The influence of parent gender on division of work in families of children with disabilities

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The influence of parent gender on division of work in families of children with disabilities

by

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A Dissertation Submitted to the Graduate Faculty in Partial Fulfillment of the Requirements for the Degree of DOCTOR OF PHILOSOPHY

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CHAPTER ONE: RESEARCH PROBLEM

Introduction

Public Law 99-457 (PL 99-457), the 1986 Amendments to the Education for all Handicapped Children Act, mandates that early intervention programs for children with disabilities between the ages of birth and three years develop Individualized Family Service Plans (IFSP's). Early intervention programs are now required to focus on the whole family rather than just on the individual identified as having special needs (Krause, 1993). With the implementation of this family focus, program developers will not only need to plan with the family needs in mind, but also with knowledge of how the intervention process affects family members, their interactions, and their gender.

Research has shown that mothers and fathers view and react to their child with disabilities very differently. The research regarding gender-specific attitudes toward children with disabilities has been sparse, with differing results. For example, some investigators have found that fathers of children with disabilities have greater levels of stress associated with their child's temperament (Noh, Dumas, Wolf, & Fisman, 1989), while mothers of young children with disabilities have been found to have higher levels of stress and depression (Beckman, 1991; Bristol, Gallagher, & Schopler, 1988). Fathers have been shown to have increased levels of stress due to their children's inability to communicate (Frey,
Greenberg, and Fewell, 1989) and around their feelings of attachment for the children (Beckman, 1991). Mothers reported more depressive symptoms and family disruption than did fathers, and fathers of children with disabilities assumed less responsibility than did comparison fathers for child care, according to the findings of Bristol, Gallagher, & Schopler (1988). These findings dispute the earlier findings of Gallagher, Scharfman, and Bristol (1984) that no difference was found in the level of father involvement in child care tasks with children with and without disabilities. Pleck (1989) and Ninio & Rinott (1988) also found that fathers are less involved in caretaking tasks, but Tallman (1965) found that fathers of children with disabilities became highly involved in child care, but only with boys. Other research has shown that fathers are more affected by the gender of the child with disabilities than the mother is, causing fathers to be at high risk for not developing strong effective ties to their young sons with disabilities (Frey, Greenburg, and Fewell, 1989, Krause, 1993; Meyer, 1986).

Maternal Emphasis in Research

Despite the findings of the articles cited above, research continues to focus on the parental subsystem in terminology only. "Taking gender seriously has until recently mostly meant taking women into account" (Morgan, 1981, as cited in McKee & O'Brien, 1983). Even those studies that presume to study parents of children with disabilities are
often studies of maternal attitudes or research about fathers' attitudes derived from or through the influence of the mothers (Bailey, Blasco, & Simeonsson, 1992; Cooper & Allred, 1992; Gallagher, Cross, & Scharfman, 1981; Krause, 1993; Linder & Chitwood, 1984; McKee & O'Brien, 1983; Meyer, 1986; Schilling, Schinke, Kirkham, 1985; Traustadottir, 1991; Willoughby & Glidden, 1995; Young & Roopnarine, 1994). McKee and O'Brien (1983) found that husbands and fathers were generally inaccessible for research, that research was dependent on wives/mothers as a point of entry, and that wives needed to be won over to give permission for husbands to be approached. In fact, in their research study, McKee and O'Brien (1983) noted that five of thirteen wives were present during their husbands' interviews, even though the wives had already completed their interviews, and it had been made explicit that the emphasis was on the husband. Likewise, Linder and Chitwood (1984) had to eliminate 13 of 152 questionnaires sent to fathers concerning their needs in relation to their child with disabilities, due to the fact the mothers had filled the survey out for the fathers.

Initially, this research study was designed to examine the impact of intervention on families. However, as the study progressed, it became increasingly interesting to the research team, that although we were discussing impact on families, we were usually considering impact on mothers.

Many factors have affected this maternal emphasis on
programs and research. Except in rare cases, it is usually mothers who care for children with disabilities (Bristol & Gallagher, 1986; Cooper & Allred, 1992; Erickson & Upshur, 1989; Harris & McHale, 1989; Ninio & Rinott, 1988). Fathers, most often the primary wage earners for families, have been unavailable for interviews, or have been assumed to be unavailable, uninterested, or uninformed (Davis & May, 1991; McBride, Brotherson, Joanning, Whiddon, and Demmitt, 1993). For whatever the reasons, more often than not, fathers have been excluded from the research process when looking at families of children with disabilities.

**Purpose of Study**

The purpose of this study is to examine the influence of gender in families of children with disabilities on family perceptions, interactions, and work roles. When possible, the male role was examined from both the female and the male perspective to gain a more reliable picture of the family.

**Research Questions**

Initially, research questions are planned and clarified to formulate the framework for the investigation (Brotherson, 1993). It is up to the researcher to determine what aspect of data collection best facilitates the purpose of the study. Important aspects to consider are: who is the intended audience; what kind of information does the researcher seek; and what is the theoretical perspective of the researcher (Brotherson, 1993). This research is based on a theoretical
orientation of systems theory. The following are the research questions which guide the study:

1. What is the relationship between parent gender and family and child characteristics in the family of a child with disabilities?

