

RECONSTITUTED FAMILIES CARING FOR
CHILDREN WITH DISABILITIES

BY

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**RECONSTITUTED FAMILIES CARING FOR
CHILDREN WITH DISABILITIES**

BY

SUSAN MORAES

A Thesis/Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial fulfillment of the requirements for the degree of

MASTER OF SOCIAL WORK

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ABSTRACT

This is a study of reconstituted families caring for children with disabilities. To date, there has been no available literature on this topic. The purpose of this qualitative research was to provide some understanding of the issues confronting blended families and in particular the mother, as the primary caregiver.

The methodology used in the study involved a qualitative grounded theory approach (Glaser & Strauss, 1967) and a quantitative measure of family adjustment.

From the study, several major themes and hypotheses were identified. These can be grouped as follows: the mother as the central parent in the family; spousal support as the most important resource to the female primary caregiver; difficulties for remarriage for the single female parent; greater difficulties for complex blended families than simple blended families; and the roles of friends and family (particularly step-grandparents) in the blended family. In addition, it is hoped that these findings may serve to generate further hypotheses with respect to the effects of children's disabilities on the blended family. Finally, the findings may be helpful to clinicians who are currently engaged in practice with reconstituted families caring for children with disabilities.

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CHAPTER ONE: INTRODUCTION

BLENDED FAMILIES CARING FOR CHILDREN WITH DISABILITIES: AN OVERVIEW

Changes in the social and economic sectors of Canadian society have had profound influences on the family system. The availability of birth control, women entering the work force, high divorce rates and the growing numbers of single parent families have all changed the profile of the traditional Canadian family. These rapidly occurring changes in society have affected the amount of resources, time and energy available to care for and nurture children (Hetherington & Clingempeel, 1992).

Divorce is another factor that has affected the traditional family. Over the past two decades, the proportion of divorced persons doubled (Hetherington & Clingempeel, 1992). The divorce rates are consistently highest for persons under the age of thirty (Hetherington & Clingempeel, 1992). Bristol, Reichle and Thomas (1987) indicate that the divorce rate may be higher in families with children with disabilities. In addition, Price-Bonham and Addison (1978) concluded that the divorce rate in families with children with disabilities is three times the national average. However, when level of income and education are held constant, there is

no difference in the divorce rates between parents of disabled and non-disabled children. Therefore, whether or not having a child with disabilities increases the likelihood of divorce is unknown presently.

There is disagreement in the literature as to whether or not single parents of children with disabilities provide more or less enriching home environments (Bristol et al., 1987). In addition, Bristol et al., (1987) indicate that it is difficult to interpret the results of research in this area because different levels of education and economic status of the parents may have just as much effect on a child as the parents' marital status.

Overall, few studies have focused on single mothers of children with disabilities and much less is known about single fathers and their children with disabilities. Furthermore, no significant research has been conducted on blended families with children with disabilities.

Many questions are asked about blended families caring for children with disabilities. For the purposes of this study, the following general research questions were identified: What role does the disability play in the blended family? What are the main stressors involved for the primary caregiver? How does the primary caregiver cope with the needs of the family? What resources are most helpful to the primary caregiver? How do primary caregivers view the future in the blended family caring for their children with disabilities?

And finally, how can professionals better understand the needs of blended families caring for children with disabilities?

Because no available literature was found in the area of blended families caring for children with disabilities, the general purpose of this qualitative study was to provide critical understanding of the issues confronting these families. The main purpose for this study was to generate hypotheses in the area of blended families caring for children with disabilities, as well as to develop questions grounded in the experiences of these families. Such questions may provide a basis for future research.

In the preliminary study, the child referred to had a behavioural disability, however, children in the main study all had a primary diagnosis of developmental delay.

The methodology used in this study followed a grounded theory approach. In-depth interviews were conducted to help identify the key areas that confronted blended families caring for children with disabilities. Interviews were used as an open ended, more discovery oriented approach to grounded theory. The qualitative research methods were also used to help understand what meanings families give to their experiences caring for a child with a disability.

In essence, the study was designed to capture the subjective perceptions of primary caregivers and their situations. The research design for understanding this process consisted of two phases. First, a preliminary study was

carried out in order to be sensitized to the issues of the primary caregiver.

The preliminary study consisted of interviewing one primary caregiver using an open ended, semi-structured interview process. The interview was tape recorded and transcribed and was used as a way to understand of some of the salient issues for the primary caregivers who participated in the study. This activity was useful for giving some sense of direction to the four semi-structured interviews that followed in the main study.

The second phase of the research was the main study and this consisted of giving questionnaires and conducting semi-structured interviews. The information from the preliminary interview along with the literature reviews on blended families and on children with disabilities suggested avenues to explore in the construction of the interview questionnaire. These interviews in the main study were used as a way of exploring in greater detail the lives of primary caregivers caring for children with disabilities and a way of identifying some of the main issues in their lives. Whereas the preliminary study was entirely qualitative in it's methodology, the main study combined qualitative and quantitative approaches employing the Family Assessment Measure (Skinner, Steinhauer & Santa-Barbara, 1983).

The chapters which follow are laid out in the following order. In chapter two, there is a review of the literature.

Two sets of literatures are reviewed, the first on blended families and the second on children with disabilities. Two separate reviews were required because there was no available literature on blended families caring for children with disabilities.

Chapter three discusses the findings of the preliminary study. The preliminary study was the beginning stage of research. During this phase, the emphasis was on exploring what issues were important to the primary caregiver. The issues that emerged in this phase, were the starting point for setting out some ideas to further explore in the main study.

The methodology used in the main study is described in chapter four. The sample design and other methodological issues pertaining to this research are discussed.

Chapter five represents the data that was collected from the main study. In particular, the experiences of the four primary caregivers and the Family Assessment Measure analysis of both primary and secondary caregivers are presented.

Chapter six discusses the analysis section of the study and main categories and patterns that emerged. Also, in this chapter is a description of some hypotheses that were generated.

Chapter seven, the conclusion chapter, offers a brief overview of the study, considers some of the major limitations of the study, and discusses recommendations that include implications for policy and practice.

CHAPTER TWO: LITERATURE REVIEW

THE BLENDED FAMILY LITERATURE

BLENDED FAMILY STRESS

Family reorganization as a result of divorce and remarriage has become an increasingly common experience for many families today. Hetherington and Clingempeel (1992) estimate that one out of ten children will experience two parental divorces before the child turns sixteen years of age. Although remarriage can mean an end to loneliness, economic stability and renewal of emotions and affection to many families, it can also mean a loss of freedom and psychological and behavioral adjustments to families (Wu, 1994).

According to Albrecht (1979), divorce is a major stress inducing life crisis. Darden and Zimmerman (1992) propose that divorce has a greater effect on men and separation has a greater effect on women. In addition, divorce related stressors may include: economic, housing, legal, the parent-child relationship, and the relationship with the ex-spouse (Albrecht, 1979).

In the process of adjustment following a divorce, Colburn, Lin and Moore (1992) found that there are differences between males and females in the ways in which they reconstruct their identities. They found that males are more

likely to externalize the problem of adjustment through romantic involvements with other females. On the other hand, females are more likely to view changes in themselves and their experiences of independence as the basis for a new identity.

Those entering into a second marriage face integrating themselves and their children into the structure of a new stepfamily (Borrine, Handal, Brown & Searight, 1991). For each member of the family, this integration involves a reworking of one's model of the family and one's expectations of family life (Garfield, 1980; Kent, 1980).

Each individual entering a marriage may have preconceived notions of what a family is and how it functions. These notions are likely to be based on prior experiences in one's family of origin, observations of other family systems, and ideas of the perfect family (Keshet, 1990).

Zeppa and Norem (1993) suggest that spouses in stepfamilies carry sets of emotional baggage from their family of origin, their first marriage, and the period of separation and divorce prior to their remarriage. Issues of guilt, loyalty conflicts, hurt, failure, anger and bitterness may interfere with the creation of appropriate boundaries, affective differentiation, and the new marital relationship in the stepfamily (Gold, Bubenzer & West, 1993b). In addition, blended families may struggle with certain tasks such as: mourning the loss of the previous family, maintenance of the

crucial marital relationship, integration of extended family, and formation of sibling alliances (Kleinman, Rosenberg & Whiteside, 1978).

As a whole, the blended family literature (Ganong & Coleman, 1993b; Gold, Bubenzer & West, 1993a; Roberts & Price, 1989) cites greater marital intimacy among several factors predictive of positive blended family functioning. Gold et al. (1993b) found that stepfamily couples are more likely to divorce than are first married couples and that marital intimacy is critical to the maintenance of the stepfamily unit. Further, the demands of parental and spousal roles simultaneously, may result in one relationship, usually the spousal relationship, being neglected (Goetting, 1982).

Santrock, Warshak and Meadows (1982) found that the presence of stepchildren increases the likelihood that a remarriage will end in divorce. Specifically, Rosenberg and Hajal (1985) found that the presence of a child from a previous marriage increases the possibility of divorce for women in remarriages, while the presence of children from the new marriage decreases the possibility of divorce and facilitates blended family cohesion.

In a study by Keshet (1990), couples from blended families indicated that when entering a new marriage they expected to share the decision making for stepchildren more equally than they actually did in their remarriages. Ganong and Coleman (1993a) found that most unhappily remarried

couples report disagreements about the discipline of children or stepchildren and about meeting children's needs more than any other disagreements. Skopin, Newman and McKenry (1993) also emphasized that disagreements regarding the raising of children that align children with their mother against the stepfather may, in turn, put the marriage at risk.

Some evidence (Cherlin, 1978; Johnson, 1980; Spanier & Fustenberg, 1982; Visher & Visher, 1985) shows that stepparents experience a substantial amount of stress from their family lives. There may be a number of stressors confronting stepparents. These include: dealing with loss of the former family arrangement, feelings of exclusion from the parent-child relationship, distant or turbulent relations with stepchildren, difficulties disciplining children (Ganong & Coleman, 1993b), financial difficulties, being at different stages of life than one's spouse, conflictual relations with one's ex-spouse, and difficulties with biological children living outside the home (Fine & Schwebel, 1991). In addition, stepparents in complex blended families (where both spouses bring children into the new marriage household) may experience greater levels of stress and less marital satisfaction than do those in simple blended families (where only one spouse brings children into the new marriage household) (Hetherington, Stanley-Hagan & Anderson, 1987). Taken together, these findings may suggest that these stressors may have an impact on adjustment in stepfamilies.

Beyond individual differences, stepparent adjustment may also depend on several other factors, including gender of the stepparent, type of stepfamily, and the length of time the stepfamily has existed (Visher & Visher, 1985). Moreover, Spanier and Fustenberg (1982) found that those stepfamilies that were together for more than seven years reported less difficulty in disciplining their step-children and greater family cohesion.

CHILDREN IN REMARRIAGES

Many children are exposed to a series of marital transitions and household reorganizations following their parents' separation and divorce (Perkins & Kahan, 1979). For many children, the period of adjustment to remarriage seems to be longer than that for divorce, especially for older children (Borrine et al., 1991). Divorce usually involves high levels of family conflict and a decrease or loss of contact with a parent, whereas remarriage involves the addition of family members (Colburn et al., 1992). Spanier and Fustenberg (1982), have argued that behaviour problems with children in remarried families may be due to lingering stresses associated with the divorce and life in a single parent household rather than to the remarriage itself.

There is great diversity in children's responses to their parents' marital transitions. In the period following remarriage, a child may give up fantasies of parental

reconciliation, may resent the new step-parent's attempts to control or discipline, and may perceive the new marital relationship as a threat to the parent-child relationship (Hetherington & Clingempeel, 1992). In addition, the child is likely to maintain membership in the families of both parents and is likely to have an expanded kinship network (Hetherington et al., 1987).

Further, Cherlin (1978) found that children in stepfamilies have more difficulty adjusting in stepfamilies with larger numbers of children, in blended families with children from the custodial parent and the step-parents' previous marriages, and in families in which a new child is born to the biological parent and step-parent.

The effects of family reorganization through divorce or remarriage may vary according to the developmental status of members of the family and their stage in the family life cycle (Hetherington & Clingempeel, 1992). Hetherington (1989) also suggests that children will cope differently to remarriage, depending on the characteristics of the child, particularly their age and gender, their available resources, their subsequent life experiences, and their interpersonal relationships. It may be that the type of behaviour problems and coping mechanisms differ for children of different ages (Hetherington, 1989; Hobart, 1989). Support systems can serve as sources of practical and emotional support for both parents and children experiencing family transitions (Hobart, 1989).

Children from divorced parents may also receive support from sibling relationships. Female siblings in divorced families may act as buffers and fill emotional voids left by unresponsive parents (Ganong & Coleman, 1993b). In contrast, male siblings living with divorced mothers with custody are more antagonistic towards their siblings. Ganong & Coleman, 1993b). Although research on siblings in blended families is limited compared to other areas of family study, it is known that siblings have a profound influence on each other (Rosenberg & Hajal, 1985). Siblings may perform many functions: identification, protection from parents and others, regulation of behaviour, socialization, support, and exchange of direct services (Keshet, 1990). In addition, sibling relationships can be extremely important in a child's psychological development (Rosenberg & Hajal, 1985).

A study by Ganong and Coleman (1993a) found that siblings in blended families report problems mainly derived from having to share resources such as parental attention, and space in the household. Generally, however, rivalrous, aggressive, coercive sibling and step-sibling relationships may be more common in stepfamilies than positive relationships, and these negative relationships may act as additional stressors in the first two years following remarriage (Hetherington, 1989).

Therefore, depending on a child's age, sex, developmental stage, and personality characteristics, children's reactions to remarriage can be widely diverse. The introduction of

stepsiblings present significant issues in terms of a child's identity and growing sense of him/herself (Rosenberg & Hajal, 1985).

BLENDED FAMILY ROLES

Remarriage when viewed as a dynamic process, involves adjustment and readjustment to parental and step-parental relationships, gains and losses of family members, boundary and role definitions, and family and individual developmental stages (Darden & Zimmerman, 1992). Thus, as members are added to the remarried family, boundaries and roles must shift in order to accommodate new experiences (Roberts & Price, 1989).

Hobart (1989) suggests that major sources of stress for blended families is the restructuring and clarification of roles. Whitsett and Land (1992) found that stepparents reported a lack of clarity regarding spousal expectations of their roles as well as being relatively unaware of what was involved in being a stepparent.

Whitsett and Land (1992) further note that in the stepparent role, components of conflict include role change, unclear family boundaries, ambiguous role expectations, and role conflict. In addition, they suggest that a stepparent may have wanted the remarriage but not necessarily the parenting role.

Both remarried mothers and fathers report less family cohesion and more poorly defined family roles and

relationships in the early months of remarriage (Santrock et al., 1982). Both stepmothers and stepfathers have also been found to take a considerably less active role in parenting than do custodial parents (Fine & Schwebel, 1991).

Zeppa and Norem (1993) found that a stepmother's relationship with her stepdaughters may appear more problematic than with stepsons. Stepmothers with stepdaughters may have greater difficulty in establishing positive relationships, perhaps because of increased loyalty conflicts for the children (Zeppa & Norem, 1993). Stepmothers have also been identified to have more adjustment problems (Peterson & Zill, 1986) and greater role strains (Whitsett & Land, 1992) than stepfathers.

Moreover, the role of the stepfather is far more common than that of the stepmother because children more frequently reside with their mothers (Spanier & Glick, 1981). Skopin et al. (1993) found that older children have more difficulty with stepfathers than younger children, and that adolescents did not develop close relationships with their stepfathers. They also suggest that a stepfather with biological children out of the home may feel guilty about abandoning his children and this may lead to competition between his new wife and his biological children.

In addition, Fine and Schwebel (1991) found that stepparents may experience distress because of the gap between their expectations and reality. A stepparent's role adjustment

may be influenced by the differences between stepparents' beliefs and experiences and those of other family members. They also found that role adjustment may be influenced by racial differences in stepfamilies.

Clearly, men and women carry out different family and stepfamily roles. Despite the increase in participation of women in the work place, women still retain primary responsibility for family life, child rearing, and home-making (Skopin et al., 1993). Men and women have also been found to perceive and interpret their experiences differently in marital and family roles (Whitsett & Land, 1992).

BLENDED FAMILY COPING BEHAVIOURS

Commonly seen are stepfamilies being forced to develop coping behaviours on their own for many of their daily encounters (Pledge, 1992). The type of coping strategies stepparents use may differ depending upon the stage of stepfamily development (Whitsett & Land, 1992). Whitsett and Land (1992) found that major coping resources may be an individual's personality characteristics, such as attitudes, skills, and beliefs that people bring to all situations and experiences.

Keshet (1990) suggests that those entering remarriage must work their expectations of family life into those of their spouses. He further suggests that those who maintain flexible family ideas have a much easier time accepting

stepfamily members. Also, the couple may need to alter their expectations in order to survive as a stepfamily.

Schultz and Schultz (1987) found that in order to turn areas of stress into satisfaction there is a need for effective communication between spouses. In addition, a satisfying relationship with friends and relatives could be related to a satisfying marital communication system in remarriage (Roberts & Price, 1989). A positive relationship with family and friends may also be viewed as acceptance of the new remarried family (Roberts & Price, 1989).

Successful remarriages may also involve negotiations in the family decision making process (Hetherington & Clingempeel, 1992). However, the most important factor may be the parental coalition (Smith, 1991). Family cohesion may also be an important variable in remarried family well being (Smith, 1991).

Although remarried couples may find themselves in many conflicts, alternatively, they may find their economic situation improved, their shared household and child care responsibilities welcomed, and their commitment a source of mutual bonding (Gold et al., 1993b).

Also, it may be that remarried families grow from shared experiences over time (Roberts & Price, 1989). Individual coping strategies may differ based on social constraints or personal support, the presence or absence of children in the remarriage, economic status, parental level of education, and

amount and level of contact with one's ex-spouse (Pledge, 1992).

Hetherington and Clingempeel (1992) indicate that certain aspects of social support are dependent on: the source of the support; the size or amount of support; the accessibility of the network; the frequency of the contact; the type of individuals acting as supports (friends, family); and the adequacy of the support.

Finally, advice offered by remarried women in a study by Hobart (1989) emphasized the importance of open and honest communication, trying to ensure compatible values and expectations before marriage, and being patient, supportive and willing to compromise with blended family members. They also emphasized communication, seeking counselling help when needed, and equal treatment of children. These responses may also highlight some of the potential difficulties that are particular concerns for remarried women (Hobart, 1989).

THE DISABILITY LITERATURE

PARENTAL STRESS AND FAMILY FUNCTIONING

The impact of a disability on a family is not restrictive to the individual with the disability but extends to all family members. Common views that exist for families of children with disabilities include high levels of stress and

low levels of family functioning (Harris & McHale, 1989). Some researchers (Beckman, 1983; Dyson & Fewell, 1986; Friedrich & Friedrich, 1981; McKinney & Peterson, 1987) have reported increased stress in families of children with disabilities, whereas others (Frey, Greenberg & Fewell, 1989; Salisbury, 1987) have reported no differences in parental well being and stress. Likewise, some researchers (Kazak, 1987; McAndrew, 1976) have reported disruptions in family activities, less marital satisfaction (Friedrich & Friedrich, 1981; Kazak, 1987), and deteriorated family physical and mental health (Friedrich, Wiltturner & Cohen, 1985). Still other studies, (Glidden, 1993; Margalit et al., 1992; Smith, 1986), have found that families caring for a child with a disability have less supportive family interrelations, less time to pursue personal activities and have more restrictive households. These discrepant results may be partly due to methodological shortcomings and socioeconomic variability (Dyson, 1993; Frey, Fewell, & Vadasy, 1989) and may reflect that there is a wide range of family responses.

Parental stress and family functioning may increase as the child with the disability grows older (Beckman, 1983; Bristol et al., 1988). As the child grows, parents are confronted with greater problems with the child's behaviour, financial burdens within the family, and long term uncertainty about the future functioning of their child with the disability (Tunali & Power, 1993). Family development and the

amount of social support may also change along the life cycle of the child with the disability (Tunali & Power, 1993), and a positive family relationship may be related to less parental stress (Dyson, 1991). In addition, Friedrich and Friedrich (1981), found that greater marital satisfaction of parents of children with disabilities was related to lower overall parental stress.

There is a significant amount of research (Beckman, 1983, 1991; Friedrich & Friedrich, 1981; Tunali & Power, 1993) which indicates that families of children with disabilities experience chronic stress related to financial hardships and strained emotional relationships between family members (Friedrich & Friedrich, 1981), modifications in family activities and goals (Beckman, 1983), stressors in the family's social life and time burdens (Beckman, 1991), stressors regarding their child's medical treatment and schooling (Beckman, 1991), and stressors associated with the parental grieving process (Tunali & Power, 1993).

