A STUDY OF THE ROLE OF GRANDPARENTS
IN THE SUPPORT OF THE FAMILY OF
A CHILD WITH A DISABILITY

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CHAPTER I

INTRODUCTION

It is well documented that parents of children with disabilities experience a significant amount of stress as a result of managing a family that has a child with a disability (Beckman, 1991; Beresford, 1994; Farber, 1959). The research has examined the levels of stress (Dyson, 1993; Miller, Gordan, Daniele, & Diller, 1992) and the causes of stress (Beresford, 1994; Havermans & Eiser, 1991). Other studies have correlated the ability of the parents to cope with the stress considering the role of social support in helping to relieve the stress (Beckman, 1991; McConachie, 1994). Although extended family has been listed as one element of the social support (Cooley, 1994), little is known about the specific support grandparents provide. The purpose of this study was to describe the types of interactions that families engage in with grandparents and identify which interactions are perceived as supportive by the mothers. Differences were examined comparing the interactions of the maternal grandparents to the paternal grandparents and the grandmothers to the grandfathers. This qualitative study used an interview method to gather data from ten mothers of children between the ages of twelve and eighteen with mental retardation at the limited level of support according to the 1992 AAMR definition (Hickson, Blackman, & Reis, 1995). The mothers were asked questions concerning the support of the grandparents. Using the Double ABCX model of how families function under stress (McCubbin & Patterson, 1981), the results were analyzed to describe a typology of interaction and resources and establish differential elements of interaction and support provided by the grandmother or grandfather and by the maternal or paternal side of the family.

Families of a Child with a Disability

Each day throughout the world children are born with disabilities. These children face various mental, physical, and health challenges as a result of their disabilities. The birth of children with life challenging disabilities places a heavy burden on their parents and families. The first hurdle that must be faced is to accept the reality of the disability (Kirk, Gallager & Anastasiow, 1997; Padrone, 1994). Families experience various reactions in the process of dealing with or accepting the limitations and challenges that are imminent due to the disability. Among these reaction are shock, anger, guilt, depression, and helplessness (Alper, Schloss, & Schloss, 1994; Shafer, 1983). These feeling, coupled with the limitations and challenges, create a great deal of stress for these families (Beresford, 1994; Dyson, 1993; Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981).

Many factors have been shown to contribute to the amount of stress experienced by the families of children with disabilities. Some of these factors are economic issues, emotional and social concerns (Dunlap & Hollinsworth, 1977), physical and health care, and family characteristics and marital stress (Nihira, Meyers, & Mink, 1980; Singhi, Goyal, Pershad, Singhi, & Walia, 1990). These factors are affected by the type or severity of the disability (Havermans & Eiser, 1991; Nihira et al., 1980; Noh, Dumas, Wolf, & Fisman, 1989), the age of the child (Dyson, 1993; Farber 1959; Gallagher, Beckman, & Cross, 1983), and the amount of support the family is receiving from outside sources (Freidrich & Friedrich, 1981; Krauss, 1993).

Although most families of children with disabilities experience an increased amount of stress, most are able to cope with the discovery of a disability. The presence of a child with a disability does not predict that the family will be dysfunctional (Dyson, 1991, 1993). One element that helps the family to remain functional is the presence of resources to help the family cope with the stress that is common in families of children with disabilities (Barakat & Linney, 1992; Beckman, 1991; McConachie, 1994).

Social Support

Social support has been a consistent finding as an important element to assist the family in coping with the stress (Fotheringham & Creal, 1974; McConachie, 1994; Slater & Wikler, 1986). Social support is defined by meeting the communication and emotional needs of the individual (Cobb, 1976). Support that meets the needs of the individual is provided by different people within the family or social network. The support can help parents of children with disabilities cope with the problems created by rearing the child (Byrne & Cunningham, 1985; McConachie, 1994).

One potential source of social support is the family network or the extended family, including the grandparents of the child. Although many individuals may be a part of the extended family, grandparents are generally central figures (Barranti, 1985; Castiglia, 1994). Within any family structure, grandparents may have several roles (Orr & VanZandt, 1987), such as providing help and support to the parents (Thomas & Sanders, 1985), and physical care and emotional support to the child (Barranti, 1985). These types of support assist the family in accepting the limitations and attending to the needs of the child (Pieper, 1976; Schell, 1981).

Grandparents can be one of the greatest sources of support; however, some studies have shown grandparents as a major source of stress (Denham & Smith, 1989; Romeis, 1980). When grandparents are unable or unwilling to accept the child with the handicapping condition, it creates problems for the parents as they attempt to deal with the needs of the child (Pieper, 1976; Romeis, 1980).

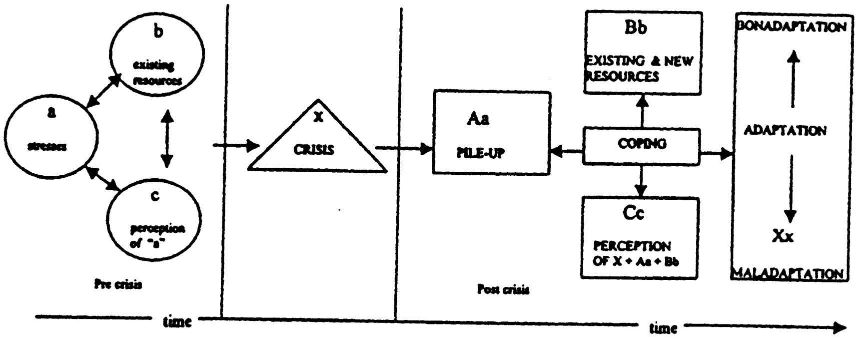
The support provided by the grandparents may have a significant impact on the ability of the mother to cope with the challenges that are presented. Maternal and paternal grandparents may provide different types of support. One study found that maternal grandmothers of children with autism appear to be more sensitive to the needs of their daughters (Harris, Handleman, & Palmer, 1985). Another study of families of children with neurological disorders indicated that the paternal grandmother presented less support and more stress (Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986).

Double ABCX Model

Some families remain together and seem to grow stronger when faced with stressful situations. Other families when presented with stressful situations do not seem to handle it in a positive manner and can even become dysfunctional. Historically, researchers in the area of family theory have searched for reasons for this occurrence (Angell, 1936; Koos, 1946). Fifty years ago Reuben Hill (1949) proposed a theory of family research known as the ABCX model. This looked at how the stressor event (A) interacted with the family resources (B) and the family's perception of the event (C) to effect the crisis of the event (X). Hill's theory dealt primarily with the resources that were available at the time the stressor event occurred. This theory was later expanded by McCubbin and Patterson (1981) to consider the build up of factors, including initial and subsequent events, resources and perceptions. This theory is known as the Double ABCX model.

The Double ABCX model considers the pile-up of events that affect the family’s reaction to the stressful situation. The Double A factor (Aa) identifies the stresses faced by the family. These include the initial stress, stress that comes from normal changes, and the stress that is directly related to coping with the event, which in this case is the child with a disability. The Double B factor (Bb) identifies the resources that are available to the family. The perceptions of the stressful event are described by the Double C factor (Cc). This includes the meaning that the family places on the situation. The Double X factor is the result of the interaction of factors Aa, Bb, and Cc. This involves a description of the adaptation that has occurred as the family adjusted to the stressful situation (see Figure 1).

Figure 1
The Double ABCX model



The present study utilized the Double ABCX theory to explain the effects of grandparents on families of children with disabilities. The theory appeared to be an effective tool to focus the information concerning grandparents into areas of concern for a family dealing with the stress related to having a child with a disability. The initial and subsequent stresses of the family and of the grandparents were considered. The resources that were provided by each of the grandparents were examined. These were used to help identify the elements that grandparents provide in assisting a family with the acceptance and care of a child with a disability.

Significance of the Study

Although studies have documented that grandparents are supportive (Dyson & Edgar, 1986; Trute & Hauch, 1988; Waisbren, 1980), they have not addressed the interactions of the grandparents and those interactions that are perceived as supportive or compared the interactions of the various grandparents to identify which is most supportive. Future research is needed in this area in order to understand further the family of a child with a disability. Qualitative research is valuable for understanding the family as the family perceives itself. Family members are the only ones with firsthand knowledge of the stresses that the family faces and the adaptations that are necessary to cope with the situation. Research is a valuable tools for obtaining this information.

In working with families of children with disabilities, it would be beneficial to identify positive and negative effects of the relationship with the grandparents. Understanding more about this relationship could help families to seek support from grandparents, help grandparents better realize what the family perceives as support and allow grandparents knowledge of what they can do to assist the family. Information on the grandparents can be beneficial to the family and also to teachers, counselors, and medical personnel as they attempt to meet the needs of the family.

The utilization of the Double ABCX model may contribute significantly to the understanding of the support that is provided by grandparents. Although it was designed to examine the immediate family in stressful situations, the model provides a basic framework for examining many issues. The premise that the stressful situation interacts with the resources and the perception of the event to lead to adaptation in the family contributes to questions about each of those factors. Questions arise about the role that grandparents play in the process of adapting to the stressful situation.

Statement of the Problem

Further study was needed to determine what interactions mothers perceive as support from the grandparents and to examine its impact on the support of the family to the stressful situation created by raising a child with a disability. In order to help families understand and utilize the relationship, it is important to gather information on the role of the grandparents in supporting a family of a child with a disability. The present study examined the existence or lack of support from maternal and paternal grandparents as perceived by the mother of the child with a disability. The purpose of this study was to describe the types of interactions that families of a child with a disability engage in with grandparents and identify which interactions are perceived as supportive by the mothers. Differences were examined comparing the interactions of the maternal grandparents to the paternal grandparents and the grandmothers to the grandfathers.

Because various levels of disabilities can create different types of problems for the families (Dyson, 1991; Farber & Rowitz, 1986), this study dealt specifically with the families of children with moderate disabilities, specifically those with mental retardation at the limited level of support. In defining mental retardation, the 1992 American Association on Mental Retardation manual states:

> Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual function (IQ of 70-75 or below), existing concurrently with related limitations in two or more of the following applicable skills areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before age 18. (AAMR, 1992, p. 1)

The limited level refers to those individuals who need consistent support but these supports are not intense (Drew, Hardman, & Logan, 1996). Moderate disabilities are those disabilities that present performance problems for the individual both in school and out of school and require specialized interventions (Beirne-Smith, Ittenbach, & Patton, 1998). The problems of those who have moderate disabilities are more frequent and more serious in that they require more services or adaptations than those with mild disabilities and typically in more than one area of functioning (Hardeman, Drew, Egan & Wolf, 1996). All children whose mothers were participants for the study have a disability that includes deficits in at least two areas of functioning and have performance problems that require specialized interventions.

Research Questions

This study used the Double ABCX family systems theory that is adapted from Hill's original ABCX theory dealing with families in crisis in order to look at post-crisis adaptations (McCubbin & Patterson, 1981). The present study describes the interactions of the grandparents, the resources provided by the grandparents, and the mother's perception of the support given by the grandparents. The major research questions were:

1. What is the nature of grandparent interactions?
2. To what extent are grandparent interactions perceived as support by the mothers of children with disabilities?
3. What are the differences of the nature of interactions and perceived support from the maternal and paternal grandmothers and grandfathers?
4. To what extent does the Double ABCX theory of family adaptation provide an understanding of the interactions and perceived support of the grandparents to the families of a child with a disability?

CHAPTER II

REVIEW OF RELEVANT LITERATURE

The birth of a child with physical or mental disabilities places a heavy burden on the parents and families of the child. Literature was reviewed to gather information on children with disabilities and their families. It is important to understand the impact that the birth of a child with a disability can have on a family. Research was reviewed in the areas of family stress and social support. Theories related to ways families handle stress were reviewed. Literature on grandparents' interactions in families without a child with a disability and with a child with a disability was reviewed in order to gain a better understanding of grandparent issues.

Stress in Families of a Child with a Disability

Most parents have idealistic expectations of their children long before the children are born. They dream about what their children will look like, how they will act, and how smart they will be. They wonder what they will become when they are adults. When a child is born or diagnosed with a physical, mental, or health challenge, the family must face a realization that these dreams that they have had for the child may not become a reality. The beginning of this realization process is sometimes referred to as a symbolic death of the child (Kirk et al., 1997). It is not a physical loss but a psychological loss. The parents mourn the loss of the child they dreamed about and yet face the prospect of raising a child that is disabled (Solnit & Stark, 1961).

The process of accepting the disability of the child and the challenges that are created by the disability are two of the first sources of stress the family will face (Beresford, 1994; Crnic, Friedrich, & Greenberg, 1983; Farber, 1959; Fotheringham & Creal, 1974; Gallagher et al., 1983; Slater & Wikler, 1986) and involves many emotions for the parents. Initially they may be shocked and deny that the disability exists or deny the negative potential of the disability. Many parents feel guilty and think that they have done something to cause the disorder. Anger is common and can be directed inwardly or at others. The uncertainty that comes with the situation can cause anxiety, confusion and helplessness. One father described his early feelings for his son who had Down Syndrome as chronic or continual sorrow (Stallings & Cook, 1997). The doctors and childcare workers can give the parents general characteristics of children with certain disabilities but they can not tell the parents exactly which characteristics their child will possess. Many parent feel overwhelmed with the situation and that can lead to self-pity, grief and depression (Fortier & Wanlass, 1994; Hunt & Marshall, 1994; Kirk et al., 1997; Kubler-Ross, 1969; Padrone, 1994; Segal, 1985; Shafer, 1983).

Negative emotions eventually give way to positive. Parents begin to understand the disability and see how it effects the child. They start to develop new hopes for their child, some similar to their initial dreams, some different. They learn to be content with what the child is able to do. Parents see the positive characteristics of their child and accept the child for who he or she is (Fortier & Wanlass, 1994; Hunt & Marshall, 1994; Kirk et al., 1997; Kubler-Ross, 1969; Padrone, 1994; Segal, 1985; Shafer, 1983). Fears are overcome by love for the child. This process does not occur over night. The emotions and intensity involved are different for each person. Throughout the lifetime of the child, these various emotions will be felt to varying degrees. (Featherstone, 1980; Meyerson, 1983) For most parents, the reoccurring of even the negative feelings are over powered by their feelings of love and acceptance of the child.

The parents of a child with a disability experience a significant amount of stress in raising the child. The amount and intensity of stress has been found to be generally higher than in those parents who have children without disabilities (Beckman, 1991; Dyson, 1987; Fisman, Wolf, Ellison, Gillis, Freeman, & Szatmari, 1996; Friedrich & Friedrich, 1981; Kazak & Marvin, 1984; Thompson, Zeman, Fanurik, & Sirotkin-Roses, 1992). Anne Kazak (1987) found that mothers of children with disabilities experienced higher levels of stress when comparing 125 parents of children who were handicapped and 127 parents of non-handicapped children. Similar results were found in a study of 69 mothers of children with physical handicaps and 63 mothers of children who are non-disabled (Miller et al., 1992). Lily Dyson (1993) studied a group of parents of children with disabilities and parents of children without disabilities. In the initial study and a follow-up study done two years later, she found a significantly increased amount of parental stress indicated by the parents of children with disabilities. In another study one hundred and fifty families were compared in relation to stress.

One-third of the families had children with physical disabilities, one-third children with mental retardation, and one-third children without disabilities. Those with children with disabilities scored twenty to twenty-five times higher on stress scales (Singhi et al., 1990).

Although most studies agree that stress increases with the presence of a child with a disability, this does not mean that families are not able to function effectively. A study of 404 families of children with disabilities found that overall the adjustment had been good and that the families did not experience major problems (Dunlap & Hollinsworth, 1977). Most families learn to deal with the stress and are able to have functional families (Dyson, 1991, 1993; Kazak & Marvin, 1984; Mullins, 1987; Naseef, 1989). Even though families are able to adapt, the stress levels can be significant.

Emotional Stress

Parents of children with disabilities experience a significant amount of emotional stress. In examining 60 books written by parents of children with disabilities, June Mullins (1987) identified emotional stress as one of the two most common themes. The previously identified research (Dyson, 1993; Kazak, 1987; Singhi et al., 1990) indicated increased emotional stress. Similar results were found in a study of parents of children with physical disabilities compared to parents of children without disabilities reporting a higher level of depression and psychological distress (Miller et al., 1992).

Time and Physical Demands

Extraordinary demands was the other prevalent theme that Mullins (1987) found in reviewing books written by parents of children with disabilities. The time involved in assisting the child in daily activities and the constant supervision can be tremendous. A study by Dunlap and Hollinsworth (1977) of four hundred families of children with developmental disabilities found that families indicated that time demands and physical demands were important factors. Family studies by Kazak and Marvin (1984) identified similar demands. In another study of 27 mothers of children with health impairments, the mothers expressed high levels of stress especially associated with the care of the child (Singer & Farkas, 1989). Providing the proper care and the constant need to monitor the child's behaviors were sources of stress indicated by parents of children with physical disabilities in a study by Tavormina and others (1981).

Severity of the Disability

Various disabilities result in different levels of stress. For example, individuals with mild disabilities commonly represent a separate study group ordinarily presenting a different set of problems for their parents than the child with more severe disabilities (Farber & Rowitz, 1986; Salisbury, 1987). The amount of time for care and difficulty in care varies with the disability (Erickson & Upshur, 1989). Singer and Farkas (1989) found that the severity of medical complications affected the family life when looking at twenty seven mothers of children with long term health impairments. Due to the increase in needed attention, physical care, and social support, the more severe the handicapping condition is, the more stressful the situation is for the family (Dunlap & Hollinsworth, 1977; Dyson, 1991; Gallagher et al., 1983; Haverman & Eiser, 1991; Lyon & Preis, 1983; Minnes, 1988a, 1988b; Noh et al., 1989; Palfrey, Walker, Butler, & Singer, 1989; Singer & Farkas, 1989).

Age of the Child

Age may be a factor in the amount of stress that is experienced. One study found that stress increased when the child reached school age (Orr, Cameron, Dobson & Day, 1993). School issues can create stress for the parent as well as the child. Being around other children makes the deficits of the child with the disability more noticeable and more troublesome (Farber, 1959; Gallagher et al., 1983). As the age increases, children may become more difficult to manage physically and emotionally. Although the levels of stress may vary due to age, many parents express that there is a level of stress present throughout the lifetime of the child (Flynt & Wood, 1989; Orr et al., 1993).

Finances

Many children with disabilities have increased financial needs. The needs of the child will vary by disability and also vary throughout the life of the child. These needs may include medical needs, therapy needs, equipment needs, childcare, tutors, educational needs, and many others. Financial concerns have been listed as sources of stress by families of children with disabilities (Dunlap & Hollinsworth, 1977; Singhi et al., 1990).

Overall Stress

Any of the conditions that have been identified can cause stress for the entire family (Farber, 1959). These various factors associated with having a child with a disability interacting together create the amount of stress and satisfaction that the family experiences (Sloper & Turner, 1993).

Grandparents as a Source of Stress

Parents are sometimes disappointed in the reaction of their parents to the birth of a child with a disability. Parents may want grandparents to be supportive and defend and protect them as they did when they were younger. All grandparents are not supportive and positive. One mother explained that, when parents find that their parents' attitudes toward the disability of the child are different from their own, it can cause a "great void and separation" (Pieper, 1976, p. 9). The parents may feel very alone and betrayed by the people who reared them (Kratochvil & Devereux, 1988).

Some grandparents may have difficulty in accepting the limitations caused by the disability of the grandchild. They may deny the severity of the handicap of the child even after the parents have accepted it (Harris et al., 1985). Since most do not live with the situation on a daily basis, it is sometimes easier for them to pretend that it does not exist. They may not see the developmental delays or the time consuming needs of the child which may cause the grandparents to minimize the problem (Kratochvil & Devereux, 1988). Because of these things the grandparents may not see the need to provide special programs and activities for the child. It has been reported that some grandparents have even discouraged the parents from participating in early intervention programs (Gabel & Kotsch, 1981). In a study of thirty-two families of children with epilepsy (Romeis, 1980), most families identified the grandparents as non-helpful and a constant source of stress and adjustment difficulties.

Mothers More Affected by Stress

It is important to look at the issue of support through the eyes of the mother. Support is needed for the entire family but especially needed by mothers, since they are usually the ones who deal with the daily physical and emotional care of the child and have been found to bear the greatest amount of stress (Kazak, 1987). A study of 113 families who had a child who was moderately to profoundly retarded found that the impact of the disability and the care for the child had a greater effect on the mother than the father (Heller, Hsieh, & Rowitz, 1997). In a study by Kazak and Marvin (1984), mothers of children with disabilities were found to be particularly vulnerable to the effects of stress. The stress of daily management had a more significant effect on mothers than it did on fathers in a study of 133 mothers and 93 fathers of children with disabilities (Tavormina et al., 1981). Mothers are usually the ones in charge of the daily care and routines involved with having a child with a disability. They generally express more needs than fathers for social support and for assistance in caring for the child (Bailey, Blasco & Simeonsson, 1992) and find social support more helpful than fathers (Krauss, 1993). Although one study of 147 parents did not find a significant difference in stress between mothers and fathers (Rousey, Best, & Blacher, 1992) several studies indicate that the mother is generally more susceptible to stress than other family members (Kazak, 1987; Kazak & Marvin, 1984; Singer & Farkas, 1989; Tavormina et al., 1981).

Social Support

In order to deal with the stress, parents of children with disabilities need to adjust to the limitations and challenges by developing coping skills that will allow them to react appropriately. Coping is defined as the things people do to avoid being harmed by life strains or to reduce stress (Pearlin, Menaghan, Lieberman, & Mullan, 1981; Pearlin & Schooler, 1978). It is important for parents to find a productive way of relieving or coping with the stress of raising a child with a disability (Crnic et al., 1983; Schilling, Gilchrist, & Schinke, 1984). One avenue that may help with reducing the strain is the use of social support.

Social support plays a significant role in the reduction of stress among the general population (Cobb, 1976; Pearlin et al., 1981; Sansom & Farnill, 1997; Wilcox, 1981). Social support, such as assistance, information, empathy, and understanding, can assist the family in responding in a more positive manner to stressful events (Byrne & Cunningham, 1985; Fotheringham & Creal, 1974; McConachie, 1994; McCubbin, McCubbin, Thompson, Han, & Allen, 1997; Slater & Wikler, 1986). Resources for social support can include friends, coworkers, people in the community, or church groups. Other resources include extended family members, such as grandparents, brothers, sisters, aunts, and uncles (Pearlin et al., 1981).

Social resources can be used to assist the parents in coping with the child who is disabled. A study of 404 families of children with disabilities found that the families have a need for social support especially for the physical and time demands (Dunlap & Hollinsworth, 1977). One study concluded that a portion of the stress may not be caused by the disability itself, but by the lack of adequate social support (Lipsky, 1985). A study by Sloper and Turner (1992) of 107 families of children with physical disabilities indicated that the mother's ability to utilize social support may be an important factor in the way they deal with future stress. A study of 60 mothers of children who were retarded found a significant negative correlation between social support and stress (Minnes, 1988a). A similar study of 54 parents, half having a child with a disability found that increased support was significantly associated with lower levels of stress (Beckman, 1991). Another study found that mothers are better able to handle the stress when they are provided with social support (Barakat & Linney, 1992).

The ability to cope with the stress through the help of social support can be linked to the families' ability to adjust to the family situation that is caused by having a child with a disability. Trute & Hauch (1988) in interviews of 36 families of children with disabilities found that positive adaptation was linked to social support. A study of 48 mothers and fathers showed that social network and family adjustment were highly related

(Frey, Greenberg, & Fewell, 1989). Because of the potential that social support has in assisting families to adapt, Slater and Wikler (1986) concluded that parents should be encouraged to obtain support from these social networks.

Family Stress Studies

For many decades there have been quests for an increased understanding of families and the ways in which they respond to stress. Some handle stressful life events as a challenge that they seek to overcome while others handle these types of events as a defeat. Early studies (e.g., Angell, 1936; Hill, 1949; Koos, 1946) were the basis for continual systematic research which used various strategies, models, and instruments to explain the variability of family response. One of the early researchers, Reuben Hill (1949) studied families separated by war in order to determine what conditions, resources and coping behaviors the families utilized in adapting to this stressful event. One of Hill's conclusions was that when the family was threatened they would work together to meet the challenge sometimes by changing their roles but usually by reinforcing the typical family patterns. He wanted to find out which family patterns lead to positive adaptations to crisis events. His research lead to the earliest conceptual framework addressing these issues known as the ABCX model.

The ABCX model focused primarily on pre-crisis elements that might explain the variability of families to cope with the stressful situation. Factor A was defined as the stressor event. Factor B identified the resources that were available to the family. Factor C was the definition the family made of the event. These three factors combined to create the crisis factor or the X factor. The three factors (ABC) influence the families ability to create the positive or prevent the negative effects that lead to the crisis (Hill, 1949). This has been the basis for continued research.