2. How does gender influence parent perceptions and interactions in the family of a child with disabilities?

3. How does gender influence social and work roles (functions) in the parents of a child with disabilities?
CHAPTER TWO: REVIEW OF THE LITERATURE

This review will examine family characteristics, family perceptions, and family interactions literature in the first segment of the review, under Family Systems Framework. The section following it will review family work and social roles and family social support. These issues will be reviewed in greater depth as they relate directly to the influence of gender on families.

Family Systems Framework

Because children are one subsystem of a family, it makes sense to examine the issues of families of children with disabilities within a family systems framework. A family systems framework helps the researcher to gain a more complete understanding of the impact of each family's unique characteristics, patterns of interactions, beliefs and perceptions, work and social roles (functions), and family life cycle (Brotherson, Oakland, Secrist-Mertz, Litchfield, and Larson, 1995).

Family Characteristics

Several variables can help to define the way a child with a disability affects a family. First, the characteristics of the disability are a major factor in determining how the family will respond to the disability. These characteristics can include the nature of the disability, the severity of the disability, and the demands of the disability (Beckman, 1983; Fortier & Wanlass, 1984).
Erickson and Upshur (1989) surveyed 202 families and found that different types of disabilities bring with them different types of demands for families. A malnourished child may need feedings every four hours around the clock for several months. A child with severe motor impairment will need alternative methods of transporting, often including heavy lifting for family members. A child with cerebral palsy is often not able to communicate his/her needs to the family member. This lack of communication can become extremely draining on the caretaker.

Second is the severity of the disability. Severe disabilities are usually diagnosed earlier than are mild disabilities as they are more visible. This may help to explain a child's condition or behavior, or it may place a child's family under more social stigma or rejection (Turnbull & Turnbull, 1990; Wikler, 1981). A milder disability may cause a sense of relief, or it may precipitate a sense of guilt for not noticing it sooner (Lonsdale, 1978; Walther-Thomas, Hazel, Schumaker, Vernon, & Deshler, in press). An earlier diagnosis may help a family to accept the diagnosis and implement intervention services, while a more mild disability, diagnosed at a later time, may involve extended confusion and frustration (Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986).

The demands of the disability also impact the effect on the family (Beckman, 1983). Beckman found that,
66% of the variance in mothers' stress could be accounted for by the unusual caretaking demands of infants with disabilities, including fussiness, irritability, and lack of responsiveness. An older child with a physical disability may require feeding, toileting, catheterization, medication, lifting, bathing, dressing, or other physical care that most children of the same age provide themselves (p. 26).

A couple's tag-team approach to feeding throughout the day and night may cause strain on their marital relationship. Inability to find respite care may inhibit family outings or other family activities. Bristol & Schopler (1983) found that families go out less often because they may fear episodes of tantrums or aggression in public. Long-term planning and financial strain are also associated with demands placed on families with children who are profoundly/severely disabled (Harris & McHale, 1989; Herman & Thompson, 1995).

Family characteristics, including size and form, cultural background, and socioeconomic status, are all important in determining the impact of the disability on the family (Hanson & Carta, 1995; Harris & McHale, 1984; Turnbull & Turnbull, 1990). Some research studies have shown that larger families are less affected by children with disabilities than are smaller families. Trevino's (1979) research of siblings of children with disabilities, found that the availability of more family members to absorb chores and work related to the
disability, may be a contributing factor. Powell and Ogle (1985) also studied sibling of children with disabilities and suggest that there may also be more children to fulfill the parents' expectations for achievement than in families with one or two children. Turnbull and Turnbull (1990), from their extensive research of families with children with disabilities, note that "Parents may be more philosophically accepting of the exceptionality when the presence of other children without exceptionalities serves as evidence that they are capable of producing 'normal' children" (p. 28).

Form is another important variable in examining families with children with disabilities. Two-parent homes may be much more successful in dealing with the stressors that go along with a child with special needs. However, two-parent homes with blended families may have added stressors which could add more tension to an already strained family situation.

Ethnicity and culture are important in determining how the family accepts and responds to the child with disabilities (Gfellner, 1990; Hanson, Lynch, & Wayman, 1990; Krahn, 1993), and can influence families' willingness to access service agencies (Krahn, 1993). Religion and involvement of extended family members can be aspects of culture that impact the manner in which the family accepts and copes with a child with special needs (Rogers-Dulan & Blacher, 1995). Extended family members that are willing, available, and capable of caring for a child with disabilities can favorably impact respite for the
family (Herman & Thompson, 1995). However, extended family that is unable to accept the child with disabilities or that pushes unwelcome advice may affect a family adversely. Culture can also impact the acceptance and care of a child with disabilities. Traditionally, American mothers have assumed, or have been given, the primary responsibility for rearing their children. Previous generations have relied upon grandmothers, siblings, and parental substitutes to help care for the children (McGoldrick, 1989). A child with disabilities may require extra time and related work, and extended family members may not be available due to geographic or employment conflicts.

The traditional American culture also reinforces the launching of children, at least by age 18 (McGoldrick, 1989). Again, this cultural expectation may be at odds for families whose children may never be able to live independently.

Socioeconomic status, including income, education, and implied social status, may also impact the family with a child with disabilities (Farber & Ryckman, 1965). Farber and Ryckman, in their classic study associated "tragic crisis" with high SES, and "role organization crisis" with lower SES (1965). Higher SES families are more achievement oriented and may be very discouraged by the impact of a severe disability on their child's future; hence, a "tragic crisis". Farber and Ryckman (1965) also found that lower SES families were more often impacted by problems associated with how to care for
their child, a "role organization crisis", as they may often regard achievement as less important than family unity.