The problems associated with the lack of adaptability of the child, the acceptability of the child by parents, and the demands placed on caregivers of children with disabilities also appear to be major sources of stress for parents (Orr, Cameron, Dobson & Day, 1993). Orr et al. (1993) also suggest that the physical, emotional, and intellectual characteristics of a child with a disability may not meet parental expectations which may lead to chronic grieving if these

feelings are not resolved over time.

There are conflicting views as to whether parental stress relates to a lack of individual family resources (Friedrich & Friedrich, 1981), increases in child care needs (Beckman, 1983), the severity of the child's disability (Friedrich et al., 1985), the type of disability (Beckman, 1991), the age of the child with the disability (Grant & McGrath, 1990), the strength of the marriage and marital integration (Friedrich & Friedrich, 1981; Trute, 1995), parental feelings of self worth (Beckman, 1981), the amount of informal supports and availability of respite services (Grant & McGrath, 1990; Trute, 1995), and the behaviour problems and gender of the child with the disability (Beckman, 1991). Most likely, a combination of these factors together may relate to family stress.

Moreover, McCubbin and Patterson (1983) suggest that aspects of the family environment and the strength of social support networks have more significant effects on parental and family stress and adaptation than do characteristics of the child with the disability.

MARITAL STRESS

Attempts to assess the influence that a child with a disability has on the marital relationship leads to inconsistent findings (Cooke, Bradshaw, Lawton & Brewer, 1986). Some authors (Kazak, 1987; Tew, Lawrence, Payne &

Rawnsley, 1977) found that caring for a child with a disability may have a severe impact on marital stability, may increase the stress on the couple, and may enhance the chances of separation and divorce. Further, Cooke et al. (1986) found that families caring for a child with a disability are more likely to break down at least once in their first ten years.

Other authors (Martin, 1975; Rousey et al., 1992), suggest that family dissolution is not greater in families caring for a child with a disability, and further, that children with disabilities may bring parents closer together. In addition, Martin (1975) suggests that those marriages that break down may have been severely strained and unstable before the birth of the child with the disability.

A study by Cooke et al. (1986) found that families with children with disabilities are more likely to be a one-parent family, especially if the disability is severe. Moreover, they found that disabled children more commonly live with their mothers. Natural fathers seem more likely to be absent in these families. They further suggest that because disabled children are more likely to be born in single mother households, remarriage for these mothers is usually difficult. They do, however, note that difficulties for remarriage may be a function of a mother's age and not necessarily the presence of a child with a disability.

Although it is suggested that marital discord and family instability may often be seen as the outcome of having a child

with a disability (Krauss, 1993), research is inconclusive. It is possible that families may fluctuate between times of strength and weakness depending on the situational context of the family unit (Trute, 1990).

THE ROLES OF FATHERS OF CHILDREN WITH DISABILITIES

Fathers of children with disabilities have often been viewed as peripheral figures in their child's development (Lillie, 1993). However, this view has been challenged with the notion that the roles of fathers and mothers of children with disabilities are different (Bailey, Blasco & Simeonsson, 1992).

Fathers have been found to focus on instrumental tasks of child rearing and are more likely than mothers to be affected by certain aspects of their children with disabilities causing them difficulty in coping (Cummings, 1976). In addition, fathers are noted to be less likely to talk about the needs and incompetencies of their children with disabilities in their work environments (Lillie, 1993). The lack of involvement by fathers of children with disabilities is explained by Lillie (1993) as: the fathers' inability to cope with the child with the disability; the fathers' discomfort with female dominated service systems; and the father's role which he regards as not including direct child care. According to Wikler, Wasow & Hatfield (1983) there may be a relationship between fathers' education, socioeconomic status

and involvement in caretaking responsibilities.

Furthermore, Lamb (1987) makes a number of suggestions about the role of fathers of children with disabilities. He indicates that the father's role is dependent on four variables: support, motivation, skills and self confidence, and institutional practices. The father may also take on the primary breadwinner role (Lamb, 1987) or the financial provider role (Sloper, Knussen, Turner & Cunningham, 1991; Trute, 1995) which may reduce the amount of time he can spend with his family and specifically his child with the disability.

Lastly, Lamb (1982) and Lillie (1993) suggest two views accounting for the non-involvement of fathers of children with disabilities. Lamb suggests that fathers are uninvolved because they are peripheral to the child's development because of their roles as primary breadwinners. Lillie suggests that fathers are uninvolved because fathers are only perceived as peripheral to their child's development by societal perceptions and cultural norms which do not see fathers as primary caregivers of disabled children.

THE ROLES OF MOTHERS OF CHILDREN WITH DISABILITIES

Although fathers are affected by the birth of a child with a disability (Cummings, 1976), the impact on fathers is quite different than the impact on mothers (Bristol, Gallagher & Schopler, 1988). Differences between parents show mothers

reporting higher levels of stress (Beckman, 1991; Kazak, 1987), more depressive symptoms and family difficulties (Bristol, Gallagher & Schopler, 1988), and more family functioning difficulties (McLinden, 1990).

There is some controversy in the literature. Smith (1986) found that fathers spent significant amounts of time with their disabled children, while McConachie (1989) documents that mothers spend much more time than fathers with their disabled children and that fathers generally assume less responsibilities than mothers for their disabled children.

Beckman (1983), Salisbury (1987), and Vincent (1988), found that single mothers raising a child with a disability report more stress than single mothers of children without a disability, and married mothers of children with and without disabilities. Vincent (1988) further reported that single mothers were more socially isolated, had less stable social networks, and received less emotional and family support. He also noted that mothers who had never been married had less support from families than mothers who had been married. Finally, he found that life satisfaction was related to internal family support for married mothers, but to external family support for unmarried mothers.

It is still uncertain whether families of children with disabilities are different from other families when matched on age, race, and socioeconomic status (Bailey et al., 1992). Salisbury (1987) suggests that mothers of children with

disabilities have less social support available and are less able to work outside the home. Moreover, Erickson and Upshur (1989) reported that mothers caring for a child with a disability experienced more caretaking difficulties than did mothers of children with no disabilities.

It appears to be well documented in the literature (Bailey, Blasco & Simeonsson, 1992; Beckman, 1991; Bristol et al., 1988; Frey, Greenberg & Fewell, 1989; Krauss, 1993) that mothers and fathers have different perspectives on their experiences caring for a child with a disability. Fathers appear to have higher levels of stress associated with their child's temperament than mothers (Bristol et al., 1988; Krauss, 1993), with their child's ability to communicate (Frey et al., 1989), and in their feelings of attachment to their child (Bailey et al., 1992; Beckman, 1991). Frey et al. (1989) also found that fathers may have more difficulty adjusting their expectations of their sons.

In addition, mothers may be mainly concerned about the emotional strain of caring for the child and the effects on the whole family, while fathers' concerns may centre around the family budget and the future of the family (Sloper et al., 1991). Sloper et al. (1991) also suggest that mothers usually take on expressive roles concerning the internal and emotional affairs in the family, and fathers take on instrumental roles concerning the external relations of the system.

OUT OF HOME PLACEMENT

Caring for children with disabilities has in the past usually occurred within the family home (Salisbury & Intagliata, 1986). However, despite this trend, some families have difficulty in caring for their children with disabilities in the home and request out of home placements (Kobe et al., 1991).

The decision by parents to request out of home placement is likely to be influenced by numerous factors such as family stress, characteristics of the child with the disability and the availability of support to the caregiver (Blacher, 1990; Bromley & Blacher, 1991). In addition, Sherman (1988) suggests that children placed out of the home tend to have more severe disabilities, greater medical or physical care needs, greater behavioral problems and fewer functional skills. He also suggests that families are more likely to place a child out of the home if they are a single parent. Similarly, according to Bromley and Blacher (1991), family characteristics that may influence the placement decision include: increased daily burden or stress, poor parental health, single parent marital status, larger family size, elderly caregivers, lower levels of functioning and increased behaviour problems of the child with the disability, and increased parental perceived daily stress.

The availability of appropriate schooling may also be linked to the placement decision. Schooling may be a source of

respite for parents and may delay the placement decision (Salisbury & Intagliata, 1986). The availability and quality of supportive services for parents of children with disabilities have also been linked to the placement decision (Blacher, 1990). Additionally, parents with less support from extended family members were more likely to place their child out of the family home (Bromley & Blacher, 1991).

Researchers (Kobe, Rojahn & Schroeder, 1991; Minnes, 1989; Sherman, 1988) suggest that support services can have an important impact upon the ability of the family to provide care within the family home, thus alleviating the need for out of home placement. Further, Kobe et al. (1991) suggest that caregivers may view placement waiting lists as the entry point to valuable services, regardless of their present need. Thus, the request for placement may become a function of projected rather than actual need by these families.

SUPPORTS FOR FAMILIES CARING FOR CHILDREN WITH DISABILITIES

The birth of a child with a disability can have a significant effect on the entire family. Often family routines are disrupted and financial as well as other support systems are strained (Cullen, MacLeod, Williams & Williams, 1991). Bristol et al. (1988) have noted that families of children with disabilities pass through stages in the adjustment process. These stages or transition periods are almost always

a time of great stress. Flynt, Wood, and Scott (1992) found that families caring for a child with a disability increased their contact with health care and school professionals over their child's life cycle. Also, the utilization of parental personal supports were found to decline as the child grows older (Krauss, 1993). Coping with a child with a disability is quite an individual family process. Krauss (1993) suggests that families of children with disabilities are unique and require support for their individual needs. These needs may depend on the family's life cycle, situation and culture (Cullen et al., 1991; Krauss, 1993).

For many families caring for a child with a disability, respite services often provide the only relief from their burden of care (Kobe et al., 1991). Most families are overwhelmingly satisfied with respite care and desire increased respite opportunities (Botuck & Winsberg, 1991). Respite has been associated with reducing the burdens of families caring for a child with a disability at home by: relieving familial stress; improving parental attitudes towards their child; improving family functioning; and reducing social isolation (Botuck & Winsberg, 1991). Furthermore, Botuck and Winsberg (1991) found that during respite, mothers experienced increased feelings of psychological well-being and lower levels of depression. They also found that mothers caring for children with severe disabilities had developed lifestyles that involved engaging

in leisure and social activities without leaving their homes.

A number of variables may be related to family adaptation to stress, such as, status of the family prior to the birth of the child, availability of financial resources, the caregiving needs of the child, social support (Beckman, 1991; Cullen et al., 1991; Flynt et al., 1992) and the cohesiveness of the couple (Trute, 1990).

A study by Bristol, Gallagher, and Schopler (1988) reported that parents of disabled children, especially fathers, had significantly more marital difficulties than parents with non-disabled children. This study found an interplay between the spousal support offered and the needs and expectations of the receiving spouse. Their analysis showed that increased spousal support related to better personal, marital and parental adaptation.

Friedrich and Friedrich (1981) also found that intimate relationships are significant sources of personal support buffering the effects of stress. They found that marital satisfaction was the best overall predictor of coping behaviour. Moreover, many authors (Blacher, 1990; Flynt et al., 1992; Parke, 1986) have found that mothers of children with disabilities identified their spouse as the greatest source of personal support. In addition, Wikler et al. (1983) indicate that smaller friendship networks and increased reliance on extended family are related to reduced parental stress caring for a child with a disability. Beckman (1991)

also found that increased informal supports for both mothers and fathers of children with disabilities were significantly associated with decreased stress.

Tunali and Power (1993) suggest that it may be important to help families see their own strengths and unique resources and compliment the family's own structure of coping in reducing familial stress. Cullen et al. (1991) further suggest that mothers of children with disabilities used talking and praying as their most frequent coping strategies. They also found that strong religious beliefs were strategies used by both parents who had made significantly positive adjustments to life caring for a child with a disability.

Furthermore, Frey, Fewell and Vadasy (1989) found that coping factors such as problem solving skills were more significant for fathers' adjustment than for mothers' adjustment. Moreover, Frey, Greenberg, and Fewell (1989) found that mothers with more helpful social support networks had better family adjustment than did fathers. They found that mothers do the majority of child rearing and that their roles involve daily problem solving and coping styles associated with greater well being. Mothers also have more child care responsibilities and value child related assistance more than fathers. They also noted that personal, familial and social attributes affected parental stress and family adaptation. Finally, they found that positive self appraisals of coping skills and positive parental beliefs were related to lower

parental stress, positive family adjustment, and lower psychological distress for both parents of children with disabilities. Parents' perceptions of their ability to control their own lives was additionally related to a positive parental outcome.

INTRODUCTION TO BLENDED FAMILIES CARING FOR CHILDREN WITH DISABILITIES

Understanding blended families caring for children with disabilities is the focus of this research study. Yet, there is no known information in the literature on this area. While there is a wealth of literature on blended families and on children with disabilities, these two issues combined have received no known research attention. Although there is some research on single parents caring for children with disabilities, the step from single parenthood to remarriage has not been taken as yet. This may be due to the fact that many single parents caring for children with disabilities are women and are less likely to remarry. Remarriage for these women are thought to be lower still if their child's disabilities are severe (Cooke et al., 1987).

There remains a considerable gap in our knowledge in the area of blended families caring for children with disabilities. It is precisely this gap that this research proposes to start to fill.

The purpose of this study was to understand some of the main issues confronting blended families caring for children with disabilities. It was hoped that through analysis of the families lived experiences, some hypotheses could be generated. These hypotheses may provide future avenues of research in the area of blended families caring for children with disabilities.

It is important to address here the issues why this study focused on the primary caregiver. The main reason for this was that it was beyond the scope of this study to focus on both primary and secondary caregivers. It was also discovered that all primary caregivers in the study were the biological mothers of the children with disabilities. Thus, it was considered that the primary caregivers (mothers) would be a good starting point for research in this area. Additional reasons for choosing the mother as the sole focus also included the fact that she was most accessible for scheduling interviews and that she had a longer "lived experience" than the stepfather with the child with the disability.

CHAPTER THREE: THE PRELIMINARY STUDY

INTRODUCTION

There were essentially two phases in carrying out this research study: the preliminary study and the main study. This chapter deals specifically with the first phase of the research. It focusses on the preliminary study giving attention to how this was carried out and the data that was collected. Chapter five deals with the second phase of the study and examines the themes that emerged in the main study phase.

Before discussing the preliminary study, some comment is warranted on the rationale for proceeding with the research in two phases. The first phase, the preliminary study, was designed to give the researcher an opportunity to get sensitized to the research topic. The second phase, the main study, was designed to give the researcher an opportunity to generate hypotheses about the research topic. Using the tenets of "grounded theory" (Glaser & Strauss, 1967), the main study was carried out in an effort to generate substantive themes. With sufficient resources, a third phase of research could have followed the first and second phases. This third phase could attempt to verify theoretical propositions and tentative research hypotheses generated through phases one and two

(Glaser & Strauss, 1967).

THE PRELIMINARY STUDY

The preliminary study was conducted with one primary caregiver who was a voluntary participant. She was selected by a member of the thesis committee. The participant was a mother in a blended family. Although the participant did not care for a child with a physical disability, she did have a biological child with behavioral difficulties that she viewed as the "child with the disability". In the main study, all the identified children had a primary diagnosis of developmental delay. However, a primary diagnosis of developmental delay was not necessary for the preliminary study.

The preliminary study interview was essentially semi-structured and was tape recorded. Arising from the literature, some general issues were used in this interview to explore the topic area. Questions in the interview were made as general as possible in order to allow the participant maximum freedom in the way that she responded to them. The preliminary study interview lasted approximately two hours. After completion of the interview, it was transcribed and categorized.

CASE DESCRIPTION OF THE PRELIMINARY STUDY

This is a complex blended family where both parents bring children into the new marriage household. Mother, Pat, age forty-five years had been married for eighteen years before divorcing her first husband. Pat has three children from her first marriage. The oldest female, nineteen years, the youngest male, fourteen years and the middle male child, sixteen years who is identified as the child with the disability.

Pat's current husband Paul, age forty-six years, has two children from his first marriage: a female, eighteen years, and a male, sixteen years.

Pat and Paul live with all of their children except Paul's eighteen year old daughter, who lives with her natural mother.

Pat and Paul are of different ethnic backgrounds. Pat is from British ancestry and Paul is from Hungarian ancestry. Both have professional occupations and have been university educated. They have a combined yearly family income of \$70,000-80,000.

Pat identifies herself as the primary caregiver of her natural child Phil, age sixteen, the child with the disability. She identifies Phil's disability as behavioral in nature.

CATEGORIZING THE PRELIMINARY STUDY

The data obtained from the preliminary study interview, as presented here, has been arranged into categories (Glaser & Strauss, 1967). The data from the interview is organized into seven broad categories. These categories represent the central issues that were encountered by the primary caregiver in her experience in a blended family caring for a child with a disability.

The categories are as follows: family relationships; effects of the disability on the primary caregiver; primary caregiver fears; social networks for the primary caregiver; beneficial coping strategies; and finally, the primary caregiver's future outlook.

FAMILY RELATIONSHIPS

There appear to be strong relationships between the primary caregiver and her spouse, the primary caregiver and her biological children, the primary caregiver and her stepson, and the stepfather and his biological son. There also appear to be conflictual relationships between the stepfather and the child with the disability, the stepfather and the primary caregiver's biological children, the primary caregiver and her stepdaughter, the stepfather and his biological daughter, and the child with the disability and all his

siblings (natural and step).

No doubt one of the strongest relationships to emerge in the interview was the parent-child relationship. The primary caregiver continued to express her protection for her child with the disability throughout the interview. This protection that the primary caregiver felt had lasted throughout the child's life.

"I'm too overprotective of him [child with the disability], I've protected this child his whole life."

This strong bond and feeling of protection that the primary caregiver has for her child with the disability may affect other relationships in the family, specifically, the relationship between the child with the disability and his siblings. The child with the disability may be resented by his siblings because of the greater amount of attention he receives from the primary caregiver and the place he holds in his mother's life. The primary caregiver conveys these feelings of resentment held by siblings in the following manner:

"It has made it very difficult in the family because again, they [siblings] resent the attention he receives."

Blending older adolescent children in a family also may be quite difficult. It was evident from the interview that there was difficulty blending the primary caregiver's family with her spouse's family. The primary caregiver spoke about

the difficulty by saying:

"I'm not quite sure whether the older kids will ever really blend."

Relationships within this family seemed to cluster around the primary caregiver. She seemed to play a central role with all members of the family. She also identified herself as playing the central role in the family, "everyone comes to me, for a problem, for something, for everything," and "I'm usually the peacemaker in the family."

It appears as though the children and especially the child with the disability, play a significant role in the spousal relationship.

"There is a number of problems we [spouses] did not consider, like the inter-relationship between the kids and ourselves."

The primary caregiver identifies a conflictual relationship with her spouse that usually involves the children.

"We've had many arguments, and it's almost always about the kids."

"It's been difficult, I tend to get defensive of any criticism, whether it be constructive or destructive. I tend to protect him [disabled child] in an almost coalition - he and I."

The primary caregiver also identifies that time alone with her spouse is rare especially due to the time demands from the child with the disability.

"The children take up a lot of my energy, so time alone with my husband is rare... we haven't yet had a holiday alone together in 2 1/2 years due to him [disabled child]."

She does however, believe that her relationship with her spouse is close: "I think we are getting closer and closer between us, but it's a struggle."

Finally, the primary caregiver indicates that both her and her husband share in the decision making within the household, however, the primary caregiver makes the primary decisions regarding the child with the disability. This may further speak to the special relationship and to the over protection that the primary caregiver has with the child with the disability.

It was clear from the data in this interview that family relationships in a blended family caring for a child with a disability was an important category. Specifically, the data may suggest that:

- * The primary caregiver plays a central connection role with many of the members of the family.
- * The primary caregiver has a strong protective feeling towards the child with the disability.
- * Siblings of the child with the disability have resentment towards him because of the greater attention and greater amount of time he receives from the primary caregiver.
- * The children, especially the identified child, play a role in the spousal relationship.

* The primary caregiver has a very strong, protective relationship with the child with the disability that can interfere in the spousal relationship.

EFFECTS OF THE DISABILITY ON THE PRIMARY CAREGIVER

The interview with the primary caregiver shows the effects of the disability on her and the whole family has been tremendous.

"It's draining, it effects the family mentally, it's been very stressful. Things are serious all the time - I've lost my sense of humour."

The primary caregiver also feels she spends much more time with the child with the disability than any other member of the family.

"It's been difficult for all of us because he [disabled child] has taken most of my attention. Because he gets more things - attention wise."

She views herself as "taking on most of the responsibilities", in the household and as the "most stressed."

The data from the interview in this category may suggest:

* The effects of the disability on the primary caregiver is very stressful because of increased responsibilities and perhaps a need for the primary caregiver to overcompensate for the disability by spending large amounts of time with the

child with the disability and the need to overprotect this child.

PRIMARY CAREGIVER FEARS

The fears of the primary caregiver are important for the discussion in this category. The fears may speak to the experiences past and future for the primary caregiver and could lead to further exploration in the main study.