Double ABCX Model

Subsequent research recognized these factors but felt that there were additional elements that influenced the X factor. In dealing with the initial stress there were additional stressors that occurred either naturally or as a result of coping with the initial stressor (Boss, 1980; Burr, 1982; McCubbin, Dahl, Lester, Benson, & Robertson, 1976; McCubbin, Hunter, & Dahl, 1975). A family could not be defined in a single time element therefore the X factor or crisis is a continuous variable that indicates the amount of disruption or incapacity of the family system (Burr, 1973). Looking at post-crisis variables could strengthen an understanding of how families cope with crisis.

Hamilton McCubbin and Joan Patterson introduced the Double ABCX Model (1981, 1982, 1983). This model incorporated the pile-up of events which influences how families react to stressful situations. The Double A factor (Aa) refers to the various stresses faced by the family. These include the initial stress, stress that occurs as normal life changes and events occur and the stress that develops as a result of the family attempting to cope with the hardships of the initial stress. The Double B factor (Bb) refers to the resources available to the family. It includes the initial resources and those resources that are strengthened or developed due to the crisis situation. In their longitudinal study of American families with a member held captive or missing in action in the Vietnam War, McCubbin and Patterson (1982) identified self-reliance, self-esteem, family integration, and social supports as resources that were developed. The Double C factor (Cc) includes the family's perception of the event and the perception of the crisis. It involves the meaning that the family gives to the entire situation. This can involve various elements including religious values, redefining of the situation, and endowing the situation with meaning. This build up of factors interacts to indicate the crisis and adaptations, which makes up the Double X factor or the continuum of family adjustment to stress over time.

There are many elements that can be considered when looking at the family resources identified in Double B factor. The definitions of resources vary among researchers. George (1980) identified four areas including financial, education, health and psychological resources. Pearlin and Schooler (1978) identified three personal psychological resources including self-esteem, self-denigration, and mastery of ones own life. Areas of family cohesion and adaptability have been measured and identified as resources (Olson & McCubbin, 1982).

Resources have also been defined as social support. Agreement does not exist on what constitutes social support (O'Reilly, 1988; Turner, 1983). Some include instrumental aid, emotional aid, and informational aid (Cobb, 1982; House, 1981). Cobb (1976) advocated the most widely referenced definition. The first area in his definition of social support is emotional support that leads an individual to feel cared for and loved. The second is esteem support that allows the individual to feel esteemed or valued. The last area is network support that causes the individual to feel like a part of a group that includes mutual obligation and understanding. It does not include any type of material support. While many use Cobb's definition it is also recognized that social support is whatever allows the individual to cope with the crisis situation. Therefore whether it is considered part of social support or separate, tangible support can provide a needed resource (Cobb, 1982; Schaefer, Coyne, & Lazarus, 1981; Thoits, 1986).

The Double ABCX Model has been used as a basis for various research. A group of researchers used it in looking at 200 families of children with cerebral palsy (McCubbin, Nevin, Cauble, Larsen, Comeau, & Patterson, 1982). Patterson and McCubbin (1983) utilized it again in a study of families with children who had cystic fibrosis. It was also used as a testable model utilizing data on Army families that had been relocated (Lavee, McCubbin, & Patterson, 1985). The model was used more recently to address the adaptation of children to divorce (Plunkett, Sanchez, Henry, & Robinson, 1997). The model has been expanded to look at more global influences including the community. This expansion is identified as the Family Adjustment and Adaptation Response Model (McCubbin & Patterson, 1983; Patterson, 1988, 1989; Patterson & Garwick, 1994).

There are some important factors to consider when looking at the Double ABCX model. Family stress is a state that arises when the demand of the situation creates an imbalance in the family functioning and demands that adaptive behavior occurs. It does not necessarily lead to distress that is an unpleasant or dysfunctional state (McCubbin & Patterson, 1981). The family adaptation is not a specifically defined, measurable entity but is a descriptive criteria (MuCubbin & Patterson, 1981) that reflects an acceptance and understanding of the situation (McCubbin & Patterson, 1983). The crisis or adaptation is a continual process which allows for fluctuations within families and variations among families. This framework is a systematic attempt to identify and describe critical variables which appear to influence a families ability to adapt to a crisis situation.

Grandparents

It has been suggested that the primary benefit of grandparents is a warm grandparent-grandchild relationship.

This relationship makes the grandchild feel loved and accepted. In a study of 199 fifth and sixth grade students, the students reported that grandparents rated next to parents for affection, warmth, and importance and that these interactions had less conflict than interactions with anyone else (Furman & Buhrmester, 1985). Grandparents are able to enjoy the child without having to take the actual responsibility of rearing the child (Gabel & Kotsch, 1981). They play an essential role in the family structure by providing warmth and pleasurable experiences (Kivnick, 1983; Wilcoxon, 1987) and are commonly the source of family information and the initiators of family gatherings (Hartshorne & Manaster, 1982). A study of seventy-nine parents concluded that they also believe that these feelings of security and belonging are very beneficial for the child (Thomas & Sanders, 1985).

Grandparents play a vital role in most families and can be an important resource. Grandparents can provide help in a variety of ways and have much to offer their children and their grandchildren (Castiglia, 1994). Extended families have always played a role in the support and development of the identity of the child in the typical family (Newman, 1989). The grandparent/grandchild relationship has the potential to strengthen family systems

(Barranti, 1985; Hagestad, 1988; Ingersoll-Dayton & Neal, 1991; Newman, 1989; Pattison, Defrancisco, Wood, Frazier, & Crowder, 1975).

In the general population, grandparents are considered important to the grandchild and to the extended family. In a study of 178 college students, grandparents are considered significant people in their lives and continue to be very important to them (Hartshorne & Manaster, 1982). One study of thirty families found that grandparents are active members of the support network for parents of young children (Tinsley & Parke, 1987).

Even though grandparents may live many miles away, they can find ways to reach out to their grandchildren and other family members in meaningful ways (Orr & VanZandt, 1987). Baranowski (1982) found that the quality of the relationship between the grandparent and the grandchild is more important than the quantity of time spent together. This quality can be achieved not only through personal visits but also through letters, tapes, and phone calls (Vadasy et al., 1986).

The relationship of grandfathers and grandchildren may vary from the relationship of grandmothers and grandchildren. In a study of 99 fathers of children with no disabilities, the role of grandfathers having a direct impact on the support of the grandchild was very limited (Kivett, 1985).

Maternal grandmothers may have a unique relationship to the family structure (Castiglia, 1994). In the general population, maternal grandmothers typically will have greater interaction with their grandchildren than any of the other grandparents (Fischer, 1983; Hartshorne & Manaster, 1982). In a study of 84 children with no disabilities, the maternal grandmother was favored most frequently by the children (Kahana & Kahana, 1970).

Grandparents of a Child with a Disability

The birth or diagnosis of a child with a disability also affects grandparents. Similar to the parents, grandparents have dreams and expectations for their grandchildren. They too feel disappointed when they realize the child has disabilities (Gabel & Kotsch,1981; George, 1988). Grandparents may also feel anger or frustration and because they are somewhat removed from the situation they may express these emotions more openly than the parents do (Pieper, 1976).

The grief that the grandparents feel has been described by some as a double grief: grief for their child and for their grandchild (Burns & Madian, 1992; Fewell, 1986; Lian and Aloia, 1994). They may feel their hurt is even greater than the parents. They feel hurt for not only the child with the disability, but also for their own child who must cope with this new challenge (George, 1988; Vadasy, Fewell, & Meyer, 1986). One grandmother said it this way, "I suffered for him, for what he might have been, should have been. I resented what his birth had done to my lovely daughter" (McPhee, 1982, p. 15).

Grandparents may blame especially the mother for the disability of the child. This is most commonly seen through the eyes of the paternal grandparents. They may vent their frustrations at the daughter-in-law even claiming that the situation is threatening the current and future happiness of their son (Gayton, 1975; Pieper, 1976).

Grandparents will also feel an array of emotions in dealing with the news that their grandchild has a disability. Those feelings will vary among grandparents, some will express those feelings openly and others will hide those feelings. With time, grandparents, like parents, will typically develop feelings of love and acceptance toward their grandchildren with disabilities (Gabel & Kotsch, 1981; McPhee, 1982: Michaelis, 1981).

Support from the grandparents can come in various ways including financial support, physical care, words of encouragement, and emotional support. Each of these types of support may assist the parent in dealing with the problems associated with having a child with a disability (Jacobsen & Humphry, 1979; Pieper, 1976; Vadasy et al., 1986; Weber & Parker, 1981). One grandmother explained that one important thing grandparents can do is to do the typical things you would do to help the family such as household chores, playing with the child, offering emotional support, and possibly offering financial support if needed (Gerver, 1983). Grandparents may assist the families of children with disabilities in several ways. They are sometimes trained to assist with the care and therapy of the child. Grandparents may be used for babysitters or temporary care givers (Gallagher et al., 1983; Pieper, 1976). Eighty-nine mothers of children with disabilities reported that they needed help with daily tasks and care of the child (Marcenko & Meyers, 1991).

Maternal grandmothers appear to be acutely sensitive to their daughters. They understand the burden and responsibility of raising a child and understand the increased burden the mother has in raising a child with a disability (Harris et al., 1985). Maternal grandmothers are most often identified as providing direct assistance with the child by helping with daily needs and routines

(Sonnek, 1986). They are sometimes more sympathetic to the needs and concerns of the mother of the child with a disability (Goldberg et al., 1986).

Parents of children with disabilities need emotional support. An important role of the grandparents of children with disabilities is the help and support that they can give to parents (Thomas & Sanders, 1985). When parents perceive grandparents as supportive, it frees the parents to focus on the needs of the child as well as their own feelings and needs (Schell, 1981). The support received from families may be more important than any other outside support. In a study of thirty families, Waisbren (1980) found that fathers who were supported by other family members engaged in more activities with the child. Mothers who received support from the extended family had greater positive feelings about the child and felt less of a need to consult with numerous doctors. Another study found that siblings also display greater self-confidence and acceptance when there is physical and emotional support from extended family members (Dyson & Edgar, 1986).

Extended families can provide support for both the child with a disability and for the parents of the child. Family members influence the development of a child by direct interactions with the child and through the nature of support provided to their parents (Cochran & Brassard, 1979; Fewell, 1986; Gabel & Kotsch, 1981). Grandparents are not always given credit for providing this type of support. Segal (1985) indicated that grandparents were seldom listed as providing significant support when mothers were asked to list those who had assisted them in the process of coping with a child with a disability. Dyson (1987) also noted that the parents in her study perceived less support from extended family than from other sources. Some feel that this may be due to a lack of understanding of the child's disability and how they can provide help to the family (Murphy & Delle Corte, 1990; Rubin & Quinn-Curran, 1983).

In most cases, grandparents indicate that they want to be helpful and supportive (Burns & Madian, 1992; Murphy & Delle Corte, 1990) and have been identified as providing that support. A study of 94 mothers of children who were deaf and blind indicated that several listed grandparents as being supportive and helpful (Vadasy & Fewell, 1986). Another study of 36 families of children with a disability identified satisfaction with the support and involvement from extended family members (Trute & Hauch, 1988).

The child with a disability possesses the same need for the warmth of a grandparent-grandchild relationship.

Children, regardless of their disability, need grandparents who can listen to them without criticizing and accept them as they are so they can grow (Orr & VanZandt, 1987). The elements that make grandparents beneficial and important to the general population are the same elements that make them beneficial and important to grandchildren with disabilities. Because of wisdom that comes from life experiences, grandparents sometimes assist the parents of the child by giving a simple or direct explanation of a seemingly complex problem by dealing directly with the issue (Pieper, 1976). Grandparents may be very positive about the child with a disability. In a study of nineteen autistic children Harris and others (1985) found that the grandparents took the more positive, optimistic, and less burdened view of the child and the situation. The grandparents attitudes may have been more positive because they had less frequent contact with the child or because they did not regard themselves as responsible for the failures, shortcomings, or mistakes of the child.

The attitude and the support of the grandfather may be different than that of the grandmother. Because of the difference in the relationship, grandfathers may sometimes have the ability to view the disability in a different way than grandmothers. The relationship that they have with the child may allow them to be less optimistic and more realistic about the child's disability than grandmothers (Harris et al., 1985).

Some grandparents feel that they are assisting the family, but it is not perceived as support by the parents of the child. They may think they are being supportive by being pessimistic, by telling the parents how they should rear the child, by suggesting alternative approaches to working with the child, by pretending the disability does not exist, or by minimizing the effects of the handicapping condition (Kratochvil & Devereux, 1988). In one survey, fathers expressed that they felt that grandmothers and grandfathers overestimate the degree of closeness and support they offer to their sons (Harris et al., 1985).

Some grandparents have thought that having a child with a disability in the family would be a devastating situation. Others feel that they add richness and joy to the family unit. One grandmother reported that having a grandchild with Down Syndrome had been a blessing to her life (Michaelis, 1981).

Further Research

There is a need to find more specific information on the use of specific types of support and its effects on the family (Krahn, 1993). The extended family, specifically the grandparents, is one source of support to be further examined to determine the relative strength of this relationship. It is important to look at their role in the families of children with disabilities (Crnic et al., 1983; Kazak & Marvin, 1984; Krahn, 1993; Seligman, 1991). Grandparents play a unique role in the support of the family of a child with disabilities. There needs to be a further understanding of this role (Seligman, 1991).

Summary

This study examined the types of interactions that families of a child with a disability engage in with grandparents and identified which interactions were perceived as supportive by the mothers. It compared the interactions of the maternal grandparents to the paternal grandparents and the grandmothers to the grandfathers. This information was used to analyze the grandparent interactions and perceived support of the grandparents. Basic elements were identified and where applicable they were related to the Double ABCX theory of family adaptation.

CHAPTER III

RESEARCH METHOD

Method

The purpose of this study was to describe the types of interactions that families of a child with a disability engage in with grandparents and identify which interactions are perceived as supportive by the mothers. Differences were examined comparing the interactions of the maternal grandparents to the paternal grandparents and the grandmothers to the grandfathers. The Double ABCX theory of family adaptations was utilized in describing the interactions and perceived support of the grandparents to the family. This chapter describes the subjects who participated in the study and the procedures that were followed. A description of the interview instrument and the ways the data were collected and analyzed is presented.

Subjects

The researcher interviewed ten mothers who are the primary care givers of children with disabilities. Two interviews were conducted in the home of the researcher, one in the researcher's office and all others were conducted in the homes of the mothers. Qualifications of the subjects were that they be the mother of a child:

> with mental retardation needing limited support and living at home;
>
> between the ages of twelve and eighteen;
>
> whose father was living in the home for at least the first five years of life;
>
> who had three living grandparents for the first five years of life.

The subjects were mothers who volunteer to be a part of this study. Initial contacts were make through acquaintances of the researcher living in the Oklahoma City area. All of these children had attended at least one activity day that is hosted twice a year by the researcher. These mothers were willing to bring their children and allow them to participate in activities that were lead by university students. This activity allows the university students to have a close experience with a child with a disability and allowed the child with the disability to spend a day away from home just having fun and getting significant attention. These mothers had already demonstrated their willingness to share their child in order for others to learn so they were open to the idea of sharing information about grandparents with the researcher.

Attempts were made to represent different ethnic and socioeconomic groups. The researcher was able to ask mothers from different socioeconomic groups to participate. The researcher attempted to contact the mothers of other children who are African American who had attended the activity days however was not able to find current phone numbers. The subjects consisted of nine caucasian mothers and one African American mother. The income levels varied with two mothers in the less than $20,000 range to three mothers in the above $60,000 range. Three mothers had between $40,000 and $60,000 in income and one had between $20,000 and $40,000 (see Table 2). Seven of the mothers currently work outside of the home, however six of these mothers were homemakers when the children were smaller. Eight of the mothers are still married to the father of the child with the disability. In the other two families the child remains close to the father and visits on a regular basis.

Table 1

Incomes for Families and Grandparents

Child	0-20,000	20,001-40,000	40,001-60,000	60,001 +
Larry	pgp	mgp		f
Rachel			f	
Tom				f/mgf/mgm/pgp
Eric	f	mgm/mgf/pgp		
Neil		mgp/pgp	f	
Bob		f	mgp/pgm	
Emily		pgm	f/mgp	
Randy		mgp/pgp	f	
Rita				f/mgp/pgp
Patti	f			

(f=family, mgp=maternal grandparents, pgp=paternal grandparents, mgm=maternal grandmother, mgf=maternal grandfather, pgf=paternal grandfather, pgm=paternal grandmother)

Procedures

The purpose of the study was explained to each subject and a consent form (see Appendix A) was obtained from each mother giving permission for the interview and the use of the information. All information obtained from the subjects is confidential and anonymous. No names are used nor any specific information that would identify the family members. Each family unit is identified by case number or a fictitious name on all transcripts and written material.

All subjects were interviewed in person by the researcher. The interviews were taped and all tapes were kept confidential. The interviewer transcribed the tapes with all names removed and replaced with the role or numerical description of the person. For example, maternal grandmother replaced Nanna Smith. All tapes were erased when the transcripts were reviewed for accuracy. Actual statements were used in reporting and comparing the data but the name of the mother making the statement is not given. The statements are referenced by the page of the written transcript. Each child with a disability is represented by a fictitious name to allow for more clarity in reading about the family. The names of the families participating in the interviews will never be published nor will any information that might lead to the identification of the families.

There were three parts to each interview. The mothers were first asked to provide some basic demographic information (see Appendix B). The mothers were then asked to provide some information about the family history. These questions (see Appendix C) were used to develop genograms (see Appendix E - individual family genograms) in order to provide a graphic representation of the family from grandparents to grandchild. The focal component involved answering standardized and follow-up questions concerning the child, the family, and the relationship with the grandparents. Standardized questions were used as the discussion was held with each mother (Appendix D). The interview guide approach was utilized with the researcher exploring some questions by probing for further detail as suggested from depth interview method (Patton, 1980). The researcher attempted to assure that responses for each appropriate question included all four grandparents. The researcher attempted to conduct the interview in such a manner that it allowed the mother to speak freely (Copeland & White, 1991).

Instruments

Questions were used to identify characteristics that might be used to relate one respondent to another. This was done by a demographic questionnaire (see Appendix B) and questions used to develop a genogram (see Appendix C). A genogram is a means of displaying family information in a graphic format. It is used to represent the family tree for at least three generations identifying family structure including the number, sex, and order of the grandchildren (McGoldrick & Gerson, 1985). In a genogram, the paternal side of the family is identified on the left and maternal on the right. Squares are used to represent the males and circles used for the females. Other elements of the genogram are given in the genogram key (see Appendix E).

The personal interviews utilized the standardized open-ended approach combined with an interview guide approach (Patton, 1980). With this approach, specific questions are asked in a predetermined order, however, the researcher must be free to explore areas in more depth (see Appendix D). This method of open-ended questions allows the researcher to determine the perception of the person being interviewed instead of suggesting and limiting what the person is thinking.

Five general categories of questions were used including knowledge, experience, value, feeling, and sensory. These were utilized in order to obtain a variety of responses (Patton, 1980). Knowledge questions were asked to identify some factual information. Some experience questions were used where the mother was asked to describe events that have occurred and specific observations she has made. There were value questions asked about the mother's opinions and what she thinks about the situation. The mother was also asked questions about how she feels, or her feelings about the grandparents and their interactions. Sensory questions were also used to get the mother to describe what she sees and hears when observing the interactions of the grandparents. Within each category of questions, present and the past interactions were sought.

Data Analysis

The data were analyzed using the basic framework of symbolic interaction (Schwartz & Jacobs, 1979) which attempts to understand and interpret reality by examining it from the viewpoint of the individuals directly involved in the situation. Particular to this study were the viewpoints of mothers of children with disabilities. The study had as its aim to seek an understanding of how the mothers perceived the support that they had received from the maternal and paternal grandparents since having a child with a disability. Using the framework of the Double ABCX theory, the data were examined in four areas. The family demands were considered both the initial and the subsequent stressors. The resources that were provided by the grandparents were analyzed to determine material and social supports that were provided. The perceptions of the mother were considered and statements that indicated the adaptation of the family were identified. The Double ABCX model was used to explain the interaction in these four areas.

The primary data collection was direct quotations from the person being interviewed. The statements were compared and categorized to statements from other interviewees and analyses were conducted. The variables were related to the Double ABCX theory and other elements that emerged were identified. These comparisons and applications were developed based on the similarities and differences in the actual comments made by the mothers.

Research Questions

The data were compared to the constructs in the Double ABCX theory and analyzed in order to answer the major research questions:

1. What is the nature of grandparent interactions?
2. To what extent are grandparent interactions perceived as support by the mothers of children with disabilities?
3. What are the differences of the nature of interactions and perceived support from the maternal and paternal grandmothers and grandfathers? and
4. To what extent does the Double ABCX theory of family adaptation provide an understanding of the interactions and perceived support of the grandparents to the families of a child with a disability?

CHAPTER IV

PRESENTATION OF THE DATA

The purpose of this study was to describe the types of interactions that families of a child with a disability engage in with grandparents and identify which interactions are perceived as supportive by the mothers. Differences were examined comparing the interactions of the maternal grandparents to the paternal grandparents and the grandmothers to the grandfathers. This chapter presents the data collected through in-depth interviews with ten mothers. The general history and areas of stress are identified for each family. The interactions of the grandparents and the response to the interactions are described. It should be noted that the descriptions of the child and family situation are from the perspective of the mother. Fictitious names have been given to each of the cases for clarity. Reference to the transcription of each interview is denoted by a two part number series. The first numeral of the reference represents the case number assigned to the mother who was interviewed. The second numeral is the page number of the transcript where the quote can be found. Transcripts are one hundred and one pages long and available to members of the committee from the researcher upon request.

Case One - Larry

Case one is a family of a child with Duchenne's Muscular Dystrophy. Larry, as described by his mother, is a "fifteen-year-old teenage boy, very much into his teen years...He's lots of fun and he laughs and he talks...and he's fun to be with" (1.1). He is in a special classroom in school however he does mainstream into a couple of elective hours.

Muscular dystrophy is a disorder characterized by progressive muscle weakness. Duchenne's muscular dystrophy is the most common and one of the most severe forms of muscular dystrophy. Weakness of the muscles begin appearing at an early age and death often occurs in the late teens or early twenties (Bigge, 1991; Hardman et al., 1996; Jones, 1988). Larry is now in an electric wheelchair. His overall health is good, but his muscles continue to weaken.

Family History

Larry is an only child and lives with his mother and father (see Appendix E for family history). The mother is a homemaker and the father is a judge for criminal appeals. The maternal grandparents both worked in companies in blue-collar positions and have been retired for about seven or eight years. The paternal grandparents were self-employed in various occupations. They retired about the time Larry was born and have been deceased for approximately five years. The maternal grandparents live about 100 miles from the family and the paternal grandparents lived about 200 miles. His paternal grandmother experienced some muscular deterioration during her last years.

Larry was not as active as other children were throughout his toddler and preschool years. The parents noticed this lack of activity, but became more alarmed when day care workers indicated their concerns. He seemed to tire easily and would cry or complain of pain especially in his legs. Because of these symptoms, the parents took him to the doctor for evaluation. After several months of testing and the mother being told he was "just a lazy child and (she) was an overprotective mother" (1.1), the doctors finally listened to the parents' concern for the pain that the child was experiencing and performed a muscle biopsy which identified the Duchenne's. Larry was diagnosed at approximately age four.

The parents were told that Larry might only live to be eight or nine so everything they did was for him in the beginning. They wanted him to be able to have all of the experiences of life that people sometimes don't have until they are older. The parents "made sure that Larry has been to most parts of the United States, he's seen the oceans, he's seen and he's done things he might not be able to do" (1.2) when he is an adult. They have been able to spend a lot of time together as a family. Although physically Larry is declining slowly, he is still active. He enjoys going to movies, bowling and other activities with his family and friends. His parents are aware of what the future holds for him but are very positive and spend time enjoying their son. The mother expressed that having a child with a disability as brought the family "closer together" (1.3).

Family Stress

Adjusting to the idea of having a child with a terminal disorder was stressful. The father had a difficult time believing and understanding the situation.

The mother felt scared and didn't feel that it was fair for such a thing to happen to her and to her husband because she felt that her husband "was such a good person and deserved a child, someone who could follow in his father's footsteps" (1.2). The mother also described a period of depression when she did not feel that she was able to do everything she felt she should have been doing. She was able to overcome this depression within a few weeks.