Higher SES families were also found to express a higher need for control of the environment, compared to lower SES families, who may have believed the environment can not be controlled (Farber & Ryckman, 1965). Farber and Ryckman (1965) noted that this may influence lower SES families to be unprepared for changes in programming and services and may facilitate a belief that it is useless to be active participants in decision making.

Income may impact availability of respite services, of supplemental insurance, and of paid help in the home. Middle income and lower income level people may be impacted, often having too much money to receive financial aid but not enough to purchase additional services or equipment. Despite enormous expenditures made through governmental subsidies, the needs of individuals with disabilities and their families often are not satisfied because, "most programs...are not designed to help all family members or to help the family learn to meet all of its obligations, functions, and responsibilities" (Bass, 1996, p. 44). The need for supplemental income may influence the decision regarding the wife's employment outside the home. Health care benefits may also influence a couple's decision regarding paid employment, as some insurance companies will pay for nursing service in the home only if both parents are employed full time.
"Preexisting conditions" on insurance policies might also dictate who continues to work full time outside the home and dictate who has or does not have opportunities to change employment and, possibly social status.

**Family Interactions**

The family is actually several parts acting together to form a whole. Therefore, interactions with a child with disabilities will necessarily impact other interactions within the family and with relationships outside the family, including social and work relationships (Harris & McHale, 1989; McGoldrick, 1989; Minuchin, 1974). A child who must eat every hour during waking hours or each four hours through the night will impact the amount of sleep and/or patience the caregiving parent will have, which may in turn impact the relationship between the parent and other children, the parent and the child requiring the extended care, and the parent and his or her spouse (Brotherson, et al., 1995). In addition, the parent who continually functions on little sleep or has a child with high care-taking demands, may possibly have impaired ability and/or relationships (Beckman, 1983). Siblings of children requiring attention may develop behavior problems to demand their share of attention (Powell & Ogle, 1985).

The couple subsystem can be seriously challenged by adding a child with disabilities, but the disability can also serve as a source of strength. (Turnbull and Turnbull, 1990).
Gath (1977) compared 30 couples with children with Down Syndrome. Although she found greater marital disharmony in the couples with children with disabilities, she also found positive effects in the couples with children with disabilities. How effectively this experience is shared can lead to marital disharmony or to a stronger marriage (Kazak & Marvin, 1984). Kazak and Marvin (1984) compared marital stress in 56 couples, half with children with disabilities and half with children without disabilities, and found no significant difference between them. They also found that almost half of the couples with children with disabilities reported stronger marriages.

Interactions with others may also help the couple to define its individual roles. Some parents look for outside supports for information about the disability or for connection. Social support from extended family, from coworkers, from organizations and professionals, and from each other can also help each member of the couple to define his/her role.

Family Perceptions

A family defines itself in part by the way its members perceive their roles and their work in the family (Turnbull & Turnbull, 1990). The way each member of the couple perceives his/her role may change after the birth of a child with disabilities. A mother who has planned to stay home with her young child to care for him/her may feel overwhelmed and
inadequate to meet the child's demands. She may also find that, unlike "normal" children, her child does not become more independent developmentally; thus, her commitment is indefinite (Wikler, 1981). The way her spouse responds to this dilemma may redefine one or both of their roles.

The couple's perceptions and expectations of themselves, of their relationship with their child, and of the disability will help to define the couple's roles for themselves and for each other (Turnbull & Turnbull, 1990). The father's usual roles of playmate and male role model will need to be redefined (Gallagher, Cross, & Scharfman, 1981; Meyer, 1986). Mothers may also have expectations for relationships with their offspring that may not fit with the child's disability. Parents, especially fathers, often see their children as extensions of themselves (Meyer, 1986). When the child has a disability, the parent must find a new way to see this child, as the previous view becomes too painful. Krahn (1993), in her article discussing social support in families of children with special needs, states, "Emotionally, parents must learn to live with the child's condition and revise their earlier dreams and expectations, concurrently assessing and sometimes challenging professional recommendations and available services" (p. 236).

The way the family copes with and comes to think of the disability over time may help it to form new expectations. For example, a father who anticipated his relationship with
his son as physical and playful may come to see the relationship as nurturing or spiritual.

**Social Roles and Family Work**

The actual definition of the work roles (functions) is based on the combined effect of the family characteristics, family interactions, and family perceptions and expectations over a period of time (Brotherson, et al., 1995). This means that work roles will be fluid, constantly adapting to meet the changing expectations, interactions, and characteristics throughout the life cycle.

An important aspect in understanding family systems is the understanding of gender. The use of the term "gender" in this paper is intended to refer to the social construction of femininity and masculinity. Role can be defined as a socially expected behavior pattern usually determined by an individual's status in society. The term "social role" is a set of norms used to explain behaviors and attitudes that are prescribed to a certain set of persons (namely mothers and fathers). "Sex roles" is not used here, due to its association with biology and sexuality, and neither is "gender role". As Lopata and Thorne (1978) point out, gender is not a role.