In this preliminary study interview, the primary caregiver identified two main fears when dealing with her past experiences. The first is her fear of dependency on her spouse:

"I don't want to be dependent again... If anything ever happened to my husband, like death, I don't want to be vulnerable again."

The second fear that the primary caregiver describes is the fear of being alone and having total responsibility of her children.

"One of my greatest fears [after my first marriage] was being alone and having sole responsibility of the children. I was the primary caregiver and I hadn't been working."

These fears may have led the primary caregiver to feel total responsibility for her children in the blended family and this may lead to her view of herself as the central person in the family and to increases in her responsibilities and levels of stress.

SOCIAL NETWORK FOR THE PRIMARY CAREGIVER

It is evident from the data that the primary caregiver's social network of friends, family and professionals are not significantly helpful to her. This may be because of the lack of development of these networks by the primary caregiver.

She does identify step parent courses and support groups taken prior to remarriage but indicates that they were not very helpful.

She indicates that there are no family members that are helpful or that she can count on:

"I have no physical support from family, my family live in another province, and my husband and his family are not close - he comes from a blended family also."

She also has a very small network of co-workers and no real network of friends.

"I go out with my co-workers more and we are developing friendships. It just so happened that when my spouse and I got divorced our friends ended up going to the other spouses and we were left with no supports."

The primary caregiver also indicates she has not encountered any professional group that could be helpful to her or her family presently. Data obtained in this interview, from this category may suggest:

* Perhaps small social networks or a lack of friendship networks for the primary caregiver can increase stress levels and inhibit stress relief because of inadequate or unavailable

supports.

* Family members are not available or supportive to the primary caregiver which may lead to increases in her level of stress.

* It appears that no professional group, or course is available to blended families caring for children with disabilities.

COPING STRATEGIES FOR THE PRIMARY CAREGIVER

Coping strategies are important for decreased stress and providing an avenue for relief for the primary caregiver. In this interview, the primary caregiver identified three main areas of coping that are helpful to her: talking to her spouse; going out with her spouse and co-workers; and taking time out for herself, for example, taking hot baths and walks.

In the interview, the primary caregiver identified her spouse as the biggest resource and source of support for her.

"He is very optimistic and when I'm down he boosts me up, he is my biggest source of support to me."

The data in the interview from this category may suggest:

* Spousal support is a major resource or source of support for the primary caregiver.

* Spousal communication, socializing out of the home, and having personal time alone may also decrease primary caregiver stress and increase primary caregiver coping.

FUTURE OUTLOOK FOR THE PRIMARY CAREGIVER

The primary caregiver's outlook for the future is important in respects to her perception of herself and her family. Future hopes may speak to successful coping strategies and a positive self perception.

The primary caregiver in the interview was very hopeful about the future. She expects a long, positive relationship with her spouse and children and sees herself as always being protective of her children and especially her child with the disability.

The data from this interview category may suggest that:
* The primary caregiver has a positive outlook for the future which may decrease her perception of the stresses she experiences or may increase her coping abilities.

SUMMARY OF THE PRELIMINARY STUDY

The preliminary study was designed to carry out seven objectives deemed necessary by the researcher before conducting the main study. The main objectives of the preliminary study were as follows: to identify the approximate length of time for each interview; to identify what the main issues were for blended families caring for children with disabilities; to test if the interview questions were open to participant responses in the best way possible in order to

tell their stories; to modify any questions that were irrelevant or not understood by participants; to give the researcher a chance to conduct preliminary analysis to further understand and practice grounded theory approaches; to give the researcher the opportunity to organize the data in appropriate categories; and finally, to give the researcher an opportunity to further explore categories found in the preliminary study, in the main study. All objectives set out for the preliminary study were achieved. The researcher's questionnaire was modified according to data obtained in the preliminary study. And the researcher was ready to collect data in the main study according to the themes found in the preliminary study.

CHAPTER FOUR: METHODOLOGY

INTRODUCTION

This chapter focusses on the way that the main study was designed and carried out. Contents of this chapter include: the research design, sample selection, interview process, data collection procedures, data analysis procedures, ethical considerations, discussions on validity and reliability of the study, discussions on combining qualitative and quantitative methods used in the study, a description of the grounded theory approach, and a discussion on accessing families in the study.

SAMPLE SELECTION

The goal of the research was to have as many participants as possible in the study. However, gaining large numbers of subjects was not necessary for statistical comparisons as this was not the purpose of the study.

The participants for the study were identified by Family Services (Children's Special Services) through a computer search of families that were remarried and had at least one child with a disability. Specific requirements for all families were as follows: at least one spouse was involved in

a second marriage or common law relationship; at least one spouse had a child with a disability, from their previous marriage living with them permanently; and the child had a physical or behavioral disability.

All families that wished to participate in the study and fit the requirements became participants in the study.

All children in the main study had a primary diagnosis of developmental delay, however, for the preliminary study, this primary diagnosis was not required.

INFORMED CONSENT PROCEDURES

As respondents committed to participate in the study, several procedures were necessary to ensure that confidentiality was protected.

Respondents who met the criteria of the study were given a letter which invited them to participate (see Appendix A). This letter described the nature of the study and the kind of commitment that was required of them. In addition there was a letter from the Children's Special Services Co-ordinator, Mr Richard Asselin, which was intended to help legitimize the study (see Appendix B). These letters directed the respondents, if they were willing to participate, to return the participation form (see Appendix C) directly to the researcher. Once the form was received, the researcher could make contact with the couple in order to set up an interview.

Once the couple agreed to participate in the study, it was necessary to protect other processes of confidentiality. In this regard, participants were assured that their names and responses would be kept in strict confidence.

It was also necessary to inform participants that the research was conducted independently from the agency and that services were not dependent on their participation or responses and that their participation was totally voluntary. This was stated in the initial phone contact to participants and in the consent forms (see Appendixes D and E).

In addition, it was necessary that the researcher acknowledge a number of ethical considerations. The following are a list of considerations that the researcher identified prior to conducting the study:

1. The researcher will actively enter a personal relationship with the participants. The researcher becomes party to participants' intimate thoughts and feelings and therefore must ensure anonymity and confidentiality.
2. The researcher will give the participants the opportunity to refuse to discuss any issues that are too uncomfortable to discuss.
3. The researcher will read all informed consent forms and answer any questions prior to the interview.
4. If participants express an interest in obtaining a copy of their transcripts or audio tapes, the researcher will comply with their requests.

5. The researcher has a responsibility to the families to respect the families' boundaries of privacy.
6. The researcher must make clear to participants their research role.
7. The researcher is aware of the possibility of inherent power imbalance between researcher and participant and is conscious of unanticipated self-exposure.
8. The researcher has a responsibility to inform participants of the results of the study.

THE INTERVIEW

All individuals who were willing to participate in the study were contacted by the researcher over the telephone and interview times were scheduled. All interviews were conducted within the participants' homes and were completed within two weeks after receiving all participant consent responses from families.

Prior to the interview, the researcher read the consent forms to the participants and answered any questions concerning the study. All participants were fully aware that they would be subjects in the study and gave consent to participate. Participants were also made aware by the researcher that the study and their participation in the study had no bearing on present or future assistance at Children's Special Services.

In addition the researcher requested consent from the participants to audio tape the interviews, explaining that after the interviews had been transcribed, the tapes would be destroyed. Participants were told that the researcher would not audio tape any interviews participants did not want to be audio taped. In these cases the researcher would take written notes of the interview.

Participants were also told that they would not be identified by their real names in the study and that their identities would not be determined by anyone except the researcher who would shred all identifiable information upon completion of the study.

During contact with the participants, the researcher explained that the oral interviews would take place only with the primary caregiver of the child with the disability and that the primary caregiver would also be required to complete a Family Assessment Measure questionnaire (see Appendixes F, G, H and I). It was further explained that the entire interview would consist of a minimum of two hours and may require a follow-up interview. During contact with the participants, the researcher also asked the secondary caregiver to complete a Family Assessment Measure questionnaire (see Appendixes F, G, H, and I) which required approximately half an hour of his time.

Interviews consisted of a series of questions and probes designed to encourage participants to reflect on significant

life events, transition points, and family experiences in the past, present and future. In the preliminary and main studies there were several exploratory areas where questions originated: the role the disability played in the family; understanding the blended family unit; family dynamics / interactions; primary caregiver stressors; resources for the primary caregiver; and the future outlook of the primary caregiver.

Following the interview, participants had another opportunity to ask any questions about the study and were informed by the researcher that a summary of findings would be mailed to all participants after the study had been completed. Feedback would be approximately 1-2 pages, outlining the major findings of the study.

The researcher transcribed each interview immediately following each interview and all files and tapes of interviews were secured in a locked cabinet by the researcher.

DATA COLLECTION PROCEDURES

All interviews were audio-taped using a small recorder placed in close proximity of the participants. Transcription for all interviews were conducted only by the researcher using literal transcription. This included repetitions, asides, and other utterances. Doing the transcription led to a greater understanding of the data, and was helpful for the

categorization of the data.

The combination of open-ended questions and probes for additional information provided the researcher with a valuable balance between respecting the participant's perspective and allowing the researcher to pursue theoretically relevant topics. The questionnaire (see Appendix J) consisted of a series of questions designed to encourage participants to tell their stories (i.e., what is it like to be in a blended family caring for a child with a disability?). The semi-structured format allowed participants to take the interview into areas of individual and family life not anticipated by the research protocol. The researcher collected, coded and analyzed data simultaneously. Data from one case provided guidance for data collection for the next cases. Also all field notes were expanded into narrative form.

The researcher documented emerging themes over the course of the study and commented on the dynamics of the families. Each individual participant was considered a separate data source. Comparisons took place among all the individuals' experiences.

From the literal transcription of interviews and line by line coding of the data (see Appendixes K and L) emerged key issues and eventually categories of interests emerged. Incidents of these categories were collected with emphasis on the diversity of data within categories. The researcher tried to distinguish between generalizing from categorized data and

awareness of the uniqueness of individual experiences.

The relationships between categories were also identified and analysis and discussion centred around those that were most significant. This also gave the researcher an opportunity to generate hypotheses and patterns, which will be discussed in detail in chapter five.

In addition to the qualitative data gathered from the interviews, quantitative data was analyzed from the FAM III questionnaire according to FAM III guidelines (Skinner et al., 1983). FAM III descriptions and interpretations are discussed in chapter four. The use of both qualitative and quantitative techniques were used in the research in order to further understand the experiences of blended families caring for children with disabilities.

DATA ANALYSIS

There is an ongoing process between data collection, identification of themes, coding and analysis in qualitative research (Glaser & Strauss, 1967).

The majority of analysis actually occurred after this researcher had left the field of study. Some analysis obviously did occur during interviews for example, decisions regarding which themes to concentrate on, how to structure probes, and so forth. However, the detailed analysis for conceptualization occurred after interview data was collected,

transcribed and coded.

The data in the main study consisted of four complete transcripts of the four primary caregivers, eight FAM III coded forms, and the researcher's analytic memos that were written during and after the course of the research. The memos were an attempt by the researcher to document personal reactions to participants, study processes, emerging themes and comments. There were approximately eighty pages of transcribed interview data, and twenty pages of analytic memos. This data was then categorized using line by line analysis. Identification of major categories emerged and were documented as themes on cue cards. The cue cards served as a sorting mechanism and individual interview data was placed on these cards according to the major categories.

The method of analysis the researcher used to arrive at the major categories was the grounded theory method described by Glaser and Strauss (1967). The researcher considered each individual interview a separate data source. This method supported the researcher's focus on key themes that emerged from the data which later became categories of interest. Relationships between categories were then identified and the most significant categories became the major categories.

This approach was most useful to the researcher as it enabled a detailed analysis of each individual's experiences and also examined the similarities and differences between each individual's experiences.

FAMILY ASSESSMENT MEASURE III PSYCHOMETRICS

The Family Assessment Measure (FAM) is a self-report questionnaire that measures family strengths and weaknesses (Skinner et al., 1983). There are three components for the FAM: 1) A general scale, 2) a dyadic relationship scale, and 3) a self rating scale. Each scale provides different information on family functioning. For purposes of this study, the General Scale was used and interpretations of FAM profiles for the families are given according to the FAM Interpretation Guidelines. The general scale examines the family as a system and takes approximately thirty minutes to administer.

The FAM is based on a Process Model of family functioning that integrates different approaches to family therapy and research (Skinner et al., 1983). The FAM III was designed to provide more differentiated information about family functioning than the FAM and FAM II (Skinner et al., 1983). The General Scale of the FAM III consists of 50 items and 9 subscales. The subscales are as follows: task accomplishment, role performance, communication, affective expression, involvement, control, values and norms, social desirability, and denial. The last two (social desirability and denial) are response style subscales. The first seven subscales provide an overall rating of family functioning.

The General Scale examines the level of health-pathology in the family from a systems perspective (Skinner et al.,

1983). Skinner et al. (1983) estimate the General Scale overall rating reliability for adults to be 0.93 and for children to be 0.94. These figures are internal consistency reliability estimates.

Skinner et al. (1983) indicate that reliability estimates consider sources of measurement error at one point in time. These can include emotional reactions, attitudes or habits that are specific to the situation at the point of testing. They further indicate that FAM profiles can not in and of themselves identify which critical aspects of each construct are a strength or weakness, rather the FAM gives an overview of family functioning and identifies areas of potential difficulty for further assessment.

Skinner et al. (1983) conclude that "empirical analyses have shown that FAM scales are quite reliable and they significantly differentiate between problem and non-problem families" (p. 104).

VALIDITY AND RELIABILITY

According to research methodology, reliability has to do with consistency and repeatability of findings (Gilgun, Daly & Handel, 1992). Findings are judged reliable when they are consistent across subjects, observers, and settings. In this research study, the researcher observed multiple participants in multiple settings.

Reliability takes on meaning when coupled with validity. The concept of validity arises from the difficulty of actually measuring what we think we are measuring (Gilgun et al., 1992).

The array of data and data sources based on interviews and direct observation provides rich in-depth information on the blended family experience with disabled children. The findings that emerge from these multiple sources will be judged more valid than those findings from a single source. Multiple forms of data provide validity checks. This research used both interviews (qualitative data) and the Family Assessment Measure questionnaire scores (quantitative data) as multiple data sources.

The researcher attempted to develop a semi-structured questionnaire in order to establish consistency in the experiences of participants. Thus, it served the purpose of allowing participants to tell their stories in their own way, however, it was structured in that the interview allowed the researcher to ask questions and gather information on certain specific study areas for consistency purposes.

The researcher recognizes that interview data is subject to participants' memories and perceptions. Some participants may need to present favourable views of themselves and their families, this may compromise reliability.

The researcher in this study was also the interviewer and the coder of interview data. The researcher assessed and coded

the interview data at three different times to determine if the same results were obtained on all three occasions. The researcher found that the same themes and categories emerged on all three occasions. The researcher is aware that some level of subjectivism when interpreting data may taint the way phenomenon are seen. Still, the researcher believes that a high level of validity is reached by getting close to a participants' subjective experiences.

The danger of subjective distortion of the data with the subject matter is perhaps more likely to colour the way that one sees a phenomenon. In such circumstances, the way that the researcher reports on findings may be more a reflection of the researcher's experience, than that of the subject. However, in doing research such as this, that seeks to understand the meaning that certain phenomenon hold for people in their lives, there is some suggestion that objectivity is most successfully achieved as the researcher gets closer to the phenomenon under study (Blumer, 1969). Blumer (1969) suggests that the best method for achieving objectivity is not for the researcher to distance himself, but to surrender himself to the phenomena that he wishes to understand. Only when the researcher gets close enough so that the phenomena can reveal itself to him, is he "being adequate to the object."

ADVANTAGES OF COMBINING QUALITATIVE AND QUANTITATIVE METHODS

The strength of qualitative data lies in its richness and depth. Qualitative methods also have theory generating capabilities. With standardized questionnaires, researchers can argue that reliability is more adequately achieved.

Quantitative data reduce social and family processes to numbers which often is not useful to the researcher wanting to understand meanings and experiences of participants. Quantitative data often does not capture the overall context and underlining mechanisms of events. Finally, biases may exist on how participants respond to standardized questions. Thus, quantitative data is strong in reliability, however, its validity may be questioned.

There are definite advantages in combining these two methods. Qualitative and quantitative analyses may be complementary depending on the research questions. Additionally, the two analytical perspectives may often grasp at "different aspects of reality" (Gilgun et al., 1992).

The researchers decided to integrate both qualitative and quantitative methods in this study in order to increase validity of results with the integration of these two methods. Thereby, enhancing the research findings.

It was also thought, by the researcher, that if results were contradictory with each other it would push the

researcher further to probe and question such discrepancies and this may redirect research processes to a more accurate direction.

Finally, other authors agree that there are definite advantages integrating qualitative and quantitative methods. These include "strengthening of the research design and analysis through their complementary nature, greater acquired insight, enhanced validity, and the potential for redirecting the inquiry in positive and fruitful directions" (Gilgun et al., 1992, p.298).

THE GROUNDED THEORY APPROACH

Grounded theory is a qualitative methodology developed by sociologists Glaser and Strauss in 1967. This method has recently been explicated by Strauss (1987), Corbin (1986) and Strauss & Corbin (1990). However, grounded theory methodology has had limited use by investigators researching families (Gilgun et al., 1992).

Grounded theory methods use a systemic qualitative analysis derived to elicit substantive and formal theory from data. The goal of this method is the development of conceptually dense theory. Strauss had written that grounded theory analysis can be used with any form of data collected. It is mostly used by researchers that have data from interviews, biographies, documents, observations and

historical sources (Strauss, 1987).

In research studies where grounded theory is used, concepts and hypotheses are derived from data and verified in the data. The researcher does not enter the study with preconceived hypotheses however, it does not prevent a sensitized view about the nature of research. Thus, grounded theory studies do not begin with hypotheses to test but rather, are used to develop concepts based on data and to develop hypotheses grounded in data (Gilgun et al., 1992).

With this methodology, questions based on "a coding paradigm" help the investigator label relationships among concepts. The coding system assists investigators to search for interactions, strategies, conditions and consequences (Gilgun et al., 1992).

The first step in attempting to understand the data is to determine the one or more story lines arising in any one interview session. Once a story line has been identified, the researcher can pursue any analytical path available within that story line and begin coding the data. Partitioning interview data first into story lines they comprise permits an open-coding approach; the same story or elements of the same story may be differently interpreted and used in pursuing different analytical paths. This approach allows meanings and explanations to emerge from participants rather than from preconceived ideas of researchers (Strauss & Corbin, 1990).

ACCESSING FAMILIES

The structure and processes of the family are unlike any other group because of the biological ties, commitment and attachment of members.

Perhaps the most fundamental methodological difficulty was the collection of data from a group that so highly values its autonomy and privacy. For the researcher seeking to gain access to family life, this ideology of privacy can manifest itself in silence. For those activities or areas of family that are highly private, access to information is very difficult.

By contrast, families also have a public side that they present. This is an attempt to present the image that everything is fine within the family. The researcher frequently has access to a family's public sphere.

The area of blended families caring for children with disabilities has numerous private aspects of family life. Some of the private aspects may include: reasons for the breakdown of the first marriage; problems encountered with blending families together; coping difficulties of the primary caregiver; and difficulties experienced with the child with the disability within the blended family structure.

For most couples who agreed to participate in the study, it seemed that they valued the opportunity to talk. This was evidenced by statements made at the end of the interview which

reflected the importance of the discussion for the participants. It was not uncommon for primary caregivers to say things like "We've talked about some things here tonight that I've wanted to say but never have" or "It was good to talk about this tonight."

Another indication of the value that was placed on the interview was the amount of time participants devoted to it. The average length of time for the interview was two and a half hours and some spent more time talking about their experiences. In many cases, primary caregivers spent time after the formal interview was finished describing other experiences they had had. In some instances, these last minute revelations constituted some of the most interesting and intimate data. It may be that an interview on sensitive family issues gives a family an opportunity for emotional catharsis which is rewarding to them.

Ironically, when it comes to highly personal issues, some people are more comfortable talking to a stranger with whom there is little possibility of future interaction than with close friends and relatives. This became particularly evident when the tape recorder had been shut off at the end of some interviews. Many of the primary caregivers indicated that they had never talked about some of these things with their spouses or with close friends or family members.

Playing the role of objective stranger/researcher (Simmel, 1950), can have adverse affects. Simmel (1950)

indicates that the researcher and the subject operate from a common understanding, there may be a tendency to take too much for granted. This can serve to inhibit the flow of data in two ways. First, the researcher may overlook certain aspects of the subject's reality because of her presumed familiarity with the topic area. The result may be blindness to certain details that might be important. Second, persons may withhold information because it is seen as too obvious to the researcher. In these situations, where the participants assumed that the researcher was "in the know," it became important that the researcher encouraged the participant to continue by saying "I'm not really sure what you mean, could you explain". At least in these situations, there was an opportunity to tease out what it was that was taken for granted.

