,000	12	46.3			2	8.3			14	28.0		
$15,001-20,000	4	15.4			9	37.6			13	26.0		
$20,001-30,000	1	3.8			5	20.8			6	12.0		
$30,001-40,000	1	3.8			2	8.3			3	6.0		
$40,0001-50,000	1	3.8			3	12.5			4	8.0		
Over $50,000	7	26.9			3	12.5			10	20.0		

The highest level of education for the majority of grandmothers was high school graduate (n = 19 or 38%), followed by some college/technical school (n = 17 or 34%). Thirty percent (n = 15) of grandmothers were retired, twenty-two percent (n = 11) were full-time homemakers, sixteen percent (n = 8) worked part-time, twelve percent (n = 6) worked full-time, and twenty percent (n = 10) stated their work status as "other" (See Table 7).

Forty-four percent (n = 22) of grandmothers were married, twenty-four percent (n = 12) were divorced, eighteen percent (n = 9) were widowed, and fourteen percent (n = 7) were single or never married (See Table 7). Household income ranged from less than $15,000 to over $50,000. Twenty-eight percent (n = 14) had incomes less than $15,000, twenty-six percent (n = 13) had incomes between $15,001-20,000, twelve percent (n = 6) had incomes between $20,001-30,000, six percent (n = 3) had incomes between $30,001-40,000, eight percent (n = 4) had incomes between $40,001-50,000, and twenty percent (n = 10) had incomes over $50,000.

Caregiver Situation

Twenty-five (or 50%) grandmothers had another adult over the age of eighteen living in the household while twenty-five (or 50%) grandmothers did not have another adult in the household (See Table 8). Twenty-four (or 96%) grandmothers responded that the other adult in the household helped with the grandchildren. One (or 4%) grandmother stated that the other adult did not help with raising the grandchildren.

Length of time as primary caregiver ranged from one year to twelve years (M = 7.24, SD = 2.89). Thirty-eight percent (n = 19) of grandmothers had been the primary caregiver for five years or less, forty-six percent (n = 23) had been the caregiver for six to ten years, and sixteen percent (n = 8) had been the primary caregiver for more than ten years (See Table 8). The length of time as caregiver was similar for both grandmothers raising grandchildren with

Table 8

Characteristics of the Caregiving Situation

	Disability					No Disability					Total			
Characteristic	n	%	M	SD	Min/ Max	n	%	M	SD	Min/ Max	n	%	M	SD
Number of grandchildren														
One	11	42.3				12	50.0				23	46.0		
Two	12	46.2				8	33.3				20	40.0		
Three	2	7.7				3	12.5				5	10.0		
Four	0	0.0				1	4.2				1	2.0		
Five	1	3.8				0	0.0				1	2.0		
Age of grandchild			8.85	2.46	4-12			8.75	2.72	3-12			8.80	2.56
Gender of grandchild														
Male	21	80.8				11	45.8				32	64.0		
Female	5	19.2				13	54.2				18	36.0		
Length as caregiver			7.08	3.07	1-12			7.42	2.73	3-12			7.24	2.89
1-5 years	11	42.3				8	33.5				19	38.0		
6-10 years	11	42.3				12	49.9				23	46.0		
10+ years	4	15.4				4	16.6				8	16.0		
Another adult present														
Yes	14	53.8				11	45.8				25	50.0		
No	12	46.2				13	54.2				25	50.0		
Adult helps														
Yes	13	92.9				11	100.0				24	96.0		
No	1	7.1				0	0.0				1	4.0		

disabilities (M = 7.08, SD = 3.07) and grandmothers raising grandchildren without disabilities (M = 7.42, SD = 2.73).

The number of grandchildren living in the household ranged from one to five (See Table 8). Forty-six percent (n = 23) had only one grandchild living in the home, forty percent (n = 20) had two grandchildren, ten percent (n = 5) had three grandchildren, two percent (n = 1) had four grandchildren, and two percent (n = 1) had five grandchildren.

Grandchildren Characteristics

Sixty-four percent (n = 32) of the participant grandchildren were male and thirty-six percent (n = 18) were female (See Table 8). Participant grandchildren had a mean age of 8.8

Table 9

Disability Categories and Level of Severity for Grandchildren

Disability	*n*	%
ADHD/ADD	7	27.0
Mild	4	
Moderate	1	
Severe	2	
Unknown	0	
Behavior Disorder	1	3.8
Mild	1	
Moderate	0	
Severe	0	
Unknown	0	
Cerebral Palsy	1	3.8
Mild	0	
Moderate	0	
Severe	1	
Unknown	0	
Fetal Alcohol Syndrome	2	7.8
Mild	0	
Moderate	1	
Severe	0	
Unknown	1	
Fragile X	1	3.8
Mild	0	
Moderate	1	
Severe	0	
Unknown	0	
Learning Disability	1	3.8
Mild	0	
Moderate	1	
Severe	0	
Unknown	0	
Multiple	12	50.0
Mild	6	
Moderate	5	
Severe	2	
Unknown	0	

years (SD = 2.56). Grandchildren with disabilities had a mean age of 8.85 years (SD = 2.46) and grandchildren without disabilities had a mean age of 8.75 years (SD = 2.72).

Disability of Grandchildren

The majority of grandchildren with disabilities had multiple disabilities (n = 13 or 50.0%). Other disability categories included ADHD/ADD (n = 7 or 27.0%), fetal alcohol syndrome (n = 2 or 7.8%), behavior disorder (n = 1 or 3.8%), cerebral palsy (n =1 or 3.8%), fragile X (n = 1 or 3.8%), and learning disability (n = 1 or 3.8%). The majority of grandchildren with disabilities (n =11 or 42.3%) were rated by grandmothers as having a mild level of severity. Thirty-five percent (n = 9) were rated as having a moderate level of severity, nineteen percent (n = 5) were rated as having a severe level of severity, and four percent (n = 1) were rated as having an unknown level of severity. The level of severity for each disability category as reported by grandmothers is presented in Table 9.

Results of Research Questions

Research Question One

What sources of supports are reported by grandmothers raising grandchildren with disabilities compared to grandmothers raising grandchildren without disabilities?

Results of Question One

No significant difference was found between grandmothers raising grandchildren with and without disabilities on the Family Support Scale total score ($t(48) = -1.445$, $p > .05$). A significant difference was found between the mean ratings of the two groups of grandmothers on the Informal Support subscale ($t(48) = -2.348$, $p < .05$) of the Family Support Scale. Informal support from friends, their own children, neighbors, other grandparents, and church members was significantly higher for grandmothers raising grandchildren without disabilities (M = 2.35,

Table 10

Comparison of Means for Family Support Composite and Subscales by Presence of Disability

Subscales	Disability M	Disability SD	No Disability M	No Disability SD	*t*	*p*
Kinship	1.42	1.10	1.90	1.18	-1.466	.149
Spouse/partner	1.29	1.31	0.95	1.15	.998	.323
Informal support	1.67	1.06	2.35	0.96	-2.348	.023*
Programs/organizations	2.16	0.90	2.51	1.12	-1.209	.232
Professional services	2.15	0.84	2.18	0.96	-.091	.928
FSS total score	33.92	14.11	39.46	12.87	-1.445	.155

Note. $p < .05$

SD = 0.96) than for grandmothers raising grandchildren with disabilities (M = 1.67, SD = 1.06). Support from formal sources (i.e., professional helpers, professional agencies) was comparable for grandmothers raising grandchildren without disabilities (M = 2.18, SD = 0.96) and grandmothers raising grandchildren with disabilities (M = 2.15, SD = 0.84). Data are presented in Table 10.

Research Question Two

What satisfaction ratings of family quality of life are reported by grandmothers raising grandchildren with disabilities compared to grandmothers raising grandchildren without disabilities?

Results of Question Two

A significant difference was found between the mean satisfaction ratings of total family quality of life of grandmothers raising grandchildren with and without disabilities

Table 11

Comparison of Means for Family Quality of Life Composite and Subscales by Presence of Disability

Subscales	Disability		No Disability			
	M	SD	M	SD	*t*	*p*
Family interaction	3.76	0.91	4.30	0.54	-2.501	.016*
Parenting	3.67	0.93	4.07	0.66	-1.755	.086
Emotional well-being	3.07	1.30	3.77	0.84	-2.257	.029*
Physical/material well-being	3.75	0.96	4.36	0.58	-2.694	.010*
Disability-related support	4.07	0.84	NA	NA		
FQOL total score with disability subscale	91.85	18.85	NA	NA		
FQOL total score without disability subscale	75.58	17.21	87.08	10.40	-2.832	.007*

Note. $p < .05$. NA = not applicable.

($t(48) = -2.832$, $p < .05$) on the Family Quality of Life Scale (See Table 11). Grandmothers raising grandchildren without disabilities rated satisfaction with total family quality of life significantly higher (M = 87.08, SD = 10.40) than grandmothers raising grandchildren with disabilities (M = 75.58, SD = 17.21). A significant difference was found between the mean satisfaction ratings of the Family Interaction subscale ($t(48) = -2.501$, $p < .05$), the mean satisfaction ratings of the Emotional Well-being subscale ($t(48) = -2.257$, $p < .05$), and the mean satisfaction ratings of the Physical/Material Well-being subscale ($t(48) = -2.694$, $p < .05$) of the two groups of grandmothers. Grandmothers raising grandchildren without disabilities rated

satisfaction with each of these subscales significantly higher than grandmothers raising grandchildren with disabilities. No significant difference was found between the mean satisfaction ratings of the Parenting subscale of the two groups ($t(48) = -1.755$, $p > .05$).

Research Question Three

Are grandmothers raising grandchildren with disabilities different from grandmothers raising grandchildren without disabilities with respect to various types of support and family quality of life?

Results of Question Three

Correlation analyses were performed to analyze the relationship between sources of support and family quality of life. The analyses revealed that there was a relationship between sources of support and family quality of life for both grandmothers raising grandchildren with and without disabilities. For grandmothers raising grandchildren with disabilities (See Table 12), sources of support were moderately correlated with satisfaction ratings of family quality of life, which included the disability-related subscale ($r = .624$, $p < .01$). For grandmothers raising grandchildren without disabilities (See Table 13), sources of support were moderately correlated with satisfaction ratings of family quality of life ($r = .513$, $p < .05$). Degrees of correlation are described by Cohen (1977) as high (above .75), moderate (.50 - .75), and low (.25 - .50).