The maternal grandparents "really filled in a void in Larry's life" (1.3), by taking on some of the daily responsibilities especially while the mother was depressed. But at the same time they were "consumed with pity for him and they wanted to give him everything" (1.2). The maternal grandparents were very religious individuals and wanted the parents to take the child to various places and have people pray for him to be healed. Although the parents believe in healing they felt if "the Lord intended to heal Larry, He would do it by (their) asking...without going across the United States to someone (they) didn't know" (1.2). The maternal grandparents were a little disappointed when the parents opted not to do this, but accepted their decision.

The paternal grandparents’ initial reaction was different. Their concern did not seem so much focused on the child but on themselves, feeling sorry for themselves as though "they were being punished" (1.3). The mother feels that the paternal grandmother seemed to take comfort and "support from her friends feeling sorry for her" (1.3) because she had a grandson born to her son with such a disability.

Stresses in raising a child with a physical and terminal disability have varied over time for this family. The physical care has changed as the child's motor ability has deteriorated. Although he was once able to walk alone and handle many of his physical needs, the child now needs assistance in physical care such as dressing and going to the restroom. When the child was small the mother could easily pick him up or assist him physically in movement but now that he is the size of a normal teenager, she can no longer manage him physically. His size and level of endurance has also created the need for an electric wheelchair. There are still many places that are not wheelchair accessible so the family must always plan ahead and at times must ask for special arrangements.

The increased physical needs of Larry due to his size have caused the family to seek outside help. The family has hired an individual as a companion for Larry and as an assistant to the mother with the physical needs during the week. The father is very involved in the physical care on the weekends and before and after work during the week.

The parents have neglected their own social life in order to stay at home with the child. At one point that was because they chose not to leave him with a babysitter, but later on it was because the parents weren't able to find someone who would stay with him or who would want him and his wheelchair in their house. Integrating Larry into normal activities has at times been difficult because so many places are wheelchair inaccessible.

There are also emotional issues that effect the parents. The mother describes the desire "to do the best for your child and you are faced with certain decisions you don't know how to handle and you don't know anyone to talk to who has to face what you face" (1.4). Many times there is a feeling of isolation from others because of the emotional and physical challenges that have to be faced. The parents live with the knowledge that Larry will someday die because of his disability.

School situations can also create stress due to the involvement that is necessary. You have to "know the rights" (1.4) of the child in order for the child to actually receive the appropriate education. The mother described the interactions with teachers and other school personnel as troublesome and sometimes problematic.

Grandparent Interaction

The amount of time that the maternal grandparents have spent with Larry has changed over the years. When he was young both grandparents worked so they were only able to see him about four times a year. Larry spent two weeks every summer at his grandparents without his parents present. When the grandparents retired, they saw Larry about once a month until the last three years when their health began to decline. They continue to visit four or five times a year but are no longer able to care for Larry at their home due to his size and their health. Throughout the years they have continued to talk on the phone twice a month and correspond by cards and letters on a monthly basis. They treat Larry in the same manner that they do their other grandchildren.

When the paternal grandparents were alive they saw Larry every four to six weeks. They were retired and would come and visit the family for a few days at a time. During these visits Larry was at daycare or school and the paternal grandparents did not actually keep the child alone, the parents were always there also. The paternal grandparents did send cards for holidays. Although they did not talk with the child on the phone, they would tell the parents to tell Larry that they loved him.

The paternal grandparents seemed to relate to Larry differently than their other grandchild. The mother felt that the other grandson was the "light of their life" (1.7) and that Larry was seen as inferior. The paternal grandparents would provide physical care for the other child and were involved in different activities with him, but not with Larry.

The family spends time with the grandparents. Both sets of grandparents always made Christmas special. Although the mother would have liked for Larry to have spent more time with the grandparents, she feels they have been an important part of Larry's and his parents' lives.

The maternal grandparents provided support to the family through physical care of the child. About a year after the diagnosis, the mother's parents came to her and told her "they wanted to do whatever was required to do to help" (1.7) the mother and father in caring for the child. This surprised the mother because her parents had taught her that when you are an adult you take care of yourself and your own family. The mother at first declined the need for help thinking it meant financial and they did not need financial help. However, the father said that they could use the help of the maternal grandparents to take care of Larry so that both of the parents could go together on business trips. This helped the mother and father "maintain a relationship which took a little bit of the stress off" (1.7). The maternal grandparents would also provide extended care for Larry by having him spend a couple of weeks each summer in their home.

The maternal grandparents also provided assistance by helping around the house when they would come for a visit. The grandfather would do things like sharpen knifes and the grandmother would offer to help with cleaning. The mother usually insisted that they just enjoy playing with Larry and she would clean, but the offer was there and the attention that the grandparents paid to Larry allowed her time to do needed things around the house.

The paternal grandparents did not provide the physical care that was provided by the maternal grandparents. The paternal grandparents did not keep Larry in their own home. When they would visit the child's home, they did not stay with Larry without the parents.

When Larry was young, much of the time the maternal grandparents could be found playing with Larry. They would bring him special treats whenever they came to visit. The mother pictures their time together as "engrossed in each other...like three peas in a pod, they are very into the three of them and they are interacting so well they don't need anyone else there and they laugh and talk and use their imaginations" (1.6). The maternal grandmother included the child in all of her crafting hobbies by bringing him little objects to paint or having him help her sew. Although the maternal grandfather did not seem to have a special hobby, he would on occasions bring wood, hammers, and nails and he and Larry would act like they were building something, talking and pretending as they spent the time working and playing together.

The paternal grandparents were very moral and honest people as described by the mother. The mother stated that they "were not the kind to laugh and they were real serious" (1.6), so most of the interactions that they had with the child were conversations that were designed to teach Larry about right and wrong. When the child was young, the paternal grandfather did occasionally "get down on the floor and ride him piggyback and play with him" (1.10) but the paternal grandmother "never did things that a child would consider special" (1.10).

Response to Interactions

The mother felt supported by the grandparents. The maternal grandparents provided emotional support by asking about the child and allowing the mother to voice her concerns. The mother also felt support from the paternal grandparents in that she believed that they would have done anything to help.

The mother believes that the maternal grandparents "love Larry with all their hearts. They have a very special love, God put a very special love in their hearts for Larry" (1.2). They were always doing things for him or with him that made Larry feel very special. The mother expressed that she felt supported by these actions, because there "is always less of a stress when your child is happy" (1.9).

The love for the child by the paternal grandparents was felt by the mother. There did not seem to be a special relationship between the paternal grandmother and the child, but the mother believes the paternal grandparents love Larry, "they just displayed it differently" (1.3).

Although the interactions were different from the various grandparents, the mother perceived that all of them contributed to the life of Larry and the family. She would have liked to have seen more of a relationship from the paternal grandparents, but she doesn't think that the lack of closeness "was anything that they did consciously" (1.8).

The mother expressed strong feelings about the importance of grandparents. She believes that "they have an important role to play in he child's life...they can teach them things that parents can't teach and...show a love...a different kind of love that...is important" (1.5). She believes that both sets of grandparents have been able to do that.

It was difficult for the paternal grandmother to realize the limitations and challenges of the child. She did not seem to acknowledge the physical challenges that Larry faced until she developed a muscular disorder during the last years of her life. She then expressed verbally some understanding of why Larry would be tired and slow.

The manner in which the grandparents interacted were different, with the maternal grandparents having a closer relationship with Larry, however, the mother is confident that both sets were available and would have provided anything that was needed. In the mother's words, "They loved him through us because they loved us and they saw us loving Larry and respected us and we did not reject Larry so they didn't. I think he felt very loved by his grandparents" (1.11).

Case Two - Rachel

Case two is the family of an eighteen-year-old female child who was born with incontinentia pigmenti. Rachel is a very social individual. She loves to talk and is described by her mother as "Miss Merry Sunshine" (2.1). Rachel is in a special classroom for all subjects in school.

Incontinentia pigmenti is a complex hereditary disease. It is associated with skin lesions. Females are predominately affected with this x-linked disease because most males die inutero. Several defects are associated with this disorder. The defects that effect Rachel include ocular problems, small nails, muscle atrophy, seizures, and mental retardation (Jones, 1988).

Family History

Rachel lives with her mother, father, and a brother who is thirteen (see Appendix E for family history). The mother worked at home for many years, but now does some office work outside the home. The father is a businessman. All four grandparents are still living and now retired.

Both sets of grandparents live approximately two hundred miles away.

When Rachel was born, the doctor that delivered her noticed a difference in coloring and some other characteristics. He called in a pediatrician who was able to identify the disorder. The parents were told that this birth defect occurs only in females and would effect "her vision, her bones, her mental capabilities, skin, nails, and teeth" (2.1). Rachel is able to get around on her own, but does have some problems with depth perception and walks with a slightly different gait than normal. She had seizures when she was young, but outgrew them before she was a year old.

Rachel's family reacts in a very positive way to her disability. To them she seems normal, except slow. She sometimes needs assistance due to her depth perception. Academically she is far behind, but verbally and socially she functions well. They are very involved in church activities and Rachel is included in all family activities.

Family Stress

Memories of the birth and diagnosis still bring back tears as the mother recalls feeling very scared. The mother and father were not certain of what expectations they could now have for Rachel. The maternal grandparents were supportive in a quiet kind of way. They didn't say anything directly regarding the disability. The mother describes the action of the paternal grandparents as denial, "I still think they are in denial and so they don't think she has a problem" (2.1).

The parents have dealt with Rachel's disability in such a manner that it has not created great hardships for the family. They feel they have been as active as they would have been without her. The mother describes Rachel as "basically normal in many ways except she is slow but other than that she does everything on her own mostly" (2.2).

Since Rachel was diagnosed at birth, the parents began early working with her physical needs. They spent many hours and much energy seeking the appropriate treatment for her. There were many trips to doctors and therapists to obtain needed services.

When Rachel was younger and wasn't walking, the parents experienced some difficulty with places that were not accessible. The mother described a time they had to carry their three-year-old daughter because the facilities they went to on vacation would not allow strollers. Since Rachel now walks, this has not continued to be a problem.

Rachel did have a seizure disorder. The seizures stopped before she was a year old. Finding childcare was not difficult, because she seemed like other children, except smaller and slower.

The paternal grandparents did create some stress for the mother when Rachel was young. They wrote a letter to the father alleging that the parents weren't doing what they "should be doing and she was essentially blaming" (2.3) them for the delay in the child's development. This was difficult to handle during a time when they were doing what the doctors told them was the best for Rachel.

Grandparent Interactions

The maternal grandparents see Rachel four or five times a year. Sometimes the visits are at Rachel's house and sometimes at the grandparents' house. Every summer Rachel spends at least one week with the maternal grandparents without the rest of the family. The maternal grandparents "come from the time where you don't do long distance phone calling unless it is an emergency" (2.2). Although they do not call Rachel, the grandmother does sent cards or letters four or five times a year.

The paternal grandparents' visits with Rachel are very similar to that of the maternal grandparents. She sees them four or five times a year for weekend or holiday visits. The paternal grandmother calls Rachel every two or three months to talk.

She is treated like the other grandchildren by each of the grandparents. They include her in all family activities and spend time with her just like they do the other grandchildren.

The grandparents play a role in the family structure. The extended family spends time together on holidays and other times of the year. Rachel is a part of the interactions just like any of the grandchildren and the mother is satisfied with the amount of interaction.

Both grandmothers have been supportive by taking care of the child. Even when she was small and was still having seizures, both grandmothers would babysit when they came to visit. Rachel's maternal grandmother would also keep Rachel for at least a week each summer.

Rachel is very verbal and social, so much of her time with the grandparents is spent in talking. Both grandmothers will take her out shopping for the day. The grandfathers pay attention to her, but neither one talks very much to any of the grandchildren so she has less direct interaction with the grandfathers than with the grandmothers.

Response to Interactions

The maternal grandparents have provided emotional support by listening. They do not offer "a lot of criticism. They may not always like what you are doing, but you won't hear it from them directly" (2.1). Listening and trying "not to be judgmental" (2.5) are important characteristics according to the mother in providing support for the family.

The mother believes that Rachel is loved by all the grandparents. They all seem to accept Rachel in the same way they do all of the grandchildren. Rachel has a good relationship with all of them.

The mother feels very comfortable with the amount of interaction Rachel has with her grandparents. The parents are very independent people and want it to be that way. Both sets of grandparents have related to Rachel and her brother in a manner in which the parents could have easily predicted based on the way they generally relate to people.

Other than the occasion of the note that the paternal grandparents sent, the mother has felt support from the paternal grandparents. She feels that they just didn't understand all the things they were doing for Rachel and she also believes that maybe they were disappointed that the parents "didn't just fall apart and need them to come in and take over" (2.3). The situation was never really discussed and there have not been any other major conflicts.

Case Three - Tom

Case three is a family of a twelve-year-old male who has Prader Willi syndrome. Due to the disability, food is a major issue in his life. Tom is described by his mother as a child who is "fun to be around. He makes me laugh...he's got so many wonderful attributes" (3.14). He likes to sit and read books or talk to others and a routine schedule is very important.

Prader-Willi syndrome is a chromosome abnormality. Characteristics of the disorder are delays in motor ability, mental development, small features and stature, and an insatiable appetite which often leads to obesity (Beirne-Smith et al., 1998; Jones, 1988). It is often associated with failure to thrive and hypotonic muscle tone when young.

Family History

Tom lives with his mother, father, and a brother who is fourteen (see Appendix E for family history). His father works for a business and his mother works in the retail market. Both parents are very active in the Prader Willi Association. His maternal grandmother did not work and enjoyed traveling. She is currently very ill and still lives within ten miles of the child. His maternal grandfather is an active businessman and lives within thirty miles from the family. The maternal grandparents were divorced before Tom was born. The paternal grandparents live a hundred and fifty miles from the child. They are both retired and spend much of their time square-dancing.

When the doctor first placed Tom on his mother's stomach she said "there is something wrong with this baby" (3.1). The doctor assured the mother that nothing was wrong. During the next couple of weeks the mother was convinced that there was a problem. She had a child who didn't eat and didn't cry, he just lay there and she knew that was not normal. At first the doctors thought that he had a basic failure-to-thrive syndrome and he would begin to improve given some time. By the second week the doctors began to run tests on the child until the diagnosis of Prader Willi syndrome was made at about five months of age.

The family has learned to live with a child with Prader Willi. They attempt to lessen the stress by not creating a fight if the child should take food that is not on his plan. As a family they are constantly aware of the types of food they bring into the house or of the foods available when they go to community activities.

Tom is now at a point that he is hard to control and must be watched constantly. The family is currently looking for a full time care center for the child to meet his specific needs. They want him to have an environment where he can make friends and do activities in a controlled positive atmosphere. They have learned to live one day at a time and enjoy Tom as he is.

Family Stress

The devastation of having a child with a disability occurred before the diagnosis actually came. Because the mother always believed that there was something wrong with her son and had convinced the father after just a few weeks that there was a problem, they were relieved when they finally received the diagnosis and knew that the child's failure-to-thrive was not immediately life threatening. The parents were still overwhelmed and felt sad but felt that they could deal with the disorder now that they knew what it was.

The initial reaction of the maternal grandparents was that the child would eventually outgrow it. The maternal grandfather soon accepted the child as he is and has an understanding of the disorder. The maternal grandmother continues to be in denial. According to the mother she "lived a lot being in denial about a lot of things so this did not come as a big surprise" (3.6) for Tom's mother.

The paternal grandparents were more realistic about the disability, however at about the same time that Tom was diagnosed, the paternal grandparents had another grandchild that was diagnosed with terminal leukemia. They had a difficult time dealing with the death of the other grandchild and it is still hard for the paternal grandparents to accept Tom as he is. They seem to "feel very sorry for him" (3.14).

Prader Willi syndrome creates stress for the child and for the family. The child is "under a tremendous amount of stress. From the moment he wakes up in the morning until he goes to sleep at night all he is thinking about is eating because he never feels full" (3.5). The family must consistently be aware of Tom’s diet. This limits the food they bring into the house and the places they go. This can be extremely stressful for the sibling.

The tantrum behavior that is also a characteristic of the syndrome causes stress for all the family members. Tom can be both physically and verbally abusive and reacts like a "total other person that even he doesn't understand" (3.2). The mother has to anticipate every situation in which she takes Tom in order to offset any stress that might trigger a tantrum. The tantrum behavior has increased tremendously as he has gotten older.

At nine years of age Tom developed a new problem. He started a fire in the house. He has been in counseling and in a treatment program for this disorder. Even with therapy, it has happened more than once. Because of his fire-starting behavior, Tom can never be left alone.

The family has had a difficult time finding the appropriate type of school program. Tom has been in private schools, however, they were not able to meet his needs. He spent a few months in a residential center that was supposed to be equipped to work with children like Tom. It was a very poor environment so he moved back home. He is currently receiving his education through home schooling. He has a tutor who works with him about three hours a day.

One result of not being in a school program has been the lack of social interaction. Tom does not have his own set of friends. He considers his brother's friends as his own and they are nice to him, however it is not the same as having your own friends. He spends most of his time with his mother, which doesn't help either one of them meet their social needs.

The stress of this disability has also effected the brother. He has to help control Tom when he becomes violent and must watch the child when the parents are not in the room.

Social activities are very limited. Someone constantly has to be with Tom and this is usually the mother. It has limited the activities that she has been able to do with the older brother. It has also limited the amount of time that she and his father are able to spend together. It is difficult to find a babysitter that they feel they can trust to watch Tom as closely as he must be watched in order to prevent a fire or a tantrum.

Grandparent Interaction

The maternal grandfather seems to have the closest relationship with Tom of all of the grandparents. He comes to visit two to three times a month. He calls and talks to Tom on the phone at least once a week.

Although the maternal grandmother lives nearest to Tom, she sees him the least. He only saw her maybe twice a year when he was young and less over the last three or four years. The mother describes the maternal grandmother as not being the “mothering type” (3.6). She was not with her own children and is even less with the grandchildren.

Tom sees his paternal grandparents about once a month. They stop by when "they are on their way to someplace" (3.7) where a square-dance contest is being held. They do not make trips especially to see the family and the family does not go to their house because they are always away. The paternal grandparents will take Tom's sibling for outings or for a visit at their home, but never Tom.

The maternal grandfather and the paternal grandparents are a part of Tom's family. They spend time together and try to include Tom when they visit and at holiday times.

The family has not received much help from the grandparents in the form of material support. The maternal grandfather is very good with Tom, however, the time he spends with him is at Tom's house. The grandfather is older and did not feel that he could physically keep up with Tom when he was younger. As Tom grew and the tantrums increased, the grandfather could not have managed Tom alone. He does spend at lot of time with him. While he is spending time with Tom the parents can devote their attention to other things even though they remain in the house. When the paternal grandparents visit with Tom, they often wander off to other parts of the house or divert their attention to Tom's brother so the parents have to remain alert.

Tom and his maternal grandfather spend a lot of time talking directly to each other. When Tom is with his maternal grandfather Tom is "telling him about all the things he had seen and done that day and (the maternal grandfather) would be listening to him" (3.10). Then the grandfather would tell the child stories. They laugh together and hug each other frequently.

When the paternal parents stop by they will interact with Tom. They like to be doing things so they will usually work a puzzle or play a simple game with him. Sometimes they will read him a story. When Tom starts reading to them they have a tendency to wonder off and talk to the rest of the family. They do not ever take Tom and do things with him, because they are afraid they will not be able to handle him.

Response to Interactions

The maternal grandfather is credited with giving the mother "a lot of emotional support because he does really understand Tom more than most people and he knows what we go through" (3.15). He provides a "great sounding board" (3.25) and provides a lot of encouragement to the child. He seems to understand and sympathize with the challenges they face.

The maternal grandfather loves Tom. He is maybe closer to Tom than to his brother simply because the sibling is more active and the grandfather likes to sit and read or talk, which is closer to Tom's personality. He treats Tom, his brother, and his other grandchildren in an equitable manner.

The mother feels the paternal grandparents really care. They come for family visits and the mother believes "they think about (the family) a lot" (3.9). The mother believes that the paternal grandparents love the entire family, yet have a difficult time understanding the child.

The mother believes the paternal grandparents could have been more supportive, especially to the father. The paternal grandparents have a neighbor, who is very young, with Prader Willi syndrome. They think she is really cute and sweet and they find it difficult to understand why Tom is not the same. They do not seem to understand the added problems that occur as the child with Prader Willi syndrome grows older.

The paternal grandparents have provided support for the sibling. They take the sibling with them to visit in their home or to travel with them. The parents do not tell Tom the truth about where the sibling is going and always find activities for Tom to be involved in so that he does not ask many questions. Even though the parents wish that Tom received this type of support from the paternal grandparents, they appreciate the fact that the grandparents provide a special support and encouragement for the sibling. The parents realize that their parents are from a generation that did not have a lot of interaction with children with disabilities so they have not expected much from them. The mother believes they "do the best they can" (3.14) and doesn't "fault them in any way" (3.14).

The parents realize that the way they live their lives is difficult for people to understand unless they have had to live with the same type of challenges. The parents realize how time consuming and physically and emotionally challenging their lives are with the child now. They realize that it is difficult for the grandparents to comprehend their struggles and needs.

The mother would like to have seen more support, especially emotionally from the paternal grandparents. She concedes that you can not expect that kind of support because the grandparents are dealing with stress themselves and are feeling hurt also for their child who must parent the child with the disability. She believes that it has not been easy for the grandparents either.

Case Four - Eric

Case four is the family of a sixteen-year-old boy with a visual and mental disability. Eric is described by his mother as being a child who will "talk your ear off when you meet and he's just a good kid" (4.1). Eric enjoys cars and always wants to know what kind of cars people drive and has the ability to remember birthdays for all his friends and family including the year of birth. He is in special education class most of the day but does mainstream for one elective.

Eric has a rare genetic disorder. The mother could not recall the name. The characteristics include a lack of growth after about age five, visual problems, mental deficits and a post nasal cleft palate deformity that causes speech problems. Eric was on growth hormone and had speech therapy until approximately age fifteen. He has a moderate/severe vision problem and he has a moderate disability with the need of limited support.

Family History

Eric lives with his parents and a sister who is fourteen (see Appendix E for family history). The father is an electrician and works in the construction field and the mother works in the home. The maternal grandmother was a housewife when the children were young. She now does housekeeping for others. The maternal grandfather worked in the oil fields. The maternal grandparents divorced before Eric was born. The paternal grandfather was a retired fireman. The paternal grandfather died when Eric was about ten years of age. The paternal grandmother is a bookkeeper. Both grandmothers live within thirty miles of the family. The maternal grandfather lives about one hundred and fifty miles away.

Eric was born with some disabilities that were not obvious at birth. The parents had few experiences with babies. Eric seemed like a normal healthy baby until he developed pneumonia at three months of age. He was in the hospital for about a month. During this time they ran tests and diagnosed several disorders. The child had a postnasal cleft palate. This was not outwardly identifiable but resulted in the need for speech therapy.

Vision for Eric was extremely limited. His optic nerve did not develop properly from birth. His parents didn't notice that he was not tracking objects until the doctors pointed it out to them.

The parents were also told that Eric would stop growing by five years of age and would have some mental delays. The parents thought the doctors must have misdiagnosed Eric because he was larger than the other children his age at one and two. By at age five he did stop growing. He started taking the growth hormone and continued until age fifteen. The parents were told that with the growth hormone he would be no taller than five feet eight inches. After stopping the growth hormone, he continued to grow and is now over six feet tall. Eric has some fine motor and eye hand coordination problems as well as being delayed in mental ability.

The family has never believed that they needed to make major adaptations. They did not have the major expectations for him that some parents do. They have always seen him as doing what is normal for him and have not set limits or extreme expectations. The father has difficulty reading and is not strong academically, however he is good with his hands, therefore the academic limitations of Eric do not trouble the family.

The major adaptation for the family has been in the visual area. They realize that they must supply visual information to Eric. In all the other areas they seem to accept Eric for who he is and what he is capable of doing. The family's easy going attitude has played a major role in adapting to the disability that Eric has. They have "always told everybody, don't treat him different unless you see him getting ready to walk off a cliff or something" (4.5). Eric enjoys doing things with the family and enjoys being around people and the family feels their lives are pretty normal.

Family Stress

The family's initial concerns were for the health of the child. The entire family was concerned about the pneumonia. They were afraid he might die so the other information did not seem critical at that point.

The grandparents all had the same initial reaction. They were very concerned that Eric might die from the pneumonia. They never seemed upset about the rest of the diagnosis.

The parents were able to respond to the visual needs of Eric. The doctors had the parents use a strobe light to strengthen the optic nerve and the mother credits this with increasing the development of the sight that the child does have. He is able to see very large print on a computer screen. He moves around in the environment fairly well, though he must be advised of holes or curbs or any other element in his path especially in new settings.