Considerably more disconcerting, however, was the possibility that subjects did not say certain things because they felt they were insignificant or too obvious to the researcher. In this regard, there may be an indeterminate amount of data that was lost.

Another potential disadvantage is the likelihood of introducing bias into the research. Personal experiences may colour perception. It is impossible to avoid some level of subjectivism when recording and interpreting data.

CHAPTER FIVE: THE MAIN STUDY

INTRODUCTION

This chapter specifically deals with the second phase of this research study and examines the process of how themes emerged.

The main study was essentially semi-structured, exploratory and qualitative. It served as a means for sensitizing the researcher to the social reality of blended families caring for children with disabilities and was the basis for identifying the issues that were considered most salient for primary caregivers. This approach allowed for the emergence of various themes and categories. From the themes described in this chapter, hypotheses were generated and are discussed in chapter six.

The people who provided the data for this second phase of the research consisted of four primary caregivers and their spouses. Although the backgrounds of each of the couples was not exactly known beforehand, the four couples who were participants did represent a range of circumstances. For example, the amount of yearly family income ranged from \$20,000 to \$80,000. Also, ethnic backgrounds and levels of education of participants were diverse. In addition, participants had a variety of ages and different social

backgrounds.

Following the principles of grounded theory, issues, concepts and categories were allowed to emerge from the interviews. In other words, this study did not set out to "prove" a set of pre-determined hypotheses. In order to identify those phenomena that were considered most important by the primary caregivers themselves, it was essential to avoid using formalized questionnaires and variables that might interfere with the more spontaneous emergence of these phenomena. Instead, a semi-structured format was used so that recurrent phenomena that emerged in the data could be identified and categorized. This is the essential nature of generating "substantive theory" which focuses on empirical or substantive issues, rather than conceptual or formal theoretical ones (Glaser & Strauss, 1967).

Of course, it is never fully possible to enter into such a situation without any sense of direction. Collecting data from a grounded approach is essentially an emergent process, which in this instance, began with the literature reviews and the preliminary study interview. Arising out of the preliminary interview were some general issues that were used as a basis for guiding the line of questioning in the main study interviews.

Questions used in the interview were made as general as possible in order to allow the primary caregivers the maximum freedom in the way that they responded to them. In addition,

other questions which were even more general were asked in order to allow primary caregivers to identify for themselves the most salient aspects of their experiences.

Interviews in the main study were tape recorded and later transcribed. All interviews lasted an average of two to three hours.

GENERATING SUBSTANTIVE THEORY

The data from the interviews in the main study, as they are presented here, have been subject to substantive analysis. They have been arranged into categories (Glaser & Strauss, 1967), each of which included descriptions of the cases. Empirical data are therefore included in order to illustrate these substantive categories. The primary aim for including this data is twofold, first to present a comprehensive picture of blended families caring for children with disabilities, particularly from the primary caregiver viewpoint. And second, to show the "grounded" roots of theory. In this respect, the emergence of these substantive categories has both methodological significance and theoretical significance because they are the building blocks for constructing the formal theory that could be tested in another research study. Hence, the primary significance of the substantive categories, as they are outlined in the following chapter, suggests hypotheses that another study could follow.

In this chapter, each of the four interviews will be presented using the following outline. First, a brief description of the family is given to give the reader a synopsis of what the family looks like. Second, the results of the FAM III completed by both spouses are illustrated. And third, the categories that emerged in the interviews with the primary caregivers are described. These three sections are presented for all four interviews sequentially. In chapter six, the researcher will provide an analysis of categories and themes that encompass all four interviews together along with the researcher's hypotheses.

CASE #1 - DESCRIPTION

This is a simple blended family, where children from only one spouse live permanently in the reconstituted household.

The mother, Ann, age thirty-three, has two children from her first marriage: a nine year old female and an eleven year old male, who is identified as the child with the disability. Ann was together with her first husband for six and a half years before divorcing. Ann's first husband later died at the age of thirty-four.

Ann's second husband, Adam, age twenty-six, also divorced his twenty-four year old wife. They have a male child, age seven, who currently lives with his biological mother.

Ann and Adam have been together for five years and have

a mutual female child, age three. Ann and Adam have similar ethnic and educational backgrounds. Both have completed high school. Their combined yearly family income is \$30,000-40,000. Ann is a full time mother and Adam is a blue collar worker.

The child with the disability, Andrew, age eleven, has Cerebral Palsy along with a primary diagnosis of developmental delay. The primary caregiver, Ann, identifies him as requiring total care now and in the future.

FAM INTERPRETATION ON CASE #1

(see Appendix F for FAM profile)

The mother's score on the defensiveness scale was 35, which is a low score and indicates that there may be slight distortions in her test. If there is any distortion in the mother's responses, they will be slightly inflated in a negative direction. The stepfather's score on defensiveness was within the normal range. Both spouses' scores on the social desirability scale were also within the normal range.

The stepfather's scores on task accomplishment and role performance are close to the family problem area which may indicate that he is not satisfied with how basic tasks are identified and accomplished in the family. In addition, he may feel there is insufficient role integration, lack of agreement regarding role definitions and/or an inability to adapt to new roles in the family life cycle.

In the areas of affective expression and involvement, both spouses are within the normal range and seem satisfied. However, the stepfather's scores are consistently lower than the mother's scores which seem to indicate that he may be more negative in his assessment than the mother.

There are two areas where the mother's scores cross over the stepfather's scores. These are on the communication and control scales. On these scales the mother identifies that communication and control are family problem areas. These are the only times where the mother appears more negative than her spouse.

Both spouses scored above 60 on the communication scale which would indicate that both agree that communication is a problem in the family. According to the qualitative data, communication between spouses may be insufficient, displaced or masked due to the lack of time spouses spend together.

Spouses also show cross over scores on the control scale. Here the mother identifies this area as a family problem and although the stepfather's scores are within the normal range, they are close to the problem level and therefore congruent with the mother's scores on this scale.

According to the qualitative data, the mother identifies herself as the primary disciplinarian and decision maker within the family. This may contribute to her perception that she may need to exert her authority to have control within the family.

The area where spouses have diverse perspectives is on the values and norms scale. The stepfather identifies the area of values and norms as a family problem, while the mother identifies the area within the normal range. This may show different spousal perceptions and may represent a conflictual area.

According to FAM guidelines, the stepfather's scores may show components of the family's value system as dissonant resulting in confusion and tension. There may be conflict between the family's values and those of the culture as a whole; explicitly stated rules may be subverted by implicit rules; and/or the degree of latitude may be inappropriate. Since there is no qualitative data on the secondary caregiver, the researcher cannot verify and interpret his scores further but can only assume from his FAM scores that he perceives a problem in the area of values and norms.

Therefore, both spouses agree communication is a problem, they see control as being of concern and widely differ on task accomplishment, role performance and values and norms.

CASE #1 - THEMES

FAMILY RELATIONSHIPS

The primary caregiver and the child with the disability have a very close relationship. The primary caregiver describes a strong bond that exists with her child with the

disability that is not there with any of her other children.

"We had a very, very close relationship when he [disabled child] was really little, very close, very unique bond... I don't have it with the other kids... And it was there from the very beginning with him [disabled child]."
(INT 1-3-22-27)

The primary caregiver and the other children (natural and step) also have a good relationship with one another, however, the primary caregiver admits that she spends much more time with her child with the disability than anyone else in the family. She does indicate that she tries to survive by adapting to the children's needs, instead of dividing time equally because there are different needs for the different children.

"...their [all her children's] needs are so different and unique, which is one of the things that helps us survive in this house is being very aware of the differences. And adapting to those instead of dividing your time so equally among them to compromise in that respect to the disability. You treat them all very uniquely, and what arises, arises and who's ever needs are greatest at one moment wins out." (INT 1-9-28-34)

Andrew and his siblings (natural and step) have a distant relationship. They seem to have mutual resentment towards one another. They also do not play or spend much time together. The primary caregiver describes the sibling relationship as follows:

"When she [sibling] got close to him [disabled child] physically, he would scream... that's

how resentful he was ... when you got someone screaming at you any time you go near them, you stop going near them so she [sibling] learned to stop going near him [disabled child]." (INT 1-4-1-5)

"Both my girls are fairly distant from him [disabled child]" (INT 1-8-51)

The stepfather, Adam, has a difficult relationship with his stepchildren. They seem to accept him as a permanent figure in the home, however, there is some grieving for the natural father. He does have a fairly good relationship with Andrew, however, he has a tendency to get frustrated with the disability. The primary caregiver describes their relationship as follows:

"I have to deal with some of his [husband's] frustrations about the disability because he's been dealing with the frustrations only for five years and I've been dealing with him [disabled child] over eleven years." (INT 1-5-49-52)

The primary caregiver also indicates there are lots of external forces that affect the marriage. She feels that although time alone with her spouse is rare, the struggles of being in a blended family have made her marriage stronger.

"It's made us stronger. We've dealt with more in the last five years than most people go through their whole life." (INT 1-8-9)

ALTERNATIVE CARE

Although the family experiences many frustrations, they are not willing to consider alternative care at the present

time. The primary caregiver occasionally thinks about alternative care because of the child with the disability's attitude. She indicates that as Andrew grows he gets more difficult to deal with and progressively more stubborn. Alternative care for the child with the disability would only be considered if the mother's physical limitations caring for Andrew and trying to care for the rest of the family were severely impaired.

PARENTING STYLE

Most of the disciplining and decision making in the family is done by the primary caregiver, especially in regards to care of the child with the disability. The primary caregiver describes how she usually ends up making final decisions:

"I usually state my point of view and he [spouse] negotiates his, I'm a better debater than him and he doesn't like to argue." (INT 1-7-43-47)

TRANSITION FROM SINGLE PARENTHOOD TO REMARRIAGE

The primary caregiver indicates when she was dating, her children screened out most of her dates. She indicates that it was difficult caring for the family as a single parent with little assistance.

"His [disabled child] disability screened out a lot of people. When you're suddenly a single parent again - it's a tough situation to be in, you meet a lot of guys that are only after one thing... but kids alone can weed out some of them, a lot of guys will run the other way.

But when you add in the disability, they run a lot quicker, and a lot faster." (INT 1-6-1-13)

The primary caregiver feels that it was difficult letting someone take over the parental role and disciplining of her own children, however, it was less stressful dealing with the responsibilities of children, finances and household care in a two parent family.

"It's less stressful when you are two people dealing with children than one person. When you're a single parent you deal with everything on your own." (INT 1-8-15-18)

It was also interesting to find that the primary caregiver's decision to remarry was not based solely on her own feelings but also on her children's feelings.

"I decided to remarry because the kids got along great with him [spouse]...my daughter had full say in him moving in." (INT 1-6-38)

EFFECTS OF THE DISABILITY ON THE FAMILY

The primary caregiver indicates that there are lots of frustrations caring for the child with the disability that the whole family goes through and lots of places that the family is prevented from going due to the disability. However, she seems to feel that it is part of daily living and it is now a natural routine.

"It's affected us quite a bit... there's a lot of things we can't do... we're more restricted..." (INT 1-2-39-44)

The primary caregiver also indicates that her spouse is

the most stressed because he hasn't dealt with her child with the disability as long as she has. She also thinks that her spouse seeks to fix things in the family but that he can't fix the child's disability, which leads to greater frustrations on his part.

STRESS ON THE PRIMARY CAREGIVER

The primary caregiver believes that she is the central person in the family and that "most things revolve around me". She feels she has a lot of emotional/mental stress that is long term. Her stresses are also in part due to the frustrations with her child's disability.

"A lot has to do with the frustrations involved with him [disabled child]...lots of frustrations with his attitude because of the disability." (INT 1-4-23).

RESOURCES

The primary caregiver has no family support from her family of origin or from her spouse's family of origin. She also feels she has very few friends she can count on for assistance, and that there are no professionals that have been helpful to her in the past. She indicates that she does not socialize out of the home very much.

"We don't do much socializing. We don't have a social life." (INT 1-12-32)

She does feel that respite has been helpful and that her biggest support is her spouse.

"He's the shoulder I lean on, he is my sounding board, a shoulder to cry on. He is definitely my biggest resource." (INT 1-12-37-40)

COPING STRATEGIES FOR THE PRIMARY CAREGIVER

The primary caregiver feels that when she is most stressed, it is helpful for her to sleep, as well as to sit and talk with her spouse.

"You do whatever it takes to alleviate stress... going to sleep...getting out of the house...sit and talk...it's just your normal everyday whatever works." (INT 1-12-3-8)

FUTURE OF THE FAMILY

The primary caregiver has a positive outlook on the future. She hopes that her children will grow independent, and that her child with the disability will participate more in the family, community and society.

LEARNED FROM THE EXPERIENCE

The primary caregiver seems to feel that she has learned to "trust and let go" and "trust her spouse more". She also seems to feel that "the disability has brought a uniqueness to the family as a whole". She believes her family is just a normal family.

"The disability brings in a uniqueness of it's own in some respects but then when you go beyond that it's no different from anyone else." (INT 1-13-40-42)

CASE #2 - DESCRIPTION

This is a complex blended family, where both spouses' children live together in the reconstituted common household.

Barbara, age twenty-nine, and her thirty-two year old husband from her first marriage had a seven year old girl, Betty, who is identified as the child with the disability. Barbara stayed together with her first husband for three and a half years before divorcing him.

Ben, age thirty, is Barbara's second husband. He has an eight year old son with his first wife, age twenty-two.

Barbara and Ben have been married for two years and have no biological children together. They live together with Barbara's child, Betty, and Ben's eight year old son.

Both Barbara and Ben have similar ethnic and educational backgrounds. Both completed high school. Both are employed outside the home and have a combined yearly family income of \$70,000-80,000.

Along with a primary diagnosis of developmental delay, Barbara identifies Betty's disability as Down's Syndrome. Barbara feels that Betty will require twenty-four hour care in the future.

FAM INTERPRETATION ON CASE #2

(see Appendix G for FAM profile)

Both spousal scores are below 40 on the defensiveness scale which may indicate a slight response style bias. If there is a distortion in the couples' scores it will involve some inflation in a negative direction. Social desirability scores are within the normal range for both spouses.

The FAM profiles of both mother and stepfather show that they perceive significant family problem areas. Both spouses scored in the family problem area on the majority of scales.

On task accomplishment and role performance, the stepfather's scores are on the boarder of the family problem area, however, the mother's scores on these scales are within the normal range which indicates they have divergent perspectives. Since the mother has a favourable view on these scales, there may be things going on in the family in which her husband knows about and she is unaware of, or she may be aware of some of the problems and may feel she is coping well or doing the best she can at this time.

Both spouses indicate and recognize there are family problems areas in communication, affective expression, involvement, control and values and norms.

The couple is fairly congruent in their profiles and share a perception that there are many problem areas. They have cross over areas on communication, involvement and values

and norms. This indicates that they agree that these areas are problem areas but vary in their perceptions of how strong the problems are in these areas.

The FAM profiles of both spouses indicate that they have serious problems and that things are not getting accomplished in an adequate manner in the family. This is consistent with the mother's qualitative data where she indicates that she was recently separated from her husband because of their many family difficulties. Also found in the qualitative data was the indication from the mother that she lacked spousal support and that this lack of support was the main factor that led to the separation. Other significant factors that led to the separation was the mother's inability to balance the needs of her child, her own needs and the needs of the marriage.

CASE #2 - THEMES

FAMILY RELATIONSHIPS

The primary caregiver and the child with the disability have a very close relationship. The primary caregiver indicates that she is very protective of her child.

"I'm so used to this child that it doesn't matter whether we are on our own or in a blended family or what - as long as I get my space to do what I need to do for her..." (INT 2-4-26-31)

"I felt very protective when intervening between her [disabled child] and him [stepson]." (INT 2-9-8)

The primary caregiver and her stepson have a distant relationship with each other. Also, the stepfather and the child with the disability have a distant relationship. The mother indicates that the stepfather does not accept the child's disability.

"He [spouse] just started resenting her [disabled child]. I wouldn't say resenting her but resenting the disability." (INT 2-6-48-50)

The child with the disability and his sibling do not have a good relationship, they seem to resent each other and do not play together.

The mother and the stepfather have a strained relationship. The mother feels that they have difficulty in their relationship because her spouse does not accept her child's disability and seems to resent the child because of her disability. She further indicates that time with her spouse alone is rare.

ALTERNATIVE CARE

The mother does not find it difficult to maintain her disabled child at home and feels that her child with the disability will be in an independent living arrangement only when she [disabled child] is ready for it. The primary caregiver says she has days of frustration but has good supports that keep her on track.

"...the transition to go from home to alternative care will be when I feel and

resources that work with her can come to a mutual agreement... so if she is ready and gained a lot and can function in a group home, I wouldn't take that away from her - it's my goal for her ... something she can be successful at." (INT 2-5-3-15)

PARENTAL STYLE

The primary caregiver and her spouse discipline their children separately. They discipline only their natural children. Barbara also indicates that decision making is shared. She indicates that Betty's natural father is not involved in their lives at all.

"He [spouse] deals with his son and I deal with my child... when it came to my child, I make all the decisions." (INT 2-8-2-7)

TRANSITION FROM SINGLE PARENTHOOD TO REMARRIAGE

The primary caregiver felt that it was hard to date when she was single and that "men don't readily accept a women with a disabled child". She also feels that working within the system is difficult as a single parent, however, there is more freedom on a personal basis.

"I was lacking in companionship... all the men could accept me but they couldn't accept my disabled child... maybe it was fear... she comes with a lot of added responsibility and it scares people out of ignorance." (INT 2-6-20-28)

The primary caregiver felt that the transition from single parenthood to remarriage was difficult. She indicates that she tried to balance the needs of her child with the needs of the marriage but that it was hard to organize

herself. She felt that her child with the disability did not want to share her with her spouse which made the transition difficult. She also felt that she did not have a foundation with the children prior to the marriage and that both herself and her spouse did not have the tools to make a smooth transition.

EFFECTS OF DISABILITY ON FAMILY

The primary caregiver indicates there were many emotional effects with the child with the disability's hospitalizations and with her spouse not understanding the effects of her child's disability. She indicates marital strain due to the effects of the disability and resentment from her spouse towards her child with the disability.

"What I did try to do was make a balance where her [disabled child] needs were being met and the marriage needs were being met... I couldn't give the marriage what it needed, my spouse was having a lot of difficulty with the disability... I lost my balance..." (INT 2-5-25-38)

"The blended family was hard enough with the normal kid and then we had the blended family with the child with the disability and that was even harder." (INT 2-7-22-24)

The primary caregiver also admits that the disability had affected her past marriage. When asked by the researcher if the disability had affected her past marriage, the primary caregiver responded:

"Yes, it did... there was so much guilt for us. My ex-spouse really had a hard time with all of it. The marriage lasted about eight months after she was born." (INT 2-6-1-9)

STRESS ON THE PRIMARY CAREGIVER

The primary caregiver describes many stressors: stress with the disabled child's school; stress due to her stepson not understanding the disability; stress from her spouse wanting more time; lack of resources; stress involved in keeping the family together and as the central person in the family; lack of tools to integrate the family; lack of support from her spouse; stress from external forces, especially her spouse's parents; job stresses; and stresses related to the child's disability as she grows older.

"I think it was the everyday living part that became an issue for my husband... when time went on I had different stresses - stresses from the disability, from his ex-wife, from my extended family, from her school, it was really stressful all together." (INT 2-6-31-38)

"... he [husband] had a hard time with her mental delay... and that's where him and I had conflict all the time." (INT 2-9-12)

"As years go by, it just increases the stress... stress on our marriage was high, on a scale of 1 to 10 it was 9. And the types of conflicts were mainly to do with the children, different parenting ideas, different ways of coping." (INT 2-11-8-11)

The primary caregiver identifies herself as central parent in the family keeping the family together.

"I see myself as the strong one and keep everyone's heads above water...maybe it's the role women play that makes her family... I was the key player to make all those triangles work and it was too much stress - I think if my spouse was on board with me, things would have been different." (INT 2-7-2-34)

RESOURCES

The primary caregiver indicates she received supports from her mother, her friends, respite services, and day care and home care services. She indicates that other professionals were not helpful and that her spouse's family do not support them at all. The mother indicates that her spouse is only a minor support to her. She feels that his lack of support is one of the major problems in their marriage.

"My mother understands because of my brother, he has Down's ... so she understands what it's like." (INT 2-3-16-18)

When the researcher asks: How much support from family/friends/professionals do you receive? The primary caregiver responds:

"Family, I would say none. Friends, I would say adequate. And professionals, I would say in between." (INT 2-12-15-17)

COPING FOR THE PRIMARY CAREGIVER

The primary caregiver indicates she coped by first accepting her child's disability. The primary caregiver's coping strategies that were most helpful to her, are as follows: trying to maintain a balance; not taking things too personally; exploding from time to time; reaching out to

people when needed; developing support networks; and spending time on social/recreational activities.