Komarovsky, (1992) in her writings on social roles, elaborates on the confusion regarding the terminology of gender roles, noting that reality demands a greater complexity for gender than the two-fold categorization of male/female.
As she points out, social norms of woman-to-woman and woman-to-man interaction complicate the "doing" of gender. Mothers must be aggressive in protecting their children. Women are encouraged to be competitive with other women via their charm and attractiveness. However, it is unacceptable for women to be competitive or aggressive when dealing with men.

History of women's roles

One cannot look at gender and at its influence on social roles without a basic understanding of the history of the oppression of women in our society. In the late eighteenth century, the involvement of middle class women in volunteer work was legitimized, although paid employment was frowned upon. The woman's rights movement, beginning in 1848 and lasting until 1920 with the passage of the Nineteenth Amendment, was the impetus for the emergence of women, especially married women, into white-collar occupations (Kandal, 1988). With these changes in the status of women in the workforce came changes in clothing styles, family relations, child care, education, and sexual mores. During the Great Depression, women were affected by numerous discriminatory state laws (Kandal, 1988). During the New Deal, the National Recovery Administration coded lower wages for women than for men doing the same work, and union contracts followed suit. Because most women worked only part-time or in domestic service, more women than men were excluded from New Deal reforms, and many teachers and government
employees were fired simply because they were women and married (Kandal, 1988).

In the period 1940 - 1945 the family as it had been known, ceased to exist. Due to the war, the industrial employment of women was predominant, and the fathers were absent from the home. With the end of the war the men returned from the military to reclaim their jobs and their work in the public sphere (the economy). Women were forced back to their kitchens and to the Victorian ideology of a full womb and selfless devotion to husband and children (Kandal, 1988). Despite the effects of the cold war, both married and unmarried women continued to enter the workforce comprising over 60 per cent of all additions to the workforce between 1949 and 1959 (Kandal, 1988). Even with their influx into the work market, women were not taken seriously as employees. Mumford & Banks (1967) noted that women will accept routine jobs that are unlikely to lead anywhere. "For most of them matrimony is their principal objective or interest and work is regarded as temporary and incidental..." (cited in Brown, 1991, p. 146).

The number of mothers employed outside the home has continued to rise. By 1993, nearly 60% of married women with children under age six participated in the paid labor force (Hanson & Carta, 1995). These figures indicate the increasing number of mothers who are experiencing the added burden of involvement in the workforce while maintaining a home and
family.

**Double burden for women**

Today, women continue to be an integral part of the workforce and are still made to choose (at some level) between career and family. As a society we have been unable to mitigate the double burden which biology and society have combined to place on women (Kandal, 1988). In Talcott Parson's words: "Women bear and nurture infants, and men, being exempted from these tasks, therefore specialize in a more instrumental direction." (as cited in Kandal, 1988, p.234).

With this double burden in mind, several studies have been conducted to examine the work role of adult family members. The literature has shown that even in egalitarian couples, social and work role differences become more obvious after the birth of a child (Darling-Fisher & Tiedje, 1990). When the child has disabilities, though, the trend is for the couple to revert to the traditional roles of the male breadwinner and stay-at-home mom (Gallagher, Cross, & Scharfman, 1981; Meyer, 1986). Schilling, et al. (1985) concur, noting that when a child requires increasing parental concern, Dad often retreats to work while Mom decreases her time at work, being much more likely to sacrifice her career to care for the child than will her husband. This is a logical choice, however, due to the fact that our social structure often discriminates financially against women in the workforce.
Studies have shown that wives holding paid employment spend less time on household tasks (excluding child care) than do wives not holding paid employment, however, reduction in family work is not commensurate to increased time in paid employment (Blood & Wolfe, 1960; Walker, 1969; Robinson, Juster, & Stafford, 1976, as cited by Pleck, 1989). Walker, in his 1970 study of husband's role performance, found that there was no variation in husbands' mean time in family roles (ave. 1.6 hours per day) associated with their wives' employment status. Numerous other studies of parents of children without disabilities support Walker's findings. When both parents in a family work, husband involvement in domestic tasks, including child care, does not increase (Baruch & Barnett, 1986; Darling-Fisher & Tiedje, 1990); Shelton, 1990; Willoughby & Glidden, 1995). However, Walker's study did find that husband's family time did increase to 2.1 hours per day when a child under age two was present in the home. Walker (1970) notes however, that, though both men's and women's family roles vary according to their employment status, fully employed men still do only a fraction of family work that fully employed women do - about one third. Because women's increased employment in the workforce has encouraged a fragmented reduction in women's family role, but almost no increase in men's family role, women face exhaustion and stress in both their work and family roles. This is especially significant in families of children with
disabilities. Bristol, Gallagher, and Schopler (1988) studied the relation between spousal support and measures of parental adaptation. They found that fathers of children with disabilities participated significantly less in caring for their children than did fathers of children without disabilities, regardless of whether or not the mothers worked outside the home. Young and Roopnarine (1994) found otherwise in their research with fathers of children with and without disabilities. Their results support the conclusions of Walker (1970), finding that fathers spent about one third of the time in the provision of child care in comparison to the mothers of both those groups. When a child with disabilities is present in the home, childcare and house work take much more time (Bailey, et al., 1992; Schilling, et al., 1985). Work force participation often exacerbates the demands of caring for children with special needs, as there are more total demands on the parents. However, it may balance the additional demands by offering the mother a satisfying role outside the home (Willoughby & Glidden, 1995). Maternal work outside the home may also increase the family income enough to provide paid domestic/child care assistance, decreasing the mother's burden. Shelton (1990), who examined the relationship between wife's employment and the distribution of household tasks, sums up wife's employment this way,

