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**GRANDPARENT SUPPORT AND THE FAMILY
WITH A CHILD WITH A DISABILITY**

By

Laureen Coutts-Clarke

B.S. The University of Maine, 1996

A THESIS

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Master of Science

(in Human Development)

The Graduate School

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May, 2002

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By Laureen Coutts-Clarke

Thesis Advisor: Dr. Gary Schilmoeller

An Abstract of the Thesis Presented
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Grandparents (70) and parents (115) completed a survey about grandparent support, involvement, and helpfulness with grandchildren with disabilities. Grandparents reported on activities they did with their grandchildren and answered open-ended questions regarding who helped them learn about the grandchild's disability and what their general reaction was to the disability. Parents answered open-ended questions regarding what were the most and least helpful things that the grandparents did to help the grandchild with the disability. Grandparents' affectional solidarity was related positively to the number of activities they did with their grandchild. Grandparents reported that information and explanations about the disability were most useful in helping grandparents understand the grandchild's situation. Grandparents also identified professionals, parents and grandparents of other children with disabilities, and printed information about the disability as things they would have found helpful. Asked for general comments, grandparents

shared both optimism and concern about the grandchild's future and the stresses on the parents of the child. Parents listed instrumental (e.g., financial, childcare) and emotional (e.g., unconditional love, praying for the family) support of grandparents as most helpful. Least helpful things included grandparents overstepping boundaries with the parents or the grandchild, not providing any or only minimal help, not understanding the grandchild's disability, blaming the parent for the grandchild's disability, and being overprotective of the grandchild. The results provide information that can be of assistance in lending insight into what grandparents and parents may want and need in terms of dealing with a disabled child. Grandparents and parents needs are discussed, as are limitations of the study, and suggestions for future research.

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS.....	ii
LIST OF TABLES.....	vi
Chapter	
1. LITERATURE REVIEW.....	1
Introduction.....	1
The Family With a Child With a Disability and Grandparent Support: Benefits to the Parents and Child With a Disability.....	2
The Family With a Child With a Disability and Grandparent Support: Grandparents' Perspective and Adjustment Issues.....	8
Purpose of This Study.....	23
2. METHODS.....	25
Sample and Procedure.....	25
Instruments.....	26
Data Analysis.....	28
3. RESULTS.....	30
Grandparent Themes.....	35
Parent Themes.....	42
4. DISCUSSION.....	49
REFERENCES.....	65
APPENDIX. Grandparent Survey.....	74
BIOGRAPHY OF THE AUTHOR.....	84

LIST OF TABLES

Table 1 - Activities Grandparents Report Doing With or for Their Grandchild With a Disability.....	32
Table 2 - Percentage Inter-rater Agreement and Percentage of Grandparents Reporting Thematic Answers to Open-ended Questions.....	34
Table 3 - Percentage Inter-rater Agreement and Percentage of Parents Reporting Thematic Answers to Open-Ended Questions.....	43

Chapter 1

LITERATURE REVIEW

Introduction

To most parents and grandparents, the birth of a child is an eagerly awaited event. They entertain thoughts about who their offspring will resemble and what the child might achieve. Because of this ideal, no one is completely prepared to be the parent or grandparent of a child with a disability. Learning that one's child has a disability represents a major loss for all concerned (Bernier, 1990). With the loss of the ideal healthy child, family members move through the process of transitioning to the reality of having a child with a disability.

In recognition of the profound difficulty of coping with a child with a disability, a substantial amount of literature addresses the ways in which family networks adjust to raising a child with a disability (Bernier, 1990). Sandler, Warren and Raver (1995) refer to the child's grandparents as one potentially significant, yet often overlooked, member of the support network. They note that grandparents' support is positively correlated with paternal adjustment. Without paternal adjustment the child with a disability may suffer the consequence of not receiving complete support and nurturing from the parents. Grandparents can enhance the coping abilities of the entire family and can provide support to the parents, thereby alleviating stresses within the family network. As a result of grandparent support the parents have less stress and the child with a disability benefits greatly, as their living environment is more relaxed. In such an environment the child with a disability is able to develop feelings of security and self-confidence (George, 1988).

The Family With a Child With a Disability and Grandparent Support: Benefits to the Parents and Child With a Disability.

With the birth of a child with a disability, parents have to adjust every aspect of their life. During this time of rapid change and considerable family instability, the success of parents can be enhanced by a new partnership with grandparents; a cooperative relationship in which each party comes to rely on the strengths of the other (Curran, 1989; Elkind, 1990; Kornhaber, 1986; Morgan, 1987; Strom, Bernard, & Strom, 1989). Grandparents who are capable and willing, may be very facilitating in terms of relieving parental stress associated with a child who has a disability.

Grandparents may extend themselves through emotional means such as sharing coping strategies, advice regarding childrearing, and offering emotional support to the parents and grandchild. Grandparents may also assist in an instrumental manner by helping with household chores and errands, shopping, accessing helpful information, community resources and services related to disabilities, and providing childcare or respite (Gardner, Scherman, Mobley, Brown, & Schutter, 1994; Seligman & Darling, 1997; Vadasy, Fewell, & Meyer, 1986).

Sonnek (1986) reported that maternal grandmothers often help with shopping and gifts for special occasions. They also serve as playmates for their grandchild with a disability help out with the child's homework, and provide financial help when needed. Baranowski and Schilmoeller (1999) note that maternal grandmothers are regarded as important sources of emotional support by being someone to talk to, someone who listens, and someone who encourages the parent when childrearing was difficult. While

grandparents are significant through their instrumental “doing”, they may be even more supportive by their emotional “being”.

In American society, women traditionally assume primary responsibility for the care of children, as well as the majority of the household chores (Marcenko & Meyers, 1991). Marcenko and Meyers (1991) found that women report that they do not receive much help with daily tasks or childcare. In terms of day-to-day responsibility for the care of the child with handicaps, that job seems to fall to mothers as well. However, those who do receive such help indicate that it is significant to them. Social systems theory suggests that support from social network members both directly and indirectly influences the behavior, knowledge, attitudes and expectations of parents and their offspring (Bronfenbrenner, 1977, 1989; Caplan, 1976; Cochran & Brassard, 1979; Hobbs, 1975; Holahan, 1977; Mitchell & Trickett, 1980). Literature indicates that social support has positive mediational effects on personal and familial well being (Bott, 1971; Dean & Lin, 1977; McCubbin et al., 1980; Mitchell & Trickett, 1980). Other research suggests that social support has second-order effects on attitudes toward parenting, styles of interaction parents manifest with their children, parental expectations for their children, and child behavior and development (Crnic, Greenberg, Ragozin, Robinson & Basham, 1983; Crockenberg, 1981; Embry, 1980; Giovanoni & Billingsley, 1970; Hetherington, Cox & Cox, 1976, 1978; Lazar & Darlington, 1982; Philliver & Graham, 1981; Weinraub & Wolf, 1983). An example of a second-order effect is when a parent feels supported, and as a result, feels more competent and confident in terms of interacting with and caring for a child with a disability. He or she may parent their child in a more relaxed and realistic manner. The child with a

disability may benefit in the sense that he or she senses the parent's feelings of comfort in parenting him or her. As a result, the child may feel safe and cared for, enabling him or her to grow in a nurturing environment--promoting a healthy development.

Baranowski and Schilmoeller (1999) find that affectional solidarity--feelings of emotional closeness between adult generations--predicts both general grandparent support and grandparent involvement with the grandchild with disabilities. In many families, the type and degree of involvement of the grandparents in the lives of their children and their children's partners are very powerful factors in determining the quality of their relationship. This involvement is affected by the initial parent-child relationship. How the parents feel about their child, and how many other children there are, may also affect the depth of the parent-child relationship (Deluca & Salerno, 1984). Deluca and Salerno (1984) note that grandparents have the greatest impact of all relatives on members of the nuclear family of a child with a disability.

Kinship links tend to be strongest along the maternal line (Troll, 1983).. Byrne, Cunningham, and Sloper (1988) find that differences exist in the frequency and amount of support from grandparents, as more support is received from maternal grandparents than paternal grandparents. Harris, Handleman and Palmer (1985) also report that the mother's family provides significantly more support than the father's family. Further, they report that high degrees of empathy exist between mothers and maternal grandmothers.

According to research reports by Dunst and Trivette (1986), mothers who report less intrafamily support and, thus, have responsibility for a larger number of household and childcare chores are less likely to manifest either facilitating (responsive and

engaging) or initiating (imposing) behaviors. Further, they state that the lack of intrafamily support (i.e., role sharing) decreases the amount and number of maternal opportunities to engage in interactions with the child, which, in turn, provides fewer opportunities to acquire parenting experience. Dunst, Trivette, and Cross (1986) also note that parents' overall well being functions as a moderating variable that influences parenting behavior. More clearly, well being and health appear to set the occasion for heightened sensitivity toward the child, and decrease intrusiveness in terms of being overbearing or controlling. Based on the Dunst et al. (1986) findings, role demands and well being are correlated, suggesting that role accumulation influences well being, which in turn influences interactive styles. Clearly one would perceive that increased role demands tire the mothers and adversely affect their well being and health, therefore affecting overall parenting behavior.

Cochran and Brassard (1979) hypothesize that members of a parent's social support network serve as models that may affect child-rearing practices and that parents are apt to adopt or modify their parenting styles if esteemed network members model healthy parenting behavior and techniques. When a family is involved in a crisis it is common for the extended family to provide support. The discovery that a child has a disability is regarded as such a family crisis (Gabel & Kotch, 1981; Seligman & Darling, 1989). How well parents cope may very well depend, to a large extent on the help, support and modeling they receive from extended family members. The grandparents are generally the first people contacted after the parents learn of the disability and, therefore, can be a key element of the support network available to parents (Cochran & Brassard, 1979; Vadasy, Fewell & Meyer, 1986). When parents

learn that their child has a disability, one of their major concerns is how their own parents (and parents-in-law) will accept the baby.

To conceptualize the family apart from its ancestral past is to ignore an integral aspect of its present life. Some contend that the influences from previous generations are of considerable significance in terms of understanding the nuclear family's dynamics (Bowen, 1978). Other researchers note that the grandparent-grandchild relationship has the potential for affecting the development of children in a way that is different from other relationships (Baranowski, 1982). Grandparents can offer unconditional acceptance, love and support to the child with the disability, without having to discipline or parent the child.

The conclusion seems logical. Grandparents' support, in terms of a family with a child with a disability, can ameliorate negative effects and promote very positive affects. The parents can benefit as a result of the grandparent support, which in turn can enhance the child's development. If grandparents are able and inclined to do so, they can extend a wealth of experience, wisdom and support, most importantly emotional support. As Baranowski and Schilmoeller (1999) note, a grandparent's emotional support might be instrumental in the sense that they may extend themselves as someone to talk to, listen and encourage. Furthermore, a grandparent can be important mainly by virtue of "being" rather than "doing." For example, a grandparent can be of assistance by providing emotional support rather than providing a service such as babysitting or shopping. Hagestad (1985) also observes that grandparents may be an "elusive" presence; by simply "being there" they comfort in a way that is not easily captured with the language and tools of social science (p.48). Hagestad depicts this as a main

stabilizing force on parents in times of need. By the grandchildren observing the support between grandparents and parents, they in turn feel supported, creating a mediated second-order effect.