FUTURE OF THE FAMILY

The primary caregiver feels she needs to go back to being a single parent at the present time, where she can concentrate on taking care of her disabled child. She hopes that in the future her relationship with her spouse will succeed.

"I see the family getting back together, I am hopeful. I see this experience as a good learning experience not a failure...I'd like to see the future where everyone is accepting of everyone in the family, there is no judgement, no criticism...I would like to see that something like a group for blended families with children with disabilities come out because it is a very separate experience than just being in a blended family." (INT 2-13-1-34)

LEARNED FROM EXPERIENCES

The primary caregiver explains that being in a blended family caring for a child with a disability has been a very challenging experience and that being in a blended family requires a lot of understanding but is also very stressful. She also believes she has a relatively normal family.

"I live pretty functional like what our neighbours can and I try to have it be as normal as possible... We can live somewhat normally." (INT 2-2-39-40)

"I see it as no different than any other family, perhaps more responsibility." (INT 2-12-40)

CASE #3 - DESCRIPTION

This is a simple blended family, where children from only one spouse are living within the reconstituted household.

The mother, Catelin, age thirty-one years, divorced her first husband, age forty-three, after four and a half years of marriage. From her first marriage, she has two children, a female, age ten, and a male, age eight, who is the child with the disability.

Catelin's current husband Cameron, was married previously to a forty-three year old woman. They had no children together.

Catelin and Cameron presently live with Catelin's two children. They have been married for four years.

Both Catelin and Cameron have similar ethnic and educational backgrounds. Both have some college education. Both work outside of the family home. They have a combined yearly family income of \$20,000-30,000.

Catelin identifies her son, C.J, as having attention deficit disorder and hyperactivity along with a primary diagnosis of developmental delay. She feels that C.J. requires constant care now and will require some care in the future.

FAM INTERPRETATION ON CASE #3

(see Appendix H for FAM profile)

The mother's scores are high on both social desirability and defensiveness scales which seem to mean that she wants to give a favourable impression of her family. She tends to show things are better than they really are and tends to tell the researcher what she would prefer to hear rather than what is really true. This would indicate that the researcher needs to be cautious generally in interpreting the mother's description of her family.

The stepfather's scores are within the normal range on the social desirability scale and low on the defensiveness scale which may mean there is a slight response style bias in his scores. That is, he may tend to overemphasize the negative aspects of family functioning but this is doubtful because his scores are well within the normal range. It would appear that the stepfather may be a low defensive person with average social desirability, thus, essentially, his scores are accurate.

Overall, the stepfather's scores show that he believes that he has an average family. If there are any possible problems, the only thing he sees is a problem is communication of feelings. This is shown with his affective expression score on the boarder of the family problem level. This is the only area that appears to be of concern to him. Unfortunately

because there is no qualitative data on the stepfather, his scores cannot be verified or interpreted further.

The mother generally describes the family as one of strength and that things in the family are going well. However, because of her high defensiveness and social desirability scores, there is a positive description that may not be totally accurate. The mother's scores are consistent with the qualitative data where she identifies a positive view of her family and does not identify significant problem areas.

CASE #3 - THEMES

FAMILY RELATIONSHIPS

There is a close relationship between the primary caregiver and the child with the disability. Although the primary caregiver gets frustrated with the child with the disability, she still is very protective of him and spends more time with him than anyone else in the family.

"I am very much overprotective of him." (INT 3-5-37)

The child with the disability has a very close relationship with his natural sibling, although there is some resentment occasionally by the sibling.

"Sometimes she [sibling] feels kind of pushed aside... and that we're [parents] paying too much attention to him (disabled child)." (INT 3-2-41-46)

The child with the disability also has a close relationship with his stepfather.

The mother and stepfather have a close relationship although they rarely spend time alone together. The mother indicates that they have been closer because of the "struggles they have gone through together."

ALTERNATIVE CARE

The mother indicates that she has not considered alternative care for the child with the disability, however, she feels it is difficult to maintain him in the family home. She hopes that his sister will care for him in the future if required.

"There is more stress, as he [disabled child] gets stronger and he grows older." (INT 3-6-14)

PARENTING STYLE

The primary caregiver indicates that both parents are strict with the children, and that decisions and disciplining are shared equally. The natural father does not have any contact with the children.

TRANSITION FROM SINGLE PARENTHOOD TO REMARRIAGE

The primary caregiver admits she was very cautious and protective of the children before marriage. She worried about the children accepting a new father figure. She was also very insecure about how long the relationship would last. She says

that when the children accepted Cameron, there was a smooth transition.

"At first I wasn't going to get married again, but I could see a bond happening between him [spouse] and the kids...I told him, if the kids don't accept you it won't work." (INT 3-4-10-22)

"I thought for the longest time no one was going to want someone with kids. And especially a disabled kid." (INT 3-4-36-38)

"I wondered how long it was going to last. I wondered if my spouse really knew what he was getting himself into. That was one of my concerns... I didn't want the kids to go through another separation - I was really scared about that." (INT 3-6-47-54)

EFFECTS OF DISABILITY ON THE FAMILY

The primary caregiver indicates that it has been very stressful for the whole family caring for the child with the disability in the home because of his need for constant care and attention. She also says it has been stressful not knowing the cause of the disability and that the diagnosis had only become known to them recently. She feels that she is the mediator in the family and the central person keeping the family together. She indicates that the stepfather finds it very stressful probably because he has not dealt with the disability from birth.

"My spouse finds it most stressful and I find it least because I've lived with it for much longer." (INT 3-6-30)

"I think the stress on our marriage is high, but we cope well." (INT 3-7-16)

STRESS ON THE PRIMARY CAREGIVER

The primary caregiver indicates that the natural father is no longer a part of the children's lives but that there is stress related to his past abuse of the children. The primary caregiver indicates that stress increases as her disabled child grows older and she worries about his future. She feels that outside influences add to her stress and that most of her conflicts with her spouse are about the children.

"I see myself as the mediator, because at times it can get pretty stressful." (INT 3-4-28)

"At times you can get so emotionally drained." (INT 3-5-16)

"At times I worry of what the future will bring." (INT 3-6-35)

RESOURCES FOR THE PRIMARY CAREGIVER

The primary caregiver indicates she receives good support from: respite services; doctors; her family; and from her friends. She also says that her spouse's family is not supportive and does not accept her children, especially the child with the disability. She feels that the biggest source of support comes from her spouse.

"My spouse is a major support. The primary support. He gives me so much emotional and physical support." (INT 3-8-11-16)

"My spouse's family has not accepted the disability, and we have accepted that." (INT 3-7-38-40)

"...even though at times we get frustrated with everything that's going on, there is that

constant communication and bond between the two of us. And we are still trying to have a child between the two of us." (INT 3-4-41-45)

The primary caregiver finds that her most helpful resource is respite services. "I'm most thankful of the services we get" (INT 3-7-44).

COPING FOR THE PRIMARY CAREGIVER

The primary caregiver feels that she is able to cope by: accepting the disability fully; unconditional love; talking to her spouse; going out with friends; and having a good relationship with family that support her.

"We [spouse and primary caregiver] communicate very well, open communication... going out with friends or giving space to each other once in a while...a lot of times I'll call my Mom or just go out with my girlfriends." (INT 3-7-16-33)

FUTURE OF THE FAMILY

The primary caregiver indicates that she hopes to keep her family functioning as normally as possible. She is very confident about her relationship with her spouse in the future and hopes to have a mutual child with her spouse. She also hopes that in the future her children will live normal functional lives and eventually have families of their own.

LEARNED FROM EXPERIENCES

The primary caregiver indicates she has learned to have a lot of patience; to balance her needs with her spouse and

her children; and has learned to compromise, restrain and share.

"We try to keep the family as normal as possible, we treat them as normal as possible... you try to treat them normally sometimes so that others will treat them normally." (INT 3-7-49-53)

"I've learned lots of patience, balance between spouses and kids and yourself. Also compromise and restraint when emotionally distressed. I've learned a lot of sharing also." (INT 3-8-40-43)

CASE #4 - DESCRIPTION

This is a simple blended family, where children from one spouse live in the reconstituted family home.

The mother, Doris, age forty, was married to her first husband, thirty-nine years of age, for seven years. They had two children together: a seven year old male and a nine year old female, who is the child with the disability.

Doris and Dennis, age thirty-one, have been married for five years and have a mutual child, female, age two. This is Dennis' first marriage. Doris and Dennis come from different ethnic backgrounds. They do have similar educational backgrounds, both have some college education. Both are in the service industry. Their combined, yearly family income is \$20,000-30,000.

Doris identifies Daisy's disability as Down's Syndrome. She feels Daisy will require constant care in the future.

FAM INTERPRETATION ON CASE #4

(see Appendix I for the FAM profile)

Both spouses are in the normal range on the defensiveness and social desirability scales. The mother's score on the social desirability scale is somewhat elevated which may mean she wants to give a slightly favourable impression of her family.

It appears that on the role performance scale the mother's score is on the boarder of the family problem area, this represents the only cross over area of spousal scores. On the task accomplishment scale, the stepfather's score is on the boarder of the family problem area. These scores are consistent with a pattern where the stepfather is more negative on task accomplishment and the mother is more negative on role performance. This pattern is not uncommon to many families and often represents a divergence of responses in the home (Trute, 1995). It often reflects a traditional delegation of duties with the wife caring for major responsibilities for the children and for household duties and the husband caring for major responsibilities outside the home and for finances in the family (Trute, 1995).

In this family, the stepfather feels that tasks are not getting accomplished as they should and the mother feels that everything is normal with tasks. However, the mother has a problem with who does certain tasks and the stepfather feels

that the delegation of roles are fine in the family.

This FAM profile is comparable to the qualitative data obtained from the mother. The mother indicated that they do not always agree on their spousal roles in the family. It appears that this family is pulled into traditional marital roles and family organization patterns, however, it seems that this is not working as well as the couple would like it to work.

Both spouses agree that communication, affective expression and involvement are within the normal range in the family. There is however, a divergent view on the control scale. There also appears to be divergent scores on the values and norms scale. Although both are in the normal range, the stepfather's score is on the boarder of the family problem area on this scale.

The mother views things on both control and values and norms scales as much better than the stepfather. According to the qualitative data from the mother, these concerns about control may have to do with her biological children with respect to the stepfather not fully accepting his non-biological children. Also consistent with the qualitative data, is the fact that the mother appears to make most of the decisions in the family and is the primary disciplinarian. The mother indicates that the stress on the stepfather is great, and it has been difficult for him to adjust to changes in family life. These changes in family life may account for the

stepfather's score on the values and norms scale. It may be possible that components of the family's value system are dissonant resulting in confusion and tension for the stepfather.

CASE #4 - THEMES

FAMILY RELATIONSHIPS

The relationship between the primary caregiver and the child with the disability is very close. The primary caregiver indicates there is a very special bond between them and that she is very protective of her disabled child.

"I'm very protective towards her... if anyone were to try to hurt her... I would become very much like the lioness..." (INT 4-4-22-25)

"I'd say I'm the most protective of her because we share a special bond." (INT 4-12-5)

She also indicates that she spends more time with the child with the disability than the other children in the home. The biological father and the child with the disability do not have a relationship. He is no longer in her life.

The child with the disability has a close relationship with her two year old sibling. According to the mother, this is because they play together and because they are emotionally at the same stage of life. The child with the disability has a distant relationship with her older brother as they no longer have anything in common.

"When he was young they were great playmates when they were the same level mentally, then he grew past her... so he doesn't have much to do with her anymore, he feels he has nothing in common with her anymore...he kind of ignores her...it's hard for him to grasp what is wrong with her." (INT 4-3-19-33)

The child with the disability has a close but conflictual relationship with her stepfather. The primary caregiver feels that the stepfather gets frustrated a lot with the disability and that the love is not the same as it is with his biological child.

"He [spouse] gets more frustrated than I do because I think it's not his child. But he deals with it fairly well, he loves her but it's not the same." (INT 4-3-40-42)

The spousal relationship is close. The mother indicates that it has become stronger with the struggles they have encountered. The mother also feels that time alone with her spouse is rare.

ALTERNATIVE CARE

The primary caregiver indicates that they have not considered alternative care for the child with the disability but that it is difficult to maintain the child with the disability at home. The mother feels that alternative care will only be considered when she can no longer care for her disabled child.

"Not as long as I can do it, I don't want her to have anybody but us." (INT 4-4-5)

PARENTING STYLE

The primary caregiver makes most of the decisions in the household, especially regarding the child with the disability. She is also the primary disciplinarian in the family.

"When we [primary caregiver and spouse] are both home, I do take that role and I'm the stronger personality in the relationship as well...I usually make the final decision and that's because he [spouse] doesn't want to make the final decision." (INT 4-5-50-53)

TRANSITION FROM SINGLE PARENTHOOD TO REMARRIAGE

The primary caregiver indicates she was overwhelmed when she was a single parent and that she did not have enough time because of her many responsibilities. She feels that there was a good transition into the remarriage because the children liked her spouse before they married. She feels that the stress is lower being in a blended family than being a single parent as the finances and all other responsibilities are equally shared. When the researcher asked, ' Why did you decide to remarry?' the primary caregiver responded:

"I never thought I would find anyone that good. So him [spouse] accepting the kids was a primary thing." (INT 4-5-11)

"When I was a single parent I just felt overwhelmed sometimes, I thought I couldn't do it anymore because I was working full time and caring for the kids full time. I was constantly worried about my job, my finances. But when we came together as a blended family a lot of the stress was lowered because he could share in the whole thing." (INT 4-8-47-54)

EFFECTS OF DISABILITY ON THE FAMILY

The primary caregiver is very protective of the child with the disability. She feels that the disability has changed her life in a positive way. She feels that her spouse has a lack of patience with the child with the disability that is not there with his biological child. The researcher asked: Can you tell me what the disability means to you? The primary caregiver responds:

"Certainly, it has changed my life, in a lot of ways. She [disabled child] is such a sweet, loving, giving child - she has taught me many things that I would have never thought about before. She takes the greatest pleasure out of the smallest, littlest accomplishments and so do I... Sometimes it's difficult with outside people accepting her." (INT 4-2-46-54)

"I don't go out as much, probable more of a home body." (INT 4-3-6)

"Sometimes I think he [spouse] doesn't have the patience I think he should have with her [disabled child]... I just think sometimes he's not so understanding as the father might have been." (INT 4-4-11-19)

The primary caregiver also admits that the disability affected her past marriage. When the researcher asks: Did the disability affect your past marriage? The primary caregiver responds:

"yes...there were times he could blame me because he knew it came from my genetics...so therefore it was my fault it happened and he would drink and blame me." (INT 4-4-39-44)

The primary caregiver feels that her spouse is the most stressed in the family.

"My spouse finds it most stressful because he wasn't there when she was born. And I just feel it's different because it's not his natural child" (INT 4-8-27-29)

STRESS ON THE PRIMARY CAREGIVER

The primary caregiver identifies many stressors: financial and job related stresses; worry about the child's future; needs of the children as stressful; child's attitude and lack of abilities as a result of her disability; and her spouses' lack of patience with her child's disability.

Time spent between the primary caregiver and her spouse is rare and can be stressful.

"It's been six months since we were last out just the two of us." (INT 4-7-15)

"The repetitiveness of things, you have to go over things over and over again... it gets very stressful and frustrating...it's also constant supervision...some days are more stressful than others and the job comes into play too." (INT 4-8-3-14)

The primary caregiver identifies the level of stress on the marriage as "medium" and identifies herself as central to the family.

"I have no doubt I am the primary person who keeps the family together." (INT 4-11-30)

RESOURCES FOR THE PRIMARY CAREGIVER

The primary caregiver identifies certain resources that

are helpful: respite, and friends and co-workers. She feels that there are no professionals that are helpful to her in the past and present. The mother says her family lives far away and that her spouse's family does not accept her disabled child. The mother views her spouse as the most helpful resource.

"My family is 1700 miles away so no physical supports but they are emotional supports for me... and no real supports from my spouse's family." (INT 4-10-8-11)

"I really had good friends and neighbours but they all moved so right now it's just the people at work." (INT 4-10-14)

"My spouse is a major support in every way, he is supportive with me and the kids... he was totally supportive of me doing what made me happy regardless of financial costs." (INT 4-10-28-34)

In addition, the primary caregiver does not engage in any social or recreational activities outside the home.

COPING USED BY THE PRIMARY CAREGIVER

The primary caregiver says she is able to cope by: taking walks to the park; taking time out for herself; reading; and going out.

"I do crossword puzzles. I used to read a lot but that takes too much concentration so now I do crosswords and I'm a fanatic." (INT 4-9-22-24)

"I don't really know what I do - I'm the mother and I just cope, I have to." (INT 4-9-30)

FUTURE OF THE FAMILY

The primary caregiver views her family as a normal family. She has concerns for the child's future. She hopes for a positive future for all her children and hopes to continue to have a close, positive relationship with her husband.

"Positive for one thing...I always think we will be a close family." (INT 4-10-48)

LEARNED FROM EXPERIENCES

The primary caregiver says she has learned that it takes a lot of work to keep her family together and that she learns something new every day. She says that she doesn't take things for granted any longer; she tries to keep her stress to a minimum; and she has a positive attitude generally.

The primary caregiver views her family as normal.

"I don't think of us as a blended family... we are all just one family...he's just Dad and I'm just Mom...it's pretty normal family life." (INT 4-5-15-22)

"I've learned that it takes a lot more work to keep it all together. Being with her [disabled child] you learn something new everyday...I appreciate a normal child develop so much more than a family that does not have a disabled child. You just don't take things for granted as much." (INT 4-11-13-20)

"Something that got me this far - that's a positive attitude and know that I just want to make her [disabled child] happy, just like I want to make the other kids happy. And she's so easily made happy. She's just a joy to have in our home." (INT 4-11-22-27)

CHAPTER SIX: ANALYSIS

INTRODUCTION

The focus of this chapter is to discuss the overall findings in the study and to examine these findings. The first section categorizes the significant themes that emerged from the data in the study and integrates these findings into the literature. The second section focusses on some of the researcher's hypotheses and identifies some promising research themes for future research.

CATEGORIZING THEMES AND INTEGRATING FINDINGS

PRIMARY CAREGIVER FEELINGS OF PROTECTION TOWARDS THE CHILD WITH THE DISABILITY

There may be a close relationship between the primary caregiver and the child with the disability perhaps because of the mother's feelings of protection. A mother's protection feelings for her children may be very strong and possibly may be stronger caring for a child with a disability that requires constant care. All the primary caregivers in the study appeared to have a very strong bond with their children with disabilities. This is consistent with the literature as Bailey et al. (1992) and Beckman (1991) found that mothers had

greater feelings of attachment to their children with disabilities than did fathers.

PRIMARY CAREGIVER'S TIME/ATTENTION TOWARDS CHILD WITH THE
DISABILITY

This study found that the primary caregiver had a limited amount of time to spend with other members of the family because of the time she spent caring for the child with the disability. The literature does not specifically address this issue. However, Erickson and Upshur (1989) found that mothers of children with disabilities had higher child care responsibilities than mothers of children with no disabilities, and this may account for the increased time spent with the child with the disability than the other family members. Other possible explanations for greater time spent with the disabled child may be that the primary caregiver may feel that other members of the family are more self-sufficient than the disabled child, and as a measure of compensation to the disabled child because of guilt feelings that the child is not like other children without disabilities.

Further, the primary caregiver spends the least amount of time on the spousal relationship. Goetting (1982) writes that the demands of parental and spousal roles on the primary caregiver may result in the spousal relationship being neglected.

SIBLING RESENTMENTS TOWARDS CHILD WITH THE DISABILITY

Feelings of resentment from siblings towards the child with the disability may be a result of the lack of time the primary caregiver spends with other members of the family. Ganong and Coleman (1993a) found that siblings in blended families had problems mainly derived from having to share resources such as parental attention and space in the household. Also, feelings of resentment that the child with the disability has towards siblings may be due to jealousy and not wanting to share the primary caregiver with other siblings. Siblings usually were not close to the child with the disability, especially if they were older siblings and if the sibling was male. This was not the case for female siblings in the study, perhaps because of a female's social role to care take and nurture. It was evident from the literature (Ganong & Coleman, 1993b) that female siblings may act as buffers and fill emotional voids left by unresponsive parents, however, male siblings may be more antagonistic.