It is possible that maternal work force participation influences different families in different ways. For
some, it may be an added strain that exacerbates the demands of caring for a child with special needs by tapping limited time and energy resources. For others who derive satisfaction from work participation, it may be seen as a break from caretaking demands. (p. 404)

The media reflects a belief that fathers are becoming more involved in child care and household work. Fathers are known to be present at births, and advertisements show fathers cleaning toilets, making dinner, and caring for children. However, according to LaRossa (1988), "the culture of fatherhood has changed more rapidly than the conduct" (p. 452). Even though both men and women report that they support an egalitarian approach to child care and household work, few of these people follow through in their own homes (Ferree, 1991; LaRossa, 1988).

One suggestion to accommodate the added burden to women's roles is to end the sex-segregated and unequal division of household work and child care. However, Pleck (1989) notes, "Expansion of the scope of the male family role without accommodating changes in the male work role will lead to role strain in men similar to the role strains now faced by working wives" (p. 167).

**Paternal influence**

Research has reflected an assumption that men's contribution to family work roles is unvarying and of little conceptual significance (McGoldrick, 1989). Economic
literature on the labor supply response uses different analytic models for husbands and wives, causing men's actual participation in family roles to be analytically invisible (Pleck, 1989). Research has continually questioned the inherent psychological harm to children thought to be caused (incorrectly) by maternal employment, but has rarely asked whether, much less how, paternal employment may effect children (Pleck, 1989). May (1986) citing Parke in Parke's book, Fathers, quotes, "We didn't just forget fathers by accident; we ignored them because of our assumption that they were less important than mothers in influencing the developing child" (p. 65).

Additionally, it is not clear how maternal employment may influence fathers' parenting involvement (Bronfenbrenner & Crouter, 1982). Stanley, Hunt, & Hunt (1986), in their survey research of 1,025 spouses who were employed outside the home for at least twenty hours per week, found that, "Whether through the direct effects of participation in child care or the indirect impact of the overload on an employed wife, a dual-earning household with children is not optimal for men of ambition" (p. 18). They further hypothesized that "Avoidance of housework, inadequate parenting, domestic violence, and high divorce rates may be among the consequences of men's sense of relative deprivation in a society in which the most rewarded and esteemed continue to be men of conventional family circumstances" (p. 18).
Research by LaRossa (1988) suggests that both women and men see father's role in the home as involved but not responsible. LaRossa (1988) explains, "Responsibility has to do with who is accountable for the child's welfare and care. Responsibility includes things like making sure that the child has clothes to wear and keeping track of when the child has to go to the pediatrician" (p.452). He further states that women are responsible for most child care activities, even though their husbands occasionally "help out" with the children (LaRossa, 1988). Crouter, Perry-Jenkins, Huston, & McHale (1987) in their research of father involvement in dual and single earner families, support LaRossa's findings. They claim that fathers increase participation in child care activities only after their wives ask for help, rather than initiating any effort on their own.

A recent article by Turbiville, Turnbull, and Turnbull (1995) does address the influence of the father's positive relationship with his child. They cited studies that support the idea that the father-child relationship does indeed influence the cognitive, social, and sex-role identification in children. However, even though there are some studies identifying the positive influence of fathers on their children, there is very little information regarding the influence on children with disabilities.
Structural buffers

Pleck (1989) discusses two structural buffers in the work-family role system. Buffers determine if change in one role (such as the extra time required to care for a child with disabilities) will lead to accommodating change in another role to which it is linked (such as the husband's contribution to family work). Structural buffers (Pleck, 1989) in the links among the roles limit the amount of change one role has on another.

The first buffer, sex-segregated market mechanisms, applies to both paid and family work. In paid work, women often times do not compete with men for the same jobs. Pleck (1989) states that, "Women are not only filling different kinds of jobs, but are in inferior positions" (p. 164). Therefore, women will usually have jobs of lower status than men, and will not be psychologically threatening to their husbands or co-workers (Pleck, 1989).

Household work and child care can also be viewed as sex-segregated, dual market. This is supported by the ideology that there are particular household activities suited to each sex and by the fact that there is differential training provided in family work (Pleck, 1989; Thompson, 1991). The result is that if the wife decreases her family role work, even if the husband perceives that the work needs doing, he will not perceive the kind of work needed as suitable to him, so his role performance will not likely increase (Pleck,
1989). For example, the wife becomes employed outside the home and does not keep up with the laundry as she had done before. The husband notes that the laundry is not being done, but he does not see laundry as work he should assume. He has not been taught how to do laundry by his parents or by his wife (differential training), nor was it modeled as appropriate by his father (sex-segregated work). Therefore, he may not assume an increase in family role work.