The parents of a child with a disability are faced with enormous doubts about their own capacities in nurturing their child's development and may experience a serious crisis of confidence in their parenting abilities. They may tend to focus solely on negative expectations - what the child will not do or be (Cunningham & Sloper, 1977). In this case, positive support and feedback serve as a facilitating factor, and as noted earlier, grandparents can be very instrumental in terms of providing this.

The fact is that many parents of children with disabilities must face problems alone or with only fragmented levels of support (Schell, 1981). As one parent states, it requires "a lot of love, perseverance, and grit" (Robinson, 1979, p.373). Sonnek (1986) notes that, "grandparents, to date, have been an unrecognized and possibly an underutilized resource in the study of the nuclear family" (p. 108). As more researchers and practitioners report on their experience and findings, more professionals will view the extended family as a potent source of support to families with a child with a disability. Murphy (1979), in his article, "In Support of Families," stated: "Something in our deeper selves, now and then, enables us to realize that what truly counts in life is not a matter of what is in you or me, but of what occurs between us. That divine spark of relationship.... may be the most fundamental life-force of all" (p.383). Murphy's (1979) words are very poignant in respect to the relationship of the extended family with a child with a disability.

Families are interrelated, with ties, both positive and negative, running through the extended family system. The grandparent's grief or rejection of the grandchild can add to parents' already burdened emotions. Likewise, the grandparent's love and support can help maintain the family's strengths (Vadasy, Fewell, & Meyer, 1986). What then enhances a grandparent's ability and willingness to become supportively involved with their child's family and the grandchild with a disability? If concern for the healthy development of the grandchild with a disability is not enough, then on what basis does a grandparent choose whether or not to participate in supporting their child and grandchild? Studies indicate that many grandparents have an interest and are willing, but that there are many factors and family dynamics that mediate grandparent's actual involvement. Thus far, this paper has primarily examined research regarding the positive and negative effects of grandparent support, with respect to the family and grandchild with a disability. Looking at the grandparent's perspective and issues regarding their adjustment to having a grandchild with a disability will provide insight in terms of the factors and dynamics that interplay within the family system.

The Family with a Child with a Disability and Grandparent Support: Grandparents' Perspective and Adjustment Issues.

Grandparents have the means to serve as therapeutic agents for their grandchild with a disability, simply by listening and encouraging them (Kahana & Kahana, 1970; Schultz, 1980). Yet, Cherlin and Furstenberg (1986) contend that with the change from traditional roles of grandparenting have come different role expectations. Grandparents feel that with unclear boundaries regarding their roles with the child and the parents, a feeling of "noninterference" has developed. This inhibits the independent involvement

by grandparents in the lives of their children and grandchildren. Grandparents often will not take the initiative without first being asked to participate by the parents. Strom (1988) suggests that part of the reason that grandparents lose touch with their assumed traditional roles is that contemporary society is future oriented and grandparental commentary is often perceived as “old-fashioned” and irrelevant to current circumstances. Johnson (1985) suggests three primary issues that influence the contemporary role of the grandparent. First, there is a wider cultural separation between generations. Second, there are few strong and explicit expectations or obligations between generations. Third, contemporary society actively encourages personal independence at the expense of the extended family system. Kivett (1991) notes that the roles of grandparent and grandchild are functions of indirect linkage, which are mediated by the parents.

Grandparenting in the 1990’s has differed from grandparenting of previous decades. While Johnson (1985) reviews the emotional causes for grandparental role crises, Barranti (1985) cites two main changes that have occurred. First, the number of three generation households is decreasing, which places grandparents in a variety of independent settings. Second, grandparents are living longer and are spending more of their lives in the grandparenting role than those of previous generations. All of these changes are serving to reshape the nature of grandparenting to include perspectives from the standpoint of the grandchild, the parent and grandparent. Parents and grandchildren have input in terms of their needs and how that effects the grandparenting role (Robertson, 1977; Troll, 1985).

Grandchildren appear to see the role of the grandparent as a significant one, with the child's foremost expectation being one of emotional gratification and nurturing (Robertson, 1977). Of equal importance is the fact that grandparents appear interested in the lives of their grandchildren. Research generally depicts grandparents as active, involved people who enjoy grandparenthood (Robertson, 1975) and are willing to take on additional roles that emphasize teaching and companionship (Scherman, Goodrich, Kelly, Russell, & Jaridi, 1988).

What is apparent is that the issues confronting grandparents of a child with a disability are complex and involve not only their relationship with their grandchild, but also with their child who is the parent of the grandchild with the disability (Berns, 1980; Vadasy, 1987). Furthermore, when a child's disability is discovered, grandparents may experience the same stress, depression, grief, anger, and uncertainty that are often observed in parents of a child with a disability. Sadly enough, this phenomenon is exacerbated by the fact that grandparents, in contrast to parents of children with disabilities, often lack access to the information and support needed to foster their own healthy adjustment (George, 1988; Vadasy, 1987).

There is evidence that suggests that the level of healthy adjustment achieved by a grandparent can have a great positive impact on the overall functioning of families of children with disabilities. Grandparents' coping skills and behavior can serve as a model for members of the family system (Vadasy, 1987). George (1988) finds that grandparents may shift from a negative to a positive attitude by attending support groups for extended family members of children with disabilities. Schilmoeller and Baranowski (1998) report that grandparents who do not attend a support group also

make the shift from a negative to a positive attitude. As grandparents adjust to the reality of having a grandchild with a disability, they perceive their sons or daughters as being more helpful than support groups, in terms of dealing with their concerns. According to Schilmoeller and Baranowski (1998), grandparents cite two major themes. Grandparents state that their children help by explaining the grandchild's disabilities. They also keep grandparents informed about the grandchild's progress. Schilmoeller and Baranowski (1998), state that while sons and daughters are noted as more helpful in the grandparents' transition, the significance of support groups should not be underestimated. As George (1988) finds, support group participants receive emotional support and experience the opportunity to learn from others. It appears that parents and support groups complement each other, but that parents may have more of the technical information regarding the child's disability and progress that the grandparents value, (Schilmoeller & Baranowski, 1998). Schilmoeller and Baranowski (1998) also indicate that grandparents who attend support groups are more involved with their grandchildren than are grandparents who do not attend support groups. Therefore, sons and daughters and support groups help facilitate the grandparents' adjustment to the grandchild's disability, as well as involvement with that grandchild.

In their 1998 study, "Intergenerational Support in Families with Disabilities: Grandparents' Perspectives," Schilmoeller and Baranowski (1998) find that the most frequently reported type of support was emotional. This emotional support appears as unconditional acceptance of the grandchild regardless how the child with the disability behaves. Grandparents also provide instrumental support in numerous ways such as

financial support, caring for the grandchild, and participating in activities with both the grandchild and the son or daughter to have fun and relieve stress.

Schilmoeller and Baranowski (1998) report that some grandparents experience long-term concern for their sons and daughters. They tend to be very generous with their time and material support of their children and grandchildren. The grandparents may feel inadequate in completely understanding not only the family's physical and material needs, but also in understanding or being able to cope with the more difficult psychological and emotional needs. Further, what is important to recognize is that many grandparents desire to support their son or daughter's family with the child with the disability. However, many grandparents may not provide as much support as they would like, because they do not know exactly what is needed or how to provide it. Also, some grandparents may feel as though they want to shelter their child from their own negative feelings upon learning of their grandchild's disability, which might impose additional stress on the parents of the child.

Schilmoeller and Baranowski (1998) report that affectional solidarity or emotional closeness with the grandchild and with the son or daughter was positively associated with the grandparents' support of the family, but that only affectional solidarity with the grandchild is positively associated with the grandparents' involvement with the grandchild. Residential distance is not related to grandparent involvement. Furthermore, learning about the grandchild's disability, accepting that the grandchild is disabled, taking an active interest in the grandchild's development, and focusing on the positive aspects regarding the grandchild are all viable through phone calls, letters, tape recordings, electronic mail, videotape and fax. Thus, residential

distance between the grandparent and family with the child with the disability can be overcome by technology (Kennedy, 1996).

Hornby and Ashworth (1994) find that many factors may influence the amount of support that grandparents are able to provide. For instance, if the grandparents are old or in poor health, the parents may not wish to burden them with additional responsibilities. Also, reasons for low levels of grandparental involvement are likely to affect parents' views of support. If lack of involvement is a result of poor health, old age, or problems with traveling, then parents are less likely to feel dissatisfied. On the other hand, if support is not forthcoming due to the grandparent's lack of interest or if the relationship between the family members is poor, then parents are apt to feel dissatisfied. Hornby and Ashworth (1994) learned that grandparents may need assistance in adjusting to the reality of having a grandchild with a disability and that it is quite likely that most grandparents will receive little help in this regard. Once the grandparents come to terms with their grandchild's disability, they may be in a better emotional state to provide social, emotional and financial support to their children and grandchildren.

Gardner et al (1994) suggest that poor adjustment by grandparents of children with special needs may well be related to their difficulty in identifying gratifying roles to assume within the context of the extended family. Instead of serving as an esteemed resource regarding child rearing, they may be viewed as unsupportive, uninformed, ineffective, and meddlesome by their overburdened child (George, 1988; Vadasy, 1987). They may have difficulty in reconciling their own ambivalent feelings of love and disappointment because of the child's disability (Berns, 1980). If parents aren't

clear about their wants and needs regarding support, then grandparents have difficulty discerning their role. Compounding the problem is the fact that the grandparent's efforts in taking on the role of supportive parent may be stifled by unclear messages from their children (the parents of the child with the disability) regarding the level of their children's own grief and concerns for the future (Berns, 1980). Therefore, the failure of grandparents to adjust to the presence of a grandchild with a disability can serve to dramatically weaken the family unit as a whole (Gardner et al., 1994).

According to Scherman, Gardner, Brown, and Schutter (1995), some grandparents express that they feel a sense of helplessness throughout their interactions with their grandchild with a disability and families. The grandparents often view themselves to be in a situation that is adversely affecting them and over which they have little or no control. However, the grandparents report that sharing their feelings with others outside the immediate family is helpful. Further, they refer to the process as being cathartic, a way to release stress and share their emotional state. The grandparents convey an interest in the following sources of support: grandparent support groups, counseling, forums through which they can discuss with other grandparents, and opportunities to share information through national associations. Research indicates that grandparents want to be better informed regarding available therapies for their grandchild, want to know more about the child's disability, and want to have some idea of the child's potential (Vadasy, Fewell, & Meyer, 1986). Seligman and Darling (1997) convey that grandparent's question whether they are doing the appropriate things for the grandchild and share anxiety regarding the future. Based on

these concerns, a workshop or support group effectively assists grandparents in coping with the crisis of childhood disability.

Seligman and Darling (1997) express that grandparents may have difficulty in terms of supporting their grandchild with a disability and family due to their own feelings of inadequacy and guilt. Grandparents may have grown up when deviations from the norm were less tolerated than it is today. In addition, the notion of the "bad seed" may have played a role, in that at some level grandparents may feel that they have passed on the defective gene, resulting in childhood disability. The feelings of self-blame can be intimidating and project anxiety on to the parents and or child. The grandparents can vacillate between taking all of the blame themselves or projecting blame onto the parents and the parents can go through the same process and so both end up trying to prove that each was pure and not responsible for the present suffering (McPhee, 1982). Furthermore, just like parents, grandparents can harbor feelings of guilt that last for a lifetime.