THE PRIMARY CAREGIVER AS CENTRAL PERSON IN THE FAMILY

The primary caregiver may identify herself as the central parent in the family, keeping her family together because of her numerous responsibilities within the family. It is obvious that she would need to be very organized in order for the many child care, household and job tasks she must accomplish daily. The primary caregiver in all cases in the study was the

mother. It may be that women themselves as well as society in general see their roles in families as primary caretakers and as the 'glue' that holds the family together. Further, Sloper et al. (1991) suggest that mothers usually take on expressive roles concerning the internal and emotional affairs in the family and this may account for primary caregivers feeling responsible for keeping their families together. According to Skopin et al. (1993), women's participation in the workplace has increased, but women still have primary responsibility for family life, child rearing, and home-making. This is consistent with the literature for mothers of children with disabilities, as they report having more child care and household responsibilities than fathers of children with disabilities (Beckman, 1991; Bristol et al., 1988).

DIFFICULTIES AS A SINGLE PARENT

The study found that most primary caregivers felt that being in a two parent family had greater benefits than being a single parent. These primary caregivers seemed to feel that the two parent family offered: sharing in the responsibilities of the children and the household duties; companionship rather than loneliness; financial stability; and greater amount of time to spend with family members. Wu (1994) found that remarriage can mean an end to loneliness, economic stability and renewal of emotions and affection to many families. Vincent (1988) also found that single mothers caring for a

child with a disability experienced more stress, were more socially isolated, had less stable social networks, and received less emotional and family support, than single mothers of children without a disability, and married mothers of children with and without disabilities.

Most primary caregivers in the study also felt that as a single parent dating was very difficult. They felt that most men did not want to get involved with a mother who had a child with a disability. Primary caregivers also felt very fortunate to find spouses willing to care for their children with disabilities and take on added responsibilities in the home. The difficulty primary caregivers may have remarrying may be due to: difficulties finding compatible mates willing to share in caretaking of a disabled child with added responsibilities; lack of trusting another person after the failure of a first marriage; being very cautious about who they will let care for their children because of their level of protection towards their children, especially the child with the disability; and, being highly sensitive and committed to their children and requiring their children to have total acceptance of a mate prior to remarriage. Cooke et al. (1986) found that children with disabilities more commonly live with their mothers and that the natural fathers are more likely to be absent in these families. They also suggest that remarriage for these single mothers is usually difficult.

DISABILITY AFFECTING FIRST MARRIAGE

Most often the primary caregivers in the study felt that their child's disability affected their first marriage. It may be difficult for the biological father to care for and accept his own child with a disability, especially if the child with the disability is male. Cummings (1976) found that fathers of children with disabilities more often had difficulty coping with their child's disability. This difficulty may stem from an identification parents have towards their children. They may see their children as extensions or products of themselves and in cases where parents have a child with a disability, this extension may prove to be too painful. It also may be too difficult for fathers to acknowledge that their disabled children will grow up and not accomplish the hopes and dreams they had for them. A father's bonding to a disabled child may be difficult because he may not identify or see himself in the child and may not view that the child is able to bond to him.

Further, fathers usually play 'bread winner' roles in the family which may not be as instrumental as a mother's nurturing role. Lamb (1987) found that fathers may take on the breadwinner role which may reduce the amount of time he can spend with his family and his disabled child. This reduction of time spent with his family may increase the stress in the family and may lead to marital breakdown. Tew et al. (1977) and Kazak (1987) found that caring for a child with a disability may increase the stress on the couple and may

enhance the chances of separation and divorce.

Finally, Whitsett and Land (1992) found that men and women may perceive and interpret their experiences differently in marital and family roles. Wikler et al. (1983) found that there may be a relationship between a fathers' education, socioeconomic status and involvement in caretaking responsibilities with a child with a disability.

STRESSES INTEGRATING BLENDED FAMILIES

The transition from single parent to blended family initially was very difficult for the majority of families in the study. This may have been due to trying to balance the needs of the child with the disability, needs of the other children and the needs of the marriage. Garfield (1980) and Kent (1980) found that for each member of the blended family, there may be a reworking of one's model of the family and one's expectations of family life. Also acceptance by the children towards the stepfather may be difficult initially.

The primary caregivers in simple blended families in the study felt they had good relationships with their spouses and felt that there was less stress being in a blended family than being a single parent. The primary caregivers in complex blended families felt that there was more stress being in a blended family than being a single parent. The study found that in complex blended families, it appears that it is more difficult to integrate families than in simple blended

families. The literature is consistent with this study as, Hetherington et al. (1987) found that stepparents in complex blended families may experience greater levels of stress and less marital satisfaction than do those in simple blended families.

ABSENCE OF THE BIOLOGICAL FATHER

The study found that the biological father of the child with the disability is usually not at all a part of the child's life. This may be because: he can not accept that his child has a disability, he may not maintain a relationship with the child because he is not in close proximity of the child and/or, he may not want to maintain any contact with his child or with his ex-spouse. It may be that the father views the child with the disability as an extension of himself and this identification may be too difficult for a parent, especially if the child is male. Frey, Greenberg and Fewell (1989) suggest that fathers may have more difficulty adjusting their expectations to their sons. Orr et al. (1993), also suggest that the physical, emotional and intellectual characteristics of a child with a disability may not meet parental expectations which may lead to chronic grieving.

MUTUAL CHILD IN REMARRIAGE

The study found that spouses that had a mutual child in the blended family would bring the couple and the family as a

whole, closer together. They felt that their separate families could be united with a mutual child. There would be no more "my child" or "your child" but rather, "our child". Parents may feel that a mutual child can solidify a marriage by increasing the biological ties that bind a family. Rosenberg and Hajal (1985) suggest that the presence of children from the new marriage decreases the possibility of divorce and facilitates blended family cohesion. However, the complexities of blending families together and caring for a child with a disability may be difficult. Having a mutual child in a remarriage may depend upon a number of factors including whether the blended family is "simple" or "complex" (Rosenberg & Hajal, 1985).

PRIMARY CAREGIVER AS DISCIPLINARIAN AND DECISION MAKER

The study found that most often the primary caregiver is the primary disciplinarian and decision maker in the family because the primary caregiver may need to feel in control - not wanting to give up control to her spouse. It may be easier for the primary caregiver to have this control because she spends more time with all the children in the family. It may also be that the primary caregiver holds a central position in the family, and perhaps children respond to this role regarding discipline and decision making. In addition, it may be too difficult for the primary caregiver to let someone else take on this parental role after she has preformed it for many

years. For women, following a divorce, being independent and in control may be critical to their new identities. Colburn et al. (1992) found that females are more likely to view changes in themselves and their experiences of independence as the basis for a new identity, following divorce.

Hobart (1989) suggests that stepparents may have a lack of clarity regarding spousal expectations of their roles as well as being unaware of what was involved in being a stepparent. Whitsett and Land (1992) suggest that a stepparent may have wanted the remarriage but not necessarily the parenting role.

Spouses in the blended families in this study tended to discipline their own biological children, especially if they were older children or the child with the disability. This may be because the primary caregiver is naturally more protective with the child with the disability. Also children, especially older children may consider discipline more valid coming from a biological parent than from a step-parent. Hetherington and Clingempeel (1992) suggest that children may resent the new step-parent's attempts to control or discipline and may perceive the new marital relationship as a threat to the parent-child relationship. In this study, it appeared that younger children tended to accept the stepfather's discipline more easily than older children when blending families together. Skopin et al. (1993) found that older children had more difficulty with stepfathers than younger children, and

that adolescents did not develop close relationships with their stepfathers.

Finally, most spousal disagreements between remarried couples in the study usually involved the children. Ganong and Coleman (1993a) found that most unhappily remarried couples report disagreements about the discipline of children or stepchildren and about meeting children's needs more than any other disagreements.

STEPFATHER LABELLED AS MOST STRESSED IN THE FAMILY

In the study, the step-father might have been viewed by the primary caregiver as the most stressed in the family because: he was caring for someone else's disabled child providing physical, emotional and financial care which he may not have been used to doing; he spent little time with his spouse because of her many responsibilities; he had increased responsibilities with the child with a disability and with the other children in the family and may have spent more time caring for the disabled child than his own biological children; he may have had some difficulties accepting the disability or lacked understanding about the disability; and he may not have had any emotional attachment or bonding with the child with the disability that a biological parent may have. This is consistent with the literature on stepfathers with children with no disabilities. Peterson and Zill (1986) found that stepmothers had more adjustment problems and stress

than stepfathers. However, stress on a parent/step-parent may vary depending on many factors such as ages of children, gender of children, and on particular family histories and stages of development in the blended family (Hetherington & Clingempeel, 1992). Fine and Schwebel (1991) suggest that stepparents may experience stress because of the gap between their expectations and reality. Orr et al. (1993) also found that lack of adaptability of the child, the acceptability of the child by parents, and the demands placed on caregivers of children with disabilities may be significant sources of stress for parents.

PRIMARY CAREGIVER STRESSES

The study found that primary caregivers face a number of sources of stress: financial burdens, perceived stigma, demands on time as a result of caretaking and requirements for the child with the disability, physical difficulties caring for the child as the child grows older, decreased time for sleep and personal activities, social isolation from friends and family, difficulties with managing the child's behaviour, and concerns about the child's future. This is consistent with the literature as Tunali and Power (1993) found that as the child with the disability grows, parents are confronted with greater problems with behaviour, financial burdens, and uncertainty about the child's future.

The primary caregivers in the study also indicated that

their level of stress was often high but that they were able to cope well. They labelled their spouse's stress as higher than their own. This may be because they underestimated her own stress or their coping strategies.

Primary caregivers may also experience grief for the loss of their expected "normal" child and may experience grief for the loss of their past "normal" nuclear family system. These two losses may be stressful and unique to primary caregivers caring for children with disabilities. The literature is consistent with this. Tunali and Power suggested that parents may have stressors associated with the parental grieving process.

PRIMARY CAREGIVER COPING STRATEGIES

Whitsett and Land (1992) suggest that the type of coping strategies parents use may differ depending on the stage of stepfamily development. They also suggest that coping resources may depend on an individual's attitudes, skills and beliefs that are brought to situations and experiences. The ability of primary caregivers to respond to the stress of having a child with a disabling condition may be based on two categories of resources available to them: internal resources (resources available inside the family system) and external resources (resources available outside the family system). Primary caregivers that are successful in coping may use internal and external means of support for strength to deal

with the special needs of their children. Two resources most helpful to primary caregivers in this study were: respite services (external resources); and spousal support (internal resources).

Primary caregivers in the study who indicated that their spouse was the most helpful resource, usually appeared to have a strong spousal relationship. Parke (1986), Blacher (1990), and Flynt et al. (1992) found that mothers of children with disabilities identified their spouse as the greatest source of personal support. Further, Friedrich and Friedrich (1981) found that intimate relationships are significant sources of personal support buffering the effects of stress.

Kobe et al. (1991) found that respite services for families caring for a child with a disability often provided the only relief from their burden of care. In this study, all primary caregivers were very satisfied with the respite services they received and often desired more respite opportunities.

Other resources that seemed helpful to primary caregivers were: a mother's satisfaction with her marriage, financial security, and support from friends and family. Frey et al. (1989) found that mothers do the majority of child rearing and that mothers have more child care responsibilities and value child related assistance more than fathers. They also suggest that parental perceptions of their ability to control their own lives is related to a positive parental outcome.

In addition, all the primary caregivers in the study noted that they engaged in many social activities inside the home. This is consistent with the literature. Botuck and Winsberg (1991) found that mothers caring for children with disabilities had developed lifestyles that involved engaging in leisure and social activities without leaving their homes.

STEPFATHER'S FAMILY OF ORIGIN NON ACCEPTANCE OF THE DISABILITY

Interactions in the extended family, especially the stepfather's family of origin may be complex. The stepfather's family of origin in all cases in this study did not accept the child with the disability and as a result were not supportive of the new spouse and the remarriage.

It may be that the parents of stepfathers may not want their sons to have increased stress and greater parental responsibilities which occur in families with a child with a disability. Step-grandparents may be very protective of their own children and may view the child with the disability and the blended family as having too much of a burden on their sons. This non-acceptance by step-grandparents can increase the stress experienced by the blended family. Dyson (1991) suggests that a positive extended family relationship may be related to less parental stress.

PRIMARY CAREGIVER'S SOCIAL NETWORK - FRIENDS AND FAMILY

Most often in the study, the primary caregivers' families of origin were supportive of the blended family and the child with the disability, however, they were either too far away geographically or they were too elderly to be physically supportive. Because of the increased responsibilities inside and outside of the family, the primary caregiver may have very little time to spend with her friends. This may account for her small social network. It may be that if the primary caregiver had a larger social network she may have lower stress levels caring for her blended family and her child with a disability. Roberts and Price (1989) found that a satisfying relationship with friends and relatives could be related to a satisfying marital communication system in remarriage and thereby lower parental stress.

Friends and neighbours can also provide an important source of support to families with a child with a disability. They can provide short term assistance such as babysitting, emotional and moral support, and community awareness and positive attitudes towards children with disabilities. Wikler et al. (1983) suggest that smaller friendship networks and increased reliance on extended family are related to reduced parental stress caring for a child with a disability.

PRIMARY CAREGIVER'S FUTURE OUTLOOK

The primary caregivers often had a positive outlook for the future of their families. Frey, Greenberg and Fewell (1989) found that positive self appraisals of coping skills and positive parental beliefs were related to lower parental stress and positive family adjustment. All the primary caregivers in the study hoped for as much normalcy as possible in their families, they worried about the future of the child with the disability, and hoped for long, positive relationships with their spouses.

In addition, many of the primary caregivers indicated that they would welcome a support group. They felt that they would gain a great deal from being able to share their reactions, problems, and experiences with other primary caregivers in blended families caring for children with disabilities. They believed that their experiences were unique and that support groups for parents of blended families or parents of disabled children separately were not inclusive enough to be helpful to them in their unique positions.

PRIMARY CAREGIVER'S LEARNED EXPERIENCES

The primary caregivers in the study indicated that they had learned many things from their experiences: trust in their spouse; need for understanding; balancing needs of their child with the disability, other children and their marriage; sharing; keeping stress to a minimum; and having a positive

attitude. The primary caregivers identified their experiences as sources of or reasons for: increased happiness and love; strengthened family ties (especially between spouses); greater pride in their child's accomplishments; greater knowledge about disabilities; learning not to take things for granted; increased tolerance, sensitivity and patience; and increased personal growth and control. Frey, Greenberg and Fewell (1989) found that mothers often viewed their past experiences caring for their children with disabilities as positive, enriching experiences.

INTEGRATING FAM PROFILES AND QUALITATIVE DATA

The couples' FAM profiles were quite consistent with the qualitative data obtained from the primary caregivers. Overall, there were several results that appeared consistently across the majority of the couples in the study.

It was found that three out of four stepfathers scored on the boarder of the family problem level on task accomplishment while, all four primary caregivers scored in the normal range or above normal on task accomplishment. Similar to task accomplishment scores was role performance. Two out of four stepfathers scored on the boarder of the family problem area on role performance. However, three out of four mothers scored in the normal range on role performance. Thus, it appears that three out of four stepfathers felt that tasks were not getting

accomplished as they should have been in the family. While all the mothers felt that there were no problems with tasks getting accomplished in the family. Also, three out of four primary caregivers felt that the roles in the family were fine, and two out of four stepfathers felt there was a problem with the delegation of roles in the family.

These findings may show that stepfathers have difficulty adapting to the role as "stepfather" in the family. According to qualitative data, the mother is the primary disciplinarian and decision maker in the home and makes all primary decisions regarding her biological child with the disability. The stepfather may feel pushed aside from traditional roles in the family and/or unsure of his role in the family. This may be consistent with the task accomplishment scale. The stepfathers in the study felt that tasks were not getting accomplished as they should have been and may have felt unsure of who was responsible for getting different tasks accomplished.

Further, it appears from the qualitative data that primary caregivers identified themselves as the central parent, and as the least stressed in the family. This may coincide with the FAM profiles where the majority of primary caregivers viewed that task accomplishment and role performance were normal in their families. It could be that primary caregivers do not feel stress with getting tasks accomplished or performing their roles in the family. However, stepfathers may feel more stress as they identified tasks as

not getting accomplished sufficiently and appeared to feel unsure about their roles in the family.

In addition, the study found that three out of four stepfathers scored in the family problem area or on the boarder of the family problem area on the values and norms scale. There was a marked divergence of views for the mothers as, three out of four mothers scored in the normal range or better on this scale. It may be that stepfathers have greater difficulty integrating themselves into the stepfamily and integrating two separate value systems into one family system. It may also be that stepfathers have more difficulty fitting into society and the larger community as stepfathers of a child with a disability.

It appears that task accomplishment, role performance, and values and norms are three areas that require further research, particularly regarding stepfathers' views of these areas of family functioning.

GENERATING HYPOTHESES

The concepts and theoretical relationships in this study were derived from data obtained from interviews and from the family assessment measure questionnaire profiles. The researcher compared data within and across families. This kind of comparison gave the researcher greater clarity with identifying similarities and differences and gaining insight

into family experiences that may be unique to one family or similar to several families.

There are extraordinary demands placed on blended families caring for children with disabilities, especially the primary caregivers.

All children in the main study had developmental delays as their primary diagnosis.

It is recognized that mothers were the key informants in the study and these hypotheses are based on their experiences and perceptions.

The researcher attempts to make the following hypotheses based on the findings from this study.

HYPOTHESIS #1

The mother in the blended family is the central (or main) parent responsible for keeping the family functioning and free from breakdown.

HYPOTHESIS #2

The mother's longer experience with childhood disability will result in stronger coping methods and less parental stress than her husband.

HYPOTHESIS #3

If the mother does not receive positive spousal support then marital and family breakdown is more likely to occur.

HYPOTHESIS #4

If the stepfather of the child with a disability does not accept and understand the nature of the child's disability, he will tend to emotionally distance himself from the child.

HYPOTHESIS #5

If the biological father does not accept the child's disability while he is married to the child's natural mother, marital breakdown is more likely to occur.

HYPOTHESIS #6

Caring for a child with a disability in the home leads to the mother spending more time and attention with the disabled child than with other members of the family.

HYPOTHESIS #7

Step-grandparents (step-father's parents) who do not accept the child with the disability, and the blended family as a whole, may feel that the blended family with the child with the disability places excessive burdens on their sons.

HYPOTHESIS #8

Mothers will be more protective of their children with disabilities than with other children in the family.

HYPOTHESIS #9

Mothers from simple blended families will view single parenthood as harder than blended family parenthood because of the lack of support (personal and financial) and the lack of shared responsibilities associated with single parenthood.

CHAPTER SEVEN: CONCLUSION

INTRODUCTION

Becoming a blended family involves reconstructing a new and unanticipated identity based on the dynamics of that particular family system. For the biological parent, step-parent and children in the blended family, the construction of this new identity may involve a process of resocialization whereby they may dismantle old images of themselves and replace them with a new picture of the family, both in their own eyes and in the eyes of others. The addition of a child with a disability into the blended family system also changes dynamics in the family in complex ways.

The focus of this chapter is to provide an overall summary of the findings and to examine the implications of these findings. At the outset of this research, a number of general research questions were constructed. A consideration of these questions, in light of the data collected, will be used to guide the summary. In addition, there is a summary of the study's design and intent and a summary of common themes found in the study. Also, the limitations of this research are discussed. Finally, there is a discussion of the implications of this research for policy and for practice and the findings are discussed as they relate to future research.

STUDY DESIGN AND INTENT

In light of the fact that there was no available literature on blended families caring for children with disabilities, this research study was developed.

The purpose of the study was to provide critical data to understand issues confronting blended families caring for children with disabilities. In particular, the study attempted to understand what meanings primary caregivers give to their experiences caring for a child with a disability within a blended family environment.

The methodology used in the study was both qualitative and quantitative. The qualitative methodology used was a grounded theory approach (Glaser & Strauss, 1967) which involved identifying themes and categorizing themes from the interview data. The quantitative methodology used was the Family Assessment Measure questionnaire (Skinner et al., 1983). The FAM III was used to identify family strengths and weaknesses from parental responses. The FAM III questionnaire was further used to verify and help interpret the interview information gathered from grounded theory approaches.

From the analysis of the data, the researcher proposed some hypotheses. It is hoped that these findings will assist other blended families caring for children with disabilities; help assist professionals working with these families; and provide promising themes for future research.

SUMMARY OF THE COMMON THEMES FOUND IN THE STUDY

There seemed to be many common themes that most of the primary caregivers referred to and discussed in their interviews. The following is a summary of themes the families had in common.

1. The primary caregiver was often very defensive and protective towards the child with the disability. This occurred inside and outside of the family household. The primary caregiver also acknowledged a very strong bond with the child with the disability and often viewed that she had the closest bond with this child.
2. The primary caregiver gave the child with the disability much more attention and time than other members of the family.
3. The child with the disability appeared not to have close and strong sibling relationships. This was especially the case when the siblings were male.
4. The primary caregiver identified herself as the central person in the family, responsible for keeping the family together and free from breakdown.
5. The primary caregivers in simple blended families often viewed single parenthood as harder than blended family parenthood because of issues of lack of companionship, problems with finances, and lack of support and shared responsibilities.
6. All primary caregivers found it very difficult dating when

they were single parents because most men in there experiences did not want to get involved with a mother with a child with a disability.