The parents did not readily accept the other areas of concern. The mother had an uncle who did not talk until age four. They just thought Eric might be slow yet would catch up and be normal. Eric has been able to achieve so many things that the parents "still don't believe all of " (4.2) the limitations the doctor said the child would have.

Grandparent Interaction

The maternal grandmother lives in the same town and sees Eric often. They go to the same church and see each other almost every Sunday. The maternal grandmother comes by Eric's house about once a week. He "calls her anytime anything exciting happens and she calls him too" (4.4). They talk about three times a week by phone.

The maternal grandfather was not a part of their lives for several years when the children were small. The last three or four years he has been much more active in their lives. He calls about once a month and either comes to visit or the family goes to his house about once a month.

The paternal grandparents always visited four or five times a year. That has remained constant even after the grandfather's death. The paternal grandmother talks with the father on the phone regularly. She does not talk with Eric or anyone else in the family when she calls.

Eric and his family are treated like all the other members of the family by both sets of grandparents. The mother believes that all of the grandparents just accepted Eric as he was from the very beginning. Eric is always included in holidays and birthdays just like all of the other grandchildren.

The family has never needed any financial support. They live a reasonable lifestyle and have always lived on what they made, not pursuing extravagant materials. The maternal grandmother would bring different items to the children or to the parents to help out. The maternal grandmother would also offer physical support by offering to take care of Eric. The mother would occasionally allow her to keep him. The mother usually preferred to spend her time with Eric.

Interactions with the maternal grandmother have always been very positive. She played all the typical games when Eric was small. Now they enjoy sitting, talking, and laughing together.

Cars are a mutual interest for Eric and his maternal grandfather. They are often looking through car magazine or talking about different types of cars. The grandfather takes Eric out on his property to look at his collection of old cars.

The paternal grandparents did not do as much with Eric. When the paternal grandfather was living, he would take Eric for rides in his truck occasionally. The paternal grandmother will talk with him. She seems to want him to act older and "has a hard time accepting his sense of humor" (4.4).

Response to Interactions

Support for the family has come mainly from the maternal side. The maternal grandmother "was always there wanting to help" (4.5), although the mother admits she did not let the maternal grandmother care for him very much because the mother wanted to do it herself. The maternal grandmother has always given emotional support by being there and listening. The mother describes her as being her best friend. In the past several years since the maternal grandfather has re-entered their lives, he has provided the same type of support.

The paternal grandmother is very supportive of the father. She does call and talk to him frequently and may talk for two hours but is less supportive of the rest of the family.

The maternal grandparents seem to enjoy spending time with and talking with the family members. They are very involved with each member of the family. The paternal grandparents exhibit love to Eric and the entire family, however do not have the closeness of the maternal grandparents.

The family's flexible attitude and relaxed personalities have kept the stress factors low. The mother feels that the members of the family "really haven't had to adapt that much because he seems normal to us, he is just like us. To us he is, to others he probably isn't" (4.3).

The mother accepts the interaction of the paternal grandmother believing that she provides support for the father. She describes the paternal grandmother by saying, "she is a mom but not a grandma...she's not a grandma with any of the grandkids" (4.4).

Case Five - Neil

Case five is the family of an eighteen-year-old child who was born prematurely and suffered from brain injury during the birth. Neil is described by his mother as "very happy. He loves people in general, he is very accepting of just about anyone...and he's just pretty much over all a positive individual" (5.1). He loves to be with people, go bowling and listen to country music. He was in a special class in school and is currently working in a sheltered workshop.

The brain trauma left Neil mentally handicapped and he has dyspraxia, which is an articulation disorder that makes it difficult to understand all of what he is saying. He has a shunt to compensate for the hydrocephalus and he has a seizure disorder that began when he was three. The seizures are controlled by medication, however he still has two or three seizures a year.

Family History

Neil has a twin brother and a brother that is twenty-two. He also has two half sisters age thirty and thirty-two (see Appendix E for family history). The half sisters lived in the same town so Neil saw them routinely. The parents divorced when Neil was about ten years of age. The brothers soon went to live with the father. Neil lives with his mother who has now remarried. His father works for an oil company and the mother has been working in various jobs in the social service area. The maternal grandfather was a rancher until he died eight years ago. The maternal grandfather had polio as a child and was disabled in one leg. The maternal grandmother was a schoolteacher who retired the year Neil was born. She is currently in failing health. The paternal grandparents are now retired. Formerly, the grandmother was a hairdresser and the grandfather worked for a business. Both sets of grandparents live about eighty miles from the family.

Because Neil was born premature and was the second born of twins, the doctors were alert for problems from the beginning. The parents were aware of the child's fragile medical condition. His child's lungs were not developed, there was a brain hemorrhage due to birth trauma and there was blood in the spinal tap the night Neil was born. Over the next few days the doctors also identified that he was hydrocephalic. The parents had been told that the child might not live due to his small size and the trouble with his lungs. They were not aware of the other concerns until the child was about four weeks old. It was then that the doctors began to talk about surgery on the brain. Until this point the mother had not been able to hold Neil because of all the lines that were attached to him. She was allowed to hold him before the surgery, she feels, "because they didn't think he would live" (5.4). Neil did survive the surgery as well as several others in later years.

Neil's disability has affected the entire family, although the family has remained strong. The siblings were constantly involving Neil in their activities. The family learned to adapt to each of the problems that arose. With the support of the grandparents they were able to meet the medical challenges of the child and provide for the other children as well. Even though the parents have divorced, they have provided a strong support system for the children.

Family Stress

Initially, the family feared for the life of their child and then had to face the knowledge that the child would never be normal. The parents knew the night that the twins were born that Neil's sibling would be fine, he just needed to grow. Neil was not as well developed and his life was in danger. Neil began to overcome the problem with the lungs. The parents were hopeful until they were informed about the other complications and the mother felt "devastated...it was a blow" (5.3). Inwardly the mother believes the father felt the same, but when the twins were "first born, especially with Neil, he was trying not to attach...so initially he was in denial" (5.3).

The maternal grandmother was the first person that the mother called. The mother recalls that the maternal grandmother "immediately got in her car and came and I know it hurt her, but she was hurting more for me...and she stayed with me through the whole thing" (5.3). The maternal grandfather "was not one to say much to discuss his feelings" (5.3). It was difficult for him. He went to the hospital once when the boys were five days old. It was too difficult, probably due to the memories he had of being sick with polio when he was young. He did not return to the hospital, yet he helped at home and with the other brother. The disability of the child was also difficult for the paternal grandparents. The paternal grandfather "doesn't say much and tries not to show emotion" (5.4). It was difficult. The mother described the paternal grandmother as broken hearted.

The mother expressed that having a child with disabilities is very stressful for the whole family. It has been particularly difficult for the twin sibling. He did not get as much attention, especially the first few years, because the child with the disability was so medically fragile and had to spend a lot of time in the hospital. The mother perceives that the twin never resented Neil but did resent the parents and the time that the parents spent with the child. The twin sibling had to go through counseling which made the parents feel very guilty. He also experienced some difficulty in school, which was later diagnosed as mild attention deficit disorder.

Outside stressors were also present at times. When Neil was about ten his father was diagnosed with cancer. The mother began experiencing migraines and the paternal grandfather was dying. The parents had begun to feel that the marriage was in trouble. The mother is certain that the build up of stress caused by having a child with a disability was not the cause, however it "contributed directly" (5.4) to the divorce.

There are various stresses related to Neil's disability that have affected the family. There was a lot of physical stress involved in the constant care of a child who is medically fragile. There was a lot of time spent in the hospital and he had to be very carefully monitored at home for his health and the seizure disorder. The financial burden was tremendous in providing for the medical care. The family experienced bankruptcy.

Grandparent Interaction

Beginning from the time the boys were three or four, both sets of grandparents would have the children come to their homes for a few days at a time and continued to do so until the last two or three years when this stopped due to their health. All of the grandparents saw Neil every four to six weeks. He now sees each of the grandparents six or seven times a year and talks with them on the phone a couple of times a month.

This family is very close. The maternal grandparents and paternal grandparents have spent a lot of time together in providing care for the family. The grandparents have spent much time with Neil and his family and the mother depicts the family as feeling very loved and supported.

Both sets of grandparents have been frequently present in the life of the child and the family. The maternal and paternal grandmothers spent a lot of time with the family, particularly the first couple of years. When Neil was in the hospital, one grandmother would be at the house and one would be at the hospital and then they would trade places. For the first few months after the boys came home, one of the grandmothers was at the house most of the time to help the mother in caring for the children.

The maternal grandmother had a son who had a seizure disorder. He had been in a car accident at age two and had seizures as a result that continued until he was twelve. Because of the experience the maternal grandmother had, the mother felt very comfortable leaving Neil with her when he was having trouble with the seizures. She was much calmer than the paternal grandmother during these times.

All the grandparents gave physical support by caring for Neil and his brothers. The grandmothers would also cook, clean the house, and do the laundry. They would bring gifts and clothes for all the boys. The grandparents were "very supportive and willing to help at the drop of a hat" (5.7) not just with Neil, but with the entire family.

The maternal grandmother loved to read to Neil. She was a very expressive reader and would many times have all three boys in her lap reading to them. She was a teacher and would work very patiently with Neil to help him learn basic skills. She "would sit down at the table and work with him on his math and his spelling or whatever homework he had" (5.7).

The maternal grandfather was very affectionate with Neil. He "was always more patient with Neil than he was with the other grandchildren" (5.7). The maternal grandfather was very protective of the child. He understood the challenges Neil faced because the grandfather had faced some of those same challenges due to his physical disability. Although he has been dead for eight years, Neil still talks frequently about him and misses his grandfather.

The paternal grandmother spent time with Neil and his brothers doing anything the boys wanted to do. "She spent lots of time entertaining them, cooking for them, baking cookies, letting them help make cookies" (5.8), and showing a great amount of affection for them.

The paternal grandfather was a little more cautious with Neil than he was with the other boys. The older sibling referred to the paternal grandfather as a "junk hauler" (5.9) because he liked to go to flea markets and auctions and trade. He would take the boys along and let them shop with him. He spent much time throughout the years with Neil "up in his lap and they would eat popcorn together and watch tv" (5.8). He had a very kind way with Neil.

Response to Interactions

The mother felt that each grandparent provided strong emotional support. She described one time when the paternal grandmother had a difficult time watching the nurses change an intravenous catheter and left the room. The mother was hurt that the grandmother didn't stay to support the child. That was the only incident where she felt a lack of support. The mother portrays all of the grandparents as being outstanding in providing support for the family.

From the very beginning the mother believes the child had "total love and support" (5.4) from all of the grandparents. Except for being a little more protective of Neil, he was treated like all the other grandchildren. He and the others were very loved.

The mother grew up in the same house as her grandparents and that relationship has always been very important to her. She does not remember ever having a babysitter because her grandparents would take care of her when her parents were not home. She wanted her children to have the same type of close relationship with their grandparents and she feels very fortunate that has occurred.

Case Six - Bob

Case six is the family of a seventeen-year-old male born with a rare type of chromosomal abnormality. Bob is characterized by his mother as "a happy child and he doesn't meet very many strangers" (6.1). He is very outgoing and active. Bob is in a special education classroom except for one hour when he is included in an art class with an assistant.

Bob is mentally retarded and has some physical disabilities. The mother could not remember the name of the chromosomal disorder other than it dealt with a midline problem. His body and facial features did not develop symmetrically. He can walk but has difficulty with gross motor movement and he has a seizure disorder. They are currently having a difficult time in managing the seizure disorder with medication. He also has a cleft palate, articulation disorders, and has had problems with pneumonia and intestinal dysfunction.

Family History

Bob lives with his mother and two sisters. One sister is a year older and the other is three years younger (see Appendix E for family history). The parents also had two other children. The first boy was stillborn. The second boy died at about two and a half years of age from a rare disorder that was not ever diagnosed. He spent the last ten months of his life in the hospital. The mother and father divorced four years ago and his father very recently remarried. The father lives about seventy miles away and the children spend one night a week with him. The mother works in office management.

Both sets of grandparents live about one hundred miles away. The maternal grandfather is a farmer and the maternal grandmother is a homemaker. The maternal grandparents have a granddaughter who is fourteen with Down Syndrome. The paternal grandfather was a minister and died just before Bob was born. The paternal grandmother is now retired after working as an accountant and a school secretary.

Bob had abnormalities from birth. He did not start breathing right away and had some birthmarks. During the first twelve hours the child had two seizures. It was also difficult for the child to digest formula. The doctors ran tests because of several characteristics that indicated some type of chromosomal abnormality. Since it is such a rare disorder, the doctors were not able to really tell the parents what they could expect from the child.

The entire family has had to adapt to having a child with a disability. It is sometimes embarrassing for the sisters, yet it has also been positive because it has taught them to be "more compassionate, more understanding with people, and it's opened their eyes to a lot of things in life" (6.10). The mother believes Bob has also had a positive effect on the friends of his sisters.

The mother refers to her child as "unique" (6.1). She believes that Bob has helped her to "view the world differently" (6.10) and appreciate all things in life, both the large and the small. "He sees things in a different way and it opens your eyes" (6.1). The family includes Bob in many social activities and has learned to enjoy the time they have with him.

Family Stress

The parents were initially worried that he might not live. The parents knew they would be able to handle whatever happened because they had already survived the death of two children. The grandparents' reactions were very similar. The grandparents also feared for the life of the child, however none of them said much. The mother believes it was difficult for the grandparents "because of everything that happened before that" (6.3) yet they were supportive from the beginning.

The stress of not knowing what could happen next is one of the most difficult elements when raising a child with a disability. There is the stress of not knowing when the next seizure is going to occur or if some other health problem will cause the child to have to go to the hospital. The stress of always having to anticipate situations that the child will be in is constantly a concern for the mother. The sisters also experience stress. They have to cope with the health problems. They have spent much time in babysitting and caring for Bob’s physical needs. They must also cope with the reaction of other people including their friends to his abnormal appearance and needs. Bob is very outgoing when he meets people. Sometimes "people stare and people make comments and it's difficult" (6.3).

The mother also worries about the grandparents. She is concerned about the "way they are having to deal with this because they are the grandparents and sometimes its harder for them because they don't know what is going on all of the time" (6.10).

Grandparent Interaction

The maternal grandparents have provided physical care. When Bob was smaller he would spend up to a week at a time at his maternal grandparents house once or twice a year. They continue to keep him occasionally overnight, though now it is at Bob's house. Since the child is now larger and the seizures are not as well controlled, the family feels it is best to have him close to his doctors.

The maternal grandparents have provided financial support. They helped the mother buy a car and later helped the mother buy a house.

Both grandmothers provided support to the family through physical care. Not only did they take care of Bob, they also took care of the siblings when Bob would be in the hospital. They also took turns staying at the hospital as needed.

The paternal grandmother has also provided physical care. Bob would spend a few nights at the grandmother's house when he was young. The visits now are mainly at Bob's house.

The family made frequent trips to visit the maternal grandparents so he has typically seen them every four to six weeks. Since the divorce the paternal grandmother continues to visit him or he goes to visit her every two or three months.

The grandparents all helped out in many occasions. They would come on a minute's notice to help with Bob or with the sisters when he was sick. They treat Bob in much the same way as all of the other grandchildren.

Bob seems to have the closest relationship with his maternal grandmother. When he is with her, they are talking and laughing. The maternal grandmother praises him and "she gets excited with him" (6.5). She likes to take Bob to ball games, to the park, or out to eat.

The maternal grandfather is good to Bob but interactions are sometimes troublesome. He is hard of hearing and has a difficult time understanding Bob's speech. The paternal grandmother relates best to young children. She has found it a little more difficult to relate to Bob now that he is older and does not play with toys as much. She still spends time with him watching television and talking some.

Response to Interactions

The mother has felt emotional support from all of the grandparents. She has recently been able to express some of her concerns about Bob to the maternal grandparents. It has been difficult for her to address some of the more serious issues, but she has felt very supported.

The mother believes that Bob is loved. She feels that all of the grandparents love him and the whole family. She also thinks that they understand that the family faces many tough obstacles.

The maternal grandfather sometimes seems frustrated and embarrassed by the child, maybe because the grandfather does not always understand what the child says and the child can be a little loud. The maternal grandfather was very close to the sibling that died and the mother thinks that it has made it harder for him to get close to Bob. The maternal grandfather also seems to be closer to the granddaughter with Down Syndrome but she is less difficult to understand so he can talk to her more easily.

Case Seven - Emily

Case seven is the family of a sixteen-year-old girl with athetoid cerebral palsy. Emily is characterized by her mother as a teenager who is starting to notice boys and is very aware of her clothes and her appearance. She likes to talk on the phone, bowl, and listen to country music. Emily is in a special class for children with mental retardation in school but mainstreams to a learning disabilities resource room for math. She is also in a regular class for computers and home economics.

Athetoid cerebral palsy is evidenced by motor problems, contorted twisting motions, lack of coordination, speech disorders, and sometimes mental deficits (Hardman et al., 1996). Emily has some mental delay and has an articulation disorder. She has some visual problems and poor gross as well as fine motor development. The parents bought Emily her first electric wheelchair when she was about six years old. This helped her to be "independent and she has been on a mad dash ever since" (7.2).

Family History

Emily lives with her mother, father, and a brother who is twelve (see Appendix E for family history). The father is in the process of beginning his own business with a friend. The mother works for a hospital in the social service area. The maternal grandparents live less than a mile from the family. The maternal grandmother was a beautician and the maternal grandfather was a businessman. Both are retired now. The paternal grandparents live about two hundred miles away. The paternal grandfather died two weeks after Emily was born. He never saw her. The paternal grandmother works in the home.

When Emily was born there were complications but the parents did not know about the cerebral palsy until the child was about two years of age. The mother was told when the child was born that the mother's "placenta was seventy-five percent calcified and that she was a larger baby before she was born" (7.1). The baby was very small and did not breathe on her own for about twenty minutes. She remained in the intensive care unit for two weeks. The parents were told that the child "was small and might take a while for her to catch up with everybody" (7.2) and that therapy would help. Nothing more was said. The mother took Emily to therapy every week and realized there were some weaknesses, however she believed the child would grow out of the problem.

Life with Emily has been challenging. The family has learned to adapt to the physical limits. The parents and brother attempt to treat her as normal as possible. The mother describes their life as a challenge, not a problem, and stated "I don't know what life would be like without her so I don't know how to compare it to anything" (7.8). The child is characterized as very positive and beautiful inside and out.

Family Stress

When Emily was two, her mother enrolled her in a water baby course. The instructor of the class came up to the mother and said, "you have the most profound handicapped child that I have ever seen" (7.2). The mother was very surprised and asked what the instructor meant. The instructor said the child had cerebral palsy. The mother was very hurt and drove straight to the therapist and then to the doctor and was told by each that the child did have cerebral palsy.

Finding out about Emily's disability was very difficult for the family. The mother was so hurt when the water instructor called her little baby girl profoundly handicapped. The mother was shocked and angry but quickly started trying to find out what the child needed. The fact that Emily was disabled was too painful for the father to discuss. "He kept it bottled up for quite a while" (7.3). The father has been able to talk about it more openly in the past few years.

The grandparents gave various initial reactions. The maternal grandmother was instantly a support. The maternal grandfather "was real quiet. He was crushed" (7.4). It was difficult for the mother to identify the reaction of the paternal grandmother. The paternal grandfather died the day they were planning to go and see the grandchild in the hospital. Dealing with the loss of the spouse was very difficult for the grandmother at that time, so she did not respond in any specific way with the grandchild.

Some stresses occur naturally when dealing with a child with a physical disability. Even though society has tried to make a more accessible environment, there are many places that are still inaccessible. Many bathrooms, even though they have a stall marked for the handicapped and may have a rail, are not built for easy access and privacy for someone in a wheelchair. As Emily has grown in size, physical care has created additional problems. Not only is the child heavier when assisting in movement, it is also more difficult to find someone who is willing to stay with the child so that the parents can have time together. The family constantly has to provide adaptations for the child even in renovating the house to make it easier for her to get around in the wheelchair.

Grandparent Interaction

The maternal grandparents live less than a mile from the house allowing Emily to have many interactions with them. When the child was younger, the maternal grandparents "saw her practically weekly and depending on what time of year it was maybe daily" (7.6). Currently, because of the age of the maternal grandparents, the child sees them two or three times a month but she talks to them on the phone once or twice a week. Because Emily's speech is slow, the maternal grandparents hung up on her the first few times she called by herself. The grandparents quickly added caller identification on their phone so that they would know it was Emily and not hang up.

Partly due to distance, Emily has limited time with her paternal grandmother. The family would visit four or five times a year for brief visits and less than that lately. The family would spend a week in the summer with the paternal great grandparents the first few years of Emily's life. In many ways, she has more memories of the interaction with the great grandparents than with the paternal grandmother.

All of the grandparents treat Emily in a very similar manner as they do the other grandchildren. They do sometimes treat her more delicately, maybe partly due to the disability and partly because she was the only female grandchild for a long time.

The maternal grandparents have provided physical support by keeping Emily to allow the parents to have some time alone for a few hours or for a few days at a time. The grandfather also built a ramp for the family so that Emily could get her wheelchair in the house. The mother is appreciative of the ramp, but wishes that the grandparents had built one on their house as well so that it would have been easier for Emily to visit their house.

Much time has been spent with the maternal grandparents. The grandmother "used to be a beautician, so she has experimented on Emily several times by giving her permanents, cutting her hair" (7.8), and putting on fake fingernails. When Emily was younger and it was easier for the maternal grandmother to physically manage the child, she took her bowling and shopping. Emily likes to help the maternal grandmother in the kitchen and the grandmother would let her help and never acknowledge the mess the child would make. The maternal grandmother and Emily talk, joke, share secrets, and "have something special between them" (7.10).

The maternal grandfather interacted in a more sedate manner. He likes to be at home in his easy chair. When the child was little, she would roll over on the floor and play with his feet. Now they have a new game of trying to "give each other wet willies" (7.10) by sticking a wet finger in the other persons ear.

The maternal grandparents have spent a significant amount of time with Emily. They have gone to several school activities in which Emily participated, including Special Olympics. The maternal grandparents would keep Emily frequently when she was younger. They are not able to do so now because of their age and health.

Most of the time spent with the paternal grandmother is when all of the family, including aunts, uncles and cousins are visiting. The mother doesn't recall any type of special activity of the child and the paternal grandmother, but the child always knew that she would get cokes when she went to her paternal grandmother's house. The grandmother tends to talk to Emily in baby talk, trying to make the words simpler, but this sometimes bothers Emily.

Response to Interactions

The mother feels that emotional support has been provided by all of the grandparents. The mother feels exceptional support from the maternal grandmother. The maternal grandmother has a special relationship with Emily and the mother worries about the grandmother aging and how Emily will face that situation.

The mother believes that Emily was loved by all of her grandparents. According to the mother, the maternal grandmother loves her and feels close to her, the maternal grandfather loves her and feels he has given her encouragement, and the paternal grandmother loves her and "gave as much as she could during the time they were together" (4.13).

The mother believes that the grandparents have done what they could do. She believes her parents were very helpful and supportive in the beginning. She contributes the lessening of support to their aging. They are still emotionally supportive, just not physically. The mother believes that the paternal grandmother had a hard life and believes she would have been more involved if she had lived closer.

Case Eight - Randy

Case eight is the family of a seventeen-year-old male with cerebral palsy as a result of a rare variant form of Lesch-Nyhan syndrome. Randy is characterized by his mother as a child who likes to be with people, he likes to talk and laugh and has very good social interaction skills. He is a "typical teenager so he is a definite headache at times" and he is easily frustrated. Randy is in a class for children with multiple disabilities. He is academically more capable than all the other children, however benefits from the lower stress level in this class.

The diagnosis of cerebral palsy occurred when the child was about eight months old. The connection to Lesch-Nyhan syndrome was not made until the child was about eight years old. According to the mother Lesch-Nyhan "is a chemical imbalance in the body. It causes real high uric acid in the body, kidney problems" (8.1) and usually self-mutilating behaviors. It is a sex-linked recessive inherited disorder that also results in disruptive actions because of the inability to control impulses (Beirne-Smith et al., 1998, Jones, 1988). The clinic that suspected this disorder tested both Randy and his older brother and found that they did have the same disorder. The form they have is so rare that there are only two other known cases in the United States. The boys both have a higher mental ability than is common for the syndrome and neither have the self-mutilating behaviors. Randy does have temper tantrums frequently when put in stressful situations and he has been known to hurt himself during a tantrum. He uses a wheelchair and has very poor gross and fine motor abilities. His speech is sometimes strained, yet can be understood. Although Randy is mentally delayed in academic areas, he has a lot of general knowledge and common sense.