Total informal social support was significantly correlated with satisfaction ratings of family quality of life for both grandmothers raising grandchildren with disabilities ($r = .560$, $p < .01$) and grandmothers raising grandchildren without disabilities ($r = .542$, $p < .01$). However, grandmothers differed in regards to helpfulness of formal support. Total formal support was significantly correlated with satisfaction ratings of family quality of life for grandmothers raising grandchildren with disabilities ($r = .549$, $p < .01$) as seen in Table 12. No significant correlation

Table 12

Correlations Between Sources of Support and Quality of Life of Grandmothers Raising Grandchildren with Disabilities (n = 26)

Variable	1	2	3	4	5
1. FSS total score	-				
2. FQOL total score	.585**	-			
3. Total Informal Social Support Score	.983**	.560**	-		
4. Total Formal Support score	.760**	.496**	.627**	-	
5. FQOL total with disability subscale score	.624**	.987**	.593*	.549**	-

Note. * $p < .05$, ** $p < .01$.

was found between total formal support and satisfaction ratings of family quality of life for grandmothers raising grandchildren without disabilities. ($r = .153$, $p > .05$) as seen in Table 13.

Research Question Four

What factors predict family supports and quality of life of grandmothers raising grandchildren with disabilities compared to grandmothers raising grandchildren without disabilities?

Table 13

Correlations Between Sources of Support and Quality of Life of Grandmothers Raising Grandchildren Without Disabilities (n = 24)

Variable	1	2	3	4
1. FSS total score	1			
2. FQOL total score	.513*	1		
3. Total Informal Social Support Score	.960**	.542**	1	
4. Total Formal support score	.582**	.153	.329	1

Note. * $p < .05$, ** $p < .01$.

Results of Question Four

Hierarchical multiple regression analysis was used in order to identify the strongest predictors of family quality of life (total satisfaction with FQOL). As a control strategy, age of grandmother, education level of grandmother, and age of grandchild were entered in Step 1 of the regression (See Table 14). Presence of child disability was entered in Step 2. Based on the statistical test of the b coefficient ($t = 2.518$, $p < .05$) for the independent variable, presence of child disability, there was a significant relationship between presence of child disability and satisfaction ratings of family quality of life. Based on Step 2 of the model, the predictor variable, presence of child disability, did contribute to the overall relationship with the dependent variable,

Table 14

Summary of the Hierarchical Regression Analysis for Variables Predicting Family Quality of Life

Model/Predictor	β	t	p	Model R^2	Adjusted R^2	ΔR^2	F
Step 1				.029	-.034	.029	.460
Age of grandmother	.153	1.009	.318				
Education level	.061	.420	.677				
Age of grandchild	-.099	-.653	.517				
Step 2				.149	.073	.120	6.338
Age of grandmother	.051	.346	.731				
Education level	.031	.223	.825				
Age of grandchild	-.065	-.451	.654				
Presence of disability	.361	2.518	.015*				

Note. *$p < .05$

family quality of life ($F(1,45) = 6.338$, $p < .05$). The increase in R^2 by including presence of child disability in the analysis was .120. Presence of child disability accounted for 12% of the unique variance during Step 2.

Hierarchical multiple regression analysis was also used in order to identify the strongest predictors of sources of support (See Table 15). As a control strategy, age of grandmother, education level of grandmother, and age of grandchild were entered in Step 1 of the regression model. Presence of disability was entered in Step 2 of the regression. The statistical test of the b coefficient ($t = 1.69$, $p > .05$) for the independent variable, presence of child disability, showed

Table 15

Summary of the Hierarchical Regression Analysis for Variables Predicting Sources of Support

Model/Predictor	β	t	p	Model R^2	Adjusted R^2	ΔR^2	F
Step 1				.012	-.052	.012	.186
Age of grandmother	-.086	-.561	.578				
Education level	-.067	-.458	.649				
Age of grandchild	.001	-.005	.996				
Step 2				.071	-.012	.059	2.842
Age of grandmother	-.157	-1.01	.320				
Education level	-.088	-.612	.544				
Age of grandchild	.024	.163	.871				
Presence of disability	.253	1.69	.099				

no significant relationship between presence of child disability and sources of support. Based on Step 2 of the model, the predictor variable, presence of child disability, did not contribute to the overall relationship with the dependent variable, sources of support (F(1,45) = 2.842, $p > .05$). Presence of child disability failed to account for a significant proportion of unique variance during Step 2 of the model.

CHAPTER 5

DISCUSSION

The purpose of this research was to examine the sources of support and family quality of life of grandmothers raising grandchildren with and without disabilities. Variables that might influence sources of support and family quality of life were considered. These variables were age of grandmothers, educational level of grandmothers, age of grandchild, and presence of child disability.

Conclusions

Sources of support. Grandmothers raising grandchildren without disabilities had significantly more helpful sources of informal support than grandmothers raising grandchildren with disabilities as evidenced by the Informal Support subscale score. This result is consistent with previous research (Emick & Hayslip, 1999; McCallion et al., 2000), which found that grandparents raising grandchildren with emotional, behavioral, and learning difficulties received less social support than those caring for grandchildren without disabilities. Caring for grandchildren with disabilities may be more demanding than caring for grandchildren without disabilities. Family and friends may not be able or willing to provide support to grandmothers raising grandchildren with disabilities, especially when the grandchildren exhibit challenging behaviors. Therefore, it would seem plausible that grandmothers raising grandchildren with disabilities would rate sources of informal support as less helpful than grandmothers raising grandchildren without disabilities.

Support from professional services was comparable for both grandmothers raising grandchildren with and without disabilities; each group of grandmothers rating helpfulness of professional services as only sometimes helpful. This finding supports previous research

(Hayslip & Kaminski, 2005b; Hayslip & Shore, 2000; Janicki et al., 2000; McCallion et al., 2000), which has shown that grandparents could not access, did not seek out, or did not utilize formal sources of support. Researchers have found that accessing and navigating the formal service network presents a multitude of challenges for grandparents who are raising their grandchildren (Grant, 2000; Janicki et al., 2000; McCallion et al., 2000). This may be the result of the formal service network not being equipped to meet the unique needs of grandparent caregivers nor being particularly sensitive to these needs. Another explanation for not accessing formal support may be the grandparents' lack of awareness of what services are available. However, even if grandparents are aware of the availability of services, a high degree of motivation and help-seeking behavior is required on the part of the grandparent to ensure assistance from the formal support system (Gerard et al., 2006). Grandmothers raising grandchildren, especially grandchildren with disabilities, may not have the motivation nor the time or energy to enlist the services they need. Janicki and colleagues (2000) found that many grandparents experienced stress when attempting to secure help or specialty services related to their grandchild's disabilities and needs. Therefore, they were low users of existing services even though they reported that they were in high need of these services.

Family quality of life. Grandmothers raising grandchildren without disabilities had significantly higher overall satisfaction ratings of family quality of life than grandmothers raising grandchildren with disabilities as evidenced by the Family Quality of Life total score. This result is consistent with the research of Zuna, Turnbull and Summers (2009) who found that families of typically developing children tended to have higher family quality of life than families of children with disabilities. Grandmothers raising grandchildren without disabilities rated

satisfaction with each aspect of family quality of life, except parenting, significantly higher than grandmothers raising grandchildren with disabilities.

The three aspects of family quality of life that were rated as significantly higher by grandmothers raising grandchildren without disabilities included emotional well-being, family interactions, and physical/material well-being. Since grandparents are often socially isolated from their peers and friends (Hayslip & Kaminski, 2005a; Smith, Beltran, Butts, & Kingson, 2000) due to the caregiving situation, their emotional well-being is affected. Grandmothers raising grandchildren with disabilities are often more socially isolated because they are unable or unwilling to access their social network due to the special needs of their grandchildren. Therefore, it is not surprising that grandmothers raising grandchildren with disabilities would rate themselves less satisfied with that aspect of family quality of life. The grandchild's disability might preclude grandmothers raising grandchildren with disabilities from participating in family events or activities, resulting in decreased contact with the family. This could explain why grandmothers raising grandchildren with disabilities rated satisfaction with family interaction significantly lower than grandmothers raising grandchildren without disabilities. The increased financial burden of raising a grandchild with disabilities may increase levels of personal distress, which could affect grandmothers' physical health. Likewise, this increased financial expense of raising a grandchild with disabilities may affect the accessibility of supports and services needed by the grandchild with a disability, especially if grandmothers do not have insurance for the grandchildren. These issues could explain why grandmothers raising grandchildren rated satisfaction with physical/material well-being as significantly lower than grandmothers raising grandchildren without disabilities.

Relationship between sources of support and family quality of life. A significant positive correlation was found between sources of support and satisfaction ratings of family quality of life for both grandmothers raising grandchildren with and without disabilities. Researchers have found that support from family and friends (i.e., informal support) enhances emotional well-being (Davis & Gavidia-Payne, 2009), especially in families of children with disabilities (King, King, Rosenbaum, & Goffin, 1999). Lack of informal support from their own children, friends, neighbors, other grandparents, and church members affects grandparents' ability to engage in social and recreational activities and to take care of their personal needs (Campbell & Miles, 2008). Without periodic relief from their child-rearing responsibilities, especially when the grandchildren have disabilities or special needs, grandmothers' emotional health may suffer. This may ultimately affect the grandmothers' interactions with their grandchild and their family's quality of life. Since previous research (Trivette & Dunst, 1992) has shown that informal support influences personal, family, and child functioning, it can be concluded from the data that having more helpful sources of support, especially informal support, may increase satisfaction ratings of family quality of life.

Presence of disability. No significant influence was found between the predictor variables (age of grandmother, education level of grandmother, age of grandchild, presence of child disability) and sources of support. None of the variables analyzed together or separately appeared to affect the helpfulness of support grandmothers received from either informal or formal sources. Only one predictor variable, presence of disability, had a significant influence on satisfaction ratings of family quality of life. When the other predictor variables were added to the model, no significant influences were found. It can be concluded from these results that presence of child disability is one predictor of grandmothers' satisfaction with their family quality of life,

with grandmothers raising grandchildren with disabilities reporting less satisfaction with their family quality of life.

These results provide support for Bronfenbrenner's (1979) ecological theory, which emphasized the significance of the external environment on families' and children's well-being. Informal support has shown the strongest relationship to any number of child, parent, and family outcomes (Dunst, 2000). Therefore, the provision or mobilization of supports and resources could improve family quality of life (Dunst & Bruder, 2002), especially for families raising grandchildren with disabilities.