7. The primary caregivers appeared to identify the child's disability as having some affect on their past marriages and in some cases the disability contributed to ending their first marriage.

8. The primary caregivers in simple blended families viewed the struggles in the couple relationship as bringing them closer together. In complex blended families, the primary caregivers viewed the struggles as a source of great stress.

9. In all cases, the biological fathers of the children with disabilities no longer played any part in the child's life and had no contact with the child.

10. Most of the primary caregivers viewed having a mutual child with their new spouse would give them a stronger marital relationship.

11. The primary caregivers in most cases made primary decisions in the household, and was the primary disciplinarian of the children. They did in all cases make all decisions concerning the care of the child with the disability.

12. The primary caregivers viewed in most cases that the step-father was usually the most stressed in the family, primarily because stepfathers had less years of experience caring for the child with the disability.

13. The primary caregivers viewed the step-father as often

frustrated, and lacked tolerance with the child with the disability. It also appeared that his frustrations may be due to the fact that it was not his natural child and that he had not cared for the child from birth.

14. The primary caregivers in all cases felt stress with trying to balance the needs of her child with the disability, the needs of the other children in the home, the needs of her spouse and the marriage, and her own personal needs.

15. The primary caregivers in all cases viewed the support of her spouse as crucial. All primary caregivers viewed spousal support as their most important resource.

16. The primary caregivers viewed that respite services were their most important external resource.

17. In all cases, the step-father's family of origin (specifically, step-grandparents) were not supportive of the blended family and did not accept the child with the disability.

18. The spousal unit in the blended family often had a very small and sometimes had no, social network. The primary caregiver often had very few, if any, friends and family support was limited.

19. The primary caregivers, in most cases, viewed her blended family like any other "normal" family and had a positive attitude towards the future.

20. The primary caregivers had similar coping strategies which involved taking time out for themselves (i.e. taking

walks and long baths etc.). They also felt that talking to friends, family and/or their spouse was a method of coping that was helpful.

21. The primary caregivers in most cases felt that having a support group for blended families caring for children with disabilities would be a helpful resource which they would utilize readily.

22. The primary caregivers indicated that they learned a great deal from their experiences in a blended family caring for a child with a disability and that they have more positive than negative experiences.

LIMITATIONS OF THE STUDY

In this section, four major limitations of the study are discussed in greater detail. These limitations are as follows: low response rates for recruiting couples for the study; interviewing only primary caregivers and not other family members; researcher bias as the interviewer and analyst; and manual coding procedures used in the study.

LOW RESPONSE RATE / LOW SAMPLE SIZE

When the effort was made to recruit couples for the study, some difficulties were encountered. The most significant among these was the difficulty of getting participants from the Winnipeg community. The reasons for low

participation might have been due to: couples feeling that they do not have the time or emotional energy to take part in the study; couples may have been very private and may have wanted their experiences kept private in the family; talking about experiences that the couple went through in the past may be too painful and too much to bear for some primary caregivers; for some couples, the timing of the request to participate may have been crucial in their decision to participate or not - particularly difficult times such as times of great stress, lack of support or depression may result in a reluctance to participate in the study. Other possible reasons for non-response may include separation or divorce, change of address, or lost participation forms.

LIMITATIONS OF INTERVIEWING ONLY THE PRIMARY CAREGIVER

The focus of this study was on mothers' perceptions of their experiences in the blended family. There may be discrepancies between responses between spouses as a function of husbands and wives having separate subjective realities that may not always coincide. Each spouse may define situations differently according to their own needs, values, attitudes and beliefs. These divergent realities or attitudes warrant attention in further research studies. Also multi-member measures, that is, gaining multiple family perceptions in this area may gain a more accurate perception of the family "in situ."

RESEARCHER BIAS

As the interviewer and the analyst in the study, this may be seen by other researchers as increasing the likelihood of bias. The use of a second rater to code interview data to establish confidence with reliability in the research study may have been useful.

MANUAL CODING TECHNIQUES

The use of a computer program to assist the researcher with coding the data and data analysis may have reduced the time and tediousness of data analysis. Also, perhaps new categories may have emerged that were overlooked by the researcher using manual coding processes.

IMPLICATIONS FOR POLICY AND PROFESSIONAL PRACTICE/

RECOMMENDATION FOR FUTURE RESEARCH

It is clear that blended families caring for children with disabilities have numerous stressors from everyday living. Primary caregivers may have certain needs which, though relatively simple, are often ignored or neglected by professionals. They may be described briefly as follows: the need for support and reassurance; the need for information; and the need for 'someone to talk to'.

Further understanding of relevant family processes are

also needed that are affected by the disabled child's age, developmental milestones (physical, social and emotional), parental expectations, and social, economic and psychological demands on the system. Research should include longitudinal and cross sectional studies as well as studies of different ages of children, as there may be differences depending on a child's stage of life entering a blended family.

Past research confirms findings that friends and family are very important for the adjustment of remarried couples (Roberts & Price, 1989). This study also appears to find that social networks are important to primary caregivers. Further research using whole family data is needed to determine other variables that might affect the adjustment of blended families. Research on how parents' coping strategies and how their behaviours affect children's adaptation into the blended family are also needed in the future.

From the literature, it appears that divorce is a stressful time despite individual differences or availability of resources for the family. There are gender differences as well. Generally, women bear the primary responsibilities for child rearing and are generally in greater financial difficulty than men after a divorce (Pledge, 1992). The transitional periods children go through between single parent households and remarried households may be stressful. Perhaps educational and psychological services that change with the changing needs of families is required for the future.

This study appears to suggest that the marital relationship is a crucial factor in blended families caring for children with disabilities. Authors (Skopin et al., 1993; Trute, 1990) have indicated that establishing strong, well functioning marital relationships appears to be significant for the stepfamily and the family with a child with a disability. In addition, more detailed studies of marital dynamics is needed.

Quality research on the role of the father and stepfather is also needed to shed some insight on their contributions and their effects on the child with the disability and the blended family. Further research on the biological father's involvement, research on stepfather acceptance of the child's disability and the effects of a mutual child on the marital relationship may also be avenues for further study.

Respite and other important services for these families also require changes and future research. It may be necessary for families to have relief services at different family life stages. The key is the flexibility of services (i.e., weekends, twice a week, emergency, vacations etc.). It appears that families place much value on respite care services. The literature suggests that families should have continuous support past early childhood to assist parents in managing stress (Dyson, 1991).

Research on ways to assist parents with maintaining coping strategies and attaining skills over time is likely to

yield important implications for the future design of services, especially as needs change through the family life cycle and over time. Equally important is the need for researchers to find out what specifically are the best resources for these families through transition stages. Clinicians may wish to explore additional resources that may have important implications for empowering personal and family strengths among parents with children with disabilities.

The potential clinical applications of the research findings are significant. Thus, it is important to understand the individual and collective experiences of blended families caring for children with disabilities. Further, future exploration of the hypotheses found in this study may suggest interventions to help these families best cope with their experiences.

Qualitative results have shown the importance of listening closely to primary caregivers' stories and concerns. Their stories may give researchers insights into meanings of many families' experiences and ultimately clues on how to assist these families. In addition, qualitative strategies like grounded theory methods in family research may help researchers view families holistically and remain open to new findings.

As a result of the complexity of family relationships, families often find themselves initially with a overwhelmingly high level of stress. This exploratory study has attempted to

offer some hypotheses about issues that blended families caring for children with disabilities experience. In particular, this study sought to understand some of the experiences of blended families caring for a child with a disability through the eyes of the primary caregiver. It was a difficult task to undertake, since as one primary caregiver pointed out: "No one who is not in such a position can truly appreciate what it is like." This is why the researcher, wherever possible and as extensively as possible used the primary caregivers' actual words.

While the results of this study are not assumed to be applicable to more diverse groups, they do offer additional information on the topic of interest. In addition, the awareness of some of the identified themes in this study may point future researchers with larger and more heterogeneous samples in directions that would be useful to explore. It is hoped that the conclusions of this study will help identify important issues for blended families caring for children with disabilities and will lead to further research in this virtually non-researched area.

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APPENDIX A

RESEARCHER'S LETTER TO THE FAMILIES

Dear parents,

I am a Masters' student in the Faculty of Social Work at the University of Manitoba and am interested in conducting research for my Masters' Thesis in the area of blended families caring for children with disabilities.

The reason I am contacting you at this time is to ask if I could interview the primary caregiver of your disabled child for a minimum of two hours and have both spouses complete a 20 minute Family Assessment Measure Questionnaire. Presently, little is known about the stresses blended families caring for children with disabilities experience.

The purpose of the study is to identify areas that impact the primary caregiver and the challenges involved in daily life. I hope that through learning from your experiences I will be able to help other blended families who have children with disabilities.

Please note that participation in this study is totally voluntary and is independent of any provider of community services. That is, if you decide to participate or not to participate in this study, it will not affect any services you may receive presently or in the future.

I am hoping to be in touch with families and conduct interviews by May, 1995 at your convenience. Again the interview will take a minimum of two hours and may require a follow-up interview.

If you would like to participate in this study please fill out the participation form attached and mail it back in the return stamped envelope provided.

I hope you will agree to participate in this study as your input is valuable and meaningful. If you have any questions or want to talk with me personally about this study, you can telephone me at

Sincerely,

Susan Moraes.



Family Services

Children's Special Services

Main Floor
114 Garry Street
Winnipeg, Manitoba, CANADA
R3C 1G1

(204) 945-3251

April 4, 1995

Dear Parents:

Children's Special Services, from time to time, participates in or supports worthwhile research projects designed to improve knowledge about which services families find helpful. In the past, research has helped to change services to make them more flexible and useful to families' needs.

Please find attached a letter from Ms. Susan Moraes concerning a research project involving blended families who are caring for a child with a disability. (Blended families are made up of re-married adults and their children). Ms. Moraes is a graduate student enrolled at the University of Manitoba, working under the supervision of a member of the Faculty of Social Work.

Ms. Moraes is looking for blended families who are caring for a child with a disability to participate in an interview about the challenges that are part of daily life. Children's Special Services supports this research project. The information will benefit both families that currently receive services, as well as those who will receive services in the future.

Please understand that participation is COMPLETELY VOLUNTARY, and that involvement will be kept in STRICT CONFIDENCE. If you choose to volunteer, please complete the Participation Form and return it to Ms. Moraes in the self-addressed, stamped envelope. If you choose not to participate, you may complete the Do Not Consent portion of the Participation Form or you may simply discard the Form. No one will call you or be in further contact with you if you choose not to participate. If you change your mind later, you may withdraw from the study at any time or contact your Family Services worker to find out how to join the study at a future date.

If you have any questions before you decide, you may contact Ms. Moraes at the telephone number in her letter.

Thank you.

Sincerely,

Richard Asselin
Provincial Coordinator
Children's Special Services

RA/dk
Encl.

APPENDIX C
PARTICIPATION FORM

We, _____, CONSENT
(print names of both parents)

to participate in the research study on blended families caring for children with disabilities. We also give permission to have our names and telephone number given to the researcher of the study.

(Signature of Parent 1)

(Signature of Parent 2)

We, _____, DO NOT CONSENT
(print names of both parents)

to participate in the research study on blended families caring for children with disabilities.

(Signature of Parent 1)

(Signature of Parent 2)

APPENDIX D

PARTICIPANT CONSENT FORM FOR PRIMARY CAREGIVER

I understand that the aim of the study is to learn about the experiences of remarried families caring for children with disabilities and to learn about the stressors involved in their lives.

My participation in this study will involve completing an open ended interview that will take a minimum of two hours, and I am aware that a follow up interview may be required. I am also aware that I will be asked to complete a Family Assessment Measure Questionnaire that will take approximately 20 minutes.

I am aware that this research will be included in the researcher's M.S.W. thesis. I understand that this research is being conducted by Susan Moraes and is independent of any provider of community services. No provider of services will know whether or not I am participating in this study. I understand that the researcher can be contacted at _____ to answer any questions regarding this study.

It is understood that my participation in this study is totally voluntary and that my right to withdraw from the study at any time without penalty is assured by the researcher. I may withdraw totally from answering any questions or may refrain from answering any particular questions.

I know that all identifiable information will be protected as strictly confidential and will not be released to anyone except in aggregated form. It is further understood that when the study is completed there will be no reference to any individual. I understand that upon completion of the study the researcher will mail a summary of the results of the study to all participants.

I have read this form, have had an opportunity to ask the researcher any questions I have about the research, and am willing to participate in this study.

My signature indicates my agreement and consent to be involved in this study and gives permission to the researcher to have the material included in the research project.

Name of Participant: _____ Date: _____

Signature of Participant: _____

Interviewer: _____

APPENDIX E

PARTICIPANT CONSENT FORM FOR SECONDARY CAREGIVER

I understand that the aim of the study is to learn about the experiences of remarried families caring for children with disabilities and to learn about the stressors involved in their lives.

I am aware that my participation in this study will involve completing a Family Assessment Measure Questionnaire only and that it will take approximately 20 minutes.

I am aware that this research will be included in the researcher's M.S.W. thesis. I understand that this research is being conducted by Susan Moraes and is independent of any provider of community services. No provider of services will know whether or not I am participating in this study. I understand that the researcher can be contacted at _____ to answer any questions regarding the research study.

It is understood that my participation in this study is totally voluntary and that my right to withdraw from this research at any time without penalty is assured by the researcher.

I know that all identifiable information will be protected as strictly confidential and will not be released to anyone except in aggregated form. It is further understood that when the study is completed there will be no reference to any individual. I understand that upon completion of the study, the researcher will mail a summary of the results to all participants.

I have read this form, have had an opportunity to ask the researcher any questions I have about the research, and am willing to participate in the research project.

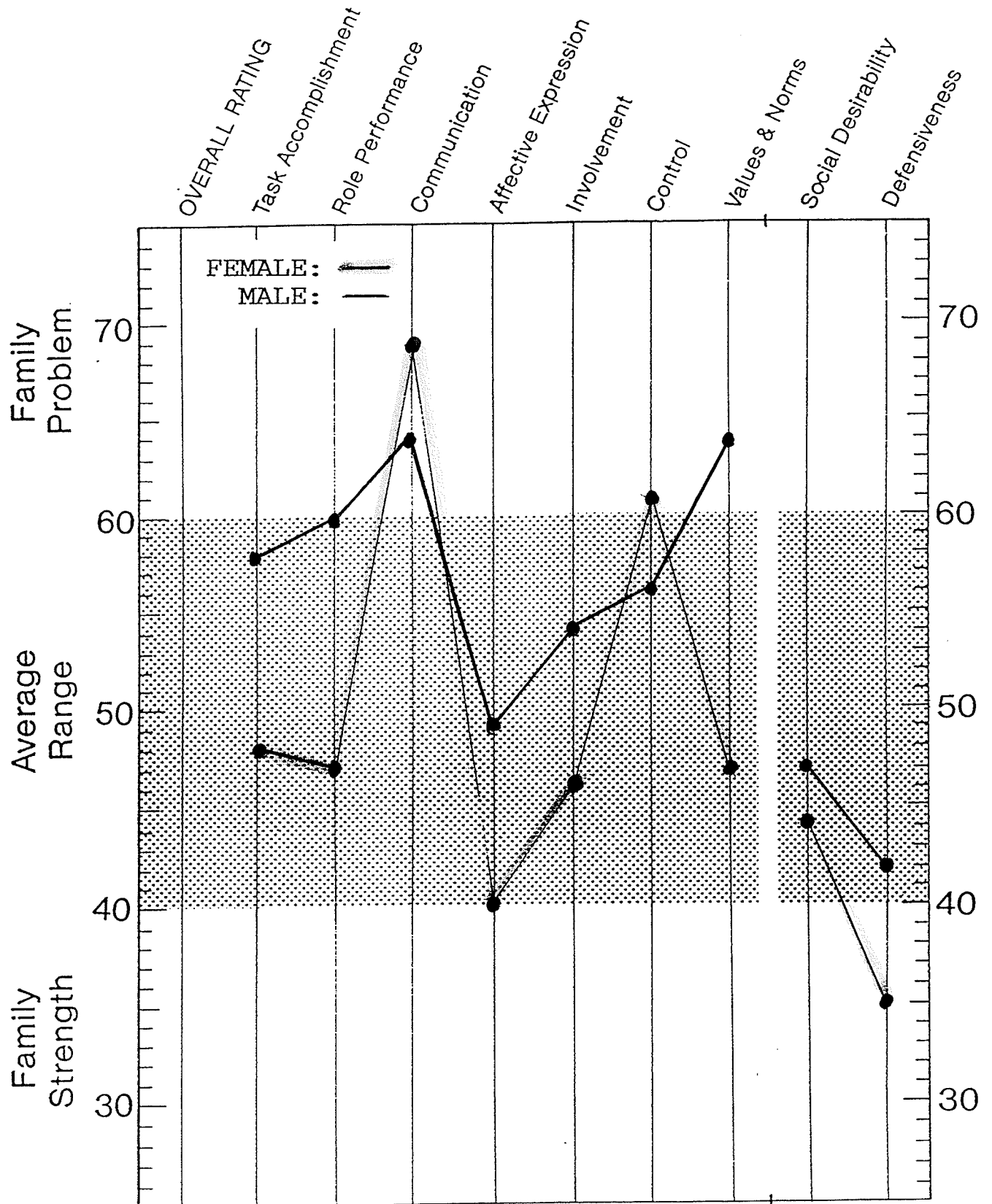
My signature indicates my agreement and consent to be involved in this study and gives permission to the researcher to have the material included in the research project.