The second structural buffer in the work-family role system is the asymmetrically permeable boundaries between work and family roles for both men and women. For women, family needs may, and often are expected to, overlap into the paid work role. Mothers are the first ones called to make arrangements for sick children and emergencies at school. Traustadottir (1991) notes that most women have managed to enter the arena of paid work, but boundaries are fragile. She states,

As soon as there is an increased demand for traditional woman's work within the home - such as caring for a child with disabilities - the boundaries shift and women come under tremendous pressure to leave the public arena and go back into the home. (p. 225)

Working women often try to accommodate both the roles of employee and mother/wife; however, "the demands of the family role are permitted to intrude into the work role more than vice versa" (Pleck, 1989, p.166). Baruch and Barnett (1986),
in their study of 160 parents of non-disabled children, found that,

Among fathers, although performance of child care tasks significantly predicts a father's greater sense of involvement with his child, it also predicts negative outcomes, such as dissatisfaction with the time the wife spends with the children and his reporting that his family responsibilities interfere with his work and that the wife's work interferes with her family responsibilities. (p. 990)

Men are expected to "manage" their families. Family responsibilities are not to interfere with their work; in fact, families should make the necessary adjustments to accommodate the demands of the husbands' work roles (Pleck, 1989). This boundary is also permeable, but in the opposite direction. Husbands often take their work home, displacing their family time.

**Maternal work**

In her writings, "Maternal Thinking: Towards a Politics of Peace", Ruddick (1989) emphasizes a different type of family work for mothers. According to Ruddick, three demands - for preservation, growth, and social acceptability - constitute maternal work. The first demand, preservation, is indicative that children share prolonged physical fragility and prolonged dependence on adults for their safety.

Second, Ruddick (1989) notes that all children are
complicated individuals and demand spiritual, intellectual, and emotional nurturance. Many persons share interest and involvement in a child's growth, but, "it is a mother who considers herself and is considered by others to be primarily responsible for arrested or defective growth" (p. 20). According to Schilling et al., (1985) this may be partially due to the idea that, because women are the ones who give birth to the child with disabilities, they are more apt to feel responsible for a disabling condition.

The third demand is not based on children's needs but is set by the social groups to which mothers belong. Social groups define the acceptable ways in which a mother must shape her child. What qualifies as acceptable varies from one culture to another but the demand for acceptability does not. Ruddick (1989) explains:

A mother's group is that set of people with whom she identifies to the degree that she would count failure to meet their criteria of acceptability as her failure. The criteria of acceptability consist of the group values that a mother has internalized as well as the values of group members whom she feels she must please....Mothers want their children to grow into people whom they themselves and those closest to them can delightedly appreciate. This demand gives an urgency - sometimes exhilarating, sometimes painful - to mother's daily lives. (p. 21)
Traustadottir (1991), in a qualitative study of 14 families of children with disabilities, looked at caring as another form of maternal work. She notes that caring is seen as the responsibility of women and that the division of labor assigns her far more responsibility for caring than it does for men. Traustadottir defines three types of caring:

1. Caring for: work The kind of work women do is different when caring for a child with disabilities. It usually requires more knowledge and technical information. This is not just traditional mothering.

2. Caring about: love Mother is seen as a natural caregiver in terms of doing the work and giving the love. Often this can put tremendous pressure on the mother who equates these roles. If the mother wants help in caring for (doing the work) she may feel that she does not care about (love) the child enough. This may put even more pressure on mothers to take on traditional role of selfless devotion to the child and family.

3. Extended caring role: Mothers often see their work as extended into the community, raising awareness, leading support groups, or advocating for change. This allows mothers an opportunity to extend their work to more career-type work.

Traustadottir (1991) also noted that all the mothers in her study were expected to take primary responsibility for the work that kept the child with disabilities within the family. It was the mother's decision to keep the child within the
family, and with that decision seemed to go the understanding that Mom would do the work. This was usually a very limiting role for the mothers, as Traustadottir notes (1991) and Cooper & Allred agree (1992), mothers of children with disabilities often arrange their entire lives around their child with disabilities. Interestingly, though, "...the majority of parents did not seem to define it as limiting to have a child with disabilities if it only limited the mother's life..." (Traustadottir, 1991, p. 223).

**Decision-making role**

Most often mothers are responsible to search for services and investigate programs, and pass information on to the father (Traustadottir, 1991). There has also been an assumption by professionals that it is the mother who will be responsible to mediate for the family and will give up her career to do so (Traustadottir, 1991). However, Linder & Chitwood (1984), in their study of 152 fathers of children with disabilities, found that fathers were angry and frustrated by inconclusive information provided by physicians through their wives. Cooper and Allred (1992) also note the father's changing role, "Traditionally, mothers have been the link between doctors and their family. But fathers appear to be increasing their involvement with doctors and in the process, are becoming frustrated" (p. 219).

This past lack of participation has not been limited to that between the physician and the father. Turbiville et al.
Note that fathers also received information from their wives regarding their children's participation in early intervention programs. They noted that "if they [fathers] are unable to respond positively to a service provider's first invitation to participate, they are usually not asked a second or third time". (p. 15). Turbiville et al. (1995) hypothesized that fathers may feel unprepared to participate as they have been receiving second-hand information for such a long time.