Implications

Results of this study underscore the critical need to provide support for grandmothers raising grandchildren, especially those grandmothers raising grandchildren with disabilities. Program strategies that strengthen grandmothers' social support and family resources are essential to increasing family quality of life. Since families play a critical role in children's development (Bailey et al., 2006), increasing family quality of life can promote positive family and child outcomes. The extent to which families have adequate formal and informal support systems is highly associated with successful adaptation (Crnic & Stormshak, 1997; Dunst, Trivette, & Hamby, 1994). Maintaining healthy social networks is an essential component for positive adaptation in the family system (Ylven et al., 2006).

A major emphasis of increasing positive adaptation for grandmothers raising grandchildren should be strengthening and building the natural support systems as well as promoting the acquisition of knowledge and skills that make a family more competent. Researchers (Kelley, Whitley, & Sipe, 2007; Kelley, Yorker, Whitley, & Sipe, 2001; Whitley, White, Kelley, & Yorker, 1999) have found that one way to accomplish this is by using a

strengths-based case management practice and group support services that build upon the strengths which grandparents already possess. Strengths-based case management approaches have been shown to enhance the well-being of caregiving grandparents (Campbell & Miles, 2008; Kelley et al., 2001). In addition, support groups for grandparents and/or grandchildren may also enhance the general well-being of grandparents while providing a nurturing environment for their grandchildren. Grandparents who have utilized support groups have reported that group meetings are helpful in obtaining information about services that are available, in providing a forum in which to share concerns about their current caregiving situation, and in reducing feelings of isolation (Cox, 2003; McCallion et al., 2004; Strom & Strom, 2000). Many grandparents regard support groups as their most valued resource (Minkler, Driver, Roe, & Bedeian, 1993). However, attendance at support group meetings is difficult for grandparents raising grandchildren with disabilities due to the special needs of the grandchildren. With a limited social support network, grandparents raising grandchildren have fewer resources available for childcare. Emick and Hayslip (1999) found in their sample that over 50% of grandparents raising grandchildren with problems had never gone to any type of supportive intervention. Support groups may be an underutilized resource for grandparents raising grandchildren with disabilities. Because of this, efforts must be made to increase the amount of support provided to grandparents raising grandchildren with disabilities.

Most of the intervention approaches are geared toward the grandparent in an attempt to strengthen the grandparent's skills in managing the behaviors of the grandchildren and/or to provide emotional support for the grandparents (Thomas, Sperry, & Yarbrough, 2000). Using family-centered help-giving practices can help families build and use informal support systems. Likewise, professionals can provide services that are individualized and supportive by

recognizing the family's prior history and focusing on their unique strengths (Smith & Dannison, 2008). If families feel confident in their abilities to handle everyday life without constant support, they may experience increased opportunities for positive family functioning; thus increasing their satisfaction with family quality of life.

Intervention approaches must take into account the unique needs of the diverse groups of grandmothers raising grandchildren. It is important to recognize the circumstances that formed the family, the cultural values and norms of the family, the family supports, and the family's unique stressors as well as the fact that grandparents may be raising one or more grandchildren with disabilities. Such recognition is critical to the design and implementation of both informal and formal support for grandmothers raising grandchildren. Understanding the specific social support needs of these grandmothers may help in the development of public policy advocating for grandmother caregivers and their grandchildren (King et al., 2006).

Appropriate policies, programs, and outreach efforts are needed to better address the needs of grandparents raising grandchildren with and without disabilities. Involving churches, senior centers, public health departments, community mental health centers, divisions of child and family services, and educational institutions in these interventions may help ensure that grandparents receive the support they require to increase their family quality of life. A positive family quality of life should be an outcome of policies and services for families (Bailey et al., 1998; Turnbull et al., 1999). Using family quality of life data would assist agencies and institutions in determining what supports and services grandparents raising grandchildren, especially grandchildren with disabilities, need in order to have positive adaptation in the family system. It could also be used to evaluate the impact of these specific services on family quality of life.

Limitations

There are several limitations to this study. These include the representativeness of the sample; the reporting of specific disabilities and severity level; the issue of self-report of disabilities; the interpretation of the Family Support Scale; the inclusion of only English-speaking grandmothers; the relatively small sample size; the lack of longitudinal data, and the contribution of the predictor variable. Each of these issues will be described below.

Representativeness of sample. The participants in this study were from the northwest sector of a southern state and may not be representative of other sections of the state or country. The participant pool was a sample of geographic convenience. In addition, participation in the study was voluntary. Grandmothers were approached by the directors of the public agencies that focus on aging as well as statewide agencies that serve children with disabilities who were enlisted to help recruit participants. The directors might have approached grandmothers they believed would more readily agree to participate. All participants who were approached and willing to participate and who met study criteria were included in the study. Refusal to participate was not recorded. Therefore, it is not known how many grandmothers were approached and refused to participate nor is it known to what extent the views of grandmothers who choose to participate were either alike or different from those who choose not to participate.

Grandmothers who were approached to participate in this study were already participating as members of a support group, receiving services themselves through the senior service centers, or receiving services for their grandchild through special education. It is not known whether this group of grandmothers differed significantly from grandmothers raising grandchildren who were not participating in or receiving services from these agencies.

Reporting of specific disability categories. Attempts were made to recruit grandmothers raising grandchildren with differing disabilities. However, a large majority (73%) of grandchildren with disabilities, as reported by the grandmothers, fell into one of two disability categories: ADHD/ADD and multiple disabilities. Since family functioning can be strongly impacted by the specific problems related to the type of disability (Ylven et al., 2006), the results of this study may not be generalizable to other grandmothers raising grandchildren with different disabilities.

Level of severity of disability. The severity level of the grandchild's disability was reported by the grandmothers. This report was based on their interpretation of what constituted severity. Since severity was based on the grandmothers' perception, it is not known whether this perception contributed to their satisfaction ratings of family quality of life. Therefore, results from this study may not be generalizable to other grandmothers' raising grandchildren with disabilities who have differing perceptions of levels of severity.

Issue of self-report of disabilities. Grandmothers reported the specific disability category for their grandchild with disabilities. The researcher did not get confirmation of the disability. There was no doctor report or proof of an Individualized Education Plan. Therefore, it is not known whether grandmothers accurately reported the disability category of their grandchild.

Interpretation of the Family Support Scale. The Family Support Scale uses a five point Likert scale. It offers a "Not Available" choice which participants could have interpreted in more than one way. Participants could have chosen the "Not Available" response if the source of support was physically not available to them (e.g., relatives live in another state). They could also have chosen the "Not Available" response if the source of support was deceased, if the

source of support was a program in which they were not enrolled, or if the source of support did not exist for the family. The researcher instructed participants to respond with "Not Available" if the source of support did not exist for them (e.g., no spouse, parents are deceased) in an attempt to address homogeneity of the interpretations for the response choices.

Inclusion of only English-speaking grandmothers. Participants included in the study were only English-speaking grandmothers. According to the Pew Research Center (2010) analysis of Decennial Census and American Community Survey data, there has been a notable increase in the number of Hispanic grandparents serving as primary caregivers over the last decade. Because of this increase, the results from the present study may not be reflective of the sources of support and satisfaction ratings of family quality of life of grandmothers who speak languages other than English.

Small sample size. Only fifty grandmothers participated in the present study. It may be difficult to generalize the findings to the population of grandmothers raising grandchildren with and without disabilities due to the relatively small sample size. A larger sample of grandmothers raising grandchildren would provide additional information regarding sources of support and satisfaction ratings of family quality of life.

Lack of longitudinal data. The present study was a cross sectional study, which takes a snapshot of the population at a particular time. Even though conclusions can be drawn about a phenomenon across a wide population, cause and effect relationships cannot be identified. Cross sectional studies can only measure frequency and prevalence of conditions or demonstrate associations. Longitudinal data might provide researchers with information regarding if sources of support and satisfaction ratings of family quality of life change over time.

Contribution of predictor variable. Presence of disability accounted for only 12% of the variance in the regression model. Presence of disability is considered a low contributor to the overall relationship with family quality of life. It is not known whether there are other predictor variables, either individually or in combination, which might contribute more to the relationship with family quality of life.

Suggestions for Future Research

Based on the findings of this study, there are some suggestions for future research. These suggestions include the following: replication of the study using grandmothers as well as grandfathers, replication of the study using grandmothers from different areas of the state or country, similar studies that include a qualitative component, similar studies that include the reason for the caregiving situation, and similar studies that include a wider range of disabilities.

Responses for sources of support and satisfaction ratings of family quality of life were provided by the grandmother caregivers in this study. Instead of basing inferences about the family on the report of only one person, it would be interesting and important to obtain responses from grandmothers as well as grandfathers in order to examine whether there were differences in their perceptions of family quality of life or the availability of sources of support. Different family members may utilize different sources of support which could impact their emotional well-being, thereby affecting the family either directly or indirectly in a positive, negative, or neutral way.

As stated previously, the results may not be generalizable to grandmothers from other areas of the state or country. Since only grandmothers from the northwest sector of one state participated, it would be important to replicate the current study with grandmothers from various sections of the state or in other states. Sources of supports, especially formal support, may be

different depending upon the area in which grandmothers live. Rural custodial grandparents may be at risk for inadequate social supports and limited access to social services (Robinson, Kropf, & Myers, 2000) as well as more social isolation due to the physical distance between neighboring families (Roberto et al., 1992). Likewise, support networks for grandparents may not be available in every county. If sources of support are available, grandparents may not have the resources or the time to access these supports.

Future research might also include a qualitative component where participants would be allowed to talk more freely rather than simply responding to items on the instruments. A mix of methodologies would allow for an in-depth picture of sources of support and satisfaction with family quality of life. Participants in this study willingly elaborated on their responses to the instrument items. They often wanted to qualify their responses with explanations. Many of the participants made comments about enjoying having someone to talk to about the issues and difficulties they were experiencing.

Another future research suggestion would be implementing a similar study in which the reason for the caregiving situation was included in the demographic data. Grandparents assume care of their grandchildren from diverse and unpredictable circumstances such as drug abuse, incarceration, violence and/or neglect, or death of a parent. These differing circumstances can put the grandparents at risk for psychological distress and most likely affect their well-being. Ross and Aday (2006) found that grandparents whose reason for caregiving was because of neglect related to parental substance abuse had lower levels of stress while grandparents whose reason was because of the death of the grandchildren's parent(s) experienced more stress. It would be beneficial to professionals to know the effect of the reason for the assumption of care

on the sources of support and family quality of life in order to provide the appropriate support and services needed by the grandparents.