Name of Participant: _____ Date: _____

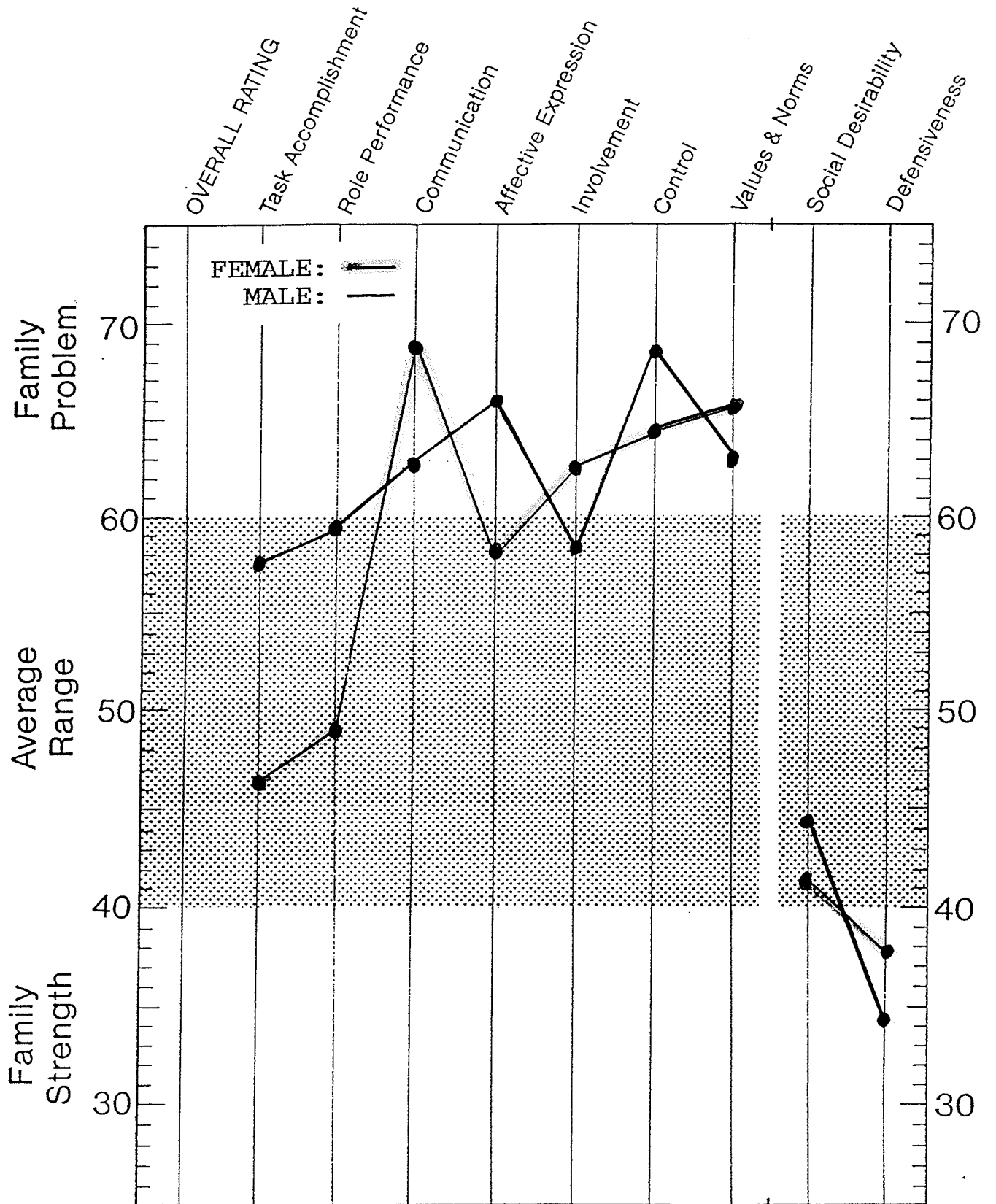
Signature of Participant: _____

Interviewer: _____

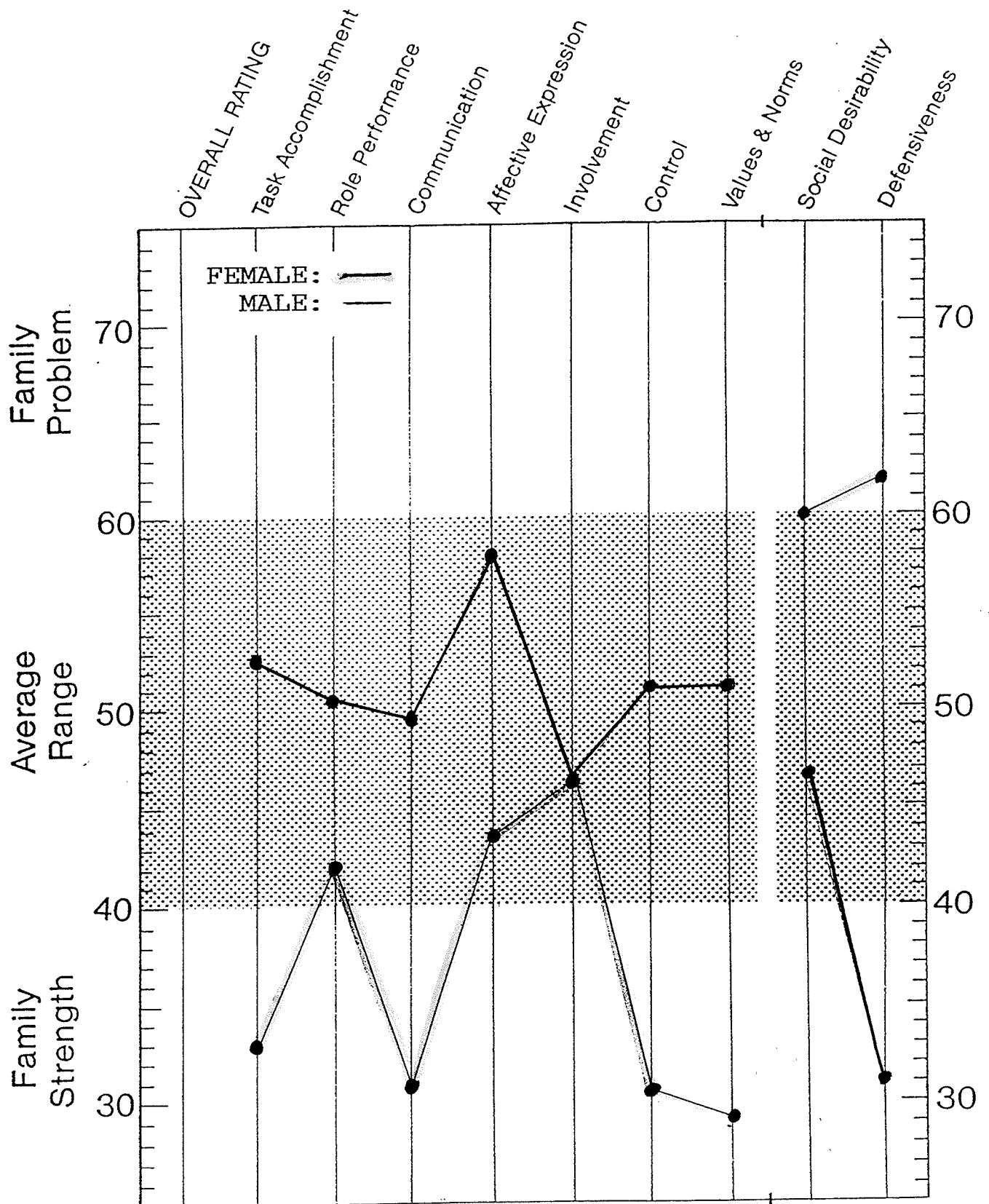
APPENDIX F
 FAM SCORES FOR CASE #1
 FAM GENERAL SCALE



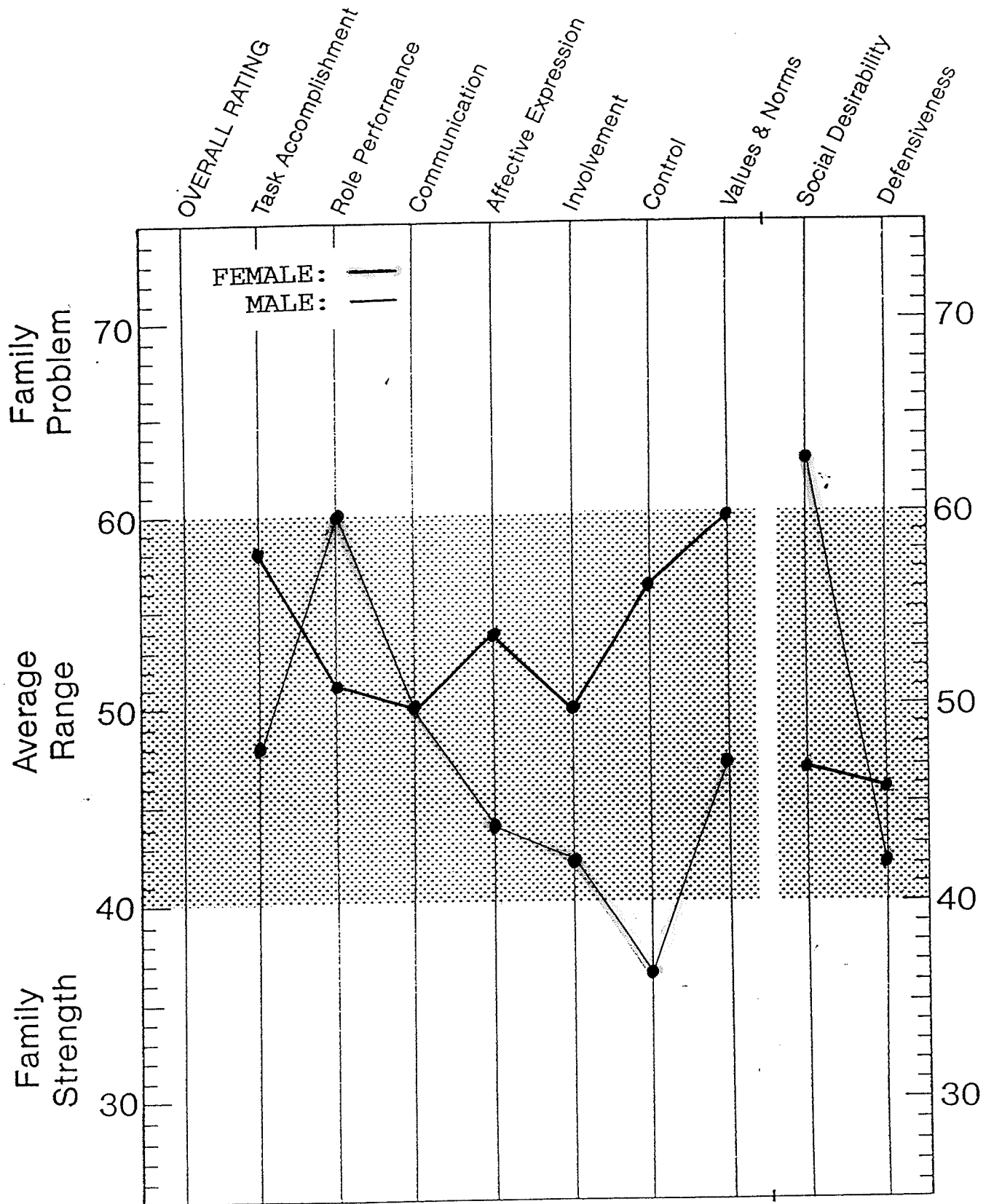
APPENDIX G
 FAM SCORES FOR CASE #2
 FAM GENERAL SCALE



APPENDIX H
 FAM SCORES FOR CASE #3
 FAM GENERAL SCALE



APPENDIX I
 FAM SCORES FOR CASE #4
 FAM GENERAL SCALE



APPENDIX J
QUESTIONNAIRE

Interview Code: _____

Family Address: _____

Phone #: _____

Father's Name: _____

Mother's Name: _____

Identified Child: _____

Age/D.O.B. of Child: _____

Number of children in the home regularly: _____

Number of children living out of the home: _____

Children's ages under sex: Males Females

How many biological children do you have? _____

How many biological children does your spouse have? _____

How many times have you been married? _____

How many years were you in your past marriage? _____

How many years have you been in your present marriage? _____

Describe your ethnicity? _____

What is your principle occupation? _____

What is your level of education? _____

How many times has your spouse been married? _____

Describe your spouses' ethnicity? _____

What is your spouses' principle occupation? _____

What is your spouses' level of education? _____

What was your gross family income (before deductions last year?

- 1) Under \$10,000
- 2) \$10,000 - \$20,000
- 3) \$20,000 - \$30,000
- 4) \$30,000 - \$40,000
- 5) \$40,000 - \$50,000
- 6) \$50,000 - \$60,000
- 7) \$60,000 - \$70,000
- 8) \$70,000 - \$80,000
- 9) \$80,000 - \$90,000
- 10) \$90,000 - \$100,000
- 11) Over \$100,000

Family Relationship Diagram:

SECTION A: THE ROLE THE DISABILITY PLAYS IN THE FAMILY

Can you describe your child's disability?

How much care does the child require now and in the future?

Can you tell me what the disability means to you?

The effects the disability has had on your life?

What has it meant for the different members of the family?

How does each person respond? How is each involved?

Who in the family takes care of the disabled child?

What role do step-siblings play in the identified child's life?

Has his/her presence made things difficult in the family?

What are some of the positive and negative elements?

How well do the children get along? Is there any conflict?

How difficult is it to maintain your child at home presently? In the future?

Do you think you may require alternative care for your child in the future? Why? Why not?

What role do you think the disability plays in your remarriage?

How does the disability effect your marriage?

Had the disability affected your past marriage?

SECTION B: UNDERSTANDING THE BLENDED FAMILY UNIT

How long had you been a single parent before remarriage?

Why did you decide to remarry after being a single parent?

What does it mean to you to be a part of a blended family?

How do you see yourself in the family?

How do you see your role as step-parent?

What was it like for you when you first came together as a blended family? What is it like now?

How does your family deal with problems in the family?

Who disciplines whom?

Who makes final decisions in the family?

Does your family negotiate decisions?

How has being part of a blended family affect your relationship with your spouse? Children? Disabled child?

How do the children feel about the remarriage? Which children are currently experiencing the most difficulties with the remarriage? Why?

SECTION C: FAMILY DYNAMICS

What are some of the strengths and weaknesses for you as the primary caregiver of your child with a disability?

What are some of the strengths and weaknesses you have as a blended family?

Which family members are close? Who in the family are distant?

What kinds of difficulties are encountered between children and parents?

How much time is spent with other children in the home? Is there a difference? How much time is spent with your disabled child?

How much time do parents spend together?

When you were growing up, how were you parented?

When your spouse was growing up, how was he parented?

How do you and your spouse parent your children now? Is it different from your past marriage? How?

In a crisis situation, what parenting style do you use?

Are there particular cultural differences between you and your spouse that influence your parenting styles?

SECTION D: STRESSORS

What kind of stress is involved with caring for a disabled child as the primary caregiver?

How are members of the family affected?

Has there been any changes in stress as your child grows older?

How stressful has the disability been in the blended family? Why?

Which members of the family find it most stressful? Least stressful? Why?

Has the disability in the family caused some stress in the marriage? Explain?

What were some of the difficulties (stressors) you experienced going through the transition from single parenthood to remarriage?

What are some of the difficulties (stressors) you see yourself and your family experiencing now? Future?

Can you comment on the level of stress on your marriage, the types of conflicts experienced and the way you and your spouse cope with the needs of your family?

How do you and your spouse deal with these stressors?

Who experiences the most stress in the family? Why?

What do you do when you feel stressed?

SECTION E: RESOURCES

What resources are available to you presently as the primary caregiver that are most helpful?

What resources are available to the couple and to the family?

Do you have more or less or the same resources (supports) available to you now or before you became a blended family?

How much time for social/recreational activities do you have outside the home?

How much support from family/friends/professionals do you have?

How much of a support is your spouse? In what ways?

Does your family receive any respite services?

What kinds of resources would you like to have?

SECTION F: WHAT THE FUTURE HOLDS

How do you see the future for yourself and your family?

What kinds of things will stay the same?

What things will be different?

With everything possible, what would you like the future to look like?

Have you learned anything significant from your experiences being in a blended family caring for a child with a disability?

Would you like to add anything further or comment about this interview today?

APPENDIX K

LIST OF CODES

A. DEMOGRAPHIC DATA

D:Family Income	D-FAM-INC
D:Kids Living In The Home	D-K-INH
D:Kids Living Out of the Home	D-K-OUTH
D:Ethnicity of Primary Caregiver	D-ETHN-PC
D:Ethnicity of Step Father	D-ETHN-SF
D:Education Level of Primary Caregiver	D-EDUC-PC
D:Education Level of Step Father	D-EDUC-SF
D:Age of Disabled Child	D-AGE-IP
D:Occupation of Primary Caregiver	D-OCCUP-PC
D:Occupation of Step Father	D-OCCUP-SF
D:Age and Sex of all the Children	D-AGE-SEX
D:Number of Biological Children of Mother	D-BIOCH-PC
D:Number of Biological Children of Step Father	D-BIOCH-SF
D:Number of Times Mother has been Married	D-XMARR-PC
D:Number of Times Step Father has been Married	D-XMARR-SF
D:Years Mother has been in Past Marriage	D-YRSPASTM
D:Years Mother has been in Present Marriage	D-YRSPRESM
D:Care Required for Disabled Child Now	D-CARREQ-N
D:Care Required for Disabled Child in the Future	D-CARREQ-F
D:Description of the Disability	D-DESC-DIS

B. FAMILY RELATIONSHIPS

FR:Relationship Between Disabled Child and Natural Father	FR-IP-NF
FR:Relationship Between Mother and Step Father	FR-M-SF
FR:Relationship Between Disabled Child and Mother	FR-IP-M
FR:Relationship Between Disabled Child and Step Father	FR-IP-SF
FR:Relationship Between Disabled Child and Natural Brother	FR-IP-BRO
FR:Relationship Between Disabled Child and Natural Sister	FR-IP-SIS
FR:Relationship Between Disabled Child and Step Brother	FR-IP-SBRO
FR:Relationship Between Mother and Step Daughter	FR-M-SDAU

FR:Relationship Between Mother and Step Son	FR-M-SSON
FR:Relationship Between Step Father and Daughter	FR-SF-DAU
FR:Relationship Between Mother and all the Children	FR-M-CHDS

C. PERSPECTIVES OF THE DISABILITY

PD:Effects of Disability on Mother	PD-EFFDIS-PC
PD:Effects of Disability on Past Marriage	PD-EFFDIS-XMARR
PD:Effects of Disability on Remarriage	PD-EFFDIS-REM
PD:Strengths of Primary Caregiver	PD-STRGTH-PC
PD:Weaknesses of Primary Caregiver	PD-WK-PC
PD:Primary Caregiver's Time with all Children	PD-PC-TIME-CHDS
PD:Primary Caregiver's Time with Disabled Child	PD-PC-TIME-IP
PD:Primary Caregiver's Time with Spouse	PD-PC-TIME-SP
PD:Alternative Care for Disabled Child	PD-ALT-CAR
PD:Maintaining Disabled Child at Home	PD-MAINT-HOM

D. FAMILY STRESS

FS:Stress on the Blended Family	FS-STR-FAM
FS:Stress on the Primary Caregiver	FS-STR-PC
FS:Stress on the Remarriage	FS-STR-REMARR

E. COPING STRATEGIES

CS:Professional Resources	CS-RES-PRO
CS:Family Resources	CS-RES-FAM
CS:Friends and Co-Worker Resources	CS-RES-FR/CO
CS:Spouse as a Resource	CS-RES-SP
CS:How Primary Caregiver Copes	CS-COPING-PC
CS:How the Step Father Copes	CS-COPING-SF

F. PAST AND FUTURE PROCESSES

P:Transition from Single Parenthood to Remarriage	P-TRANSSP-REM
P:Single Parenthood	P-SING-PAR
P:View of the Family	P-VIEWFAM
P:Future of the Family	P-FUT-FAM
P:What has been Learned	P-LEARN

APPENDIX L

DEFINITIONS OF CODES

A. D:	All demographic data on the blended family.
FAM-INC	The total family income before deductions in 1994.
K-INH	The number of biological children living in the blended family home.
K-OUTH	The number of biological children living out of the blended family home.
ETHN-PC	Mother's ethnic background.
ETHN-SF	Step Father's ethnic background.
EDUC-PC	The education level completed by Mother.
EDUC-SF	The education level completed by Step Father.
AGE-IP	The age of the disabled child as of the interview date.
OCCUP-PC	The occupation of the Mother.
OCCUP-SF	The occupation of the Step Father.
AGE-SEX	The ages and sex of both biological children of Mother and Step Father.
BIOCH-PC	The number of biological children the Mother has.
BIOCH-SF	The number of biological children the Step Father has.
XMARR-PC	The number of times the Mother has been married.
XMARR -SF	The number of times the Step Father has been married.
YRSPAST-M	The number of years Mother was in past marriage.
YRSPRES-M	The number of years Mother is in present

- marriage.
- CARREQ-N How much care the disabled child requires now.
- CARREQ-F How much care the disabled child requires in the future.
- DESC-DIS The description of the child's disability.
- B. FR: The relationships between members of the blended family.**
- IP-NF Relationship between the disabled child and the natural father.
- M-SF Relationship between the Mother and the Step Father.
- IP-M Relationship between the disabled child and the Mother.
- IP-SF Relationship between the disabled child and the Step Father.
- IP-BRO Relationship between the disabled child and his/her natural brother.
- IP-SIS Relationship between the disabled child and his/her natural sister.
- M-SDAU Relationship between Mother and Step-daughter.
- M-SSON Relationship between Mother and Step-son.
- M-CHDS Relationship between Mother and all her natural and step children.
- SF-DAU Relationship between Step Father and Daughter.
- C. PD: Mother's perspective of the effects of the child's disability on herself and the blended family.**
- EFFDIS-PC The effects of the child's disability on the Mother.

- EFFDIS-XMARR The effects of the child's disability on the Mother's past marriage.
- EFFDIS-REM The effects of the child's disability on the remarriage.
- STRGH-PC The Primary Caregiver's strengths caring for disabled child.
- WK-PC The Primary Caregiver's weaknesses caring for disabled child.
- PC-TIME-CHDS The amount of time Mother spends with other children in the blended family.
- PC-TIME-IP The amount of time Mother spends with disabled child in the blended family.
- PC-TIME-SP The amount of time Mother spends with Spouse in blended family.
- ALT-CAR Primary Caregiver's perspective of obtaining alternative care for disabled child.
- MAINT-HOM Primary Caregiver's perspective of maintaining the disabled child at home.
- D. FS: The stresses experienced by members of the blended family.
- STR-FAM The stressors on the blended family as a whole.
- STR-PC The stressors on the Mother (Primary Caregiver).
- STR-REMARR The stressors on the remarried couple.
- E. CS: Strategies used by the blended family to help cope with the stressors.
- RES-PRO The professional resources the blended family uses.
- RES-FAM Extended family resources used by the blended family.

RES-FR/CO	Friends or Co-workers as resources.
RES-SP	Spouse as a resource for Primary Caregiver.
COPING-PC	How the Primary Caregiver copes with stresses by herself (on her own).
COPING-SF	How the Step Father copes with stresses by himself.
F. P:	The processes or changes over time. Also the transition periods and past and future views of the blended family.
TRANSSP-REM	The transition period from single parenthood to remarriage.
SING-PAR	The experiences of single parenthood for the Primary Caregiver.
VIEWFAM	Primary caregiver's view of the blended family.
FUT-FAM	Primary Caregiver's view of the future of the blended family.
LEARN	What the Primary Caregiver learned from her experiences caring for a disabled child within a blended family system.