Family History

Randy has a brother who is four years older and now lives away from home. Another brother who is seven years older lives at home with Randy and his mother and father and shares the same type of disability (see Appendix E for family history). The father works for a company and the mother is a homemaker. The maternal grandfather is now retired from the post office and the maternal grandmother has always been a homemaker. They live about two hundred miles away from the family. The paternal grandfather drove for an independent tank company and the paternal grandmother worked for a chicken hatchery. The paternal grandfather died eight years ago and the paternal grandmother is in failing health in a nursing home. They lived about a hundred miles away from the family.

The mother began watching Randy almost from the beginning. The child had negative factor blood and the mother had positive factor. The second child who was normal had the same type of blood as the mother. Randy shared the same type as the older brother who had cerebral palsy. Since the mother was watching closely, she noticed when the child began to fall behind developmentally and the doctors tested the child, diagnosing the cerebral palsy at about eight months.

The family has adapted as needed to the challenges of having two children with disabilities. The family has not set limits and finds a way to do anything they want to do. They have had tremendous support from the grandparents. When the family has needed outside help they have been able to find programs and services to meet the needs of the children and the family. The family does not look for stress or difficulty, they just adapt to each situation.

Family Stress

The parents had been told that the disability of the first child was accidental and would not occur again. The parents questioned the doctor about how the cerebral palsy would effect this child and how it was possible for them to have a second child with this type of disability. The doctor was not very helpful and said to the parents "lets just put it this way, you have bad luck" (8.3). Other doctors were no more helpful in answering their questions until one who worked at a center for cerebral palsy wanted to do some additional genetic testing because of the similarity in the two boys and found the cause of the disorder.

Even though this child was the second child in the family with a disorder the initial diagnosis was still difficult. The mother "wasn't really prepared for another one" (8.4) at least emotionally. The mother came home and cried. She reacted the same way that she did when she was told that the first child was disabled. The difference was that with Randy the mother was aware of what programs were available and how to obtain the necessary services. The father also was shocked in the beginning, because the second child was normal and they expected the third child to be normal also.

The grandparents all reacted the same way they had when the first child was diagnosed. In front of the parents, none of them reacted outwardly. The grandfathers are both very quiet and neither said much. The grandmothers both hugged the mother and pledged their support. When the oldest child was diagnosed, the paternal grandmother suggested that the parents find out what caused the disorder before having another child. Of course the parents were told it was just an exception and wouldn't happen again. Since they have a second child that was normal, all were surprised by the diagnosis.

The greatest element that continues to provide stress is the physical needs of the child. Randy must have assistance in every function. He is not able to dress himself, bath himself, or take care of other physical needs without assistance. This dependence has always been evident but has become more problematic due to his size. Having two children who need this type of assistance has doubled the stress for the family.

The family must deal with accessibility issues. They have two sons that are in wheelchairs. They must be able to assist the boys in pushing the wheelchairs on long outings as well as find places that are accessible for two wheelchairs.

Randy's emotional tantrums are also challenging. The family must be mindful of situations that may increase the chance of a tantrum. These tantrums are embarrassing to Randy and to the entire family.

Other family members have faced challenges as well. Living with two siblings who are handicapped was not always easy for the middle child. The expectations seemed much greater for the child without disabilities. He was expected to do well in school and assist in the home. The family also faced the "sandwich generation where you are dealing with your kids and dealing with your parents"

(8.6). The paternal grandparents were aging and failing in health and that increases the physical and emotional stress level for the parents.

Grandparent Interaction

Randy is with the maternal grandparents five or six times a year. He talks on the phone with the maternal grandmother about twice a month. The family visits the paternal grandparents every two to three weeks.

Both parents have very supportive relationships with their in-laws. The mother describes the paternal grandmother as "the most absolutely marvelous person I have ever known next to my mother...I was not the daughter in law that took her son away, I was her new daughter" (8.13).

Both sets of grandparents provided physical support for the family. When Randy was little he would spend a day or two with each of the grandparents. The maternal grandparents kept him a little more often simply because of the age and health of the paternal grandparents. Sometimes those visits would be by himself, sometimes with his brothers. When the mother needed extra help or one of the boys was in the hospital, the maternal and paternal grandparents would come to help.

Although the family never needed to ask for financial support they knew all the grandparents would help if it were needed. The paternal grandparents did loan the parents a car so that the mother could drive the child to therapy before the parents could afford a second car.

When Randy is with the maternal grandmother she will put her arm around him and read to him, talk to him, laugh with him, and scold him if he does something wrong, just like she does the other grandchildren. The maternal grandfather loves to tease with Randy and the mother says the grandfather has a tendency to spoil him just like he does the rest of the grandchildren. The maternal grandfather will hand out money to all the grandchildren or take them to Walmart to buy something. He and Randy enjoy watching football on television together.

The paternal grandmother always wants a kiss and then wants each of the children to sit and talk for a while. She shows some favoritism for the oldest sibling over all the grandchildren. He was the first grandson. She does have a good relationship with Randy. The paternal grandfather would tease the child and "he could pick them out of a bad mood real fast" (8.9).

Reaction to Interactions

The grandparents provided emotional support by "just always being there to talk to because if something comes up and you have this thing working on you and you can talk to somebody about it, it helps" (8.13).

The family felt loved and supported by each of the grandparents. The grandmothers especially were very involved with Randy. The mother reports that the grandfathers were both very supportive, though they were not as "hand-on" (8.15) with the children.

The mother claims that the family couldn't "have asked for a better set of grandparents, either side, because they have always just been there, the best they were physically able to do. They dealt with us" (8.14).

Case Nine - Rita

Case nine is a family of a fifteen-year-old female with Prader Willi Syndrome. Rita is described by her mother as delightful and "always has a smile on her face" (9.1). She is a little shy when meeting new people. She is in a self-contained class for children who are mentally retarded. She mainstreams for one elective.

Prader-Willi syndrome is a chromosomal abnormality. Characteristics of the disorder are delays in motor ability, mental development, small features and stature, and an insatiable appetite which often leads to obesity (Beirne-Smith et al., 1998, Jones, 1988). It is often associated with failure to thrive and hyptonic muscle tone when young.

Rita is mentally retarded at the limited level. She is able to do many things for herself with limited support. She has some delay in fine motor control. Rita is somewhat difficult to understand due to an articulation disorder.

Family History

Rita lives with her mother, father, and a sister who is fourteen (see Appendix E for family history). The father is a businessman and the mother now works outside the home in an office. She worked in the home when Rita and her sister were younger. Both sets of grandparents live more than eight hundred miles away which limits their interaction.

From the time of Rita's birth, it was obvious that something was wrong. Diagnosis took about two years. She had "low muscle tone, was floppy, she couldn't take a bottle, she didn't cry much, and she was pretty lethargic" (9.1). The doctors did not initially run any tests they just tried to treat the symptoms. One of the doctors was finally able to diagnose Rita with Prader Willi Syndrome. She was immediately enrolled in a clinic program where research was being done so the parents were able to access good information on the disability.

The family has managed to deal with the daily needs of a child with Prader Willi. The family is aware of what they eat and have make it easier for the child to eat in a healthy way. Rita is not overweight at this time, although she has added some weight in the last year. Even though most of the time she does not make an issue of food, she is constantly hungry and has to accept this challenge.

Family Stress

By the time Rita was diagnosed, the family had already experienced deep feelings of concerns. The parents were concerned because of her failure to develop. The parents were uneasy because of the lack of diagnosis. Once the diagnosis was made, the parents were concerned about what this would mean for the child.

The maternal grandfather was a doctor and knew something was wrong, but did not want to admit that his granddaughter was mentally retarded. This identification seemed to hurt him, however the mother feels "he got over it in his own way" (9.3). The maternal grandmother and the paternal grandparents were supportive and wanted to know more information about Rita's disability.

There is continual stress in raising a child with Prader Willi. Rita has a nutritional plan that must be very carefully followed. The parents must be prepared for special occasions and how to handle the food issues involved. The family must be constantly aware of the types of foods that are brought into the house. This becomes a family issue with the parents and the sister providing support and encouragement by basically having the same diet as Rita.

Due in large part to the syndrome, Rita has frequent intervals of inappropriate behavior. She is easily frustrated and responds by crying. She is not able to hide her agitation and will talk to herself about the situation.

The pace in which a person does things changes when there is a child with a disability. Rita moves slower than other children. It takes more time to get ready to go places quickly or make a fast run into the store. The family has learned to slow down and plan ahead.

Grandparent Interaction

Rita sees her maternal grandparents about two times a year. They would like to spend more time with her if they were geographically closer. The maternal grandmother routinely calls or sends cards. Because of physical distance, Rita sees her paternal grandparents only once a year.

All of the grandparents treat Rita the same way they treat the other grandchildren except for the maternal grandmother. She tends to favor Rita. The mother feels this is fine because Rita "needs all the help she can get" (9.4).

The family had the support of the grandparents. They have taken care of Rita and her sister whenever the parents needed them to do so. Both sets of grandparents offered financial support. The family did not need it. The paternal grandfather once called to see if Rita participated in Special Olympics. He had been asked to donate and wanted to know if it would benefit her. Even though he donates in his own state, he feels that it helps to show support for her and others like her.

Rita has the closest relationship with the maternal grandmother. When the maternal grandmother visits the two of them are constantly together. Sitting side by side, the maternal grandmother and Rita will read a book, play a game, or just talk. The mother describes them as "on the same wave length. They are just like clones of each other.

They have the same tastes" (9.2). The maternal grandfather hugs Rita and sits with her but has a difficult time understanding her speech. The mother usually stays close in order to interpret.

The paternal grandparents enjoy their visits with Rita and the family. They have a difficult time understanding Rita's speech. In order to "help bridge the communication" (9.3) deficits, the paternal grandparents play card games. The grandparents and the child enjoy this activity. This allows them to spend time together taking the tension off the child's articulation. The sibling does spend some additional time with the paternal grandparents. She visits them about once a year by herself.

Reaction to Interactions

The mother "always knew" (9.4) she had the support of the grandparents. There were times when the grandparents questioned whether the therapies and surgeries were necessary. They did not understand why she needed them. When the parents explained everyone was supportive.

The mother feels that all of the grandparents love Rita. The maternal grandmother is most able to show those feeling. The others are good to her and care about her, they can not interact with her as easily.

The mother acknowledges the support of the grandparents by stating "each in their own way have done all they could" (9.5). Distance from the family seems to have a major impact on the physical support and on the opportunities for interaction by the grandparents.

Case 10 - Patti

Case ten is the family of a fifteen-year-old female with physical and mental disabilities due to spinal meningitis when she was an infant. Patti is described by her mother as "very independent. She is very loveable. She loves people and is very easy to get along with" (10.1). She is in a self-contained class for students with mental retardation and is included in a regular class for one elective a day.

Patti has a moderate disability with the need for limited support. She is hemiplegic and mentally retarded due to infection created by the spinal meningitis when she was young.

Family History

Patti lives at home with her mother, father, and a brother who is fourteen (see Appendix E for family history). These two children were born into the family after the parents had already raised three children, a son and two nieces whose mother had died. The father is a baker and the mother is a missionary singer. The maternal grandfather is a minister and lives about two hundred miles away. The maternal grandmother was a nurse and lived only a few miles from the family. She died two years ago. The paternal grandparents live over a thousand miles away. The paternal grandparents have another granddaughter who has moderate to severe mental and physical disabilities.

Patti was born premature and developed spinal meningitis which exposed her to the potential for a disability. Patti was a little lethargic and had some slowness on the left side but no one told the mother that there was a problem until the pediatrician noticed it sometime during the first year.

The mother believes that Patti can do anything that she wants to do and does not set limits. The mother understands that the child is mentally retarded though she has developed a positive attitude about Patti in order to help her believe in herself. Patti is very happy. The family enjoys her personality and "just takes every day as it comes and goes on" (10.6).

Family Stress

When Patti was diagnosed, the father did not show any reaction, which is considered normal behavior for him. The mother was hurt. She "believes in the power of prayer so (she) didn't worry about it" (10.2).

The grandparents had very little visible reaction. The paternal grandparents were living far away and did not seem to be disturbed by the news. The maternal side of the family is very religious and they all said they would pray for her.

There has been some limited stress involved in raising a child with a disability. The mother has not been able to work as much, because she didn't want to take Patti out of school to go on her mission trips. The mother has limited the trips to weekends and summers. This has eliminated the problem of childcare as Rita is always with her mother. People involved in the type of activities in which the mother participates have always been accepting of Patti.

The family receives a subsidy because of Patti's disability. The family has to be constantly aware of the amount they make. If they make too much in a given month, the state takes away Patti's money. Finances are sometimes hard, but the family has been able to do fine with no other outside help.

Grandparent Interactions

The time spent with grandparents varied greatly. The family would visit the maternal grandfather about every other month. They would talk with him on the phone about once a month. The maternal grandmother lived less than a mile away. She would see Patti three or four times a week and sometimes daily.

The mother claims that the whole family "has just chipped in so there hasn't been a problem" (10.6). The maternal family seems to be very close and visit often.

Because of distance, Patti sees her paternal grandparents approximately once every five years. They have, in the past, sent an occasional gift at Christmas or a card but those times were rare. The paternal grandparents have a closer relationship with the grandchildren that live close to them. There is no real relationship with Patti, her brother, or any of the other grandchildren who are separated by distance.

The maternal grandmother, who is now deceased, would always bring things for Patti and she kept Patti anytime the mother needed to go out. The maternal grandmother was crippled by arthritis and wished that she had been able to do more activities with the child.

Talking and singing are a big part of the interactions between Patti and the maternal grandparents. The maternal grandfather sings and talks with Patti. She loves to "get up on him and mess with him, hug him, and kiss him" (10.4). Patti spent a lot of time with the maternal grandmother. When Patti was with the grandmother she would "rub her little head, rub her legs and arms"(10.4) as they would talk and sing to each other. The paternal grandparents were always kind to Patti. They did not see her enough to form any relationship.

Response to Interactions

The mother feels very supported by the maternal grandparents and by prayer. The family loves Patti. Her nephews are very protective of her. Her maternal grandparents love her very much. The paternal grandparents are good to her when they are with her, but do not seem to be a major part of the life of the family.

The mother has never been concerned about Patti's disability. She believes in the power of prayer and knows the maternal side of the family has her in their prayers. She believes that "everybody caters to Patti cause she is such a doll, so jovial you can't help but enjoy her."

(10.6)

CHAPTER V

INTERPRETATION OF THE RESULTS

Introduction

The data collected were analyzed to answer the research questions. The basic elements of the Double ABCX model of the family adaptation system were used in the analysis. This chapter is arranged to discuss the nature of the interactions of the grandparent and the perceptions of the mother to these interactions. Next the differences in the interactions between paternal and maternal and between grandmother and grandfather are described. Then the data are used to identify ways each case relates to the constructs of the Double ABCX theory. Data that does not relate specially to the Double ABCX is also discussed.

In reporting the data, the families are indicated by the case number or fictitious name of the child. When a numeral is used, the first numeral indicates the case number assigned and the numeral after the period indicates the page number of the transcript from which the information was taken. Direct quotes are indicated by quotation marks.

The Nature of Grandparent Interactions

Research Question #1: What is the nature of grandparent interactions? The interactions of the grandparents vary from the amount of time spent to the types of activities. The amounts of visits with the grandparents vary from less than once a year (10.3) to once a week (4.4, 7.6, 10.3)(see Table 2). The types of activities vary with each of the grandparents and with the interest of the child. A complete description of these interactions can be found in Chapter IV with each case study under Grandparent Interaction. The only exceptions are the maternal grandmother of Tom who is described as not having a relationship with any of the grandchildren (3.10) and the paternal grandparents of Patti who only see her every three to five years (10.5). In every other case the grandparents have some type of interaction with the grandchild. The interactions do not seem to be different than typical interactions that you would find between a grandparent and a grandchild. Some examples include playing with toys (1.11), talking (2.2, 3.10), playing games (4.6, 9.3), watching TV (5.7, 6.5), shopping (7.8), teasing (8.8), and singing (10.4).

Table 2
Number of Visits of Grandparents and Grandchildren

Child	weekly	2-3 weeks	4-6 weeks	4-6x/year	1-3x/year	less
Larry			mgp/pgp			
Rachel			mgp/pgp			
Tom		mgf	pgp		mgm	
Eric	mgm		mgf	pgm		
Neil			mgp/pgp			
Bob			mgp	pgp		
Emily	mgp			pgm		
Randy			mgp/pgp			
Rita					mgp/pgp	
Patti	mgm			mgf		pgp

(mgp=maternal grandparents, mgf=maternal grandfather, mgm=materal grandmother, pgp=paternal grandparents, pgf=paternal grandfather, pgm=paternal grandmother)

Perceptions of Support

Research Question #2: To what extent are grandparent interactions perceived as support by the mothers of children with disabilities. Each of the mothers felt supported by at least one grandparent. There was only one grandparent that was actually identified as not supportive (maternal grandmother, 3.4). She was also not considered to be a supportive mother. Two grandparents where identified as not providing support (paternal grandparents, 10.4). That was due to a lack of relationship to the entire family because of distance and family personality.

The support came in different forms from the various grandparents. Nine of the maternal grandparents provided some type of babysitting support (1.5, 2.2, 4.5, 5.6, 6.3, 7.9, 8.7, 9.4, 10.6) as well as six of the paternal grandparents (2.2, 5.6, 6.3, 7.9, 8.7, 9.4). Every mother felt the support that occurs from believing that you child is loved (1.6, 2.4, 3.15, 4.6, 5.4, 6.9, 7.13, 8.13, 9.4, 10.2). Even though the grandparents may have different ways of exhibiting the love, it was believed to exist in each of the grandparents.

Mothers recalled special activities with the grandparents that lead them to feel that the child was valued. Only three grandparents where not described as providing this type of support. One was Tom's maternal grandmother (3.10) who was not close to him or the other grandchildren even though she lived in the same town and Patti's paternal grandparents (10.4) who have seen her only five or six times in her life and do not have a relationship with her.

Only five of the thirty-eight grandparents represented treated the child with the disability any different than the rest of the grandchildren (1.4 paternal grandparents, 3.4 paternal grandparents, 6.6 maternal grandfather). This allowed the mother to feel that the child was considered an important part of the family structure.

Differences in Interactions

Research Question #3: What are the differences of the nature of interactions and perceived support from the maternal and paternal grandmothers and grandfathers? The support given by the maternal side of the family was generally greater than the support from the paternal side. Nine sets of maternal grandparents provided babysitting (1.5, 2.2, 4.5, 5.6, 6.3, 7.9, 8.7, 9.4, 10.6) as compared to six sets of paternal grandparents (2.2, 5.6, 6.3, 7.9, 8.7, 9.4). Seven sets of maternal grandparents (1.5, 2.2, 5.6, 6.3, 7.9, 8.7, 9.4) provided overnight care compared to four sets of paternal grandparents (2.2, 5.6, 6.3, 8.7). Six sets of maternal grandparents (1.9, 4.5, 5.6, 6.10, 7.13, 8.8) provided some type of material support compared to two sets of paternal grandparents (5.6, 8.14). Ten mothers indicated a special support from the maternal grandparents (1.4, 2.4, 3.15, 4.5, 5.9, 6.10, 7.13, 8.15, 9.4, 10.6) with two indicating an equal support from the paternal side (5.9, 8.14). In eight of the nine cases where the maternal grandmother was rated as the most supportive

(1, 2, 4, 5, 6, 7, 8, 9, 10) the maternal grandfather was listed as second most supportive.

The grandmothers were generally credited with being more supportive than the grandfathers. In thirteen out of seventeen comparisons of support of the grandmother verses the grandfather of the same side of the family the grandmother was rated higher than the grandfather (1.10 maternal, 2.5 maternal and paternal, 3.16 paternal, 4.5 maternal, 5.10 maternal and paternal, 6.11 maternal, 7.14 maternal, 8.15 maternal and paternal, 9.5 maternal, 10.6 maternal). In two cases the grandmothers and grandfathers were rated equal (9.5 paternal, 10.6 paternal). Two mothers rated the grandmothers lower than the grandfathers (1.10 paternal, 3.16 maternal).

Six of the ten mothers mentioned specifically that there was a difference in the activities of the grandfather. Even when the mothers would indicate that the grandparents kept the child, they would add that it was the mother who actually interacted with the child. One mother said that the grandmothers would take the child on outings or keep the child but that the grandfather has never "taken him alone" (6.7). Emily's mother said that she was surprised when the maternal grandfather kept the child "all by himself, which is huge for my dad. It's just huge"

(7.9). Larry's maternal grandfather spent a lot of time with him but she credits the grandmother as "probably the one who sees they get here" (1.10). Rachel's mother describes her father and father-in-law as "from the generation where men didn't really socially interact" (2.2). "In their own way the fathers do the supporting but it may not be quite as hands on as the mothers" (8.15) was said by Randy's mother and is a good description of what was insinuated by the other mothers. Another mother said it this way, "men support in a different way, both grandfathers are supportive and care deeply and love him equally but men just show it different" (5.10).

Utilization of the Double ABCX theory

Research Question #4: To what extent does the Double ABCX theory of family adaptation provide an understanding of the interactions and perceived support of the grandparents to the families of a child with a disability? The Double ABCX model focuses on the family's ability to adapt and function within an environment that is created due to stressful events within the family. The Double ABCX model asserts that the stressor events (Double A) interacting with the resources of the family (Double B) interacting with the family's perception of the events

(Double C) produce the crisis or adaptation of the crisis (Double X). This theory was used as a framework to interpret and understand the role of the grandparents in the family system.

The Double ABCX model allows the interactions of the grandparents to be easily identified. Through examining each of the elements of the model it is possible to make comparisons between the families. First the ways that the disabilities of the child are perceived as a stressor are discussed. The initial stress of the parents and the grandparents are discussed. Subsequent areas of stress that affect the families are identified, including ordinary stresses and stresses caused by the disability (Double A). The second major area examined is the family resource (Double B). This includes material resources and social support. The role of grandparents in providing resources for the family is discussed and the differences between the resources provided by the maternal and paternal grandparents are considered. The third area is family perception (Double C) or how the family redefines or gives meaning to the situation. Family adaptation (Double X) is also examined to understand the acceptance of the family or the new level of balance that occurs due to having a child in the family with a disability. Family adaptation is a descriptive criterion of family post crisis outcome, rather than a clearly defined and operational set of measures (McCubbin & Patterson, 1981) therefore descriptions of the family are reported.

Family Demands

The disability of the child creates the stressful event. The A factor of the Double ABCX theory deals with the demands that are created by the stressful event. When a child is diagnosed with a disability, the situation creates initial stress for both the parents and the grandparents. There are also additional stresses that develop as a natural part of life or are created as a direct or indirect result of the disability. All of the mothers described some type of initial stress for the parents and the grandparents. Each gave at least one additional stress that was evident during the life of the child.

Initial stress. Every mother identified some type of emotion that she and her husband experienced when finding out their child was disabled. Two mothers indicated that they were "worried" (6.2) or "afraid" (4.2) that the child would not live. Three mothers (1.1, 2.1, 9.1) used the term "scared", two saying that they did not know what to expect (2.1, 9.1). The other stated that she and her husband did not understand why it was happening (1.1). Two mothers described being "devastated" (3.6, 5.3) along with their husbands. However one of these indicated that they were relieved to get an actual diagnosis (3.6). "Hurt" was the descriptive term used by two mothers: one saying it "hurt me real bad" (7.2) and one saying it hurt but she knew the "power of prayer" (10.2) so she wasn't worried. One mother described her and her husband being "upset" (9.1), while another used the words "overwhelmed and sad" (3.6). Two mothers indicated feeling "shocked" (6.2, 8.3). One mother and father "didn't believe" (4,1) the diagnosis initially. Three mothers described their husbands' reactions a little differently than their own. One said her husband "doesn't react" (10.2), while another said her husband was "trying not to attach" to the child and was "in denial" (5.3), with the third indicating that her husband did not want to talk about it and tried to hide his emotions (7.4).

These emotions match with what are described as common stressful feelings that occur while accepting the child with a disability that have been previously reported (Fortier & Wanlass, 1994; Kirk et al., 1997; Segal, 1985). Further evidence of the pain of the initial diagnosis was seen when seven out of the ten mothers cried when telling about their initial feelings (1, 2, 3, 4, 5, 7, 9). The birth of a child with a disability causes stress for the family.