Similar studies such as this one that incorporated a wider range of disabilities would be a final area of future research. The special needs of the grandchildren often determine the nature of the child-rearing stresses experienced by the grandparents (Kelley, 1993). Some disabilities may require specialized health care, including medication, psychological interventions, or behavioral interventions, making childrearing even more demanding for grandparents. The extra demands placed on grandparents for nurturing and support have been associated with higher levels of stress (Burton, 1992). The complex needs of the grandchildren with disabilities may compromise the grandparent's ability to parent effectively and be a source of ongoing stress (Campbell & Miles, 2008; Grant, 2000). These factors may influence the family as a system and family functioning in a negative way by affecting the sources of support for grandparents and ultimately their family quality of life.

In summary, grandparents raising grandchildren has become a common phenomenon across the country. This reconfiguration of the family is diverse and has occurred across every socioeconomic and ethnic group (Fuller-Thomson et al., 1997; Minkler & Roe, 1993). As a result, grandparents are experiencing increased psychological distress. One of the most well documented contributors to this distress has been social isolation (Dowdell, 1995; Kelley, 1993; Minkler & Roe, 1993). The availability of social support, both formal and informal, has been shown to have a powerful impact on grandparents' emotional health and well-being (Davis & Gavidia-Payne, 2009; Dunst et al., 1988; Gerard et al., 2006; Giarrusso, Silverstein et al., 2000), thereby influencing family functioning. A family's social networks, which include a mix of intrafamily, informal, community, and formal social network members, are an essential

component for positive family functioning (Dunst, 2000). Results of this study underscore the importance of the accessibility of informal supports for grandmothers raising grandchildren with and without disabilities. Having more helpful sources of informal support may increase satisfaction with family quality of life for grandmothers raising grandchildren. Through family support services, professionals can promote the families' abilities to obtain and mobilize resources and strengthen their support networks. Strengthening grandparents' support networks, especially grandparents raising grandchildren with disabilities, could have a positive effect on family quality of life, specifically, and positive child and family outcomes, in general.

References

Americans with Disabilities Act of 1990, 42 U. S. C. ~ 12101 *et seq*. (1990).

Baird, A. (2003). Through my eyes: Service needs of grandparents who raise their grandchildren from the perspective of a custodial grandmother. In B. Hayslip & J. Hicks Patrick (Eds.), *Working with custodial grandparents* (pp. 59-68). New York: Springer.

Bailey, D. B., Bruder, M. B., Hebbeler, K., Carta, J., deFosset, M., Greenwood, C., et al. (2006). Recommended outcomes for families of young children with disabilities. *Journal of Early Intervention, 28,* 227-251.

Bailey, D. B., McWilliam, R. A., Darkes, L. A., Hebbeler, K., Simeonsson, R. J., Spiker, D., et al. (1998). Family outcomes in early intervention: A framework for program evaluation and efficacy research. *Exceptional Children, 64,* 313-328.

Baker, D. B. (2000). Custodial grandparenting and ADHD. In B. Hayslip & R. Goldberg-Glen (Eds.), *Grandparents raising grandchildren: Theoretical, empirical, and clinical perspectives* (pp. 221-238). New York: Springer.

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Endelbrock, C., & Low, C. (2003). Preschool children with and without developmental delay: Behavior problems and parenting stress over time. *Journal of Intellectual Disability Research, 47,* 217-230.

Barrera, M. (1986). Distinctions between social support concepts, measures, and models. *American Journal of Community Psychology, 14,* 413-445.

Beach Center on Disability (2006). Beach Center Family Quality of Life Scale. Retrieved June 16, 2009, from http://www.beachcenter.org/toolkit/default.asp?act=fql.

Beverly, C. L. (1995). Grandparents raising young children with disabilities or at risk for disabilities: Their demands, capabilities, and adaptation. *Dissertation Abstracts International, 56-11A,* 4347.

Beverly, C. L. (1998). Custodial grandparents: Familial contexts for early intervention and special education. *Infant-Toddler Intervention, 8,* 135-147.

Bowers, B. F., & Myers, B. J. (1999). Grandmothers providing care for grandchildren: Consequences of various levels of caregiving. *Family Relations, 48,* 303-311.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University.

Brown, D. R., & Boyce-Mathis, A. (2000). Surrogate parenting across generations: African American women caring for a child with special needs. *Journal of Mental Health and Aging, 6,* 339-351.

Brown, R. I., MacAdam-Crisp, J., Wang, M., & Iarocci, G. (2006). Family quality of life when there is a child with a developmental disability. *Journal of Policy and Practice in Intellectual Disabilities, 3*, 238-245.

Brown, I., Neikrug, S., & Brown, R. I. (2000). *Family quality of life survey.* Toronto: Center for Health Promotion, University of Toronto.

Brown, J., Nolan, M., & Davies, S. (2001). Who's the expert? Redefining lay and professional relationships. In M. Nolan, S. Davies, & G. Grant (Eds.), *Working with older people and their families* (pp. 19-32). Buckingham, UK: Open University Press.

Bruder, M. B. (2000). Family-centered early intervention: Clarifying our values for the new millennium. *Topics in Early Childhood Special Education, 20,* 105-115.

Bryson, K., & Casper, L. M. (1999). Co-resident grandparents and grandchildren. In *Current Population Reports, Special Studies, U. S. Bureau of the Census.* Washington, DC: U. S. Government Printing Office.

Bullock, K. (2004). The changing role of grandparents in rural families: The results of an exploratory study in southeastern North Carolina. *Families in Society, 85,* 45-55.

Burnette, D. (1997). Grandparents raising grandchildren in the inner city. *Families in Society, 78,* 489-501.

Burnette, D. (1999). Physical and emotional well-being of custodial grandparents in Latino families. *American Journal of Orthopsychiatry, 69,* 305-317.

Burnette. D. (2000). Latino grandparents rearing grandchildren with special needs: Effects on depressive symptomatology. *Journal of Gerontological Social Work, 33,* 1-16.

Burton, L. M. (1992). Black grandparents rearing children of drug-addicted parents: Stressors, outcomes, and social service needs. *The Gerontologist, 32*, 744-751.

Campbell, L. & Miles, M. S. (2008). Implementing parenting programs for custodial grandparents. In B. Hayslip & P. Kaminski (Eds.), *Parenting the custodial grandchild: Implications for clinical practice* (pp. 115-130). New York: Springer.

Carpenter, B. (1997). *Families in context: Emerging trends in family support and early intervention.* London: David Fulton.

Chalfie, J. (1994). *Going it alone: A closer look at grandparents parenting grandchildren*. Washington, DC: American Association of Retired Persons.

Cohen, J. (1977). *Statistical power analysis for the behavioral sciences* (rev.ed.). New York: Academic Press.

Cohen, C. S. & Pyle, R. (2000). Support groups in the lives of grandmothers. In C. Cox (Ed.), *To grandmother's house we go and stay: Perspectives on custodial grandparents* (pp. 3-19). New York: Springer.

Cox, C. (2000). *To grandmother's house we go and stay: Perspectives on custodial grandparents.* New York: Springer.

Cox, C. (2003). Designing interventions for grandparent caregivers: The need for an ecological perspective for practice. *Families in Society, 84,* 127-134.

Crnic, K. A., Friedrich, W. N., & Greenberg, M. T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. *American Journal of Mental Deficiency, 88,* 125-138.

Crnic, K., & Greenberg, M. (1990). Minor parenting stresses with young children. *Child Development, 61,* 1628-1637.

Crnic, K., Greenberg, M., & Slough, N. (1986). Early stress and social support influences on mothers' and high-risk infants' functioning in late infancy. *Infant Mental Health Journal, 7,* 19-33.

Crnic, K., & Stormshak, E. (1997). The effectiveness of providing social support for families of children at risk. In M. Guralnick (Ed.), *The effectiveness of early intervention* (pp. 209-226). Baltimore: Brooks.

Crowther, M., & Rodriguez, R. (2003). A stress and coping model of custodial grandparents among African-Americans. In B. Hayslip & J. Hicks Patrick (Eds.), *Working with custodial grandparents* (pp. 145-162). New York: Springer.

Cuellar, N. & Butts, J. (1999). Caregiver distress: What nurses in rural settings can do to help. *Nursing Forum: An Independent Voice for Nursing, 34,* 24-30.

Darling, S. M., & Gallagher, P. A. (2004). Needs of and supports for African American and European American caregivers of young children with special needs in urban and rural settings. *Topics in Early Childhood Special Education, 24,* 98-109.

Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Australian Society for the Study of Intellectual Disability, 34,* 153-162.

DeToledo, S., & Brown, D. E. (1995). *Grandparents as parents: A survival guide for raising a second family.* New York: Guilford Press.

Dowdell, E. (1995). Caregiver burden: Grandmothers raising their high risk grandchildren. *Journal of Psychosocial Nursing, 33,* 27-30.

Dressel, P. L., & Barnhill, S. K. (1994). Reframing gerontological thought and practice: The case of grandmothers with daughters in prison. *The Gerontologist, 34,* 685-691.

Dubowitz, H., Feigelman, S., Harrington, D., Starr, R., & Zuravin, S. (1994). Children in kinship care: How do they fare? *Children and Youth Services Review, 16,* 85-106.

Dunst, C. J. (2000). Revisiting "Rethinking early intervention." *Topics in Early Childhood Special Education, 20,* 95-104.

Dunst, C. J., & Bruder, M. B. (2002). Valued outcomes of service coordination, early intervention, and natural environments. *Exceptional Children, 68,* 361-375.

Dunst, C. J., Jenkins, B., & Trivette, C. M. (1984). Family Support Scale: Reliability and validity. *Journal of Individual, Family, and Community Wellness, 1,* 45-52.

Dunst, C. J., Jenkins, V., & Trivette, C. M. (1986). Family support scale. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Enabling and empowering families: Principles and guidelines for practice* (p. 157). Cambridge, MA: Brookline Books.

Dunst, C. J., & Trivette, C. M. (1988). Determinants of parent and child interactive behavior. In K. Marfo (Ed.), *Parent-child interaction and development disabilities* (pp. 3-31). New York: Praeger.

Dunst, C., Trivette, C., & Deal, A. (1988). *Enabling and empowering families: Principles and guidelines for practice.* Cambridge, MA: Brookline Books.

Dunst, C., Trivette, C., & Deal, A. (1994). *Supporting and strengthening families: Methods, strategies, and practices.* Cambridge, MA: Brookline Books.

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (1994). *Measuring social support in families with young children with disabilities.* Cambridge, MA: Brookline Books.

Dunst, C. J., Trivette, C. M., & Johanson, C. (1994). Parent-professional collaboration and partnerships. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Supporting and strengthening families: Methods, strategies, and practices* (pp. 197-211). Cambridge, MA: Brookline Books.