**Social Support Systems**

**Effects of social support systems**

Social support has been examined from many different perspectives. It has been viewed as services (Krahn, 1993), as resources, tangible goods, and information (Dunst, Trivette, & Cross, 1986), and as relationships (Hirsch, 1980). Krahn (1993) discusses the structural characteristics of support as size, density, multiplexity, and reciprocity. Size describes the number of supportive persons; density refers to the extent of the relationships within the network; multiplexity refers to the number of different forms of assistance; and reciprocity describes the degree of balance between help-giving and help-receiving. Krahn (1993) found that network size and density, which are the typical measurements used to describe social support, indicate that non-working mothers are relatively socially isolated, particularly when they have low financial and educational
resources (Krahn, 1993). This is relevant to families of children with disabilities, as those mothers often are unable to hold paid employment due to the demands of caring for their children.

Reciprocity is also a significant construct for families of children with disabilities. Krahn states, "The norm of reciprocity presumes that persons who by their circumstances are forced to accept assistance without being able to reciprocate are placed in an uncomfortable position that will lead them to take alternative actions" (p. 240). Families of children with disabilities may find themselves in nonreciprocal relationships, especially with family members.

The seeking and receiving of social support is an interactive process. Support seeking behaviors can elicit support needed or discourage the giving of support. For example, Shapiro (1983), in his study of children with physical disabilities, found that mothers may contribute to their own isolation from their spouses by forming intense dyadic relationships with their children with disabilities. Mothers of children with disabilities require more support and assistance from their spouses, but often become more removed from fathers who take on fewer and fewer parental responsibilities (Schilling, et al., 1985). These avoidant behaviors by both parents can keep the mothers from pursuing further interaction, leading to higher stress and lower self-esteem (Schilling, et al., 1985).
Families are supposed to lend support in time of need but
do not always do so effectively. Informal support systems can
have negative results for families. These could include
feeling smothered and controlled, feeling obligated to
conform, and feeling a sense of inadequacy. Morgan (1982)
studied support among family members using focus groups, and
found that 40% of the descriptions of support were negative.
Family members received more negative descriptions than did
non-family members, perhaps due to the possibility that the
family unit may constitute the autonomy of its members. The
family most often wants its members to be self-supporting, but
the family with a child with disabilities may be helpless to
achieve this objective. Young and Roopnarine (1994), in their
research with children with and without disabilities, found
that mothers of children with disabilities said they received
more support from their extended family than did the fathers.
Tallman (1965) noted that traditionally, fathers have been the
primary breadwinners and providers. Recently, fathers have
been less successful as the lone providers for their families.
This factor, paired with the belief that families want their
members to be self-supporting, may make the extended family
seem nonsupportive to some fathers.

**Differences in women's and men's support systems**

Women may seek more support and comfort from other
sources than do men, because women tend to value the fact that
help can come from others (Burda, Vaux, & Schill, 1984; Cooper
& Allred, 1992; Goldberg et al., 1986), and because they develop affectively-richer friendships than men do (Schilling et al., 1985). Goldberg and her colleagues, in their study of 59 families of children with disabilities, found that mothers receive more support from outside the family than do fathers. They believe this may be due to the fact that mothers are more often in contact with professionals, or it might be because there is a general awareness that mothers experience most of the burden of care for these children (Goldberg, 1986).

Generally, mothers draw more from strong networks, usually close friends and family members (Harris & McHale, 1989; Krause, 1993; Schilling et al., 1985). Mothers also use social support more, reporting they must often turn to other women for support needs (Bailey et al., 1992; Schilling et al., 1985).

Men tend to keep problems to themselves (Goldberg, Marlovitch, MacGregor, & Lojkasek, 1986; Krause, 1993). Men usually draw on work associates and relationships are usually less intimate, and physical escape is more likely to be seen in men than in women (Schilling et al., 1985). The problem of male inexpressiveness "lies not in men's inexpressiveness per se, but in the power and investment men hold as a group in the existing institutional and social framework" (Sattel, 1983, p.19). Therefore, the social support group is not viewed as an appropriate place to get intimate support; men draw that from their wives (Krause, 1993; Meyer, 1986).
Social networks decrease in early childhood years for mothers due to increased time at home. During this same period, fathers' social networks note increases in social relationships and rising importance in their careers, so that, at a time when more spousal attachment and support is needed by mothers, it may be most lacking (Schilling, et al., 1985).

**External support systems**

Frey, Fewell, & Vadas (1989) note that a high level of satisfaction with support from family and friends helps to defray the negative effects of events that are unexpected or stressful. Services have responded to needs for more social support by helping to create an expansion of individuals' networks and personal resources, according to Dunst, Trivette, & Deal (1988). However, according to Krause (1993) "...both programmatically and in research, the focus has been on maternal social support networks" (p. 395). Mothers are more likely to have contact with persons who can give supportive counsel, i.e. parents, educators, and professionals (Frey, Greenberg, & Fewell, 1989; Goldberg et al., 1986), and the amount of assistance provided by others is an important aspect of the social network (Bailey et al., 1992; Frey et al., 1989; Krause, 1993). McLinden (1990), in a study of mothers and fathers of children with disabilities, found mothers to have a much higher need for time and opportunity to talk with other parents of children with disabilities. Mothers have a more broad based view of support and don't tend to separate
personal and family concern, unlike fathers who do differentiate family needs from individual ones (Bailey et al., 1992).