The mothers expressed a variety of reactions from the grandparents. Five of the ten mothers expressed that at least one of the grandparents (a total of 17) had a difficult time when they heard about the child. Six of these, the maternal and paternal grandparents of Eric (4.2) and the maternal grandparents of Bob (6.2) were described as being afraid the child would die and this seemed to be more of a concern than the disability. The maternal grandparents of Larry who has muscular dystrophy were described as being "consumed with pity" (1.2) and the paternal set of grandparents were characterized as feeling sorry for themselves (1.3). The mother of Tom the child with Prader Willi said the paternal grandparents didn't deal with the news well (3.6). Neil's mother described it as being very hard for all the grandparents but when describing the paternal grandmother said "it broke her heart" and said about the maternal grandmother "I know it hurt her but she was hurting more for me" (5.3).

The word support or supportive was used to characterized twelve of the grandparents (2.1-maternal grandparents; 5.2-maternal and paternal grandparents; 7.4-maternal grandparents; 9.3-maternal and paternal grandparents). Other terms indicating support were used for sixteen additional grandparents (3.6-maternal grandfather, 4.3 maternal and paternal grandparents, 6.2 maternal grandparents and paternal grandmother, 8.4 maternal and paternal grandparents, 10.2 maternal and paternal grandparents). Randy's mother used the phrase "grouped around us" (8.4) to describe the maternal and paternal grandparents. Tom's mother described the maternal grandfather as "good" (3.6). The maternal grandparents and paternal grandmother "helped out" (6.2) as reported by Bob's mother. Eric's maternal and paternal grandparents "just accepted" (4.3) him according to the mother. Patti's mother related that the maternal and paternal grandparents didn't say anything they simply "love her" (10.2).

Five grandfathers were described as being "quiet". One maternal grandfather was described as "not one to discuss his feelings" (5.2) and the paternal grandfather as someone who "tries not to show emotion" (5.2). "Real quiet" (7.4) for a maternal grandfather and "very quiet" (8.4) for both maternal and paternal grandfathers were used as descriptions.

Denial was the reaction from three. One set of paternal grandparents were identified as "in denial" (2.1) from the beginning and continue to be and one maternal grandmother was identified as "always in denial, but ... lived a lot being in denial about a lot of things so this did not come as a big surprise" (3.6).

Two mothers indicated that the religion of the grandparents were a part of their reactions. The maternal grandparents of Larry, the child with muscular dystrophy, wanted the parents to have him prayed for in order to obtain healing (1.2). The other mother said that both sets of grandparents prayed for the granddaughter so "no one was worried about her" (10.2).

The initial responses of grandparents vary just like they do for parents. The responses reported in this study might not have been the actual emotions that the grandparents felt. It describes what the mother perceived the response to be. The majority felt that the grandparents cared about them and the child. This is evidenced the mothers indicating that twenty-eight of the thirty-nine grandparents provided support from the beginning (1.2 maternal grandparents, 2.1 maternal grandparents, 3.6 maternal grandfather, 4.3 maternal and paternal grandparents, 5.2 maternal and paternal grandparents, 6.2 maternal grandparents and paternal grandmother, 7.4 maternal grandparents, 8.4 maternal and paternal grandparents, 9.3 maternal and paternal grandparents, 10.2 maternal grandparents).

Subsequent stress. Subsequent stressors are those events that occur as a direct result of the disability or those stressors that occur naturally, but add stress to the lives of the family members. The mothers were asked what it had been like to have a child in the family with disabilities and probed with a question of what kind of stress is involved. The mothers responded with the stresses, they did not choose them from a list of stressors.

Two answers were given most commonly to the question of stress. The first was the stress of physical care. Five mothers (1.4, 3.2, 5.5, 7.7, 8.6) reported the physical care of the child as being stressful. The daily routine just to "dress them and get them off to school" (8.6) can be very time consuming. Finding someone that you can trust to babysit for the child is never an easy task further more, as Emily's mother admits, as the child gets bigger "it's getting a lot harder to find people to help watch her...when you call somebody you feel guilty about asking them" (7.8). Larry's mother reported that the "physical stress now is because (he) is so big and I can't handle him" (1.4). For all five of these mothers the daily routine continues and the lifting and care has increased with the growth of the child.

The second element that was identified by five of the parents was the stress that it created for the siblings (3.13, 5.4, 6.10, 8.6, 9.6). One mother described the situation for the sibling as being "hardest on (him) because he was the odd man out, he was the normal one" (8.6). The expectations for the normal child are different. They may have to do more for themselves. One mother stated she believed that the sibling felt as if he was "having to compete for my (the mother's) time" (5.4). She also describes the sibling as being "hurt, just feeling somehow rejected, not loved as much" (5.4). Two of the mothers described how the siblings even had to share their friends with the disabled child by spending time with the child when their friends came to play (3.13, 6.10). Tom's mother said of the sibling "it's been hard for him to have his own life" (3.13). They may even give up some activities as another mother admitted, "sometimes we would stay home instead because it was too difficult" (6.10) to get the child ready and deal with the problems associated with it.

The three mothers of children that are in wheelchairs (1.4, 7.7, 8.6) mentioned the problems associated with physical accessibility. One additional mother who had a child that was in a stroller until the child was about three related that they were not allowed to take her stroller in some areas when vacationing and had to instead carry the child (2.2). All three mothers of children in wheelchairs mentioned public places where accessibility was difficult (1.4, 7.7, 8.6). Two of the mothers described how it was difficult or impossible for the child to go to the houses of the grandparents because the houses had not been built wheelchair accessible.

Concerns for the medical needs of the child were mentioned in four cases and a closely related health problem for two others. The parents of Larry who has muscular dystrophy have a continual awareness that he may die young (1.2). Because of the use of growth hormones, Eric has to have frequent blood tests that are very stressful to him and to the family (4.3). Neil has spent much time in the hospital over the years due to physical problems that produced concern for his overall health (5.4). Bob's increase in the amount and intensity of his seizures worries his mother and family (6.3). Closely related to the medical concerns are the health concerns of the two mothers of the children with Prader Willi Syndrome (3.5, 9.4). The tendency to overeat or to eat unhealthy foods that contributes to the overall medical condition of the children is a continuous struggle and something both families must guard against.

Dealing with a child with disabilities creates some emotionally challenging issues as indicated by five mothers (1.4, 2.3, 3.2, 6.3, 9.6). One mother describes it as being emotionally difficult because "you want to do what is best for your child and you are faced with certain decisions you don't know how to handle and you don't know anyone to talk to who has to face what you face" (1.4). One mother describes dealing with the behaviors of the child as being emotionally draining (3.2). Dealing with how other people may react (2.3, 6.3, 9.5) or just hurting for how you think the child is feeling (3.2) or worrying about the future (1.4, 6.4) can all be difficult emotionally for the entire family.

Three families mentioned that they had given up much of their social life for the child. Larry's mother said "the fact is we cut off all our social at that point because we didn't want to leave him with babysitters and we didn't go anyplace that you couldn't take him which limits you a lot" (1.3). Emily's mother admitted, "honestly, I don't think that my husband and I ever have time to ourselves, but I guess that is the way it is" (7.13). Tom's mother states the she and her husband can not go out at the same time because "we no longer have anybody who babysits for us. I haven't found anyone that I feel comfortable leaving him with" (3.12). All three of these families have difficulty finding the time and resources to enjoy a social life.

The two mothers that were divorced admitted that the stress of having a child with a disability played a part in the parents’ divorce. Neil's mother stated "I have no doubt that, not (his) problems per say, not (him), but just the situation contributed directly to us divorcing" (5.4). Bob's mother discusses the disability as being an element, "it's going to because of the time involved and focusing in on the one child more than the marriage, sometimes, but I don't think that was the thing, it may have had a little part of it but not all" (6.9).

School was an element of stress for two of the mothers (1.4, 3.2). One mother did not feel that the people in the school really cared about the same issues she did and that they did not want to be at conferences to discuss the needs of the child (1.4). The other mother did not feel that she had been able to find the appropriate type of program for her son's needs and was currently paying someone to home-school the child (3.2).

Financial problems were identified as stressful for two families (5.5, 10.1). One family had many medical expenses and had experienced bankruptcy (5.5). The other family was receiving money specifically for the child and had to watch the amount of income they made in order to not lose the funding for the child (10.1).

Every family experienced some type of stress that came as a result of living with a child with a disability. The stresses were different for each family, but some type of stress existed for all the families.

Family Resources

The Double B factor refers to the family resources. These include both existing and new resources. These can include material resources and social support. Social support includes emotional support, esteem support and network support (Cobb, 1976). Each area of social support was provided to each family by at least one grandparent, most commonly the maternal grandmother. The Double B factor allowed a comparison of the resources that were provided by the grandparents. Common resources were identified.

<u>Material support.</u> The most common material resource was childcare which was provided by fifteen of the twenty sets of grandparents. The maternal side of the families were usually more supportive than the paternal side in providing care for the child. Babysitting for at least a few hours was provided by nine of the maternal grandparents (1, 2, 4, 5, 6, 7, 8, 9, 10) with only 6 paternal grandparents giving support through babysitting (2, 5, 6, 7, 8, 9). Additionally seven maternal grandparents (1, 2, 5, 6, 7, 8, 9) provided overnight care with times ranging from a couple of nights up to a week at a time. One additional grandmother (4.5) offered to do so, but the mother did not want to have the child gone at night. Only four paternal grandparents (2, 5, 6, 8) ever kept the child overnight. Two of the paternal grandparents (9.4, 3.9) did not provide overnight care for the child with the disability, yet did take the sibling for overnight visits. In each of the cases, although the mothers indicated that the grandparents kept the child, they also reported that it was actually the grandmothers that provided the majority of the care.

Six sets of maternal grandparents (1, 4, 5, 6, 7, 8) and two sets of paternal grandparents (5, 8) were mentioned as providing additional material supports. These included things like helping around the house, such as cleaning and cooking.

Financial support was discussed by six of the mothers. Two mothers (1.10, 9.4) mentioned that it was offered and they knew it was available but it was not needed. Two others (4.5, 5.10) said that they did not need any financial help, however, the grandparents would bring gifts of clothes for the children or things for the house from time to time. Emily's family did not need financial help but the maternal grandfather did provide his services and supplies to build a ramp for the child's house. Randy's paternal grandparents did loan the family a car (8.14) for a while. The mother was taking the child for therapy and they only had one car so that helped the family. Bob's maternal grandparents did help his mother get a car loan and a loan for the house (6.10).

Each of the families reported some type of support for the family from at least one of the grandparents. Physical care of the child or the sibling was provided by at least one of the grandparents for each of the families. Some additional physical or financial support was given in several families with several mentioning that they knew help was available if needed.

Emotional support. Emotional support comes when the family feels loved. Every mother believed that each of the grandparents loved the child each in their own way (1.6, 2.4, 3.15, 4.6, 5.4, 6.9, 7.13, 8.13, 9.4, 10.2). Some were more physical, verbal, or visual in displaying the love than others were. An example of the love that was more visible came from Larry's mother when she described the times the child was with his grandparents by saying "they'd be engrossed in each other...they love each other so totally that it's just fun to sit and watch them together" (1.6). Another mother described a more physical type of love when describing what she sees when the child and maternal grandfather are together. "They hug a lot. (Tom) is very physical in showing his love. My dad likes that" (3.10). Rita's mother gives an example of both kind of love when she says the maternal grandmother "just loves her, she gets the biggest kick out of her" and says the maternal grandfather "loves her too it just wasn't as visible" (9.4). Emily's mother didn't feel that the paternal grandmother had a very close relationship with Emily. She did believe the grandmother "loved her" and added, "I think she gave as much as she could to her during the time they were together" (7.13). Love was not something that the mothers were asked to define. It was just a word each of them used to describe how they believed each of the grandparents felt toward the grandchild. Even though all of the relationships were not described as close, the mothers believed that each one of the grandparents, maternal and paternal, loved the child.

Listening is another valuable element in feeling emotional support. When asked what advise she would give to a grandparent who had a child with a disability, Rachel's mother replied, "just be a good listener, that's the important thing is to listen" (2.5). Three of the mothers described discussions with their parents about the future of the child (1.7, 5.9, 6.8) one had also had those discussions with the paternal grandparents (5.9). Bob's mother said, "A couple of times I've talked about, worried about what he was going to do when he got older" (6.8) with the maternal grandparents. She described specifically talking about the serious issues with the maternal grandfather. "He's the one who doesn't really offer advise, but he listens and kind of helps, understands and he's real solid and doesn't get shook up real easily" (6.10). Larry's mother spoke of one conversation that was initiated by the maternal grandfather about the future of the child (1.7).

All ten of the mothers reported feeling supported by at least one grandparent. Ten of the mothers indicated that they felt a special support from the maternal side of the family (1.7, 2.4, 3.15, 4.5, 5.9, 6.10. 7.13, 8.15, 9.4, 10.6) and two mothers indicated an equal support from the paternal side (5.9 8.14). One described her parents as being "the kind of parents that are supportive. They don't offer a lot of criticism" (2.1). Another mother said, "I'm really close to my dad so he was very supportive emotionally" (3.9), "I know I can call him any morning, noon, or night" (3.15). Emily's mother said, "Emotionally my mom has been there a lot and I think she talks about it with my dad, but my dad has never been one to show emotion at all" (7.13). One mother simply stated, "I always knew I had support" (9.4).

When asked to identify which grandparent had been most supportive, the first choice was always from the maternal side. Nine of the mothers chose the maternal grandmother as most supportive (1.10, 2.5, 4.5, 5.10, 6.11, 7.17, 8.15, 9.5, 10.6). One chose the maternal grandfather (3.16). Neil's mother and Randy's mother rated the maternal grandmothers as most supportive, but quickly added that all four grandparents were practically equivalent in their support with both making a statement about men supporting in a different way (5.10, 8.15). The statement of one of the mothers speaks directly of the support that both of these mothers felt. She said of both sets of grandparents, "Emotionally, always an arm around the shoulder. I really can't think how anybody could be any better than they have been to us" (8.14)

The person rated most commonly as the second most supportive was the maternal grandfather. In two of the cases as previously reported the mother rated them as almost equivalent in their support (5.10, 8.15). In an additional case listed above, the maternal grandfather was listed as the most supportive. In five additional cases (1.10, 2.5, 4.5, 7.14, 10.6) the maternal grandfather was listed as the second most supportive. Clearly the mothers rated the maternal side of the family as being more supportive.

All the mothers indicated that the paternal side was supportive even though they may have ranked third and fourth. Two of the paternal grandmothers (3.16, 6.11) were actually ranked second highest for providing support. For one mother who ranked the paternal grandparents as third and fourth, she believed, "My mom and dad are supportive of all of us, (my husband's) mother is there for him" (4.5). Only three of the mothers indicated that they believed the paternal side of the family could have been more supportive (1.10, 2.5, 3.9). One mother stated directly that, "I think (my husband's) parents could have been more supportive, definitely to him" (3.9).

The feeling that supports were there for the family seemed very important to the mothers. The mothers indicated that they believed their children were loved and they felt supported by various grandparents. Although the support may not have been completely described, it is evident from the information given that the mothers felt supported.

Esteem support. Esteem support occurs when the individual feels valued or important. The evidence that the grandparents provided esteem support is seen in looking at the interactions of the child with each of the individual grandparents. One mother in talking about the things that the grandparents did for the child said the grandparents did things that make Larry "feel very special, so that is less of a stress when your child is happy" (1.9). The mothers reported activities that were done with the children and the grandparents. In all but three cases something positive was reported. One mother reported that the maternal grandmother "never did things that a child would consider special" (1.11). One child had very little interaction with his maternal grandmother. The mother had very little interaction with the maternal grandmother as she was growing up. She did not expect him to have a relationship with the grandmother (3.10). Another child, due to distance, has spent very little time in her life with the paternal grandparents, thus the mother was not able to recall anything they ever did with her (10.3).

The interactions of the grandparents varied greatly. A more complete example of these can be seen in Chapter IV (see Grandparent Interactions) where the interactions are described for each child. Some examples would include Patti with her maternal grandmother singing and "pampering each other" (10.4); Larry's paternal grandfather "riding piggyback" (1.11); Neil watching television and eating popcorn with his paternal grandfather (5.7); Rita and her maternal grandmother sitting side by side in a chair reading a book (9.3); Eric talking about cars with his maternal grandfather (4.6); and Emily giving her paternal grandfather "wet willies" (7.8).

Mothers perceive esteem support when they see the grandparents interacting with the child. Every child had at least one grandparent that spent some special time with the child.

Network support. Network support is seen when the family believes it is a part of a larger network of people involving mutual obligation and understanding. Evidence of the mutual obligation and understanding is the amount of time that the family spends with the extended family or more specifically the grandparents. In seven of the ten families (1, 2, 4, 5, 6, 7, 8) the child sees all of his or her grandparents at least four to six times a year. In one additional case the child (3) sees three of the four grandparents during this time frame. Nine of the ten see at least one grandparent no less than once every six weeks (1, 2, 3, 4, 5, 6, 7, 8, 10).

Distance can influence the amount of time a family can be together. In one family (10) the paternal grandparents live over a thousand miles away and in another family the maternal and paternal grandparents live over eight hundred miles away (9). Patti's family sees the paternal grandparents every two to five years (10). Rita sees her grandparents from one to three times a year though the distance is farther than most in the study (9). The maternal grandmother of Tom lives within fifteen miles of his house and she only visits one or two times a year (3). Distance does not effect this relationship.

Another indicator that the child with a disability is a part of a larger network is the way they are treated in comparison to other grandchildren in the family. Only four paternal grandparents (1.7, 3.7) and one maternal grandfather (6.6) were perceived as treating the child with a disability any worse than the other grandchildren. One mother said, concerning the paternal grandparents, "They were different toward (Larry) than their other grandson. The other grandson was the light of their life, (Larry) was inferior because he was handicapped" (1.7). Tom's paternal grandparents will take his brother on trips or to visit their house although they never take Tom (3.7). One mother said concerning the maternal grandfather, "He just doesn't know how to take (Bob) and (Bob) is loud and that bothers him and he tends to not talk to him as much and is more distant" (6.6). Even though the mother indicated they treat them differently than the other grandchildren, all three talked about how they do things with the child and are good to the child.

The mothers indicated that all of the other grandparents treated the child with the disability equally as well as the other grandchildren. There were various levels: for example, Tom's mother said the maternal grandmother treated him like all the others in that she did not have a relationship with any of the grandchildren (3.7). Patti does not see her paternal grandparents except for every few years and does not have a real relationship with them. This is true for all the grandchildren who do not live within a hundred miles of the grandparents (10.5). A couple of mothers indicated that they were treated the same but the grandparents were a little more patient or protective (5.7) or more delicate (7.6). One mother said what several described when she expressed that you do not treat everyone exactly the same because, "They are all at different stages at different times. I never thought one was treated better than another" (9.4). They might do different things because of the various interests and abilities.

All families are different. They relate to each other differently. The mothers in this study had varying relationships with their own parents and with their spouse’s parents. It would be natural for the children to also have varying relationships with the grandparents. This was true for this group of children.

Family Perception

The family perception is how the family redefines the elements in their lives or compromises to make the situation seem more tolerable. The Double C factor provided a means to examine the perception of the mothers as they applied their perception to the support that was provided by the grandmothers. When discussing the relationship between the grandparents and the family, the mothers were in general very positive. Even when they discussed things that they would have liked to be different, they justified why these occurred. Examples are given for each family situation where they indicated any dissatisfaction.

Larry's mother reported total satisfaction with the relationship between Larry and his maternal grandparents. She felt he was not treated as well as he could have been by the paternal grandparents. She would have liked to see a closer relationship between them. As she stated, "I would have liked to have seen (Larry) accepted a little bit more by (the paternal grandparents) but I honestly don't think they didn't think he was accepted. I think maybe because I was seeing what my parents were doing, that it made me think they would do the same" (1.8). She went further to explain that she thinks "both sets would have done anything that had to be done, they would have provided him with anything he needed physically. I think they loved him. They loved him through us because they loved us and they saw us loving (Larry) and respected us and we did not reject (Larry) so they didn't...I think he felt very loved by his grandparents" (1.11).

Rachel's mother related one experience that was very traumatic to her at the time. In her words, "My mother-in-law wrote my husband a letter, saying that we weren't doing what we should have been doing and she was essentially blaming us for (Rachel) not doing better than she was doing" (2.3). This initially hurt the mother because they were doing all that the doctors were telling them to do. None of the family let this interfere with the overall relationship. The mother stated, "Other than that one letter, I don't know if we have ever really talked about it because (my husband) and I are really independent people. We always have been and I think that's part of their problem with it because we didn't just fall apart and need them to come in and take over" (2.3).

Tom's mother believes the paternal grandparents love Tom. She also feels they feel sorry for him and "its very hard for them to accept him just the way he is" (3.14).

She acknowledges that the paternal grandparents are from a "different generation" where they are not used to dealing with people with disabilities. She also believes "they do the best they can. I don't fault them in anyway" (3.14).

Eric's paternal grandmother treats him like the other grandchildren, but she is not really close to any of them. His mother acknowledges that she is a nice person and is a good mother to her son. "She's a mom. She is not a grandma with any of the grandkids. I guess she's just not comfortable" (4.4).

Bob's mother admits that the maternal grandfather does not spend a lot of time interacting with Bob and sometimes has a hard time being patient with him. She realizes that part of it is because her father doesn't hear well and he has a difficult time understanding Bob because of Bob's severe articulation disorder (6.5). The grandfather gets upset when he is loud or does not behave, but the mother thinks that it embarrasses the grandfather (6.11). The mother also feels a great amount of support from the maternal grandfather. She identifies him as one that is very good to talk with about anything (6.10).

Although the mother expressed some concerns about the grandparents that are identified in this section they also indicated understanding. They may have wanted more of a relationship for their child, yet they seemed to accept that it had not occurred and that, in the total scheme of their lives, it was not a major problem.

Family Adaptation

Family adaptation reflects an acceptance and understanding of the situation. An examination of the Double X factor provided a framework for examining statements and actions of the family that would indicate that they have been able to accept the disability of the child. This was evident in each of the families in the study by how the mothers described the child who has a disability or how they described the family situation. Examples are given of a statement of acceptance provided by each mother. Larry's mother said, "We have a good relation and he's fun to be with" (1.1) and, as a family, "we became closer together" (1.3). Rachel's mother describes her as "Miss Merry Sunshine" (1.1) and "basically normal in many ways. She is just slow" (2.2). "He is fun to be around, he makes me laugh" (3.14) is how Tom is described by his mother and she believes life with him "wasn't a hardship, it was just different" (3.13). Eric is "just a good kid" according to his mother and she says, "We haven't had to adapt that much because he seems normal to us. He is just like us, to us he is, to other's he probably isn't" (4.3). Neil's mother believes he has been easier to raise at times than his normal sibling and "just pretty much overall a positive individual" (5.1). "Unique" is the word that Bob's mother uses to describe him and believes the situation has "developed a lot of love and closeness" (6.3). Emily has a "beautiful personality" (7.1) according to her mother and she describes their life as a challenge, not a problem (7.8). "Normal everyday life goes on" (8.5) and he is a "fun kid" (8.1) according to Randy's mother. Even though she deals with two children with disabilities, she talks very positively about their lives. Rita's mother believes you make adjustments just like any family, but it has been "alright" (9.6) and she has a daughter that "always has a smile on her face" (9.1). Patti is "so jovial, you can't help but enjoy her" (10.6), according to her mother who also believes "you just have to forget about the handicap and try to make it a success" (10.7).

Adaptation is a process. These mothers provide evidence in the interviews of continuously adapting to situations. They seem to have a desire to provide the best possible life for the child and the entire family.

Beyond the Double ABCX

The use of the Double ABCX model allowed comparisons between and within families. Common elements were identified for the families in the study. Although the model provided a structure for examining the different types of support provided by the maternal and paternal grandmothers and grandfathers, its use was limited. The model assumes that family demands (A) combined with family resources (B) along with family perceptions (C) leads to family adaptation (X). This study only examined one aspect of family resources, the grandparents. Therefore, the theory was helpful in identifying the types of grandparent interaction and support but it could not be concluded that the support was the cause for the family's adaptation. The adaptation of the family may have been more heavily supported by other factors. The grandparent support was only one element of that process. Five of the ten mothers identified a source other than the grandparents that had been supportive (2.2, 3.13, 6.10, 7.9, 10.6). They were not asked about other sources of support, but in these five cases outside examples were given. Four of these identified friends as being supportive (2.2, 3.13, 6.10, 7.5). One of these stated that, "Our friends in some ways understand it a lot better than our parents do" (3.13). Two indicated that they received support from the people in their church (2.2, 10.6). Two of the five indicated that they received support from one or more of their own or their husband's siblings (7.9, 10.6).