Edwards, O. W. (1998). Helping grandkin-grandchildren raised by grandparents: Expanding psychology in the schools. *Psychology in the Schools, 35,* 173-181.

Emick, M., & Hayslip, B. (1996). Custodial grandparenting: New roles for middle-aged adults. *International Journal of Aging and Human Development, 48,* 35-61.

Emick, M., & Hayslip, B. (1999). Custodial grandparenting: Stresses, coping skills, and relationships with grandchildren. *International Journal of Aging and Human Development, 48,* 35-62.

Erhle, G. M., & Day, H. D. (1994). Adjustment and family functioning of grandmothers raising their grandchildren. *Contemporary Family Therapy, 16,* 67-82.

Fiedler, C. R., Simpson, R. L., & Clark, D. M. (2007). *Parents and families of children with disabilities: Effective school-based support services.* Upper Saddle River, NJ: Pearson Education.

Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations, 46,* 359-371.

Force, L. T., Botsford, A., Pisano, P. A., & Holbert, A. (2000). Grandparents raising grandchildren with and without a developmental disability. *Journal of Gerontological Social Work, 33,* 5-21.

Fuller-Thomson, E., & Minkler, M. (2000a). America's grandparent caregivers: Who are they? In B. Hayslip & R. Goldberg-Glen (Eds.), *Grandparents raising grandchildren: Theoretical, empirical, and clinical perspectives* (pp. 3-22). New York: Springer.

Fuller-Thomson, E., & Minkler, M. (2000b). The mental and physical health of grandmothers who are raising their grandchildren. *Journal of Mental Health and Aging, 6,* 311-323.

Fuller-Thomson, E., & Minkler, M. (2001). American grandparents providing extensive childcare to their grandchildren: Prevalence and profile. *The Gerontologist, 41,* 201-209.

Fuller-Thomson, E., Minkler, M., & Driver, D. (1997). A profile of grandparents raising grandchildren in the United States. *The Gerontologist, 39*, 677-686.

Gallagher, P. A., Kresak, K., & Rhodes, C. A. (2010). Perceived needs of grandmothers of children with disabilities. *Topics in Early Childhood Special Education, 30,* 56-64.

Gatti, F. L., & Musatti, T. (1999). Grandmothers' involvement in grandchildren's care: Attitudes, feelings, and emotions. *Family Relations, 48,* 35-42.

Gerard, J. M., Landry-Meyer, L., & Roe, J. G. (2006). Grandparents raising grandchildren: The role of social support in coping with caregiving challenges. *International Journal of Aging and Human Development, 62,* 359-383.

Ghuman, H. S., Weist, M. D., & Shafer, M. E. (1999). Demographic and clinical characteristics of emotionally disturbed children being raised by grandparents. *Psychiatric Services, 50,* 1496-1498.

Giarrusso, R., Feng, D., Silverstein, M., & Marenco, A. (2000). Primary and secondary stressors of raising grandchildren: Evidence from a national survey. *Journal of Mental Health and Aging, 6,* 291-310.

Giarrusso, R., Silverstein, M., & Feng, D. (2000). Psychological costs and benefits of raising grandchildren: Evidence from a national survey of grandparents. In C. Cox (Ed.), *To grandmother's house we go and stay: Perspectives on custodial grandparents* (pp. 71-90). New York: Springer.

Goldenberg, H., & Goldenberg, I. (1990). *Counseling today's families.* Pacific Grove, CA: Brooks Cole.

Goodman, C., & Silverstein, M. (2002). Grandmothers raising grandchildren: Family structure and well-being in culturally diverse families. *The Gerontologist, 42,* 676-689.

Grant, R. (2000). The special needs of children in kinship care. *Journal of Gerontological Social Work, 33,* 17-38.

Guralnick, M. J. (1997). *The effectiveness of early intervention.* Baltimore, MD: Brookes.

Hartman, A., & Laird, J. (1987). Family practice. In A. Minahan (Ed.), *Encyclopedia of Social Work* (pp. 575-589). Silver Spring, MD: National Association of Social Workers.

Hastings, R. (2002). Parental stress and behavior problems of children with developmental disability. *Journal of Intellectual and Developmental Disability, 27,* 149-160.

Hastings, R. P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and expressed emotion: Cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *American Journal on Mental Retardation, 111,* 48-61.

Hayes, A. (1996). Family life in community context. In B. Stratford & P. Gunn (Eds.), *Approaches to Down syndrome* (pp. 367-404). London: Cassell.

Hayslip, B., & Goldberg-Glen, R. (2000). *Grandparents raising grandchildren: Theoretical, empirical, and clinical perspectives*. New York: Springer Publishing.

Hayslip, B., & Hicks Patrick, J. (2006). *Custodial grandparenting: Individual, cultural, and ethnic diversity*. New York: Springer.

Hayslip, B., & Kaminski, P. L. (2005a). Grandparents raising their grandchildren. In R. K. Caputo (Ed.), *Challenges of aging on U. S. families: Policy and practice implications* (pp. 147-169). Binghamton, NY: Hayworth Press.

Hayslip, B., & Kaminski, P. L. (2005b). Grandparents raising their grandchildren: A review of the literature and suggestions for practice. *The Gerontologist, 45,* 262-269.

Hayslip, B., & Kaminski, P. (2008). *Parenting the custodial grandchild: Implications for clinical practice.* New York: Springer.

Hayslip, B., King, J. K., & Jooste, J. L. (2008). Grandchildren's difficulties and strengths impact the mental health of their grandparents. In B. Hayslip & P. Kaminski (Eds.), *Parenting the custodial grandchild: Implications for clinical practice* (pp. 53-74). New York: Springer.

Hayslip, B., & Shore, R. J. (2000). Custodial grandparenting and mental health. *Journal of Mental Health and Aging, 6,* 367-384.

Hayslip, B., Shore, R. J., Henderson, C. E., & Lambert, P. L. (1998). Custodial grandparenting and the impact of grandchildren with problems on role satisfaction and role meaning. *Journal of Gerontology: Social Sciences*, *53,* S164-S173.

Hayslip, B., Temple, J. R., Shore, R. J., & Henderson, C. E. (2006). Determinants of role satisfaction among traditional and custodial grandparents. In B. Hayslip & J. Hicks Patrick (Eds.), *Custodial grandparenting: Individual, cultural, and ethnic diversity* (pp. 21-36). New York: Springer.

Hobbs, N., Dokecki, P. R., Hoover-Dempsey, K. V., Moroney, R. M., Shayne, M. W., & Weeks, K. H. (1984). *Strengthening families.* San Francisco, CA: Jossey-Bass.

Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the Beach Center Family Quality of Life Scale. *Journal of Marriage and Family, 68,* 1069-1083.

Hughes, R. S. (1999). An investigation of coping skills of parents of children with disabilities: Implications for service providers. *Education and Training in Mental Retardation and Developmental Disabilities, 34,* 271-280.

Individuals with Disabilities Education Improvement Act of 2004, 20 U. S. C. ~ 1400 *et seq*. (2004) (reauthorization of the Individuals with Disabilities Act of 1990).

Janicki, M. P., McCallion, P., Grant-Griffin, L., & Kolomer, S. R. (2000). Grandparent caregivers I: Characteristics of the grandparents and the children with disabilities they care for. *Journal of Gerontological Social Work, 33,* 41-62.

Jendrek, M. (1993). Grandparents who parent their grandchildren: Effects on lifestyle. *Journal of Marriage and the Family, 55,* 609-621.

Jendrek, M. P. (1994). Grandparents who parent their grandchildren: Circumstances and decisions. *The Gerontologist, 34*, 206-216.

Kelley, S. J. (1993). Caregiver stress in grandparents raising grandchildren. *IMAGE: Journal of Nursing Scholarship, 25,* 331-337.

Kelley, S. J., Whitley, D., & Sipe, T. A. (2007). Results of an interdisciplinary intervention to improve the psychosocial well-being and physical functioning of African American grandmothers raising grandchildren. *Journal of Intergenerational Relationships, 5*, 45-64.

Kelley, S. J., Whitley, D. M., Sipe, T. A., & Yorker, B. C. (2000). Psychological distress in grandmother kinship care providers: The role of resources, social support, and physical health. *Child Abuse and Neglect, 24,* 311-321.

Kelley, S. J., Yorker, B. C., & Whitley, D. (1997). To grandma's house we go….and stay. *Journal of Gerontological Nursing, 12*, 13-20.

Kelley, S. J., Yorker, B. C., Whitley, D., & Sipe, T. A. (2001). A multi-modal intervention for grandparents raising grandchildren: Results of a pilot study. *Child Welfare, 80*, 27-50.

King, J., Hayslip, B., & Kaminski, P. (2006). Variability in the need for formal and informal social support among grandparent caregivers: A pilot study. In B. Hayslip & J. Hicks Patrick (Eds.), *Custodial grandparenting: Individual, cultural, and ethnic diversity* (pp. 55-74). New York: Springer.

King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family-centered caregiving and well-being of parents of children with disabilities: Linking process to outcome. *Journal of Pediatric Psychology, 24,* 41-53.

Knox, M., Parmenter, T. R., Atkinson, N., & Yazbeck, M. (2000). Family control: The views of families who have a child with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 13,* 17-28.

Kolomer, S., McCallion, P., & Janicki, M. P. (2002). African-American grandmother carers of children with disabilities: Preliminary comparisons. *Journal of Gerontological Social Work, 33,* 45-63.

Kolomer, S., McCallion, D., & Overeynder, J. (2003). Why support groups help: Successful interventions for grandparent caregivers of children with developmental disabilities. In B. Hayslip & J. Hicks Patrick (Eds.), *Working with custodial grandparents* (pp. 111-126). New York: Springer.

Kraus, M. W., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family settings: Positive and negative aspects of residential status. *Journal of Intellectual Disability Research, 49,* 111-124.

Landry-Meyer, L. (1999). Research into action: Recommendations and intervention strategies for grandparent caregivers. *Family Relations, 48,* 381-391.

Landry-Meyer, L., Gerard, J. M., & Guzell, J. R. (2005). Caregiver stress among grandparents raising grandchildren: The functional role of social support. *Marriage and Family Review, 37,* 171-190.

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behavior problems on caregiver stress in young children with autism spectrum disorders. *Journal of Intellectual Disability Research, 50,* 172-183.

Mannan, H., Summers, J. A., Turnbull, A. P., & Poston, D. J. (2006). A review of outcome measures in early childhood programs. *Journal of Policy and Practice in Intellectual Disabilities, 3,* 219-228.