In general, the birth of a grandchild normally reassures the grandparent. However, when the child is born with a disability, it introduces uncertainty in terms of what lies ahead for the family. The birth of a grandchild with a disability evokes certain emotions such as fear, anxiety, anger and despair (Meyers & Vadasy, 1986). Marsh (1992) conveys that the grandparents' experience a dual hurt, for their child, as well as the grandchild. The grandparents contend with feelings of despair in terms of their child's happiness as they see their offspring preparing to deal with a family crisis that won't disappear and that cannot be fixed. In order to avoid the pain of reality, grandparents may go into denial regarding the grandchild's problem ("There's nothing

wrong with her”), trivialize it (“She’ll grow out of it”), or fantasize of unrealistic cures (Meyers & Vadasy, 1986). While the parents are coping with their own pain, the parents are compelled to deal with their own parents’ or parents-in-law’s reactions. Generally speaking, strong negative reactions from extended family members can lead to divisiveness or cut-off between and within generations (Walsh, 1989).

Grandparents may be mourning at the same time the parents are grieving (Seligman & Darling, 1997). Further, in the crisis-laden initial point of discovery, both parents and grandparents may be coping with great loss and grief; as a result, they may be unable to be supportive of one another. Grandparents may be in a state of “diminished capacity” for providing assistance to their children (Gabel & Kotsh, 1981). As research indicates, the intergenerational family interaction that is often the most strained, is that between the mother and child’s paternal grandmother (Farber & Ryckman, 1965; Holt, 1958; Kahana & Kahana, 1970). As Pieper (1976) depicts, paternal grandmothers have been known to blame the mother for the child’s disability, as well as having burdened her son’s life.

Seligman and Darling (1997) state that, although resentment, guilt, and anger can be destructive, such feelings must be viewed in context. Negative emotions should probably be anticipated and accepted, especially at the onset. To discourage family members from conveying their pain through anger is to encourage its expression in more indirect ways. Major underlying issues that are never directly confronted may affect the lives of family members in more covert ways. McPhee (1982) depicted her feelings regarding her grandchild’s disability. When learning of her grandchild’s disability, she explained her feelings as being those of anger, hostility, resentment and

despair. She cried, prayed and yelled at God often. Although McPhee (1982) had not come to terms with the acceptance of her grandchild's disability, she realized that she had been feeling sorry for her daughter, as well as herself. She came to accept that she had to look at her grandson for what he was, not for what he could be. Clearly, this is a classic case in which the grandparents need to deal with their own emotions regarding the child's disability, before they can provide any support to the parents and the child with the disability. If the grandparents do not deal with their own emotions, it may have consequences for the entire family. Seligman and Darling (1997) suggest that grandparents, by their reactions and lack of support, can be a source of considerable consternation to the nuclear family coping with childhood disability. The sense of threat and vulnerability, the loss they experience, the ambiguity the situation holds for them, their denial and lack of acceptance can serve to be very burdensome for the family.

Seligman and Darling (1997) suggest that the most significant type of help from the extended family is emotional support. The support of grandparents during the initial diagnostic phase and throughout the child's developmental stages adds immeasurably to the parents' ability to cope, and it provides excellent role models for the siblings as well. Click (1986, p.3), a grandparent of a child with a disability, wrote:

You think that after you've raised your children, you can stop being a parent and become a person again. And then your adult child experiences tragedy and loss, and your heart aches with the knowledge of your own impotence and how you yearn to go back to the days when a band aid and a kiss could fix anything. Who are we to try to advise our

children? How can we see beyond the moment, how can we diminish their pain or give them faith in the future? Mostly, all we can do is wait, offer them our patience and our constancy, and try to keep our own hope alive.

Click's (1986) words clearly depict how immeasurable a grandparent's perspective, acceptance and support can be in terms of a family's overall adjustment to a child with a disability.

Gardner et al. (1994) and Sherman et al (1995) report that grandparents of a child with a disability in the United States express, without parent solicitation, a desire to be more directly involved with their grandchildren. But, they also hold a belief that they must wait to be asked by the parents first, because they do not see it as their place to interfere in the families of their children. Conversely, Nybo, Scherman, and Freeman (1998), in their study regarding children with a disability, find that the most salient factor in grandparents extending support appears to be an unwritten norm within the grandparents' role to help out in times of trouble. With either explicit or implicit parental permission, grandparents are immensely helpful and powerful figures in the family adjustment process. Their unstated goal appears to be to accept the circumstances regarding the child with a disability, normalize the situation, and go on as before. Geographic locale limits involvement, but not emotional concern or caring. Further, the quality of the relationship with the parent appears to have a great influence on the role of each grandparent. Financial resources of the grandparents are a secondary factor. Nybo, Scherman, and Freeman (1998) also learn that, problems with personal adjustment on the behalf of grandparents appear to hamper their overall

involvement, or at least to skew the value of involvement, in terms of helping the family adjust. It is apparent that grandparents do go through an adjustment process similar to that experienced by the parents. Problems associated with the grandparents' difficulties are lack of access to medical and professional information, a need to support their child and grandchild at the expense of their own adjustment, and lack of a peer group with which to share personal issues.

In a study regarding black children with Sickle Cell Disease, Dilworth-Anderson (1994) report that grandparents provide support to mothers and their children that complements that of fathers, and they remain in the system of care longer than any other relative in the family. Findings indicate a need to design family interventions for sick children and their parents to involve grandparents. The findings provide insight into the importance of grandparents as secondary caregivers to their grandchildren, and indicate that grandparents and fathers are called on the most for support. Dilworth-Anderson (1994) suggests that when sick children and their primary caregivers receive tangible support from grandparents and emotional support from fathers, they function well in spite of chronic illness and limited resources. Furthermore, unlike fathers and others serving as secondary caregivers, grandparents remain in the sick children's system of care from diagnosis to the time the study was conducted. Clearly, the results of this study supports previous findings, in that a grandparent's support can be and is a constant, stabilizing force in terms of the family with a child with a disability.

Based on a review of literature regarding grandparents of children with disabilities, Hastings (1997) finds that grandparents often are one of the most significant sources of support for families of children with disabilities. Healthcare professionals

often may be aware of this, and may attempt to include grandparents in the care and education of children with disabilities. Grandparents also have needs that may require support from professionals working with families of children with disabilities. Hastings (1997) postulates that further research is needed concerning the roles and needs of grandparents of children with disabilities themselves.

Kivnick (1983) portrays that grandparents derive meaning in later life from their grandparental role, such as being a valued elder who teaches and guides grandchildren. It is evident, based on the research reviewed in this present paper, that grandparent involvement and support in terms of the family with the child with a disability can and may produce very positive outcomes for all members within the family network. Grandparents may be a key element in the overall adjustment process and functionality within the family system.

Throughout this review of research reports and other literature, many reoccurring findings appeared. In the family with the child with the disability, grandparent support can be a significant resource. Grandparents have a need to be supportive and are willing to do so. In order to provide this support, grandparents need to deal with their emotional reactions to having a grandchild with a disability. Similar to parents, grandparents experience a grieving process in respect to the child's disability.

Like parents, grandparents have a need to be informed of the child's disability and development. Grandparents like to be kept informed, included and yearn to be asked to assist. But the grandparents often feel that they do not want to burden the family, and so the issue of "non-interference" can become a roadblock to their support.

Affectional solidarity or emotional closeness, and pre-existing relational ties appear to be significant factors, which play a part in the grandparent's role in respect to the nuclear family with the child with a disability. Residential proximity appears to affect grandparent's support to a certain degree but can be overcome by technology. It is apparent that it may affect the amount of instrumental support that grandparents extended, merely due to the geographical distance. However, technology may assist in maintaining emotional support, as well as certain types of instrumental (i.e.: purchasing clothing for the child, assisting monetarily, sending cards, letters, information regarding services, etc.).

In his study, "The Grandfather-Grandchild Relationship: Meaning and Exchange," Baranowski (1990) examined the personal meaning of grandfatherhood and the nature of the grandfather-grandchild relationship as an exchange process. Although Baranowski's (1990) study focused on grandfathers' perspectives and relationships with their grandchildren, the results lend meaning and insight in terms of grandparenting and how they involve themselves with their grandchildren. Baranowski (1990) found that grandfathers' poor health played a role in the grandfather-grandchild relationship, as well as residential proximity-in the sense that frequency of interaction between grandfather and grandchild was highly correlated with where the grandfather lived in relation to the grandchild.

Baranowski (1990) provided a list of 26 activities to the grandparents. The activity scale consisted of activities that grandparents often do with their grandchildren. Activities thought appropriate for the list were gathered from previous studies and from the pilot study for Baranowski's (1990) research. Among the items were interactions

such as celebrating a holiday, gift giving, playing together, watching television, talking about future plans and assisting with household tasks.

The activities engaged in by grandfather-grandchild dyads were also examined by Baranowski (1990) to determine if health influenced their likelihood of occurrence. He found that conversation and gift giving were more often about the grandchild rather than the grandfather. Conversation most often centered on the grandchild's daily activities and what the grandchild's plans for the future were, and gifts were given to the grandchild more often than the grandfather received them. Baranowski (1990) learned that all activities examined were more likely to have occurred if the grandfather was in poor health. Poor health was more likely to increase the likelihood of activities geared toward the grandchild's world. What Baranowski (1990) found was that conversations between grandfather and grandchild and giving of gifts in both directions were more likely to occur if the grandfather was in poor health. Furthermore, he determined that poor health increases activity directed toward the welfare of grandchildren more than it increases activity geared toward the welfare of grandfathers. As one grandfather that was involved in the Baranowski (1990) study stated, "the getting is in the giving."

Baranowski and Schilmoeller (1991) examined the influence of grandchild gender on grandfather-grandchild interaction patterns and attitudes about grandparenthood. Baranowski and Schilmoeller (1991) noted that greater geographic distance between grandfather and grandchild residences was predictive of less frequent contact. The sex of the grandchild was not a significant indicator of frequency of interaction.

Using the Activity Scale from Baranowski (1990), Baranowski and Schilmoeller (1991) asked grandfathers to indicate those activities they had engaged in with the grandchild during their most recent visit. Of the twenty-six activities assessed, there was a significantly greater occurrence of one “passive” interaction (i.e., watching television) with girls and one “active” interaction (i.e., playing sports or games) with boys. According to Baranowski and Schilmoeller (1991), the few times in which differences were found, they could be assessed as being in the direction of conformity to traditional patterns of sex-typed activities.

As discussed previously, a grandparent’s support can be immeasurable--by extending unconditional love and support, this may relieve stress for the family system and be instrumental in the child’s positive development. The grandparent-grandchild relationship has the potential for affecting the development of children in a way that is different from other relationships (Baranowski, 1982).

Purpose of This Study

In their study, Schilmoeller and Baranowski (1998) assessed what grandparents did to help their grandchild with a disability using a twelve-item Grandparent Support Scale where grandparents checked what they did to support the family. Items included things like listening to grandchild who needed someone to talk to, taking care of grandchild, loaning or giving son or daughter money, and helping son or daughter with household chores. On this instrument, items included things for supporting both the parents and the child with the disability. Schilmoeller and Baranowski (1998) also gave the parents a list of 26 activities that grandparents often do with their grandchildren. However, those data were not analyzed for their article. In addition, grandparents were

asked several open-ended questions about what parents did to help grandparents understand their grandchild's disability and what more parents could have done to help. Some of the grandparents' answers were used in the discussion of the Schilmoeller and Baranowski (1998) article, but the answers were not analyzed and reported in the results.