There were two major elements that emerged from the data analysis that were not addressed in the Double ABCX model. These elements were the identification of the most supportive grandparent and the effects of personality or previous relationship on the perception of the mother.

The use of the Double ABCX would not have identified which grandparent was most supportive. Although it was useful in organizing interactions of the grandparents it was not intended to look at each area of support separately. It was designed to examine the total resources that families have available to help them adapt. Each mother indicated support from the grandparents with the exception of three grandparents (3.10, 10.5), however if the researcher had asked the mother to list resources that had helped them to adapt, it is possible that the grandparents might not have been mentioned in some cases.

Another element that was not easily identified by the Double ABCX was the effect that the personality of the grandparent or the previous relationship with the mother and father had on the mother's perception. Eight of the mothers gave an explanation for why they believed the grandparents responded as they did (1.6, 2.2, 3.6, 4.1, 6.7, 7.6, 8.13, 10.4). Two mothers used the term "different generation" to describe why they thought the grandparents interacted in the way they did (2.2, 3.6). It was not a negative judgement, merely an identification of their expectations. One mother describes the maternal side as always being "real close" and the paternal side as "just different" (10.4). Tom's mother indicated that they did not expect the interactions to be any different than they were (3.6). Larry's mother recalls interactions with the paternal grandparents as being more serious because that is "just how they lived their life" and the interactions with the maternal grandparents as "fun" because that is how the grandparent "remember their grandparents" (1.6).

CHAPTER VI

SUMMARY AND CONCLUSIONS

The purpose of this study was to describe the types of interactions that families of a child with a disability engage in with grandparents and to identify which interaction are perceived as supportive by the mothers. The differences between the interactions of the grandmothers and grandfathers were studied along with the differences between maternal and paternal grandparents. These areas were examined in order to answer the research questions. The framework of the Double ABCX theory of family adaptation was utilized to organize the types of interactions and support that were provided by the grandparents. This chapter summarizes the results of the study. The implications of the research are proposed and recommendations are given. Benefits and limitations of this study are discussed. Suggestions for further research are offered.

Results of the Study

The study provided information on the interactions that the grandparents engaged in with the child with a disability and with the family of the child. The Double ABCX model of family adaptation was used to analyze the data. The use of the model identified resources that were available to the family from the grandparents. The model also provided a framework for the perceptions of the mother about the role of the grandparents. The first findings in this section were the result of the use of the Double ABCX model. Additional findings will be given that were not a direct result of the Double ABCX model.

The mothers identified direct interactions with the child, whether it was babysitting, sitting and talking, shopping, reading a book, or playing a game as important. Although the interactions varied for each grandparent and grandchild, the mothers identified these types of interactions as being supportive. They also identified activities with the family, including helping around the house, being involved with the siblings, or listening to the parents as being supportive.

Grandparents can provide material and social support. Each family had received material or social support from at least one grandparent. The mothers believed the family and the child had received emotional, esteem, and network support from one or more grandparents.

Grandfathers do not always show their support in the same way that grandmothers do. Four mothers specifically spoke about the difference in the grandfathers (2, 5, 7, 8). One mother said that her father was "from a generation where men didn't socially interact" (2.3). In speaking about his relationship with the granddaughter she says he "pays attention to her...but she is closer to her grandmother" (2.3). Emily's mother described her father as being there in his own way and thinking that he is interacting. "I don't think he realizes he doesn't do anything with anybody because he has never done anything with anybody" (7.13). Randy's mother explained that "in their own way the fathers do the supporting but it may not be quite as hands on as the mothers" (8.15). Neil's mother made a similar statement; "Men support in a different way. Both grandfathers were supportive and cared deeply and loved him equally but men just show it differently" (5.10). The mothers feel support from the grandfathers even though they do not provide as much physical or direct support as the grandmothers.

Maternal grandfathers may have more of an emotional role than a physical one. Three mothers identified that they talked to the maternal grandfathers about the difficult issues such as the future of the child (1, 3, 6). One described her father as a "good sounding board" (3.15), another as a "deep thinker", as "solid", and as a "really good listener" (6.8).

Interactions with grandparents change over time. These changes occur because of the increased size of the child and the decreased ability of the grandparents to provide direct care for the child (1, 5, 6, 7, 8). Another reason for the change is the interest of the child including the type of activities the child enjoys (1, 4, 6, 7, 8, 9). The age and health of the grandparents have caused changes in the interactions within all of the families.

The maternal grandparents have more frequent interactions with the child. Five of the maternal grandparents visited more frequently than the paternal grandparents (3, 4, 6, 7, 10). The other five visited as frequently (1, 2, 5, 8, 9). Distance may have influenced the number of visits made by the grandparents. Seven of the maternal grandparents live closer than the paternal grandparents live. Interactions also occurred through phone calls or cards. Nine of the mothers indicated more frequent interaction by phone or by mail with the maternal grandparents (1, 2, 3, 4, 6, 7, 8, 9, 10). The same amount of interaction from both maternal and paternal grandparents was reported by Neil's mother (5).

The financial situation of the parents and the grandparents was not a determining factor in support. Seven of the mothers said that they knew the grandparents would have helped if financial assistance had been needed (1, 4, 5, 6, 7, 8, 9). Six of the families had income greater or equal to the grandparents (1, 3, 5, 7, 8, 9). Only two had lower incomes (4, 6) with two not providing information on grandparent incomes (2, 10). Of the two families where the income was lower, one mother (6) had accepted financial help after her divorce. The other mother (4) said they did not need any financial help.

Grandparents were only one source of support that the mothers felt. Even though the mothers were not asked about any other type of support, five mothers mentioned other people who had been supportive. Three mothers described having support from people at church (2, 6, 10). Two mothers described help that they received from their siblings or their husband's siblings (7, 10). Support was also perceived from the friends of the sibling of the child with a disability (3, 6). One mother gave a bus driver credit for being supportive (7) and another claimed that the housekeeper was a major source of support (3).

Mothers want to feel support from the paternal grandparents. Three mothers expressed a desire to have a closer relationship with the paternal grandparents (1, 3, 4). One paternal grandmother did have a close relationship with the father, yet not with the grandson or with the rest of the family (4.5). Eric's mother wanted the support for the entire family (4.5). Tom's mother felt that the paternal grandparents could have been more supportive especially of their son (3.9), even if they were not as supportive to the rest of the family.

Mothers of a child with a disability may not expect the grandparents to have a major role in the support of the family. Three mothers mentioned specifically that they were independent of their parents (2.3, 3.13, 4.5). They wanted the independence and did not want their parents to feel that they were expected to provide support.

The mothers of the children with a disability justified the actions and reactions of the grandparents both maternal and paternal. In every situation where the mother made a negative comment about the grandparents, the mother gave an explanation and acceptance of the action.

Larry's mother wanted the paternal grandparents to visually show Larry more love. She accepted that "it wasn't anything that they were doing consciously" (1.6). Rachel's grandparents had sent a note to the father blaming him and the mother for Rachel's condition. The mother claims that was the only time there was a problem and she believes the grandparent felt left out and unneeded (2.3). Tom's mother believes the situation as been difficult for the paternal grandparents, yet they are doing "the best they can" (3.14). Bob's mother thinks that the maternal grandfather is embarrassed when Bob is loud. She justifies his reaction because he is shy and she believes he provides strong emotional support in other ways (6.9). In every situation in every family the mothers defended the grandparents.

Love and support were the two elements that the mothers felt were most important from grandparents. Five of the ten mothers said that it is very important to love the child (1, 4, 6, 7, 8). Eight mothers (2, 3, 5, 6, 7, 8, 10) used words that indicated support was important. They felt it was important to be available, listen, and provide help to the family and the child.

There were some findings that went beyond the Double ABCX model. The model itself did not identify which grandparent the mother believed to be most supportive. This was found through direct questioning that went beyond the model. There were other findings that were a result of the comparison of demographic information or the contrast of other information provided by the mothers.

Maternal grandparents provided more support than paternal grandparents did according to this study. Nine maternal grandmothers (1, 2, 4, 5, 6, 7, 8, 9, 10) and one maternal grandfather (3) were identified as most supportive for the mother. Maternal grandparents provided more short term childcare (nine to six) and long term childcare (seven to four).

Grandmothers were generally rated higher in providing direct support than grandfathers. In thirteen out of seventeen comparisons with grandparent of the same side of the family, the grandmother was rated highest. The maternal grandmother was listed as the most supportive grandparent except in one case (3).

The relationship with the grandparents before the birth of the child had a notable impact on the relationship that they had with the family after the birth. The two families that rated the paternal grandparents almost equally to the maternal grandparents (5, 8) both described how they were welcomed into the family when they married and felt supported from the beginning of the relationship. Two mothers (4, 7) described having a very close relationship with their mother and that same type of close relationship had developed with the child. Tom's mother did not have a good relationship with her mother. She did not expect her to have a good relationship with any of the grandchildren and she did not (3). Patti's grandparents did not interact any more with the family before her birth so it was no surprise that they did not attempt to form a close relationship to Patti (10). Larry's mother had a good relationship with both sets of grandparents before he was born. Both grandparents had a good relationship with the child although the paternal grandparents were not as close as the mother would have preferred. She spoke of the importance of the previous relationship with this statement: "They loved him through us because they loved us and they saw us loving (the child) and respected us and we did not reject (the child) so they didn't" (1.11).

There were two differences observed when interviewing the mother who is African American. She was more resistant to give family information than the other mothers. She also mentioned prayer and religious beliefs several times. Three other mothers (1, 2, 6) mentioned religious beliefs or church, however only once briefly.

The siblings are an important part of the family structure. Four mothers acknowledge that the siblings have to deal with increased stress because of the child with the disability (3, 5, 6, 8). One grandfather expressed his concern to the mother because he felt the siblings might be embarrassed by some of the child's actions (6.11). Tom's paternal grandparents would take the sibling on vacations with them. They never invited Tom, however the mother felt that it was important for the sibling to have the attention from the grandparents (3.7). Rita's parents allowed the same type of thing to occur with the sibling (9.4). The mother didn't think they were treating the girls differently just interacting differently because of the disability. The grandparents could not provide the supervision that Rita needed in a vacation setting. Grandparents can support the family by providing needed attention to the siblings.

No difference could be found in support and interaction due to the experience of having another grandchild with a disability. Four maternal grandparents (2, 5, 6, 8) and six paternal grandparents (3, 4, 5, 6, 8, 10) have one other grandchild with a disability. Three of the grandparents (Bob's(6) maternal grandfather and Patti's (10) paternal grandparents) are reported to have a better relationship with the other grandchild. Bob's mother believes the maternal grandfather has a closer relationship to the granddaughter who has Down Syndrome because he can understand her speech and she is quieter than Bob. Patti's mother is not certain the relationship is closer with the other granddaughter, but believes that it is because of distance. The mothers of the other children reported that the ways the grandchildren were treated were very similar to how all the grandchildren were treated. Relationships for those children whose grandparents did not have another grandchild with a disability were comparable with those who did. The father of one of the children has a learning disability (4). His mother is described as a good mother but not a good grandmother. She has very limited interaction with the grandchildren including the one with a disability.

There were some areas of the study where no differences in support or interactions could be found. These areas included the age of the grandparents. All the grandparents were in their sixties or seventies except for one set that were in their fifties (4). The number of siblings did not effect the interactions. There was one only child (1), five with one sibling (2, 3, 4, 7, 9), two with two siblings (8, 10), and two with four siblings (5, 6). No differences were found due to the number of siblings or the order the child had among the grandchildren. There were no first grandchildren. Three of the children were the youngest grandchild for at least one set of grandparents (1, 3, 5). Of these, only Larry's paternal grandparents (1) were indicated to treat him any differently than the other grandchildren. Larry is the only child in the study who had grandparents (paternal) with only two grandchildren. The mother believed that Larry was treated differently from the other grandchild because of his disability.

Distance from the grandparent was not a major factor in the relationship with the child and the support that the mother perceived. Three of the children lived within 15 miles of the maternal grandmother (3, 7, 10). Although Emily (7) and Patti (10) have a very good relationship with their grandmothers, Tom (3) has no relationship with his grandmother. The mother reports that he has not seen her in a couple of years and probably would not know her if she walked through the door. Before that time she saw him only once or twice a year and did not interact with him. Two of the children live over 1000 miles from their paternal grandparents (9, 10). Rita's grandparents (9) make an effort to see her at least once a year and communicate occasionally with cards. When they are together, the grandparents interact directly with her even though they have difficulty understanding her speech. Patti (10) sees her grandparents every three to five years. The paternal grandparents are nice to her when they see her, however they do not really have a relationship with her according to the mother.

The number of visits of the grandparents did not determine the amount of support that was perceived by the mother. The grandparents visited the grandchild at least six times a year with the exception of four sets (3 maternal grandmother, 9 maternal and paternal grandparents, 10 paternal grandparents). The maternal and paternal grandparents of Rita were perceived as very supportive by the mother even though she they were among those who visited less frequently (9). The grandparents within a family that visited an equal number of times were rated differently by the mother. Both sets of Larry's grandparents (1) visited every four to six weeks, however the maternal side was perceived as being much more supportive. The mothers seemed to place more importance on the things the grandparents did with the grandchildren than with the amount of time they spent together.

Divorce did not interfere with the interaction of the grandparents. In both families where the parents were divorced (5, 6), the grandparents continued to visit with the same frequency. There were three families where the maternal grandparents were divorced (3, 4, 10). In two of the cases (4, 10) the maternal grandmothers lived closer and saw the child more frequently than the grandfathers. The mothers' indicated the grandfathers were supportive. Tom's (3) maternal grandfather was very supportive of Tom, however the grandmother was not. The divorce had nothing to do with her lack of support and did not keep the grandfather from being supportive of the child and the family.

Interactions with the grandchildren are important in the perception of support for the family of a child with a disability. This was evident from the elements that were identified by the use of the Double ABCX and by those elements that were found which were not directly related to the model.

Implications of the Study

Grandparent interactions are important to the child and to the family. The mothers perceived these interactions as supportive. The interactions varied depending on the interest and ability of the child and the personality of the grandparents. It is important to realize that, although each grandparent did not participate in the same type of activities with the child, the mothers saw the interactions that they had as affirming the child and the family. One mother indicated this by saying that the things the grandparents do cause the child to "feel very special so that is always less of a stress when your child is happy" (1.9). Direct interaction with the child is a way that grandparents can reduce the stress for the family. This information is important to all grandparents of children with a disability. The interactions that they have with their grandchildren with disabilities can be very critical for the family, even if it is just sitting and talking with the child or reading the child a book.

Helping with the direct care of the child was the most commonly mentioned area of resource support. This would include care for a couple of hours to a few days which allows the parents to have time for each other, outside interests, or other family members. Because every mother mentioned this, it is an area where grandparents can provide a very valuable resource for the family that would be seen as supportive by the mothers.

Another implication of the study is that the maternal side of the family is more supportive than the paternal side of the family. One consideration must be that the information was given by mothers and therefore could be biased information. However mothers were used because studies have shown that the mothers are more vulnerable to stress because of the amount of time they spend in daily care of the child (Bailey et al., 1992; Kazak, 1987; Krauss, 1993; Tavormina et al., 1981).

Grandmothers tend to provide more support than grandfathers is another implication of the study. This is usually because of the direct interaction. Grandfathers can, however, provide support for the family. Examples were given of how they supported in a less active way and they were also identified as good listeners. The support from grandmothers came most commonly through physical care and emotional support to the mothers.

The overall implication of the study is that grandparents, both maternal and paternal, grandmothers and grandfathers can provide support for the family. The Double ABCX model provides a means of categorizing the area in which the grandparents can provide support. These include providing needed materials and social support to the family.

Recommendations

The first recommendation that would result from this study is for the parents and grandparents of the child with the disability to be aware of the demands that the event places on the family. Grandparents need to be aware of the stress that this causes for the family. The parents need to be aware that the grandparents are also experiencing their own stress, even though it may not be clearly stated. Grandparents need to be aware that the demands do not end with the diagnosis and that the parents continue to face stresses that arise naturally as a part of raising a child with a disability.

The greatest recommendation that comes as a result of this study is for the grandparents to be actively involved in the life of the child. The mothers of children with disabilities perceived this as important. The resources that were identified by the mothers were rarely financial. The resources that provided support were not physical materials, but spending time with the child. Allowing the parents to do other things or to relax was provided when the grandparents would babysit with the child for a few hours or days. Grandparents should be aware of the need to provide direct interactions with the child with the disability.

Another recommendation would be to help the grandparents to provide social support to the family. The child and the family need emotional support. They need to feel loved. This can be accomplished through words, through listening, and by actions. The family needs to feel that the child is valued. Voluntary interactions from the grandparents through activities, cards, calls, and visits help the family to feel that the child is important. The family also needs to feel that the child is a part of a network where they share mutual concerns. Including the child in activities and treating the child like the other grandchildren are ways that this can be accomplished. Grandparents can play a vital role in the area of providing and increasing family resources.

These recommendations allow for increased interactions with the child. When the parents can see that their child is included, treated well, and is happy, then it allows them to have a more positive outlook on the situation. The increased resources and the perception of support allow the family to be more accepting of the child with the disability and make adapting to the situation easier.

Benefits of the Study

This study contributes to the research of families and families of a child with a disability. Information about the mother's perception of the role of grandparents was presented in this qualitative study. It allowed the researcher to gain insight into the family and the family dynamics. This study identified information specific to the role of grandparents in the family of a child with a disability. Further research of this nature could provide information about the role of grandparents in other families dealing with a different type of stressful situation. This type of qualitative research could also provide information about the role of immediate family members or other extended family members in adapting to stressful situations.

Practical information that was identified through this study is also beneficial. Professionals working with families to provide support and suggestions can use the information. Grandparents of a child with a disability can use the information to provide the type of support that mothers perceived to be helpful. Families can identify with the families in the study and see that the responses that they have from the grandparents are similar to the reactions that other families experience.

Another benefit of the study was the ability to utilize the Double ABCX model. This allowed the researcher to have a general framework. It provided the basis for questions that addressed the central issues of the research. The theory provided an organization of the reaction of the family to the crisis situation. These elements were advantageous to the study. This study might be further used to study intergenerational relations. It could provide a basis for studies from the viewpoint of other family members. Examining other extended family members would be possible with this method. The support that is provided by non-family members who are in close contact with the family could be evaluated using the Double ABCX model.

Limitations of the Study

The study was limited due to the small size of the sample. The use of a larger group of families might have provided different information. Different results might have also occurred with a larger sampling of families from diverse cultural backgrounds.

The study was also limited because it relied on the perception of a single member of the family. It only provided information as perceived by the mothers. The results might have been different if the questions had been asked of the fathers. If the questions were asked of the grandparents, it might be possible to see what they are doing that they consider supportive. It might be very different than what the mother perceives.

Another limitation of the study was the age of the children. It may have been difficult to acknowledge all of the supports and interaction that have been present through out the years. As the grandparents and the child age the level and types of interactions would naturally change. The mothers might have mentioned other things if the age and needs of the child were different.

The researcher was acquainted with each of the mothers that were interviewed. The mothers might have been more negative if they were talking with someone that did not know their families. However, knowing the researcher may have also caused them to feel more comfortable and allowed them to talk more openly.

Another major limitation of the study was that it only looked at the resources that were provided by the grandparents. This only gives a partial picture of the resources that the family has utilized in adapting to the child with a disability. Other resources might have been provided by other extended family members or by friends. It was not possible from this study to determine the extent to which the grandparent support contributed to the adaptation of the family.

Further Research

There are some related areas that should be researched. One area would be to conduct the same type of research on the support provided by the grandparents as perceived by the child with the disability. Another would be to use the perceptions of the fathers or the siblings. Examining how grandparents perceive that they are providing support to the family would also be valuable. It would be very interesting to use the same families as subjects and compare the differences in how members from the same family perceive the interactions and support.

A long-term study of several families that examine the types and levels of support throughout the life of the child would provide valuable information. The needs of the child and the family will change as the child matures. The reactions of the grandparents would probably change because of aging and interests. A long-term study could explore the levels of interactions and support and how they change.

Some additional related research questions might explore ways to improve the interactions. Using the Double ABCX model, questions could be developed and asked of different family members to further examine the adaptation of the family of the child with a disability. This type of research might attempt to identify ways to increase resources or educate for improved resources.

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APPENDIX A

Interview Consent Form

"I, ______________________________, hereby agree to be interviewed by Coralee Risley and authorize her to conduct the research in the following manner:"

- An interview will be conducted with questions being asked about my child, my family, and the grandparents of my child.
- The interview will take approximately two hours.
- The interview will be taped and a transcript made from the tape. The only person hearing the tape will be Coralee Risley. The transcript may be seen by members of the dissertation committee.
- When the tape is transcribed, no names will be written, the individuals will be referred to in general terms (child, mother, maternal grandmother, etc.) and each interview identified by number.
- All information will be kept confidential and the tape will be erased after the research is completed.
- In comparing the information given in the interview and in writing the results, actual words from the interview will be used but will not be identified by name.
- The names of the families participating in the interviews will never be published nor will any information that might lead to the families being identified.
- I understand that if I feel uncomfortable with a question, I do not have to supply an answer.
- I understand that the interviewer is seeking information and is not judging me or any member of my family.

This interview is being done as part of a dissertation entitled "The role of grandparents in the support and care of the family of a child with a disability". The purpose of the study is to understand the relationship that grandparents have with a child with a disability and the child's family, to find the common areas of support that are provided by the grandparents and to identify elements of the relationship that might help other families.

"I understand that my participation is voluntary and I can withdraw from the process at any time." I have read and fully understand the consent form and sign it voluntarily and freely. A copy has been given to me.

Date ______________Time________Signature __________________________

"I certify that I have personally explained all of the elements of this form to the subject before requesting a signature."

Signature ____

APPENDIX B

Demographic Questionnaire

Information on the child

Child's age __________ Gender: _____male _____female

Ethnic group: ____ African American ____ Asian American ___Caucasian

____ Hispanic American ____ Native American ____ other

Child lives with: (check all that apply) ____ mother ___ father

____ sister(s) ages______________ ____ brother(s) ages

____ stepmother ____ stepfather ____ others (please specify)

Information on the parents

Mother's age: ___20-29 ___30-39 ___40-49 ___50-59 ___60+

Ethnic group: ____African American ____Asian American ____Caucasian

____Hispanic American ____ Native American ____ other

Average Income: ___0-20,000 ___22,001-40,000

___40,001-60,000 ___above 60,000

Father's age: ___20-29 ___30-39 ___40-49 ___50-59 ___60+

Ethnic group: ____African American ____Asian American ____ Caucasian

____Hispanic American ____Native American ____ other

Average Income: ___0-20,000 ___22,001-40,000

___40,001-60,000 ___above 60,000

Information on maternal grandparents

Grandmother's age: ___30-40 ___41-50 ___51-60 ___61-70 ___70+

Grandfather's age: ___30-40 ___41-50 ___51-60 ___61-70 ___70+

(If the following are different, identify by M or F)

Ethnic group: ____African American ____Asian American ____Caucasian

____Hispanic American ____Native American ____other

Average Income: ___0-20,000 ___22,001-40,000

___40,001-60,000 ___above 60,000

Distance in miles grandparents live from child: ___0-15 ___16-45

___46-100 ___101-250 ___251-500 ___500-1000 ___1001+

Information on paternal grandparents

Grandmother's age: ___30-40 ___41-50 ___51-60 ___61-70 ___70+

Grandfather's age: ___30-40 ___41-50 ___51-60 ___61-70 ___70+

(If the following are different, identify by M or F)

Ethnic group: ____African American ____Asian American ____Caucasian
____Hispanic American ____Native American ____ other

Average Income: ___0-20,000 ___22,001-40,000
___40,001-60,000 ___above 60,000

Distance in miles grandparents live from child: ___0-15 ___16-45
___46-100 _____101-250 ___251-500 ___500-1000 ___1001+

APPENDIX C

Genogram Questions

I would like to have some information that would provide an understanding of your family pattern and background. Let's begin with your parents.

1. How many children did they have together?
2. What is the order of birth and sex of the children?
3. Were there any children by other unions?
4. What is the order of birth and sex for those?
5. Are any of these family members disabled?
6. Do your parents have any other family members that are disabled?
7. Are any of your sibling married?
8. Do any of your siblings have children?
9. What are their birth orders, sex and ages of those children?
10. Are any of these children disabled?
11. How many children do you have?
12. What are their birth orders, sex and ages?
13. Do any of your other children have a disability?

Now let me ask you some of the same questions about your child's father's family.