McCallion, P., Janicki, M., Grant-Griffin, L., & Kolomer, S. R. (2000). Grandparent caregivers II: Service needs and service provision issues. *Journal of Gerontological Social Work, 33,* 63-90.

McCallion, P., Janicki, M., & Kolomer, S. R. (2004). Controlled evaluation of support groups for grandparent caregivers of children with developmental disabilities and delays. *American Journal on Mental Retardation*, *109*, 352-361.

McCubbin, H., Joy, C., Cauble, A., Comeau, J., Patterson, J., & Needle, R. (1980). Family stress, coping, and social support: A decade review. *Journal of Marriage and the Family, 42,* 855-871.

McKinney, J., McGrew, K., & Nelson, I. (2003). Grandparent caregivers to children with developmental disabilities: Added challenges. In B. Hayslip & J. Hicks Patrick (Eds.), *Working with custodial grandparents* (pp. 93-110). New York: Springer.

Merriwether-deVries, C., Burton, L. M., & Eggelletion, L. (1996). Early parenting and intergenerational family relationships within families. In J. Graber, J. Brooks-Gunn, & A. C. Petersen (Eds.), *Transitions through adolescence.* Mahwah, NJ: Lawrence Erlbaum.

Minkler, M., Driver, D., Roe, K. M., & Bedeian, K. (1993). Community interventions to support grandparent caregivers. *The Gerontologist, 38,* 807-811.

Minkler, M., & Fuller-Thomson, E. (1999). The health of grandparents raising grandchildren: Results of a national study. *American Journal of Public Health, 89,* 1384-1390.

Minkler, M., Fuller-Thomson, E., Miller, D., & Driver, D. (1997). Depression in grandparents raising grandchildren. *Archives of Family Medicine, 6,* 445-452.

Minkler, M., Fuller-Thomson, E., Miller, D., & Driver, D. (2000). Grandparent caregiving and depression. In B. Hayslip & R. Goldberg-Glen (Eds.), *Grandparents raising grandchildren: Theoretical, empirical, and clinical perspectives* (pp. 207-220). New York: Springer.

Minkler, M., & Roe, K.M. (1993). Grandmothers as caregivers: Raising children of the crack cocaine epidemic. *Family Caregiver Applications Series: Volume 2*. Newbury Park, CA: Sage.

Minkler, M., Roe, K. M., & Price, M. (1992). The physical and emotional health of grandmothers raising grandchildren in the crack cocaine epidemic. *The Gerontologist, 32,* 5752-5761.

Minkler, M., Roe, K. M., & Robertson-Berkeley, R. J. (1994). Raising grandchildren from crack-cocaine households: Effects on family and friendship ties of African-American women. *American Journal of Orthopsychiatry, 64,* 20-29.

Minuchin, S. (1974). *Families and family therapy.* Cambridge, MA: Harvard University Press.

Musil, C. (1998). Health, stress, coping, and social support in grandmother caregivers. *Health Care for Women International, 19,* 101-114.

Musil, C., & Ahn, S. (1997). *Grandmothers raising grandchildren: Is support linked to depression?* Paper presented at the meeting of the Gerontological Society of America, Cincinnati.

Musil, C., Schrader, S., & Mutikani, J. (2000). Social support, stress, and the special coping tasks of grandmother caregivers. In C. Cox (Ed.), *To grandmother's house we go and stay: Perspectives on custodial grandparents* (pp. 56-70). New York: Springer.

Park, J., Hoffman, L., Marquis, J., Turnbull, A., Poston, D., Mannan, H., et al. (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research, 47,* 367-384.

Park, J., Turnbull, A. P., & Turnbull, H. R. (2002). Impacts of poverty on quality of life in families of children with disabilities. *Exceptional Children, 68,* 151-170.

Pew Research Center (2010). Pew Research Center analysis of Decennial Census and American Community Survey Data. Retrieved October 30, 2011, from pewresearch.org/pubs/1724/sharp-increase-children-with-grandparent-caregivers.

Pinson-Millburn, N. M., Fabian, E. S., Schlossberg, N. K., & Pyle, M. (1996). Grandparents raising grandchildren. *Journal of Counseling and Development, 74,* 548-555.

Porterfield, J., Dressel, P., & Barnhill, S. (2000). Special situations of incarcerated parents. In C. Cox (Ed.), *To grandmother's house we go and stay: Perspectives in custodial grandparents.* New York: Springer.

Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life: A qualitative study. *Mental Retardation, 41,* 313-328.

Pruchno, R. (1999). Raising grandchildren: The experience of black and white grandmothers. *The Gerontologist, 39,* 209-221.

Purcell, M. L., Turnbull, A. P., & Jackson, C. W. (2006). Linking early childhood inclusion and family quality of life: Current literature and future directions. *Young Exceptional Children, 9,* 11-19.

Racicot, L. (2003). *Understanding the needs and issues of grandfamilies: A survey of grandparents raising grandchildren.* Paper presented at the Society for Research on Child Development Biennial Meeting. University of Massachusetts-Amherst.

Rehabilitation Act of 1973, Pub. L. No. 93-112 ~ 104 *et seq*. (1973).

Roach, M. A., & Orsmond, G. I. (1999). Mothers and fathers of children with Down syndrome: Parental stress and involvement in childcare. *American Journal on Mental Retardation, 104,* 422-436.

Roberto, K. A., & Qualls, S. H. (2003). Intervention strategies for grandparents raising grandchildren: Lessons learned from caregiving literature. In B. Hayslip & J. Hicks Patrick (Eds.), *Working with custodial grandparents* (pp. 13-26). New York: Springer.

Roberto, K., Richter, J., Bottenberg, D., & MacCormack, R. (1992). Provider/client views: Health-care needs of the rural elderly. *Journal of Gerontological Nursing, 18,* 31-37.

Robinson, M. M., Kropf, N. P., & Myers, L. L. (2000). Grandparents raising grandchildren in rural communities. *Journal of Mental Health and Aging, 6*, 353-365.

Roe, K. M., Minkler, M., Saunders, F. F., & Thompson, G. (1996). Health of grandmothers raising children of the crack cocaine epidemic. *Medical Care, 34,* 1072-1084.

Ross, M. E., & Aday, L. (2006). Stress and coping in African American grandparents who are raising their grandchildren. *Journal of Family Issues, 27*, 912-932.

Sands, R. G., & Goldberg-Glen, R. S. (1998). Impact of employment and serious illness on grandmothers who are raising their grandchildren. *Journal of Women and Aging, 10,* 41-58.

Sands, R. G., & Goldberg-Glen, R. S. (2000). Factors associated with stress among grandparents raising their grandchildren. *Family Relations, 49,* 97-105.

Schalock, R. L., & Alonso, M. A. V. (2002). *Handbook on quality of life for human service practitioners.* Washington, DC: American Association on Mental Retardation.

Scorgie, K., Wilgosh, L., & McDonald, L. (1998). Stress and coping in families of children with disabilities: An examination of recent literature. *Developmental Disabilities Bulletin, 26,* 22-42.

Seligman, M., & Darling, R. B. (2007). *Ordinary families, special children: A systems approach to childhood disability.* New York: Guilford Press.

Shore, R. J., & Hayslip, B. (1990). *Comparisons of custodial and non-custodial grandparents.* Paper presented at the Gerontological Society of America, Boston.

Shore, R. J., & Hayslip, B. (1994). Custodial grandparenting: Implications for children's development. In A. Gottfried & A. Gottfried (Eds.), *Redefining families: Implications for children's development.* New York: Plenum.

Silverstein, N., & Vehvilainen, L. (2000). Grandparents and schools: Issues and potential challenges. In C. Cox (Ed.), *To grandmother's house we go and stay: Perspectives on custodial grandparents* (pp. 268-282). New York: Springer.

Simmons, T., & Dye, J. I. (2003). *Grandparents living with children: 2000* (Census 2000 Brief Report C2KBR-31). Washington, DC: U.S. Census Bureau

Smith, C. J., Beltran, A., Butts, D. M., & Kingson, E. R. (2000). Grandparents raising grandchildren. *Journal of Gerontological Social Work, 34*, 81-94.

Smith, A. B., & Dannison, L. L. (2002). Educating educators: Programming to support grandparent-headed families. *Contemporary Education, 72,* 47-51.

Smith, A. B., & Dannison, L. L. (2008). Preschool children and caregiving grandparents: Enhancing family strengths. In B. Hayslip & P. Kaminski (Eds.), *Parenting the custodial grandchild: Implications for clinical practice* (pp. 237-250). New York: Springer.

Smith, G. C., & Palmieri, P. A. (2007). Risk of psychological difficulties among children raised by custodial grandparents. *Psychiatric Services, 58,* 1303-1310.

Smith-Bird, E., & Turnbull, A. P. (2005). Linking positive behavior support to family quality-of-life outcomes. *Journal of Positive Behavior Interventions, 7,* 174-180.

Solomon, J. C., & Marx, J. (2000). The physical, mental, and social health of custodial grandparents. In B. Hayslip & R. Goldberg-Glen (Eds.), *Grandparents raising grandchildren: Theoretical, empirical, clinical perspectives* (pp. 183-207). New York: Springer.

Stoneman, Z., & Brody, G. H. (1984). Research with families of severely handicapped children: Theoretical and methodological considerations. In J. Blacher (Ed.), *Severely handicapped young children and their families* (pp. 179-214). New York: Academic Press.

Strom, R. D., & Strom, S. K. (2000). Meeting the challenge of raising grandchildren. *International Journal of Aging and Human Development, 51,* 183-198.

Summers, J. A., Poston, D. J., Turnbull, A. P., Marquis, J., Hoffman, L., Mannan, H., et al. (2005). Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research, 49,* 777-783.

Szinovacz, M. (1998). Grandparents today: A demographic profile. *The Gerontologist, 38,* 37-52.

Tabachnick, B. G., & Fidell, L. S. (2007). *Using multivariate statistics* (5th ed.). Boston, MA: Pearson.

Thomas, J. L., Sperry, L., & Yarbrough, M. S. (2000). Grandparents as parents: Research findings and policy recommendations. *Child Psychiatry and Human Development, 31*, 3-22.

Trivette, C. M., & Dunst, C. J. (1992). Characteristics and influences of role division and social support among mothers of handicapped preschoolers. *Topics in Early Childhood Special Education, 12*, 367-385.

Turbin, S. (1993). A nursing success story: Moral support for grandparents who care. *American Journal of Nursing, April,* 52-56.