The purpose of this study will be to analyze grandparents' responses to the activities list and to analyze the open-ended questions from both grandparents and parents. Specific research questions will be:

1. What are the activities that grandparents report doing with their grandchildren with disabilities?
2. Is the number of these activities related to affectional solidarity with the grandchild and the parents?
3. Is the number of these activities related to the residential proximity to the grandchild?
4. Is the number of these activities related to the grandparents' health and education?
5. Are there specific themes that grandparents and parents reported in the open-ended questions that help understand what grandparents want in order to be more helpful and what their general reactions are to having a grandchild with a disability?

Chapter 2

METHODS

Sample and Procedure

Grandparents were recruited through a United Cerebral Palsy center (UCP). The center provided direct services to parents of children with disabilities coming from a mixed urban and rural population in Maine. After approval by a university human subjects review board, questionnaires were distributed to parents by the UCP center staff. Parents were asked to give the surveys to the grandparents. Both parents and grandparents were provided with self-addressed postage paid envelopes to return the questionnaires.

Seventy grandparents (65 grandmothers and five grandfathers) and 115 parents (105 mothers and 10 fathers) returned the surveys and questionnaires. The percentage of grandparents who returned surveys is unknown due to the fact that the UCP center mailed the questionnaires to the parents in order to ensure confidentiality of their clients. What is not known is how many parents gave a survey to a grandparent.

The mean age of the grandparents was 61.9 years (range = 43 - 82). Twenty percent were not high school graduates, 39% were high school graduates, 16% had some college experience, 19% were college graduates, and seven percent had some post graduate experience. Sixty-eight percent were married and 32% were single. Ninety-seven percent were white (non-Hispanic) and three percent were Native American. This proportion reflects the population of Maine (Schilmoeller & Baranowski, 1998).

The mean age of the grandchildren at the time of the study was 7.9 years (range=1-19 years). In terms of their grandchild's disability, grandparents reported a variety. The most frequently reported disability was cerebral palsy (29%), developmental delays (20%), communication or language disorders (11%), attention deficit disorder or attention deficit hyperactivity disorder (10%), seizures (10%), and autism (9%). Others reported disabilities that were included disruptive behavior disorder, Down's syndrome, vision impairment, and hearing impairment. Forty-six percent of the children were reported to have multiple disabilities, ranging from two to four disabilities.

Instruments

Schilmoeller and Baranowski (1998) measured several different variables in their questionnaire (see complete questionnaire in the Appendix). They measured the feelings of the grandparents at the time the grandparents learned about the grandchild's disability as well as at the time the grandparents filled out the questionnaire.

Grandparents also indicated how involved they were with the grandchild with a disability by completing a 12-item scale. Each item was rated from "strongly agree" to "strongly disagree." They also indicated how supportive they were of the family of the grandchild with a disability by checking which of 12 types of support (e.g., "help take care of grandchild") they provided. Results of the analyses of these variables were reported in an earlier article (Schilmoeller & Baranowski, 1998).

To measure affectional solidarity, Schilmoeller and Baranowski (1998) asked the grandparents to answer a question developed by Bengston and Schrader (1982): "Taking everything into consideration, how close do you feel is the relationship

between your and your grandchild with a disability.” Grandparents could choose from six choices ranging from “not close” to “extremely close.” Residential proximity was measured by reporting how close the grandparents lived to the grandchild with the disability, selecting from “lived together,” “1 to 50 miles,” “51 - 150 miles,” “151 - 500 miles,” and “501 or more miles.” To rate their health, grandparents checked one of the following choices: “very good,” “good,” “moderately good,” “moderately poor,” “poor,” and “very poor.” Grandparents indicated their educational level by checking one of five choices: “attended school, but did not graduate from high school,” “graduated from high school,” “some college, but did not graduate,” “graduated from college,” “some graduate work, but no postgraduate degree,” and “graduated with postgraduate degree (e.g., Masters, Doctorate).” The present study explored the variables of health, education, affectional solidarity, and residential proximity as they relate to the activities that grandparents reported doing with the grandchild with a disability.

To measure what grandparents did with or for their grandchild with the disability, Schilmoeller and Baranowski (1998) provided a list of 26 activities to grandparents. The list was based on the earlier research done by Baranowski (1990). Examples of the activities are “Celebrated a holiday or family occasion,” “Played together (i.e.: game, sport, with toys),” “Watched television with him/her,” and “Talked about what he/she had done recently.” Grandparents were asked to check the activities that they had participated in, with or for their grandchild with a disability the last time they saw him or her. They were also asked to include and describe anything that they had done with their grandchild that was not listed on the activities list.

The present study examined the activities that the grandparents reported doing with or for their grandchild with a disability, to lend insight about what grandparents may actually be doing. Both parents and grandparents were given the opportunity to answer open-ended questions regarding the child with a disability (Baranowski & Schilmoeller, 1999; Schilmoeller & Baranowski, 1998). Grandparents could answer these questions: 1) "What have your grandchild's parents done that was useful or effective in helping you understand your grandchild's disability?" 2) "What else would be helpful or who else could help or did help you understand your grandchild's disability?" 3) "Please feel free to write down anything you feel we ought to know." Parents could answer these questions: 1) "What is the single most helpful thing this grandparent has done to help you raise your child with a disability?" 2) "What is the single least helpful or most aggravating thing?" 3) "Please share with us any of your thoughts or feelings related to the statements listed above."

Data Analysis

1. What are the activities that grandparents' report doing with their grandchildren with disabilities? The percentage of respondents who reported doing each of the activities are presented in the present study.
2. Is the number of these activities related to affectional solidarity with the grandchild and the parents? A Pearson Correlation Co-efficient will be calculated to examine the relationship between the grandparent-grandchild affectional solidarity and the number of activities the grandparents report doing with the grandchild.
3. Is the number of these activities related to the residential proximity to the grandchild? A Pearson Correlation Co-efficient will be calculated to examine the

relationship between grandparent-grandchild residential proximity and the number of activities the grandparents report doing with the grandchild.

4. Is the number of activities related to the grandparents' health and education? A Pearson Correlation Co-efficient will be calculated to examine the relationship between the grandparents' health/education and the number of activities the grandparents report doing with the grandchild.

5. Are there specific themes that grandparents and parents reported in the open-ended questions that help understand what grandparents want in order to be more helpful and what their general reactions are to having a grandchild with a disability? The open-ended questions will be examined to determine whether there are specific recurring concerns and answers to the questions.

Chapter 3

RESULTS

What activities do grandparents report doing with or for their grandchild with a disability? From the 70 surveys, of the 26 items presented on the activity scale, one half or more of the grandparents reported doing eight of the activities (see Table 1). Sixty-three of the 70 (90%) who responded reported that they hugged their grandchild, 59 (84%) reported that they ate a meal together, 50 (71%) celebrated a holiday, 44 (63%) played together, 39 (56%) watched television, 38 (54%) babysat, 36 (51%) talked about what the grandchild did recently, and 35 (50%) went for a walk/drive. Forty-seven percent of the grandparents gave the grandchild a gift. One third or fewer reported doing other activities.

Is the number of these activities related to affectional solidarity with the grandchild and the parents? A Pearson Correlation Coefficient was calculated to examine the relationship between the grandparent-grandchild affectional solidarity and the number of activities the grandparents report doing with the grandchild. The number of activities that grandparents did with their grandchildren correlated positively with their affectional solidarity ($r = 0.3514$, $p < .01$). That is, the closer the grandparents felt toward their grandchildren the more activities they reported doing with the grandchildren.

Is the number of these activities related to the residential proximity to the grandchild? A Pearson Correlation Coefficient was also calculated to examine the relationship between grandparent-grandchild residential proximity and the number of

activities the grandparents report doing with the grandchild. Grandparent-grandchild residential proximity was not significantly correlated with the number of activities that grandparents reported doing with their grandchildren ($r = -0.0211$, $p > .01$).

Table 1

**Activities Grandparents Report Doing With or for Their Grandchild With a
Disability (N = 70)**

Activity	Frequency	Percentage
Hugged	63	90.0
Ate Meal Together	59	84.3
Celebrate Holiday	50	71.4
Played Together	44	62.9
Watched TV with Grandchild	39	55.7
Babysat	38	54.3
Talked about What Grandchild Did Recently	36	51.4
Went for Walk/Drive	35	50.0
Gave Grandchild a Gift	33	47.1
Disciplined Grandchild	25	35.7
Went Shopping	22	31.4
Talked about What You Did Recently	21	30.0
Read to Grandchild	19	27.1
Received a Gift From Grandchild	14	20.0
Gave Grandchild Advice	13	18.6
Watched Grandchild in an Event	12	17.1
Helped Grandchild with Homework	12	17.1
Grandchild Did Chores for You	12	17.1
Went to Religious Service	10	14.3
Taught Hobby/Skill to Grandchild	8	11.4
Talked about Grandchild's Future Plans	7	10.0
Argued with Grandchild	7	10.0
Went to Event Together	6	8.6
Talked to Grandchild about History	6	8.6
Talked about Your Future Plans	4	5.7
Learned Hobby/Skill from Grandchild	4	5.7

Is the number of activities related to the grandparents' health or education? The relationship between the grandparents' health/education and the number of activities the grandparents report doing with the grandchild was also examined by calculating a Pearson Correlation Coefficient. The grandparents' health was not significantly correlated with the number of activities that grandparents reported doing with their grandchildren ($r = 0.0042$, $p > .01$). The grandparents' education also was not significantly correlated with the number of activities that grandparents reported doing with their grandchildren ($r = 0.0080$, $p > .01$).

Are there specific themes that grandparents and parents reported in the open-ended questions that help understand what grandparents want in order to be more helpful and what their general reactions are to having a grandchild with a disability? Answers to the open-ended questions were analyzed for reoccurring themes. Definitions were written for each of the themes. Using these definitions, a second rater independently analyzed the participants' answers to each question. For each theme, the percentage of inter-rater agreement was calculated for each participant's answer by dividing the number of agreements by the number of agreements plus disagreements and multiplying by 100. The percentages of inter-rater agreement for the grandparent themes are reported in Table 2.

Table 2

Percentage Inter-rater Agreement and Percentage of Grandparents Reporting Thematic Answers to Open-Ended Questions (N=70)

<u>Grandparent Responses</u>	<u>Percentage Inter-rater Agreement</u>	<u>Percentage of Grandparents Responding</u>
<i>What have your grandchild's parents done that was useful or effective in helping you understand your grandchild's disability? (N=57)</i>		
Informed about child's disability.	82%	49%
Explained about child's disability.	74%	26%
<i>What else would be helpful or who else could help or did help you understand your grandchild's disability? (N=45)</i>		
Other professionals	83%	33%
The parents of the child with the disability	63%	18%
Parents of other children with special needs	100%	16%
Printed material	100%	13%
Grandparents of other children with special needs	100%	9%
The grandparents' own educational/professional training	80%	9%

Table 2 (continued)

In the space below or on the back, please feel free to write down anything you feel we ought to know.