14. How many children did they have together?
15. What is the order of birth and sex of the children?
16. Were there any children by other unions?
17. What is the order of birth and sex for those?
18. Are any of these family members disabled?
19. Do his parents have any other family members that are disabled?
20. Are any of the father's siblings married?
21. Do any of his siblings have children?
22. What are their birth orders, sex and ages of those children?
23. Are any of these children disabled?
24. Does the father have any children from another union?
25. What are their birth orders, sex and ages?
26. Are any of these children disabled?

APPENDIX D

Interview Questions

1. Tell me about your child.
2. What type of school program does the child currently receive?
3. Tell me about your child's disability. (Probe for when and how it was identified.
4. How did you and your husband react initially?
5. How did your mother react initially? ...your father? ...your husband's mother? ...your husband's father?
6. What is it like for your family to have a child with a disability? (Probe for stresses or benefits)
7. How often do the grandparents see the child.
8. What type of interaction and communication did the child have with the grandparents after birth? ...before starting school? ...in the early grades? ...currently?
9. How do you feel about the amount of interaction and type of interaction? (possible follow up: To what extent is it important or positive for you or the child?)
10. What would you see and hear when the child and the grandparents are together in a room? (possible follow up: What are their favorite things to do together?)
11. What types of conversations do you have with the grandparents about the grandchild?
12. To what degree do you believe the grandparents understand the limitations and challenges that your child must face? (possible follow up: To what extent has this changed?)

13. Describe how you think each grandparent feels about the child.

14. To what extent have the grandparents added to or helped to lessen the level of stress for the family and the child?

15. What types of support have the grandparents provided? (possible follow-up: To what extent have the grandparents provided social, emotional and/or financial support?)

16. What types of negative reactions have you or the child received from the grandparents?

17. Which of the grandparents are most supportive? Why would you say that? Who would be next? Why?

APPENDIX E

Family Genograms

Genogram Key

Male - □

Female - ○

Child in the study - ◈ ◉

Others with disability - ▣ ◎

Disability outside immediate family - ▽

Divorce - //

Adopted - ⁞

Miscarriage - ●

Grandfather - GF

Nephew - Ne

Great nephew - GNe

Infant - In

Epilepsy - Ep

Sudden Infant Death Syndrome - SID

Cerebral palsy - CP

Learning Disability - LD

Attention Deficit Disorder - ADD

Mental Retardation - MR

Emotionally Disturbed - ED

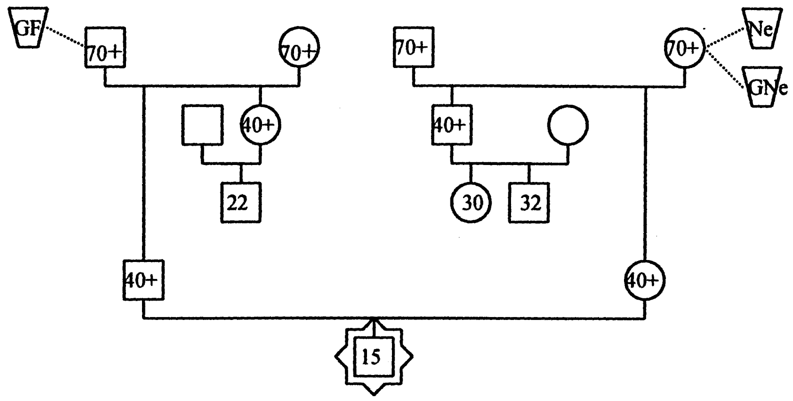
Brother - B

Part of the family living together ⬚

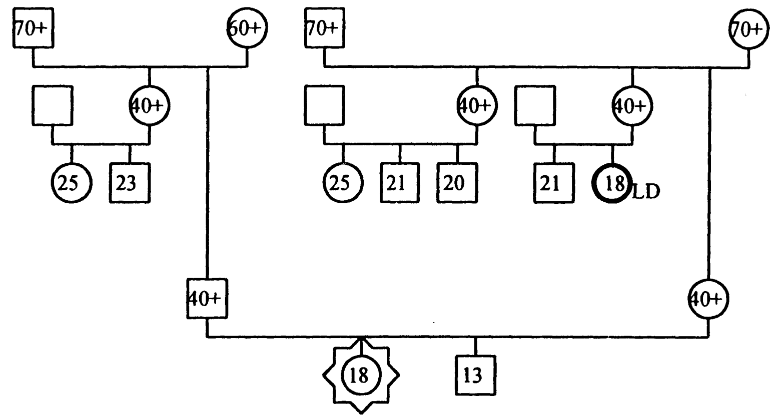
Paternal side of the family begins on the left.

Maternal side of the family is to the right.

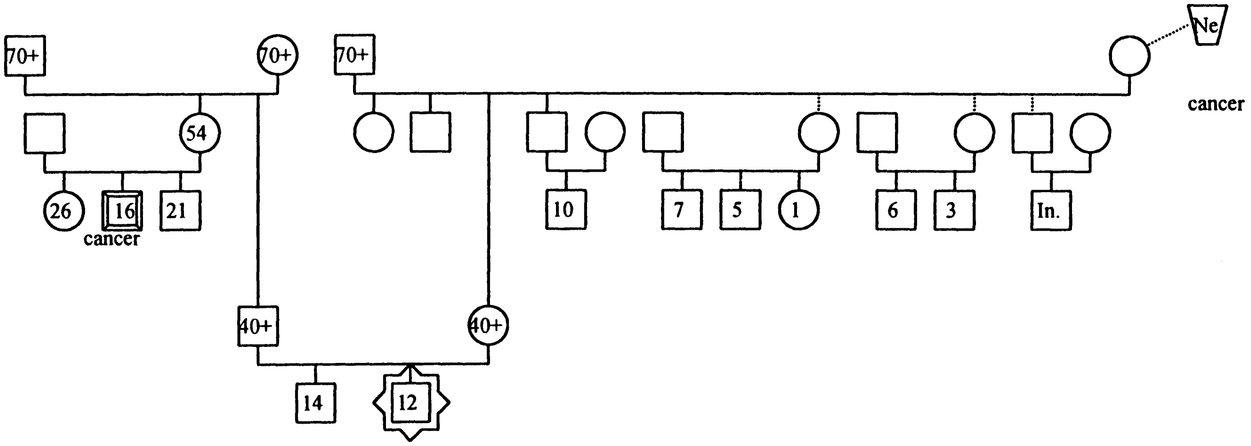
CASE ONE --- LARRY'S FAMILY GENOGRAM



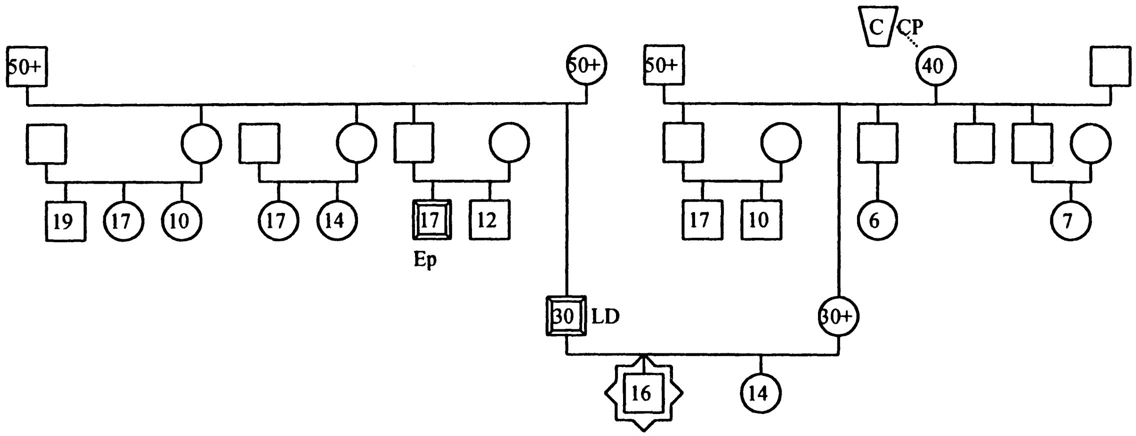
CASE TWO – RACHEL'S FAMILY GENOGRAM



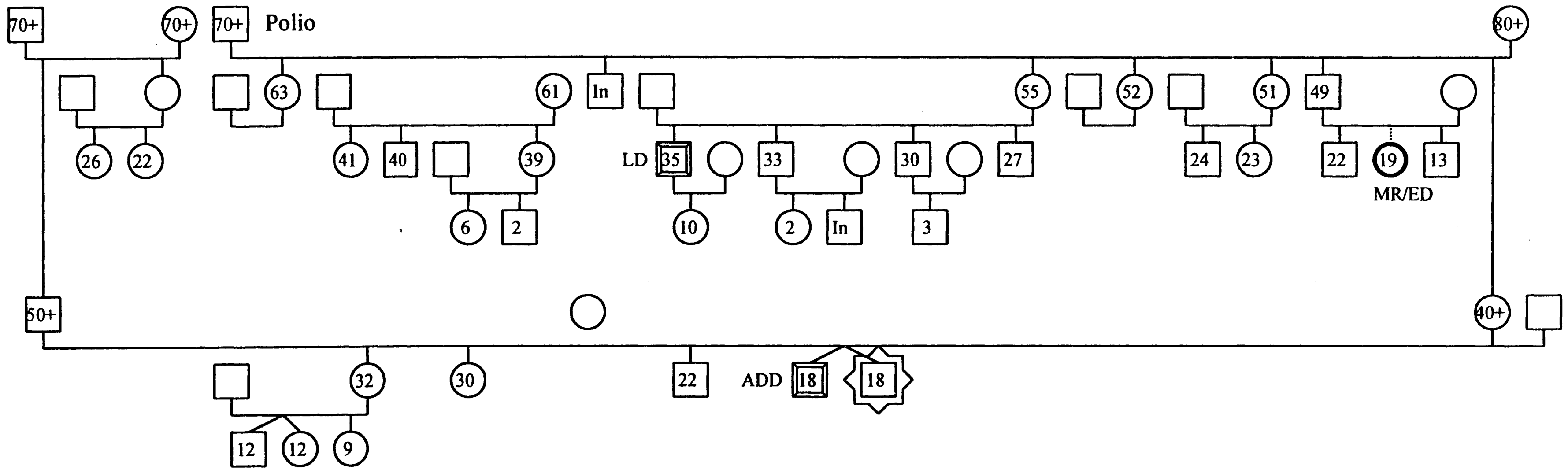
CASE THREE – TOM'S FAMILY GENOGRAM



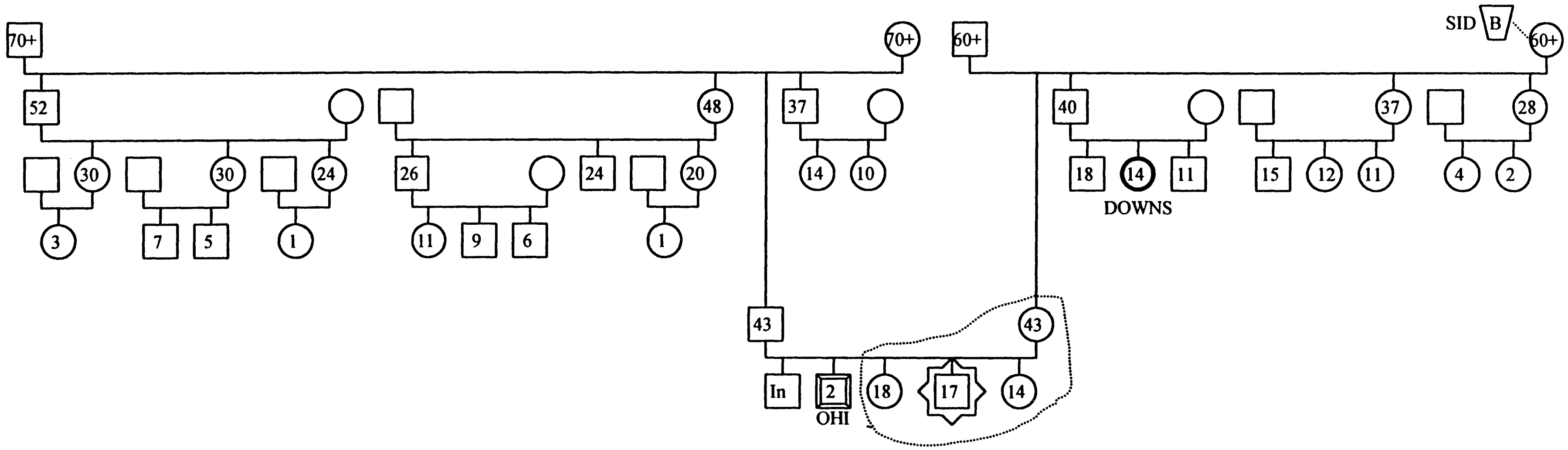
CASE FOUR – ERIC'S FAMILY GENOGRAM



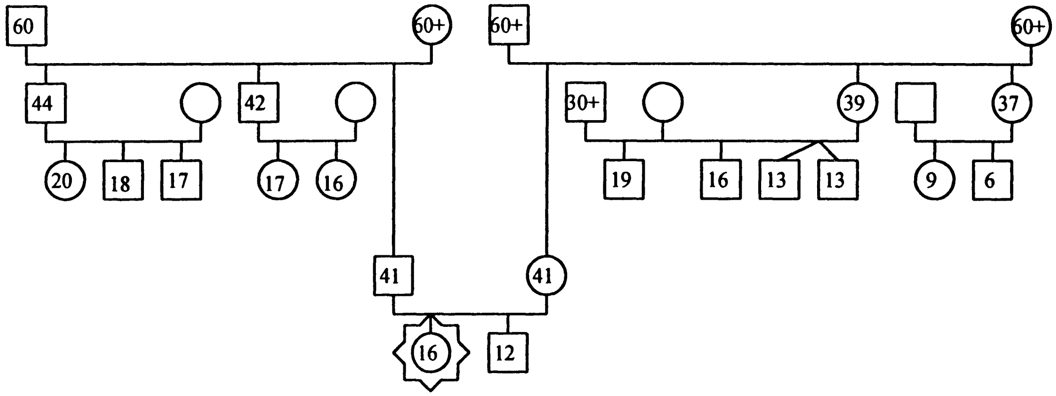
CASE FIVE – NEIL'S FAMILY



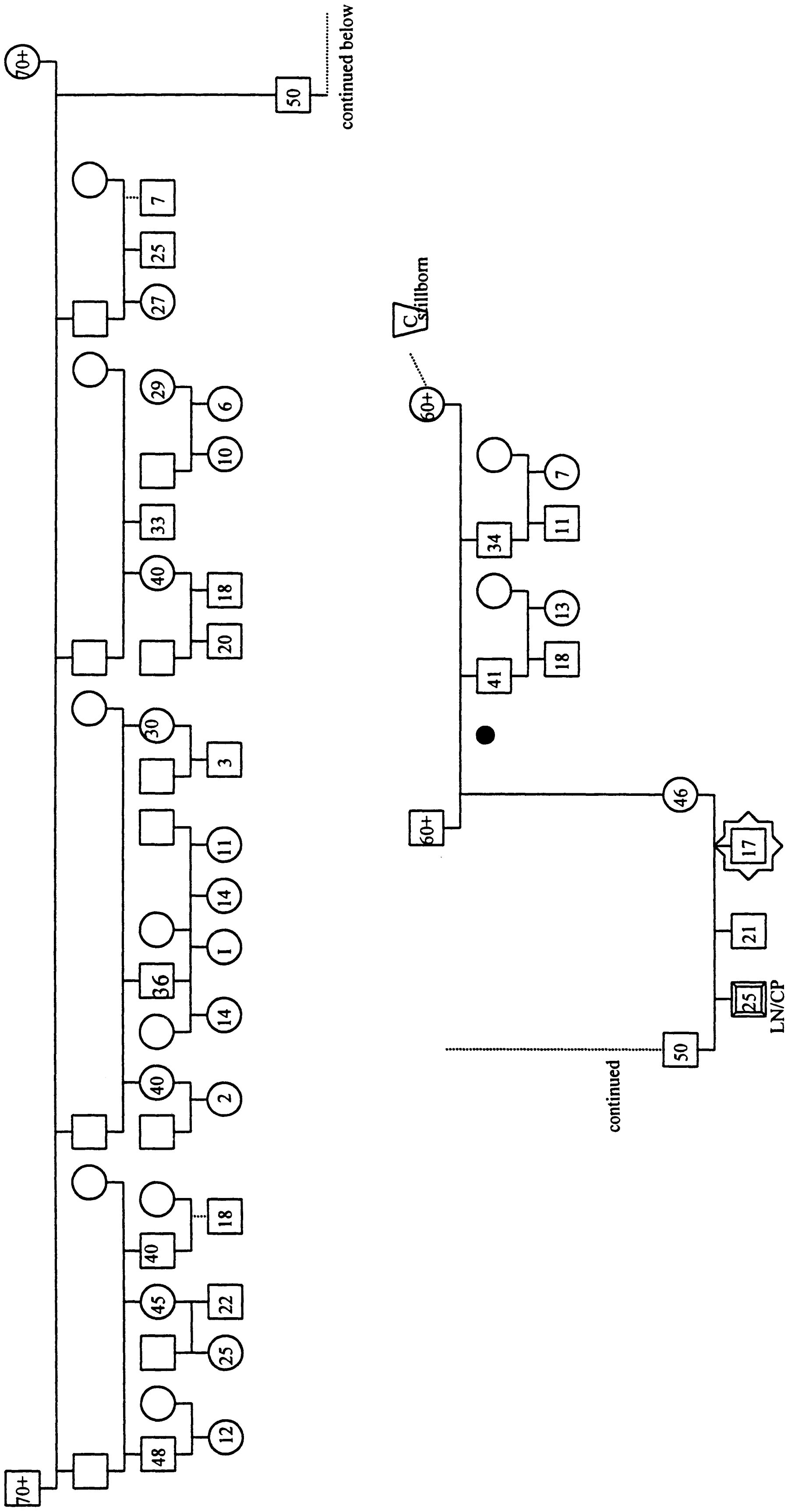
CASE SIX – BOB'S FAMILY GENOGRAM



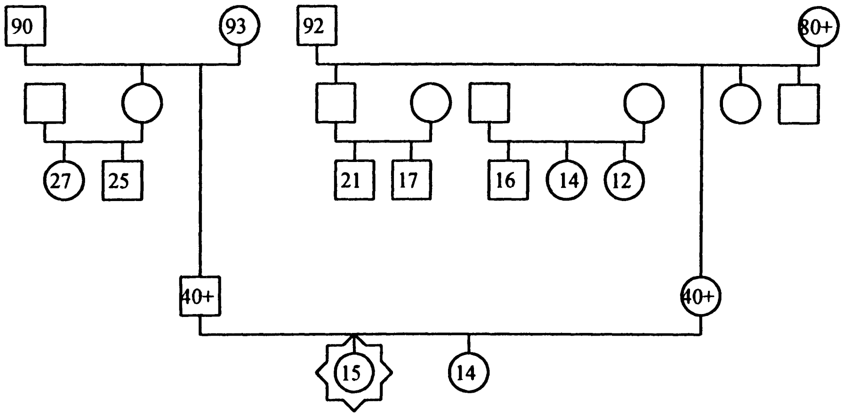
CASE SEVEN– EMILY'S FAMILY GENOGRAM



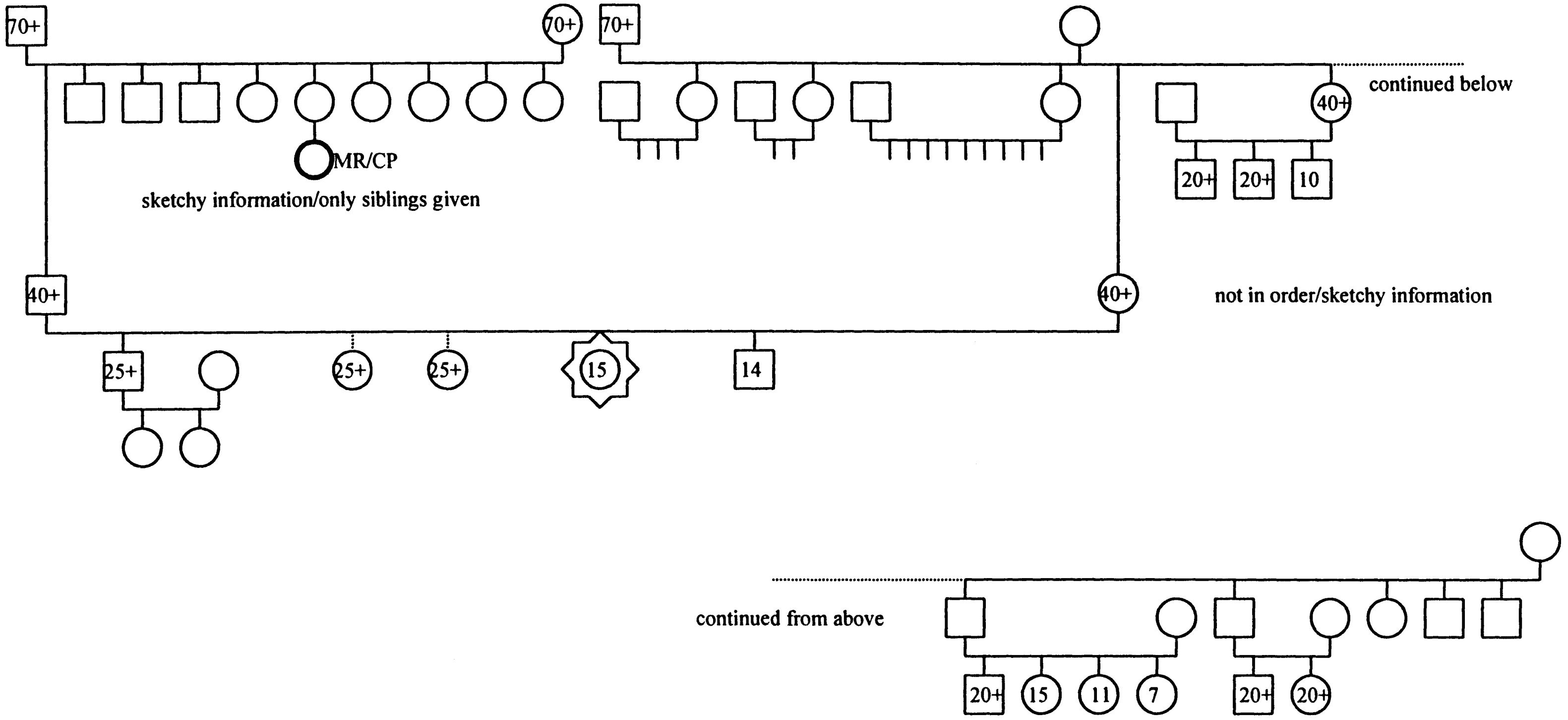
CASE EIGHT– RANDY'S FAMILY GENOGRAM



CASE NINE – RITA'S FAMILY GENOGRAM



CASE TEN – PATTI'S FAMILY GENOGRAM



APPENDIX F

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
HUMAN SUBJECTS REVIEW

Date: 09-05-95 **IRB#:** ED-96-022

Proposal Title: A STUDY OF THE ROLE OF GRANDPARENTS IN THE SUPPORT OF THE FAMILY OF A CHILD WITH A DISABILITY

Principal Investigator(s): J. Barbara Wilkinson, Coralee Risley

Reviewed and Processed as: Exempt

Approval Status Recommended by Reviewer(s): Approved

ALL APPROVALS MAY BE SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW BOARD AT NEXT MEETING.
APPROVAL STATUS PERIOD VALID FOR ONE CALENDAR YEAR AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR BOARD APPROVAL.
ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

Comments, Modifications/Conditions for Approval or Reasons for Deferral or Disapproval are as follows:

Signature: ______________________ **Date: October 10, 1995**

Chair of Institutional Review Board

VITA

Patty Coralee Risley

Candidate for the Degree of

Doctor of Philosophy

Thesis: A STUDY OF THE ROLE OF GRANDPARENTS IN THE SUPPORT OF THE FAMILY OF A CHILD WITH A DISABILITY

Major Field: Applied Behavioral Studies

Biographical:

Education:

Bachelor of Science in Education
Oklahoma Christian University, 1979

Masters in Education
Central State University, 1983

Completed the requirements for the Doctorate of Philosophy degree at Oklahoma State University in May, 1999.

Experience:

Oklahoma Christian University 1986-98
Assistant Professor
Special Education, Elementary Education, Early Childhood Education

Oklahoma City Public Schools 1979-86
Special Education Teacher
Physically Handicapped, Mentally Retarded, Multi-handicapped

Private Summer School 1983-85
Director and Teacher
Students with Disabilities

Professional Memberships:

Council for Exceptional Children
Phi Delta Kappa