Turnbull, H. R., Beegle, G., & Stowe, M. J. (2001). The core concepts of disability policy affecting families who have children with disabilities. *Journal of Disability Policy Studies, 12,* 133-143.

Turnbull, A. B., Blue-Banning, M., Turbiville, V., & Park, J. (1999). From parent education to partnership education: A call for a transformed focus. *Topics in Early Childhood Special Education, 19,* 164-172.

Turnbull, A. P., Brown, I., & Turnbull, H. R. (2004). *Families and people with mental retardation and quality of life: International perspectives.* Washington, DC: American Association on Mental Retardation.

Turnbull, A. P., Summers, J. A., Lee, S. H., & Kyzar, K. (2007). Conceptualization and measurement of family outcomes associated with families of individuals with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13,* 346-356.

Turnbull, A. P., & Turnbull, H. R. (1990). *Families, professionals, and exceptionality: A special partnership* (2nd ed.). New York: Merrill.

Turnbull, A. P., & Turnbull, H. R. (2005). *Families, professionals, and exceptionality: Collaborating for empowerment* (5th ed.). Upper Saddle River, NJ: Merrill.

Turnbull, A. P., Turnbull, H. R., Erwin, E., & Soodak, L. (2006). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust.* Upper Saddle River, NJ: Merrill/Prentice Hall.

U. S. Bureau of the Census (2001a). *Census 2000 Supplemental Survey: Profile of selected social characteristics.* Washington, DC: U.S. Bureau of the Census.

U. S. Bureau of the Census. (2001b). *Coresident grandparents and grandchildren.* Retrieved July 20, 2009, from http://www.census.gov.

U.S. Bureau of the Census (2003). *Grandparents living with grandchildren: 2000.* Retrieved February 21, 2009 from http://www.census.gov/prod/2003pubs/c2kbr-31.pdf

U. S. Bureau of the Census (2005-2007). American Community Survey (ACS) Subject Table S1002, Grandparents. Retrieved April 6, 2010 from http://www.factfinder.census.gov.

Waldrop, D., & Weber, J. A. (2001). From grandparent to caregiver: The stress and satisfaction of raising grandchildren. *Families in Society: The Journal of Contemporary Human Services, 82,* 461-472.

Wang, M., Turnbull, A. P., Summers, J. A., Little, T. D., Poston, D. J., Mannan, H., et al. (2004). Severity of disability and income as predictors of parents' satisfaction with their family quality of life during early childhood years. *Research and Practice for Persons with Severe Disabilities, 29,* 82-94.

Werner, S., Edwards, M., Baum, N., Brown, I., Brown, R. I., & Isaacs, B. J. (2009). Family quality of life among families with a member who has an intellectual disability: An

exploratory examination of key domains and dimensions of the revised FQOL survey. *Journal of Intellectual Disability Research, 56,* 501-511.

Williamson, J., Softas-Nall, B., & Miller, J. (2003). Grandmothers raising grandchildren: An exploration of their experiences and emotions. *Family Journal, 11,* 23-32.

Whitechurch, G. G., & Constantine, L. L. (1993). Systems theory. In P. G. Boss, W. J. Boherty, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.), *Sourcebook of family theories and methods: A contextual approach* (pp. 325-352). New York: Plenum.

Whitley, D. M., & Kelley, S. (2008). Developmental screening and evaluation results of young African American grandchildren raised by grandparents: Thoughts for research and practice. *Arete, 32,* 38-57.

Whitley, D. M., Kelley, S. J., & Sipe, T. A. (2001). Grandmothers raising grandchildren: Are they at increased risk of health problems? *Health and Social Work, 26,* 105-114.

Whitley, D. M., White, K. R., Kelley, S. J., & Yorker, B. (1999). Strengths-based case management: The application to grandparents raising grandchildren. *Families in Society, March-April*, 110-119.

Wohl, E., Lahner, J., & Jooste, J. (2003). Group processes among grandparents raising grandchildren. In B. Hayslip & J. Hicks Patrick (Eds.), *Working with custodial grandparents* (pp. 195-212). New York: Springer.

Woodworth, R. S. (1996). You're not alone…You're one in a million. *Child Welfare, 75,* 619-635.

Yau, M. K., & Li-Tang, C. W. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes. *British Journal of Developmental Disability, 45,* 38-51.

Ylven, R., Bjorck-Akesson, E., & Granlund, M. (2006). Literature review of positive functioning in families with children with a disability. *Journal of Policy and Practice in Intellectual Disabilities, 3,* 253-270.

Zeitlin, S., & Rosenblatt, W. P. (1985). *Family stress: A coping model for intervention.* Paper presented at the annual convention of the Council for Exceptional Children, Anaheim, CA. (ERIC Document Reproduction Service No. ED258388).

Zuna, N., Selig, J. P., Summers, J. A., & Turnbull, A. P. (2009). Confirmation factor analysis of a FQOL scale for families of kindergarten children without disabilities. *Journal of Early Intervention, 31,* 111-125.

Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., & Xu, S. (2009). Theorizing about family quality of life. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disability: From theory to practice.* Dordrecht, The Netherlands: Springer.

Zuna, N., Turnbull, A., & Summers, J. A. (2009). Family quality of life: Moving from measurement to application. *Journal of Policy and Practice in Intellectual Disabilities, 6,* 25-31.

APPENDIXES

APPENDIX A

Invitation to Grandmothers Raising Young Grandchildren

You are invited to participate in a research study on the sources of support and family quality of life of grandmothers raising young grandchildren ages 3-12 years. Participation in this study may not benefit you personally, but overall we hope to gain valuable information about ways to better serves families raising grandchildren. There will be convenient meeting times in your area. Participation will only take about 30 minutes of your time. A $10.00 gift card will be given for completed surveys.

For more information, please contact:
Karen Kresak
Georgia State University
Dept. of Educational Psychology and Special Education
Atlanta, GA 30303
Phone: 770-598-2019
Email: kkresak1@student.gsu.edu

Permission to Contact

_____ I am not interested, please do not contact me.

_____ Yes, I am interested in being part of the study.

You may contact me at:

Name: ____

Address: ____

City: _____________________ Zip: ___________ County:__________________

Phone numbers: ____

Email: ____

Signature: ____

APPENDIX B

Georgia State University
Department of Educational Psychology and Special Education
Informed Consent

Title: Grandmothers Raising Young Children With and Without Disabilities

Principal Investigator: Peggy Gallagher, Georgia State University
Student Investigator: Karen Kresak, Georgia State University

I. Purpose:

You are invited to participate in a research study. The purpose of the study is to investigate the sources of support and quality of life of families raising young grandchildren. You are invited to participate because you are raising a young grandchild. A total of 50 participants will be recruited for this study. Participation will require 30 minutes of your time over one interview session.

II. Procedures:

If you decide to participate, you will fill out surveys with the researcher. The interview session will take place at a time and location that is convenient to you. There will be only one interview session. The session will last 30 minutes. You will be given a $10.00 gift card after the surveys are completed.

III. Risks:

In this study, you will not have any more risks than you would in a normal day of life.

IV. Benefits:

Participation in this study may not benefit you personally. Overall, we hope to gain information about better ways to serve families raising grandchildren with and without disabilities.

V. Voluntary Participation and Withdrawal:

Participation in research is voluntary. You do not have to be in this study. If you decide to be in this study and change your mind, you have the right to drop out at any time. You may skip

questions or stop participating at any time. Whatever you decide, you will not lose any benefits to which you are otherwise entitled.

VI. Confidentiality:

We will keep your records private to the extent allowed by law. Peggy Gallagher and Karen Kresak will have access to the information you provide. Information may also be shared with those who make sure the study is done correctly (GSU Institutional Review Board, the Office for Human Research Protection (OHRP), and/or the Food and Drug Administration (FDA)). We will use a study number rather than your name on study records. The information you provide will be stored in a locked cabinet in the Department of Educational Psychology and Special Education office. A code sheet that identifies you will be stored separately from the data in order to protect your privacy. The code sheet will be destroyed after the study is completed. Your name and other facts that might point to you will not appear when we present this study or publish its results. The findings will be summarized and reported in group form. You will not be identified personally.

VII. Contact Persons:

Contact Peggy Gallagher at 404-413-8041 or Karen Kresak at 770-598-2019 or kkresak1@student.gsu.edu if you have questions about this study. If you have questions or concerns about your rights as a participant in this research study, you may contact Susan Vogtner in the Office of Research Integrity at 404-413-3513 or svogtner1@gsu.edu.

VIII. Copy of Consent Form to Subject:

We will give you a copy of this consent form to keep.

If you are willing to volunteer for this research, please sign below.

____ ____________________
Participant Date

____ ____________________
Principal Investigator or Researcher Obtaining Consent Date

APPENDIX C

Family Support Scale

Carl J. Dunst, Carol M. Trivette, and Vicki Jenkins

Name_______________________________ Date_______________

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

How ***helpful*** has each of the following been to you in terms of raising your child(ren)?	Not Available	Not at All Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
1. My parents	NA	1	2	3	4	5
2. My spouse or partner's parents	NA	1	2	3	4	5
3. My relatives/kin	NA	1	2	3	4	5
4. My spouse or partner's relatives/kin	NA	1	2	3	4	5
5. My spouse or partner	NA	1	2	3	4	5
6. My friends	NA	1	2	3	4	5
7. My spouse or partner's friends	NA	1	2	3	4	5
8. My older child(ren)	NA	1	2	3	4	5
9. Neighbors	NA	1	2	3	4	5
10. Other parents	NA	1	2	3	4	5
11. Co-workers	NA	1	2	3	4	5
12. Parent group members	NA	1	2	3	4	5
13. Social groups/clubs	NA	1	2	3	4	5
14. Church members/minister	NA	1	2	3	4	5
15. My family or child's physician	NA	1	2	3	4	5
16. Early childhood intervention program	NA	1	2	3	4	5
17. School/daycare center	NA	1	2	3	4	5
18. Professional helpers (social workers, therapists, teachers, etc.)	NA	1	2	3	4	5
19. Professional agencies (public health, social services, mental health, etc.)	NA	1	2	3	4	5
20. ____________________	NA	1	2	3	4	5
21. ____________________	NA	1	2	3	4	5

Family Support Scale: Reliability and Validity (8614) provided courtesy of the Winterberry Press
www.WBPress.com

APPENDIX D

FAMILY QUALITY OF LIFE (cont.)