(N=40)

Positive statements regarding the grandchild	72%	33%
Worry about the parent/the grandchild	77%	25%
Grandparent helps the parent or the Grandchild	90%	23%
Hopeful/Prays for the best	89%	20%
Positive statements regarding the parent	75%	15%
Grandparent talks about stress/challenges	60%	15%
The grandchild with the disability is a source of joy	83%	13%
The grandparent offers advice	100%	8%

Grandparent Themes

What have your grandchild's parents done that was useful or effective in helping you understand your grandchild's disability? From the 70 surveys, 57 (81%) respondents offered comments that fit two themes – parents shared information with the grandparents and parents explained the grandchild's disability (see Table 2). Twenty-eight of the 57 (49%) who responded stated that the grandchild's parents informed them about the child's disability. For example, grandparents offered the following comments:

- Keep us informed - has given us articles to read and explained what to do when our grandchild is in our care.
- Supplied us with reading materials on “her” disability and most important how to communicate now with her.
- My daughter has read and studied much about autism and has shared that with us. She also shares things that she has learned from her own experience with our grandson.
- Keeping me up to date on doctor’s explanations of child’s illness.

Fifteen grandparents (26%) reported that the grandchild’s parents explained to them about the child’s disability, describing the child’s disability, helping the grandparents understand the situation, or making the situation clearer. For example, grandparents reported that their son or daughter:

- Explained what she understands about it and has shown me papers the doctor gave her to understand better.
- Helped us to understand and accept her moods.
- Is a nurse and was able to describe more fully what C.P. entails and what the future may hold.
- Explained cause and effect.

What else would be helpful or who else could help or did help you understand your grandchild’s disability? Forty-five grandparents (64%) wrote answers to this question (see Table 2). Grandparents listed professionals such as doctors, therapists, special educators (33%), the grandchild’s parents (18%), and parents of other children with special needs (16%) as the three most frequent sources of

understanding. For professional help, one grandparent gained insight “when I went to one of his [grandchild’s] team meetings, and watched him on T.V. from one of his tapes that his speech therapist tapes.” Another grandparent noted that “A family meeting with health care providers, and social services for broad general and specific information and support would have been helpful. I need to know I am helping the most positive way.”

Eight grandparents reported that the parents helped them understand the grandchild’s disability. The grandparents’ answers in this category tended to be quite short. For example, one grandparent said, “Most help comes from the child’s mother.” Another said even more briefly, “Her mother and father.”

Grandparents also said parents of other children with disabilities helped them understand their grandchild’ disability. For example, grandparents said:

- I don’t think I’ll ever fully understand. I’ve read a lot of letters from people who also have children with this illness.
- [It would be helpful] to hear from other families with children with the same disability and his degree. There is [sic] so many with less and more.

Three other sources of help or potential help in understanding the disability were printed material (13%), grandparents of other children with disabilities (9%), and the grandparents’ own educational or professional training (9%). One grandparent noted that “Reading about his difficulties helped me to understand the burdens upon my grandchild’s parents.” Another recognized the contribution of grandparents of other children with disabilities by saying “Other friends who have disabled grandchildren help reinforce a feeling of acceptance and joy in the child for what she does give the family.”

The third open-ended question that was presented to the grandparents read - **There are many things about grandparenting a child with a disability that we have not asked. In the space below or on the back, please feel free to write down anything you feel we ought to know.** From the 70 surveys, 40 (57%) grandparents offered comments (see Table 2). The comments were separated into several categories of themes. In a positive vein, grandparents offered positive statements regarding their son or daughter, positive statements regarding the grandchild with the disability, and comments about how the grandchild was a source of joy to the grandparent. On the other hand, grandparents also worried about the parent and the grandchild and talked about the stresses and challenges they faced. Finally, grandparents reported helping the parents or the grandchild, being hopeful or praying for the best, and offering advice to the parents.

One third of the grandparents reported positive statements regarding the grandchild, speaking highly about the grandchildren with the disabilities, complimenting them, and holding them in high regard. They often noted that they learned from the grandchild with the disability:

- We, as grandparents have felt BLESSED by a very “special” granddaughter who has taught us so much about tolerance.
- Until I had this little boy in my life, I felt sorry for people with disabilities. I was always thanking God we are lucky. Now I look at people totally differently. Kyle is such a wonderful little boy. There’s something special in everything he works so hard at doing.

Five grandparents (13%) specifically referred to the grandchild as a source of joy. One, for example, said simply, "He is the joy of my life and quite a little fighter." Another said, "Every accomplishment achieved by our grandchild, no matter how small, is a source of joy to us."

Six grandparents (15%) also complimented the grandchild's parents. "I am mad about my daughter – have tremendous admiration and respect for her – I tell her this often," reported one grandparent. Another observed, "Since the automobile accident nine years ago, his parents have faced his future with love and strength."

But grandparents worried about the parent or the grandchild with the disability, too. One fourth of the grandparents stated that they worried about such things as the parent or the grandchild's health, their physical, emotional or spiritual state. They also worried about the current status as well as the future. The following statements reflect some of the grandparents' thoughts and concerns:

- We worry about our daughter's overwhelming responsibilities. We worry about the future. The grandson does some things well, but has social problems and self-control problems that we hope he can learn to handle, but we aren't sure. We worry more about his attention deficit than his cerebral palsy.
- Equal in my concern for my grandson is my daughter and son-in-law's support-physically, emotionally, financially and spiritually. I wish for more emotional and psycho-social support from the professional caregivers they see- i.e.- parents' support forum.
- I can't help worrying for Josh's future. He is so trusting and vulnerable. I hope he will always have only loving people to care for him.

- There are a lot of worries, but I always hope for the best and most of all lots of love for that child.

Fifteen percent of the grandparents shared concerns about the stress/challenges involved in parenting or grandparenting a child with a disability. The grandparents discussed the difficulties, hardships, worries and uncertainties. Comments were both simple and elaborate. For example:

- Caring for my granddaughter has been overwhelming and a bit uncertain at times.
- Because of the nature of autism, it is very difficult to bond with this grandchild. He usually does not greet me, or return my greetings. If he initiates conversations, he demands that he be heard, will talk over the other conversations, and become angry if he's ignored. Since L. is the oldest child in the family, he has become the model for behaviors of the other siblings. I wish that he had more contact with other children and that his siblings had more contact with other children as well.
- The child does not respond to people in any way. He is very destructive-one never knows when he will throw large objects with no direction planned. He is a beautiful child and we pray he will with God's blessing improve-but doctors have no idea what will occur in the future.

Nine grandparents (23%) said that they help the parent or the grandchild.

Providing childcare for the grandchild was an important example of grandparents' help.

For example:

- We see her and the grandchildren several times a week. We often help by taking care of the grandchildren so she can get some relief and get shopping done, or other things.
- We, as grandparents, spend time with him every week as his mother is continuing her education and it is difficult to have a sitter who is not well acquainted with him.
- I also care for my grandson while his parents work. I thoroughly enjoy every minute I have him. Being the only grandchild thus far, he is very much loved.

One fifth of the grandparents were hopeful and prayed for the best with respect to the grandchild with the disability. They stated that they were hopeful regarding the child's situation and that they prayed for improvement and progress. The following example captures both the grandparents' hope for the grandchild as well as prayers for both the child and the parent.

- I hope she get better as she get older. But we pray to God every day. I still have hope for this baby to walk later in life, etc. I keep telling my daughter there is a reason for everything, but I don't know, this little baby had a lot of operations??? in two years. It awful. But God is gonna help us and I pray for the parent to keep up the good work that they're doing.

And another grandparent simply said:

- We are always praying that we can do more to "brighten" my granddaughter's life.

Parent Themes

Parents were asked, **“What is the single most helpful thing this grandparent has done to help you raise your child with a disability?”** Of the 115 surveys, 108 (94%) of the parents answered this question (see Table 3). Nearly half of the parents (45/108 – 45%) said that the grandparent helped with the child. The parents stated that the grandparents did things such as babysitting, spent time with, played with, or read to the child. The parents also reported that the grandparent helped by taking the child to various appointments, or by teaching the child skills such as to walk or talk. For example, parents said:

- This grandparent babysits quite frequently so my husband and I can have breaks. Parents need time alone to refocus and be a real couple. If we didn't have this we feel we wouldn't be able to raise our child properly. There would be too much stress.
- She knows what this child is going through because she and two of her own children have the same disability as this grandchild has. She plays games and read books and she takes care of the grandchild when I have to be away out of town with the parent who has the same disability as she has.
- My mother is extremely concerned with helping my child to walk and talk. She works with him daily and has even gone to therapy with him so she can work with him correctly. She has been able to make great progress with him even when no one else could.

Thus both parents and child benefited from grandparents' help.

Table 3

Percentage Inter-rater Agreement and Percentage of Parents Reporting Thematic Answers to Open-Ended Questions (N=115)

<u>Parent Responses</u>	<u>Percentage Inter-rater Agreement</u>	<u>Percentage of Parents Responding</u>
<i>What is the single most helpful thing this grandparent has done to help you raise your child with a disability? (N=108)</i>		
Grandparent helps with the child	86%	45%
Financial assistance	82%	13%
Supportive	82%	9%
Treats the child the same as others	77%	9%
Shares information/advice	89%	7%
Gives unconditional love	88%	6%
Prays	100%	3%
Nothing	100%	6%
<i>What is the single least helpful or most aggravating thing? (N=87)</i>		
Grandparent oversteps boundaries with the parents and/or the child	75%	31%

Table 3 (continued)

Grandparent avoids/provides minimal to no help to the parent and/or the child	78%	24%
Grandparent doesn't know what to say or do/doesn't understand the child's disability	75%	10%
Grandparent is overprotective	90%	10%
Nothing	100%	9%
Grandparent blames parent	100%	5%

In the space below, please share with us any of your thoughts or feelings related to the statements listed above. (N=60)

Grandparent is helpful/supportive	89%	44%
Grandparent does not help	75%	30%
Grandparent is critical of parents/blames Parents	100%	5%
Grandparent spoils the grandchild	100%	5%

The second most frequent helpful thing reported by parents (13%) was financial assistance from the grandparents. The parent stated that the grandparent loaned or gave money to them, or provided them with things that they needed such as transportation, clothing, food or shelter. A few of the parents' comments are as follows:

- He has provided more financial support for the child than any other grandparent I know.

- She loans money when I really need it; she helped me buy a car two years ago, so I can continue to work and take my son to counseling.
- Is there when we need to get away. Give us vehicle to use for trips for doctor out of town, money.
- When I needed to borrow money, because I had just returned to work after two and a half years. When we need a ride.

Parents reported five additional types of help from the grandparents, though none of these types was listed by more than 10% of the parents. Those five themes included 1) grandparents were supportive, 2) grandparents treated the grandchild the same as other grandchildren, 3) grandparents shared information and advice with parents, 4) grandparents gave unconditional love to the grandchild, and 5) grandparents prayed for the grandchild and the parents.

Interestingly, seven of the 108 parent responses (6%) said that the grandparents did nothing to help with the grandchild even though the question asked *for the most helpful thing* grandparents did.

In a second open-ended question, parents were asked, **“What is the single least helpful or most aggravating thing grandparents did?”** The two most frequent answers from parents were that grandparents overstepped boundaries with parents or the child and that grandparents avoided the family or provided minimal to no help to the parent or child. Nearly one-third (31%) of the parents said grandparents voiced their opinion too much, were critical, second guessed the parents or professionals, or caused problems with the parent or grandchild (see Table 3). For example, parents said:

- She causes problems between me my husband and I by feeling sorry for me and making comments about how hard I have it, making my husband feel guilty or like he doesn't do enough (parent's wording).
- My mother is a rather critical person when it comes to me or any of my siblings caring for our children differently than she does.

In the last example, the parent noted that the criticism was not specific to this parent when dealing with the grandchild with the disability but was general to how the grandparent's children raised their children in general.

About one-fourth (24%) of the parents noted that grandparents either avoided or provided minimal help to the family. Two parents reported:

- She sometimes leaves when he is having tantrums and raises his voice. She really doesn't deal with it well. She refuses to babysit; she has a fear he will get out of control and she won't be able to redirect him.
- Before my father's illness (which now consumes her time, thoughts, and energies) she was unwilling/unable to care for the child as she did the other "normal" grandchildren-the seizure disorder scares her, as it seems to most potential caregivers.

Parents also listed three additional unhelpful or aggravating things that grandparents did. Parents said that grandparents didn't know what to say or didn't understand the child's disability (10%), grandparents were overprotective(10%), or that grandparents blamed the parents for the child's disability (5%).

While the question asked for the *least helpful* thing that grandparents did, nearly one in ten (9%) of the parents said "nothing!" In their words:

- With all honesty, I can not think of a thing that is aggravating to me that she does. We are extremely close and have always worked closely to give my son the best possible care.
- Fortunately, I can't think of anything that would be negative in nature. Very supportive. I wish they lived closer, especially for my wife's support.
- Nothing-they are extremely close-and have similar personalities, senses of humor, etc.
- I can not think of a single thing to write here.

In a third open-ended item, parents were invited to “ *Please share with us any of your thoughts or feelings related to the statements listed above. We welcome your comments!*” Four themes emerged from the parents’ general comments (see Table 3). The two most frequently reported themes were opposites. About two in five (44%) of the parents reported that the grandparents were helpful or supportive. Grandparents showed this support by giving general assistance, by accepting the situation, and by extending love and support. As the following comments show, the parents felt blessed and fortunate to have such supportive grandparents:

- I have been extremely blessed to have such loving, caring parents and in-laws. My parents have been a great help in my son's progress, and my in-laws are also great with him although they live 300 miles away. My parents accepted my son's disability from the start, although they were sad for him. My in-laws had a little bit harder time, but are now very accepting.
- I am very fortunate to have such a loving, caring and supportive family. Everyone is wonderful and accepting of my son's disability.

On the other hand, nearly a third of the parents (30%) stated that the grandparents **did not** offer assistance and **were not involved** with the family or the grandchild with the disability. One parent reported “My parents have never helped at all and were making the child worse just having them in the child’s presence.” And another stated even more briefly, “We received zero help from my mother-in-law.”

Finally, parents reported two additional themes, though only 5% of the parents reported each of these themes. Three parents said that the grandparent was critical of the parent or blamed the parent for the grandchild’s disability. And three parents noted that the grandparents spoiled the grandchild.

Chapter 4

DISCUSSION

For all 70 grandparents that responded, one half or more of the grandparents reported doing eight of the 26 activities that were presented on the activity scale. Respondents reported that they hugged their grandchild, ate a meal together, celebrated a holiday, played together, watched television, babysat, talked about what the grandchild did recently, or went for a walk/drive. Almost half (47%) of the grandparents gave the grandchild a gift. One third or fewer reported doing other activities. Baranowski's (1990) study, which focused on grandfathers' perspectives and relationships with their grandchildren, had similar findings as the present study. He found that conversation and gift giving were more often about the grandchild rather than the grandfather. Conversation most often centered on the grandchild's daily activities and what the grandchild's plans for the future were, and gifts were given to the grandchild more often than the grandfather received them. These patterns were consistent with the patterns found in the present sample of grandparents who had a grandchild with a disability

Grandparents were also asked to report any other activities that may not have been provided on the list. Grandparents reported additional things such as recognizing the grandchild's progress, encouraging, praising, nurturing and affirming the grandchild. The additional activities that the grandparents reported are similar to what Kahana and Kahana (1970) and Schultz (1980) reported, in the sense that grandparents

have the means to serve as therapeutic agents for their grandchild with a disability, simply by listening and encouraging them.

Examining the relationship between the grandparent-grandchild affectional solidarity and the number of activities the grandparents report doing with the grandchild, the present study found that there was a positive correlation such that the closer the grandparents felt toward their grandchildren the more activities they reported doing with the grandchildren. This is consistent with the Schilmoeller and Baranowski (1998) finding that affectional solidarity with the grandchild was predictive of the grandparents' involvement with the grandchild.

Grandparent-grandchild residential proximity was not significantly correlated with the number of activities that grandparents reported doing with their grandchildren. Such a finding also is consistent with that of Schilmoeller and Baranowski (1998) who reported that residential distance was not related to grandparent involvement with the grandchild. However, they reported mixed results. They noted that closer geographic distance was predictive of greater overall grandparent support from respondents' mothers and from the other parent's mother. Geographic distance was not predictive of grandparent involvement with the grandchild with disabilities. Conversely, Baranowski (1990) found that interaction between grandfather and grandchild was highly correlated with where the grandfather lived in relation to the grandchild. Also, Baranowski and Schilmoeller (1991) noted that greater geographic distance between grandfather and grandchild residences was predictive of less frequent contact. Nybo, Scherman, and Freeman (1998) reported that geographic locale limits grandparent involvement, but not emotional concern or caring.

A limitation of the present study may be the language that was used in the question that was posed to the grandparents, as the question read “What did you do with or for your grandchild **the last time you saw him/her?**” The words “**the last time you saw him/her**” may have in fact limited the grandparents’ responses in terms of reported activities. It is suggested that future studies may consider asking the grandparent what they did with or for their grandchild “**the last time they had contact with their grandchild.**” As Kennedy (1996) reported, distance can be transcended by technology. Despite a grandparents geographic locale in relation to the grandchild, a grandparent can and may still be actively involved with their grandchild by other means such as phone calls, electronic mail, tape recordings, letters, fax and videotapes. In a future study it may be beneficial to exclude “the last time you saw him/her” from the activities list and add list items such as phone calls, electronic mail, tape recordings, letters, fax and videotapes. The additional activities that the grandparents reported in the present study clearly suggest that grandparent-grandchild residential distance does not have to necessarily prohibit a grandparent’s involvement in activities with and for the grandchild with a disability. A grandparent can recognize progress, listen, encourage, praise, nurture and affirm a grandchild without physically being there.

Grandparents’ health was not significantly correlated with the number of activities that grandparents reported doing with their grandchildren. This finding may be due to the fact that of the 70 grandparents that reported, 79 % reported having either good or very good health. A sample that included more grandparents in poorer health might show different results. For example, Hornby and Ashworth (1994) found that many factors may influence the amount of support that grandparents are able to provide.

For instance, if the grandparents are old or in poor health, the parents may not wish to burden them with additional responsibilities. This issue may account for the lack of grandparent support in the sense that parents do not want to place more stress upon them due to their poor health. On the other hand, Baranowski (1990) reported that grandfather's poor health played a role in the grandfather-grandchild relationship. Baranowski (1990) learned that all activities examined were more likely to have occurred if the grandfather was in poor health. Poor health was more likely to increase the activities geared toward the grandchild's world.

Grandparents' education was not significantly correlated with the number of activities that grandparents reported doing with their grandchildren. On the other hand, Schilmoeller and Baranowski (1998) reported that higher grandparent education was predictive of greater grandparent involvement. Looking at the items in their grandparent involvement scale, involvement items included such things as learning about the grandchild's special needs, understanding what the grandchild's disability is all about, and feeling comfortable spending time with the grandchild. It may not necessarily be that the higher educated the grandparent is, the more activities the grandparent does with the grandchild. However, it may be that the higher educated the grandparent is, the more equipped the grandparent is in terms of accessing information regarding the grandchild's disability, networking, understanding what the disability is all about, thus feeling comfortable spending time with the grandchild.

The present study found that there were specific themes that grandparents and parents reported in the open-ended questions that help understand what grandparents want in order to be more helpful and what their general reactions are to having a

grandchild with a disability. Both grandparents and parents reported specific re-occurring concerns and answers to the questions. When grandparents were asked, "what their grandchild's parents had done that was useful or effective in helping them understand their grandchild's disability," 81 % of the grandparents wrote comments. These grandparents cited two specific themes: 1) Their children kept grandparents informed about the grandchild's disability; and 2) Sons and daughters helped by explaining the grandchild's disabilities. Schilmoeller and Baranowski (1998) report that as grandparents adjust to the reality of having a grandchild with a disability, they perceive their sons and daughters as being more helpful than support groups, in terms of dealing with their concerns. Grandparents state that their children help by explaining the grandchild's disabilities. They also keep grandparents informed about the grandchild's progress. George (1988) finds that parents and support groups compliment each other, but that parents may have more of the technical information regarding the child's disability and progress that the grandparents value.

When asked, "what else would be helpful or who else could help or did help you understand your grandchild's disability," forty-five (64%) grandparents had responses. Grandparents listed professionals (such as doctors, therapists, and special educators), the grandchild's parents, and parents of other children with special needs as the most frequent sources of understanding. Three other themes appeared as sources of help or potential help in terms of understanding the disability - printed material, grandparents of other children with disabilities, and the grandparents' own educational or professional training. Nybo, Scherman, and Freeman (1998) report that grandparents' problems adjusting to the disability of the grandchild appear to hamper their overall involvement,

or at least to skew the value of involvement, in terms of helping the family adjust. It is evident that grandparents do go through an adjustment process similar to that experienced by the parents. Problems associated with the grandparents' difficulties are lack of access to medical and professional information, a need to support their child and grandchild at the expense of their own adjustment, and lack of a peer group with which to share personal issues. Hastings (1997) notes that grandparents often are one of the most significant sources of support for families of children with disabilities. Healthcare professionals should be aware of this, and should attempt to include grandparents in the care and education of children with disabilities when possible. Grandparents also have needs that may require support from professionals working with families of children with disabilities.

Vadasy, Fewell, and Meyer (1986) also indicate that grandparents want to be better informed regarding available therapies for their grandchild, want to know more about the child's disability, and want to have some idea of the child's potential. Scherman et al. (1995) state that grandparents report that sharing their feelings with others outside the immediate family is helpful. They refer to the process as being cathartic, a means to release stress and share emotional feelings. Grandparents shared that they have an interest in the following sources of support in terms of dealing with their grandchild's disability: grandparent support groups, counseling, forums through which they can discuss with other grandparents, and opportunities to share information through national organizations. Seligman and Darling (1997) find that grandparents question whether they are doing the appropriate things for their grandchild and face anxiety regarding the future. Based on these concerns, a workshop or support group

might assist grandparents in coping, understanding and coming to terms with the crisis of childhood disability. The present study's findings complement the above noted studies in the sense that grandparents clearly appreciate and desire to have access to all pertinent information regarding their grandchild's disability. As Schilmoeller and Baranowski (1998) noted, support groups are more likely to afford contact with professionals who work with the child with a disability and other family members who experience the grandparents' perspective of being related but who are not in the position of being direct care providers. Support groups may enable grandparents to talk with various people who can share a wealth of information about childhood disabilities, ways in which to cope and better understand. It makes sense that the parents and the child with the disability may benefit from the grandparents' access to information, as well as their overall adjustment.