How satisfied am I that...	*Very Dissatisfied*	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
1. My family enjoys spending time together.	☐	☐	☐	☐	☐
2. My family members help the children learn to be independent.	☐	☐	☐	☐	☐
3. My family has the support we need to relieve stress.	☐	☐	☐	☐	☐
4. My family members have friends or others who provide support.	☐	☐	☐	☐	☐
5. My family members help the children with schoolwork and activities.	☐	☐	☐	☐	☐
6. My family members have transportation to get to the places they need to be.	☐	☐	☐	☐	☐
7. My family members talk openly with each other.	☐	☐	☐	☐	☐
8. My family members teach the children how to get along with others.	☐	☐	☐	☐	☐
9. My family members have some time to pursue our own interests.	☐	☐	☐	☐	☐
10. Our family solves problems together.	☐	☐	☐	☐	☐
11. My family members support each other to accomplish goals.	☐	☐	☐	☐	☐
12. My family members show that they love and care for each other.	☐	☐	☐	☐	☐
13. My family has outside help available to us to take care of special needs of all family members.	☐	☐	☐	☐	☐
14. Adults in our family teach the children to make good decisions.	☐	☐	☐	☐	☐

FAMILY QUALITY OF LIFE (cont.)

How satisfied am I that...	*Very Dissatisfied*	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
15. My family gets medical care when needed.	☐	☐	☐	☐	☐
16. My family has a way to take care of our expenses.	☐	☐	☐	☐	☐
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	☐	☐	☐	☐	☐
18. My family is able to handle life's ups and downs.	☐	☐	☐	☐	☐
19. Adults in my family have time to take care of the individual needs of every child.	☐	☐	☐	☐	☐
20. My family gets dental care when needed.	☐	☐	☐	☐	☐
21. My family feels safe at home, work, school, and in our neighborhood.	☐	☐	☐	☐	☐
22. My family member with a disability has support to accomplish goals at school or at workplace.	☐	☐	☐	☐	☐
23. My family member with a disability has support to accomplish goals at home.	☐	☐	☐	☐	☐
24. My family member with a disability has support to make friends.	☐	☐	☐	☐	☐
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	☐	☐	☐	☐	☐

Thank you! You have finished completing this survey. Please make sure you erase any extra marks and have answered all the questions.

Note: Beach Center on Disability (2006). Beach Center Family Quality of Life Scale. Retrieved from http://www.beachcenter.org/toolkit/default.asp?act=fql.

APPENDIX E

ID#: ______________________

Sources of Support and Quality of Life of Grandmothers Raising Young Grandchildren

1. What county do you live in? ________________________

2. What is your age? __________________

3. What is the highest grade you have completed?

   ____5th ____6th ____7th ____8th ____9th ____10th ____11th
   ____High school graduate or GED (12th)
   ____Some college/technical school
   ____ 1 year (13th)
   ____ 2 years (14th)
   ____ 3 years (15th)
   ____College graduate (16th)
   ____Some graduate school
   ____ 1 year (17th)
   ____Graduate degree (18th)
   ____Other

4. What is your race/ethnicity?
   ____Native American ____Caucasian ____Asian ____Multiracial

   ____African American ____Hispanic ____Other (specify)____________

5. What is your marital status?
   ____Married
   ____Widowed
   ____Divorced
   ____Single/never married

6. Is there another adult (over the age of 18) present in the home?
   ____Yes
   ____No

If yes, please answer the following question:

7. Does the adult help care for the grandchildren?
   _____ Yes _____ No

8. What is your work status?
   ____Working full-time
   ____Working part-time
   ____Retired
   ____Full-time Homemaker
   ____Other

9. What is your household income?
   ____Less than $15,000
   ____Between $15,001-20,000
   ____Between $20,001-30,000
   ____Between $30,001-40,000
   ____Between $40,001-50,000
   ____Over $50,000

10. How long have you been the primary caregiver? ___________________________

11. How many grandchildren live in your household? _________________________

12. How long have your grandchildren been living in your household? ___________

13. What are the ages and gender of the grandchildren who live in your household?

    Age_______ _____Male _____Female

    Age _______ _____Male _____Female

    Age _______ _____Male _____Female

    Age _______ _____Male _____Female

14. Do any of your grandchildren who live in your household have special needs?
    ____Yes ____No

    If yes, please circle the child with special needs in Question 13 and answer the following questions:

15. Which area best describes your grandchild's special needs?
    ____Blind/Low Vision
    ____Deaf/Hard of Hearing
    ____Cerebral Palsy
    ____Down Syndrome
    ____Seizure Disorder
    ____Spina Bifida
    ____Autism/PDD
    ____Fragile X

____Orthopedic Impairment
____Speech/Language Impairment
____Behavior Disorder
____Genetic Disorder
____ADHD/ADD
____Fetal Alcohol Syndrome
____Other Health Impairment
____Other (specify)____________________________________

16. What is the severity of your grandchild's disability?
____Mild
____Moderate
____Severe
____Very Severe
____Unknown

APPENDIX F

Family Quality of Life Survey

This survey is about how you feel about your life together as a family.

Your “family” may include many people – mother, father, partners, children, aunts, uncles, grandparents, etc.

For this survey, please consider your family as those people:

-who think of themselves as part of your family (even though they may or may not be related by blood or marriage), and

-who support and care for each other **on a regular basis.**

For this survey, please **do not** think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past 12 months.

The items on the survey are things that hundreds of families have said are important for a good family quality of life. I want to know how **satisfied** you are with these things in your family.

APPENDIX G

Your help is truly appreciated.

If you wish to contact the researcher, you can do so at:

Karen Kresak

Georgia State University

Phone: 770-598-2019

APPENDIX H

NON-COMMERCIAL COPYRIGHT LICENSE AGREEMENT

This Agreement made the 20th day of November, 2009, by and between Smoky Mountain Research Institute, Inc. d/b/a Winterberry Press ("Licensor") and Karen Kresak ("Licensee").

THE LICENSOR AND LICENSEE AGREE THAT:

1. Rights Granted

The Licensor grants to the Licensee for the full term of this Agreement the non-exclusive right to copy the content described as: Family Support Scale: Reliability and Validity (8614) Published by Smoky Mountain Research Institute, Inc. d/b/a Winterberry Press (hereinafter called "Licensed Material") for incorporation into: Student Thesis: SOURCES OF SUPPORT AND FAMILY QUALITY OF LIFE OF GRANDPARENTS RAISING GRANDCHILDREN WITH AND WITHOUT DISABILITIES (hereinafter called the "Work") and to reproduce and distribute the Licensed Material through the following outlet(s): Internal Academic distribution to fulfill degree requirements.
The rights granted under this Agreement shall be granted worldwide (the "Territory").

2. Licensee's Rights and Obligations

Licensee shall be solely responsible for providing all funding and technical expertise for the development and marketing of the Work. Licensee shall be the sole owner of the Work and all proprietary rights in and to the Work; except, such ownership shall not include ownership of the copyright in and to the Licensed Material or any other rights to the Licensed Material not specifically granted in Section 1 above. Licensee will also provide Licensor with a complete copy of final thesis and a copy of translated Family Support Scale: Reliability and Validity (8614) for review.

3. Fees

Licensor shall waive any license fee for approved, academic use. Transfer or any other use of copyright licences will require a review prior to such use.

4. Credit & Samples

All versions of the Work that include the Licensed Material shall contain complete credit with the Licensed Material the following legible content: Family Support Scale: Reliability and Validity (8614) provided courtesy of the Winterberry Press www.WBPress.com. This will be included in the footnote for the material and in publication credits. Upon publication, Licensee shall furnish one copy of the compete Work to Licensor. The preferred format for all samples is unlocked Acrobat PDF.

5. Specific Restrictions on Use of Licensed Material

Licensed Material is solely for the use of the Licensee. Licensee shall not modify, copy, distribute, transmit, display, perform, reproduce, publish, license, create derivative works from, sublicense, transfer, assign, rent, sell or otherwise convey Licensed Material obtained from Licensor in any way not specifically granted in Section 1 above without the prior written consent from Licensor. Licensee shall not remove, obscure or modify any copyright or other notices included in the Licensed Material. Licensee shall not use Licensed Material for any purpose that is unlawful or prohibited by these Terms of Use. Other than as specifically permitted in this Agreement, Licensee shall not use the Licensed Material for any commercial purpose, including but not limited to the sale of the Licensed Material.

6. Governing Law and Forum
This Agreement shall be governed according to the laws of the State of North Carolina U.S.A, International Copyright agreements and all other applicable laws, applicable to agreements made and to be wholly performed therein.

7. Assignment and Transfer
The Licensee may not assign, directly or indirectly, all or part of its rights or obligations under this Agreement without the prior written consent of the Licensor, which consent shall not be unreasonably withheld or delayed.

IN WITNESS WHEREOF, the parties have duly executed this Agreement as of the date first written above.
Licensor:
Smoky Mountain Research Institute, Inc.
dba Winterberry Press
Address: 128 S. Sterling St. Morganton, NC 28655-3473
FAX: 828-255-9035

Licensee:
Karen Kresak
1559 Twin Courts Lane
Marietta, GA 30008
770-437-9213 (home)
770-598-2019 (cell)
Doctoral Student
Georgia State University
Major advisor: Peggy Gallagher

Signature: Karen Kresak

Address: 1559 Twin Courts Ln. Marietta, GA 30008
Telephone: 770)437-9213

For Licensor: Bruce Baughman
Bruce Baughman
General Manager
Winterberry Press

APPENDIX I

FW: FQOL scale

Summers, Jean Ann [jsummers@mail.ku.edu]

You replied on 1/4/2010 6:00 PM.

Sent: Monday, June 01, 2009 6:57 AM

To: Karen Kresak

Attachments: FQOL JMF 2006.pdf (132 KB)[Open as Web Page]; KS Impact Study.pdf (271 KB)[Open as Web Page]; FQOL Survey.pdf (118 KB)[Open as Web Page]

Thank you for your request to use our Beach Center Family Quality of Life Scale.

I am attaching a pdf file with the scale, along with a couple of articles describing the psychometric properties and an application. As you know, we are granting permission for you to use our scale at no cost, with the provision that you provide proper credit and referencing in any reports you develop from the use of our measures. Also, if you decide to use the scale, we hope you will be willing to share the results of your study with us. We want to continue compiling evidence about the validity and other characteristics of our measures.

Thank you again for your interest. Please keep us posted about the progress of your research.

Jean Ann Summers, Ph.D.
Research Professor,
Schiefelbusch Institute for Lifespan Studies
Research Director
Beach Center on Families and Disability
University of Kansas
1200 Sunnyside, Room 3144
Lawrence, Kansas 66045
Phone: 785-864-7602
Fax: 785-864-7605
e-mail: jsummers@ku.edu