Grandparents were also asked to "list any additional comments, thoughts or feelings about grandparenting a child with a disability." Fifty-seven percent of the grandparents offered comments. Grandparents offered positive statements regarding their son or daughter, and the grandchild with the disability. They also commented about how the grandchild was a source of joy. On the other hand, grandparents also worried about the parent and the grandchild and talked about the stresses and challenges they faced. These themes are similar to findings reported by Berns (1980) and Vadasy (1987). They note that issues confronting grandparents of a child with a disability are complex and involve not only their relationship with their grandchild, but also with their child who is the parent of the child with the disability. Furthermore, when a child's disability is discovered, grandparents may experience the same stress, depression, grief,

anger and uncertainty that are often observed in parents of a child with a disability. Schilmoeller and Baranowski (1998) also note that some grandparents experience long-term concern for their sons or daughters. Seligman and Darling (1997) find that grandparents express anxiety regarding the future with respect to the family with the child with the disability and that the grandparents may be mourning at the same time the parents are grieving. Meyers and Vadasy (1986) also find that the birth of a grandchild with a disability evokes certain emotions such as fear, anxiety, anger and despair. The grandparent worries about what the future holds for the family. Marsh (1993) reports that the grandparents experience a dual hurt, for their child as well as the grandchild. They contend with feelings of despair in terms of their child's happiness as they see their offspring deal with a family crisis that won't disappear and that can not be "fixed."

The present study's findings complement the previously cited studies in that grandparents too may contend with feelings, thoughts and worries very similar to those of the parent. The grandparent may worry about the parent as well the child with disability. The grandparent may deal with variety of emotions such as anxiety regarding both the present and the future, as well as fear and worry for the parent and the grandchild in terms of their health and well being – physically, emotionally and spiritually. The grandparent may cope with great amounts of stress - difficulties, challenges and hardships in terms of dealing with the disability. Still, it is interesting to note that while grandparents speak of stress, fears and worries regarding the child with the disability, they also speak in a positive light. Grandparents make positive statements regarding the parent and/or grandchild. They compliment the parent and/or the

grandchild. They refer to the grandchild with the disability as being a source of joy. They hope for the best and pray that things will improve.

Parents were asked to “list the single most helpful thing that the grandparent has done to help them raise their child with a disability.” Seventy-nine percent of the parents responded to this question. Two frequently reported themes emerged. The parents stated that the grandparents did such things as babysitting, spent time with, played with, read to the child, took the child to various appointments, or taught the child skills such as to walk or talk. The second most frequent helpful thing reported by the parents was financial assistance from the grandparents. These findings are similar to those of Kivnick (1983) who found that grandparents may derive meaning in later life from their grandparental role, such as being a valued elder who teaches and guides grandchildren, and Sonnek (1986) who reported that maternal grandmothers often help with shopping and gifts for special occasions. They may also serve as playmates for their grandchild with the disability, help out with the child’s homework, and provide financial help when needed. In the present study, parents reported five additional types of help from the grandparents. Grandparents were supportive, treated the grandchild the same as other grandchildren, shared information and advice with parents, gave unconditional love to the grandchild, and prayed for the grandchild and the parents.

Schilmoeller and Baranowski (1998) found that the type of support most frequently reported by grandparents was emotional. This emotional support appears as unconditional acceptance of the grandchild regardless how the child with disability behaves. Grandparents also provide instrumental support in a variety of ways such as financial support, caring for the grandchild, and participating in activities with the

grandchild and the parent in order to have fun and relieve stress. Baranowski and Schilmoeller (1999) note that a grandparent's emotional support might be instrumental in the sense that they extend themselves as someone to talk to, listen and encourage. Furthermore, a grandparent can be important mainly by virtue of "being" rather than "doing." For instance, a grandparent can be of assistance by providing emotional support rather than providing a service such as babysitting or shopping. The present study complements the previously noted studies in the respect that the grandparent may help in many ways. For instance, the grandparent may help by "instrumentally" or physically lending assistance such as babysitting, playing with or teaching the grandchild, or providing financial assistance or other needed items to the family. The grandparent may also help in an "emotional" manner by simply listening, sharing, supporting and loving. What is interesting is that parents too listed "praying" as one of the ways in which grandparents were helpful.

Interestingly, 6% of the parents said that the grandparents did nothing to help with the grandchild even though the question specifically asked *for the most helpful thing* grandparents did. Seligman and Darling (1997) found that some grandparents may have difficulty in terms of supporting their grandchild with a disability and family due to their own feelings of inadequacy and guilt. Schilmoeller and Baranowski (1998) found that grandparents may also feel inadequate in completely understanding not only the family's physical and material needs, but in understanding or being able to cope with the more difficult psychological and emotional needs. What is important to recognize is that many grandparents desire to support, but may not provide as much

support as they would like because they do not know exactly what is needed or how to provide it.

Parents were also asked to “*list the single least helpful or most aggravating thing that grandparents did.*” The two most frequent answers from parents were that the grandparents overstepped boundaries with parents or the child and that grandparents avoided the family or provided minimal to no help to the parent or the child. Parents also said that grandparents didn’t know what to say or didn’t understand the child’s disability, were overprotective, or blamed the parents for the child’s disability.

Cherlin and Furstenburg (1986) reported that with the change from traditional roles of grandparenting have come different role expectations. Grandparents feel that with unclear boundaries regarding their roles with the child and the parents, a feeling of “noninterference” has developed. This inhibits the independent involvement by grandparents in the lives of their children and grandchildren. Grandparents often will not take the initiative without first being asked to participate by the parents. Conversely, Nybo, Scherman, and Freeman (1998), in their study regarding children with a disability, find that the most salient factor, in grandparents extending support, appears to be an unwritten norm within the grandparents’ role to help out in times of trouble. With either explicit or implicit parental permission, grandparents are immensely helpful and powerful figures in the family adjustment process. Their unstated goal appears to be to accept the circumstances regarding the disabled child, normalize the situation, and go on as before. Gardner et al. (1994) report that poor adjustment by grandparents of children with special needs may well be related to their difficulty in identifying gratifying roles to assume within the context of the extended family. George (1988) and

Vadasy (1987) find that when a grandparent is not clear in terms of their role they may be viewed as unsupportive, uninformed, ineffective, and meddlesome by their overburdened child - as opposed to be held in the regard as an esteemed resource regarding childrearing. Berns (1980) states that if parents are not clear about their wants and needs regarding support, then grandparents have difficulty discerning their role. Grandparents' efforts in taking on the role of supportive parent may be stifled by unclear messages from their children (the parents of the child with the disability) regarding the level of their children's own grief and concerns for the future. According to Scherman et al. (1995), some grandparents express that they feel a sense of helplessness throughout their interactions with their grandchild with the disability and family. The grandparents often view themselves to be in a situation that is adversely affecting them and over which they have little or no control.

Gabel and Kotsch (1981) report that grandparents may have strong and disruptive emotional reactions when they discover that their grandchild is handicapped. One consequence is a diminished capacity to provide social support for the child's parents. Hornby and Ashworth (1994) find that grandparents may need assistance in adjusting to the reality of having a grandchild with a disability and that it is quite likely that most grandparents will receive little help in this regard. Once the grandparents come to terms with their grandchild's disability, they may be in a better emotional state to provide social, emotional and financial support to their children and grandchildren. The current study supplements the previous noted studies in the respect that it is noted that grandparents may have to contend with issues in terms of dealing with, understanding and accepting the situation involving a grandchild with a disability. They

may have to discuss, discern and learn how they can help their child as well as the grandchild. If they can learn these skills, parents, grandparents and the child with the disability may benefit.

While the question asked for the *least helpful* thing that grandparents did, 9 % of the parents said “nothing!” As it was noted in the present study, some parents reported that the grandparent did “nothing!” that was least helpful or aggravating. It may be that those particular grandparents were in a better space in terms of being able to extend support. They may have come to terms with the disability, which allowed them to avail themselves. Future studies may shed more light in terms of what assists a grandparent in being willing and able to offer support to the family with the child with the disability.

Finally, parents were asked to “share any of their thoughts or feelings related to the questions that were previously asked of them.” Four themes emerged from the parents’ general comments. The two most frequently reported themes were opposing. Approximately 44 % of the parents reported that the grandparents were helpful or supportive. Grandparents showed their support by giving general assistance, by accepting the situation, and by extending love and support. On the other hand, nearly a third of the parents (30%) stated that the grandparents did not offer assistance and were not involved with the family or the grandchild with the disability. Parents also reported two additional themes, although, only 5 % of the parents reported each of these themes. Three parents stated that the grandparent was critical of the parent or blamed the parent for the grandchild’s disability. Three of the parents also stated that the grandparents spoiled the grandchild.

Sandler, Warren, and Raver (1995) find that the child's grandparents may be a potentially significant, yet often overlooked, member of the support network. They note that the grandparents' support is positively correlated with paternal adjustment. Without paternal adjustment the child with a disability may suffer the consequence of not receiving complete support and nurturing from the parents. Grandparents can enhance the coping abilities of the entire family and can provide support to the parents, thereby alleviating stresses within the family network. Grandparent support may relieve some of the parents' stress, as a result, the child with the disability may benefit greatly, as their living environment is more relaxed. George (1988) reports that a more relaxed living environment may help the child with a disability to develop feelings of security and self-confidence. Thus, both parents and the child may benefit from the grandparents' general assistance, acceptance, love and support. Likewise, the grandparents may benefit in the sense that they may feel needed, valued and involved.

As the present study has noted, grandparents too may move through an adjustment process in terms of dealing with, adjusting to, and accepting the situation of having a grandchild with a disability. George (1988) reports that support groups may be very facilitating in assisting grandparents to adjust, as they may afford the grandparents the opportunity to receive emotional support and experience the opportunity to learn from others. Based on these findings, it is suggested that the issue of grandparent support groups not be overlooked, as it may be a key element in the entire family system's well-being and adjustment process. Seligman and Darling (1997) note that although resentment, guilt and anger can be destructive, such feelings must be viewed in context. Negative emotions should probably be anticipated and accepted, especially

at the onset. To discourage family members from expressing their pain through anger is to encourage its expression in more indirect ways. Major underlying issues that are never directly confronted may affect the lives of family members in more covert ways. Seligman and Darling (1997) also suggest that grandparents, by their reactions and lack of support, can be a source of considerable consternation to the nuclear family coping with childhood disability. The sense of threat and vulnerability, the loss they experience, the ambiguity the situation holds for them, their denial and lack of acceptance can serve to be burdensome for the family system.

Though the present study lends insight and meaning into grandparent and parent thoughts feelings, wants and needs in dealing with a child with a disability, it should be noted that there are limitations of this study. It should be taken into account that parents distributed the surveys to grandparents and that selection bias may be an issue. There were also far more female than male respondents for grandparents as well as parents. And, the sample was predominately white and less urban than the nation as a whole, which reflects the population of the state of Maine. Future studies may broaden the perspective in terms of grandparents'/parents' wants and needs in dealing with the child with a disability, and how support groups may enhance their overall adjustment process. Support groups may afford both the parents and the grandparents the opportunity to tap into a variety of resources in terms of dealing with a child with a disability such as speaking with professionals, other parents and grandparents, and access to new information. Support groups may also serve as a therapeutic means in terms of releasing and dealing with ones' emotions. Furthermore, it may be interesting to investigate whether or not support groups may have a mediated second-order effect upon the child

with the disability. As Hagestad (1985) notes, grandparents may be an “elusive” presence; by simply “being there” they comfort in a way that is not easily captured with the language and tools of science (p.48). This comfort may be a main stabilizing force on parents in times of need. By the grandchildren observing the support between grandparents and parents, they too may feel supported, creating a mediated second-order effect. According to the findings of the present study, and the previously noted findings, it makes sense that support groups may be very instrumental for the grandparents and parents as well as the child, in terms of having to cope with and adjust to a disability. Baranowski (1982) notes that the grandparent-grandchild relationship has the potential for affecting the development of children in a way that is different from other relationships.

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APPENDIX

Grandparent Survey

We are trying to learn what it is like for grandparents who have a grandchild with a disability. Your answers will be a first step in helping others understand how disabilities affect individuals and their families, and your ideas will help us provide information to other grandparents who are facing a similar situation. There are no right or wrong answers to any of the questions, just answers that are true for you.

1. What disability does your grandchild have? (If you have more than one grandchild with a disability, think of the oldest child with a disability of the parent who gave you this questionnaire and answer the questions below thinking of that one.)

2. How old is this grandchild? _____ years

3. This grandchild is a: _____ female _____ male

4. Here is a list of feelings that some grandparents have said they felt when they first learned about their grandchild's disability. We realize that not all grandparents feel the same way. Would you please check those words that describe how you felt **when you first learned about your grandchild's disability?**

_____ cheated	_____ worried	_____ curious	_____ confident
_____ strong	_____ sad	_____ involved	_____ calm
_____ uncomfortable	_____ shocked	_____ frightened	_____ helpless
_____ grateful	_____ accepting	_____ useful	_____ hopeful
_____ confused	_____ angry	_____ fortunate	_____ overwhelmed

Please feel free to list other words that you felt if they are not listed above:

Some grandparents say that their feelings change toward their grandchild who has a disability as they know the grandchild longer. Would you please check those words that describe **how you feel now** about your grandchild with a disability?

- | | | | |
|--|------------------------------------|-------------------------------------|--------------------------------------|
| <input type="checkbox"/> cheated | <input type="checkbox"/> worried | <input type="checkbox"/> curious | <input type="checkbox"/> confident |
| <input type="checkbox"/> strong | <input type="checkbox"/> sad | <input type="checkbox"/> involved | <input type="checkbox"/> calm |
| <input type="checkbox"/> uncomfortable | <input type="checkbox"/> shocked | <input type="checkbox"/> frightened | <input type="checkbox"/> helpless |
| <input type="checkbox"/> grateful | <input type="checkbox"/> accepting | <input type="checkbox"/> useful | <input type="checkbox"/> hopeful |
| <input type="checkbox"/> confused | <input type="checkbox"/> angry | <input type="checkbox"/> fortunate | <input type="checkbox"/> overwhelmed |

Please feel free to list other words that you feel if they are not listed here:

- 5 Listed below are 12 different types of help and assistance which grandparents sometimes give their children and grandchildren. **With regard to your grandchild with a disability**, please indicate which of these you provide by checking the items.

- Listen to your grandchild when she or he needs someone to talk to.
- Help take care of your grandchild.
- Talk with your son or daughter when they have questions about raising your grandchild.
- Loan or give your son or daughter money when they need it.
- Encourage son or daughter to keep going when things get hard.
- Accept your grandchild regardless of how (s)he behaves or acts.
- Help son or daughter with household chores.
- Do things with son or daughter and his or her children to have fun, just relax, or joke around.
- Take time to do things with your grandchild

_____ Take son or daughter or grandchild places when they need transportation.

_____ Try to get services from professionals when your son or daughter feels that they can't get what they need or want.

_____ Help your son or daughter learn about services for your grandchild.

6. Overall, how helpful has your son or daughter been in helping you deal with your concerns about your grandchild with a disability?

Not at all helpful	Sometimes helpful	Generally helpful	Very helpful	Extremely helpful
_____	_____	_____	_____	_____

7. What have your grandchild's parents done that was useful or effective in helping you understand your grandchild's disability?

8. What else would be helpful or who else could help or did help you understand your grandchild's disability?

9. Have you attended any support or education groups related to your grandchild's disability?

_____ yes _____no

If yes, how helpful was the group in helping you deal with your concerns about your grandchild with a disability?

Not at all helpful	Sometimes helpful	Generally helpful	Very helpful	Extremely helpful
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10. Overall, how helpful do you feel you have been in terms of helping your grandchild with a disability reach his or her full potential?

Not at all helpful	Sometimes helpful	Generally helpful	Very helpful	Extremely helpful
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11. About how far from you does your grandchild with a disability live? (Check one)

_____ 501 or more miles
 _____ 151 to 500 miles
 _____ 51 to 150 miles
 _____ 1 to 50 miles
 _____ live together

12. Does your son or daughter have the child with the disability?

_____ Son _____ Daughter

13. How often do you do things together with your son or daughter? (Check one)

_____ Almost never
 _____ About once a year
 _____ Several times a year
 _____ Every other month or so
 _____ About once a month

- About once a week
- Several times a week
- Almost every day

14. How often do you do things together with your grandchild who has a disability?
(Check one)

- Almost never
- About once a year
- Several times a year
- Every other month or so
- About once a month
- About once a week
- Several times a week
- Almost every day

15. Taking everything into consideration, how close do you feel is the relationship between you and your son or daughter who has the child with a disability?

- Not close at all
- Not very close
- Somewhat close
- Pretty close
- Very close
- Extremely close

16. Taking everything into consideration, how close do you feel is the relationship between you and your grandchild with a disability?

- Not close at all
- Not very close
- Somewhat close
- Pretty close
- Very close
- Extremely close

17. Below are some statements that describe how some grandparents of children with a disability help their sons or daughters and their families. With reference to your son or daughter who has the child with a disability, please answer the following by circling the response that best describes this yourself:

Response Choices						
1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree		
1.	I have made an effort to learn about my grandchild's disability.	1	2	3	4	5
2.	I think my son or daughter or my grandchild's other parent are responsible for the grandchild having a disability.	1	2	3	4	5
3.	I am willing to listen to their ideas about what is best for this child.	1	2	3	4	5
4.	I feel comfortable spending time with my grandchild.	1	2	3	4	5
5.	I wonder if they are raising my grandchild in the best way possible.	1	2	3	4	5
6.	I accept the fact that this grandchild has a disability.	1	2	3	4	5
(continued)						

Response Choices						
1	2	3	4	5		
Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree		
7.	I had a difficult time at first accepting that this grandchild has a disability.	1	2	3	4	5
8.	I offer helpful advice about how to raise this grandchild.	1	2	3	4	5
9.	I am critical of the way they raise this child.	1	2	3	4	5
10.	I understand what this grandchild's disability is all about.	1	2	3	4	5
11.	I focus on the positive things about this child and not just the problems.	1	2	3	4	5
12.	I don't really get along with this grandchild very well.	1	2	3	4	5
13.	I have been helpful in working and playing with my grandchild to increase the child's skills.	1	2	3	4	5
14.	I haven't been able to spend much time with this grandchild because he/she lives so far away.	1	2	3	4	5
15.	I am interested in how this grandchild is growing and changing.	1	2	3	4	5
16.	I treat my grandchild with a disability as well as I treat my other grandchildren.	1	2	3	4	5

18. Below is a list of activities that grandparents have told us they do with their grandchildren. The last time you saw the grandchild with a disability, what did you do with or for this grandchild? (Check all that apply)

- Celebrated a holiday or family occasion
- Played together (ex.: game, sport, with toys)
- Taught him/her a hobby, sport, or skill
- Learned a hobby, sport, or skill from him/her
- Babysat or took care of him/her
- Ate a meal together
- Went for a walk or drive together
- Went to a movie, play, or sports event together
- Went shopping
- Went to a religious service
- Hugged him/her
- Watched him/her take part in a school, sport or church event
- Gave him/her advice
- Talked to him/her about family or community history
- Talked about what you'd done recently
- Talked about what he/she had done recently
- Talked about his/her future plans
- Talked about your future plans
- Gave him/her a gift
- Received a gift from him/her
- Disciplined or scolded him/her
- He/she did chores or errands for you
- Helped him/her with work or homework
- Argued or disagreed about something
- Read to him/her
- Watched television with him/her

If you did anything with or for this grandchild that is not listed above, please describe what you did:

NEXT WE'D LIKE TO KNOW ABOUT YOU:

19. Your age: _____ years

Are you the Grandmother _____ or Grandfather _____

20. Years of formal education completed: (check one)

- Attended school, but did not graduate from high school
- Graduated from high school
- Some college, but did not graduate
- Graduated from college
- Some graduate work, but no postgraduate degree
- Graduated with postgraduate degree (e.g., Masters, Doctorate)

21. Marital status: (check one)

- Married
- Widowed, remarried
- Widowed, not remarried
- Divorced, remarried
- Divorced, not remarried
- Separated
- Single, never married

22. Current employment status: (check one)

- Employed full-time
- Employed part-time
- Unemployed
- Retired, not employed

23. Please list your occupation in the space below. Be specific as possible (for example: electrician, dentist, school teacher, secretary, store clerk, truck driver, homemaker). If you are retired or unemployed, please list the last regular job you held.

24. Your ethnic background: (check one)

- White (non-Hispanic)
 Hispanic
 Black
 American Indian
 Asian or Pacific Islander
 Other (Please specify) _____

25. How would you rate your personal health?

- Very good
 Good
 Moderately good
 Moderately poor
 Poor
 Very poor

26. Which of the following best describes where you live?

- City
 Town or village
 Suburb
 Farm
 In the country, not on a farm

27. How many grandchildren do you have? _____

FINALLY, we would like to return to the topic of being a grandparent of a child who has a disability. There are many things about grandparenting a child with a disability that we have not asked. In the space below or on the back, please feel free to write down anything you feel we ought to know.

WE WELCOME YOUR COMMENTS!

BIOGRAPHY OF THE AUTHOR

Laureen (Churchill) Coutts-Clarke was born the second of five children to Sandra and John Churchill. She was born in Bangor, Maine and grew up in the greater Bangor area. She graduated from John Bapst Preparatory High School in 1978. She attended The Bangor Community College and graduated with an Associates Degree in Law Enforcement in 1980. In 1996, Laureen graduated with highest distinction from The University of Maine at Orono, with a B.S. in Child Development and Family Studies. She resides in Brewer, Maine along with her husband Geoffrey, 17-year-old son Jonathan and golden retriever Jay.

She has worked with youths and their families through the Bangor Police Department, the Bangor/Brewer School Systems, the Catholic Diocese/ Juvenile Jail Diversion Program, and the Department of Corrections/Juvenile Probation & Parole. Laureen taught math and English at Bishop State Community College while residing in Mobile, Alabama for one year in 1997. She has written and published pamphlets regarding the Maine laws for drugs and alcohol for area police and school departments. She has also worked as a Drug and Alcohol Counselor with adolescents and their families. She has been a member of the Kappa Omicron Nu Honor Society and has enjoyed serving on various committees that serve families and youths within the State of Maine. Laureen is a candidate for the Master of Science degree in Human Development from The University of Maine in May, 2002.