The review of the family systems literature has shown that the family can be impacted in several ways. The nature, severity, and demands of the disability help to define how the family responds to the disability (Beckman, 1983; Fortier & Wanlass, 1984). Family characteristics, including size and form, cultural background, and SES are all important in determining the impact of the disability on the family (Hanson & Carta, 1995; Harris & McHale, 1984; Turnbull & Turnbull, 1990). The demands of caring for a child with disabilities impacts the relationships between the child and other family members and also impacts the relationships family members have with others, both within and outside the family (Harris & McHale, 1989; McGoldrick, 1989; Minuchin, 1974). The literature has also shown that the couple's perceptions and expectations of themselves, of their relationship with their child, and of the disability will help to define the couple's roles for themselves and for each other (Turnbull & Turnbull, 1990).

The history of women's roles in society shows that there is a double burden on women. Women are often forced to choose between career and family, or end up assuming responsibility for work both inside and outside the home. Many women continue to enter the work force, but husbands' involvement in
domestic work is not commensurate to the women's decrease in domestic work. The demands of having a child with disabilities exacerbate the role of the mother which is already strained.
CHAPTER THREE: METHODOLOGY

Qualitative Research Design

Many researchers believe that the quantitative paradigm has limited our understanding of children and families (Brotherson, 1993). Qualitative research methodology is appreciating a resurgence of popularity as a valid and reliable method to study families. It is based on a theoretical position referred to as phenomenology (Stainback & Stainback, 1984b). Phenomenologists seek to understand the perceptions people hold of events in their environments. In order to gain this understanding, qualitative researchers perform meticulous inquiry, observe participants, and conduct indepth interviewing (Stainback & Stainback, 1984b; Taylor & Bogdan, 1984).

There are several assumptions that differentiate qualitative and quantitative paradigms (Brotherson, 1993; Stainback & Stainback, 1984b; Taylor & Bogdan, 1984). One paradigmatic difference is that of nature of reality. The qualitative paradigm holds that multiple constructions of reality exist, and that understanding human relations is a study of interactions, factors, and processes as they are constructed in the minds of people (Stainback & Stainback, 1984b). Qualitative research is inductive, rather than deductive. Concepts, insights, and understandings are allowed to emerge from patterns of response.

Qualitative research is holistic rather than
reductionist. Individuals, settings, families, or other aspects of the phenomenon being explored are not collapsed into preconceived categories or variables, but rather are seen as a part of a larger, complete and interactive system (Taylor & Bogdan, 1984).

Qualitative research is a search for shared meanings and recognizes the effects of the research process upon all the participants, including the inquirer and the respondents (Brotherson, 1993; Stainback & Stainback, 1984b; Taylor & Bogdan, 1984). Qualitative research allows the researcher to understand the respondents from their own frame of reference, the effort being to experience reality as others perceive it (Taylor and Bogdan, 1984). The research is nonjudgemental and views all information as important.

Qualitative researchers view truth as a matter of perspectives (Brotherson, 1993). The emphasis is on developing working hypotheses that can be helpful in understanding similar situations, not on generating universalities that are lasting, context-free truths (Brotherson, 1993). Qualitative researchers strive to represent a true picture of what is being studied, a search for shared meanings.

This research is based on a theoretical orientation of systems theory. Following are the research questions which guide the study:

1. What is the relationship between parent gender and
family and child characteristics in the family of a child with disabilities?

2. How does gender influence parent perceptions and interactions in the family of a child with disabilities?

3. How does gender influence social and work roles (functions) in the parents of a child with disabilities?

Sample

Purposive sampling was used for this study in order to gain the insights of mothers and fathers of children with disabilities. Purposive sampling is based upon specific criteria identified by the researcher as being most relevant to the study (Brotherson, 1993). Within this framework, it was also the desire of the researcher to obtain as much diversity as possible to provide a breadth and depth to the study. In purposive sampling, selection of subjects may change, depending on the collected data and the suggested direction of the research process as to who may add more depth to emerging themes (Stainback & Stainback, 1984a).

The families chosen for this study were part of a larger study conducted jointly with Iowa State University, Iowa Methodist Medical Center, and Smouse Opportunity School, to look at families undergoing intervention around the issues of nutrition. During the 1990-1991 school year, 66 children were referred for in-depth screening. Of this group, 48 children
fell below the 5th percentile of weight for height, and they received full intervention for malnutrition. Evaluation of the program examined the effectiveness of the program on specific child and family outcomes.

Many children with severe disabilities are at risk for malnourishment due to a variety of feeding and nutrition difficulties which may include inability to chew or swallow, inability to absorb nutrients efficiently, constipation, interactions between food and drugs, or an increased need for calories and nutrients (Brotherson, Oakland, Secrist-Mertz, Litchfield, & Larson, 1995). These families often decide to surgically place a gastrostomy tube (feeding tube or G-tube) to help the child gain the necessary nutrition. The G-tube is placed directly into the stomach or small intestine and may be needed for an extended period time or even permanently (Brotherson, et al., 1995).

Ten families were selected that had completed or were currently receiving nutrition intervention. Seven families were from the original group, and three additional families were added who were receiving services from a nearby school system. Table 1 shows the family demographics.

The disabilities of the children vary from very severely disabled to moderately disabled. Diagnoses of the children include cerebral palsy, metochroniatic leukodystrophy, convulsive disorders, visual impairments, neuromuscular disease, CHARGE syndrome, intra-uterine drug exposure, mental
<table>
<thead>
<tr>
<th>Family</th>
<th>Child's Description</th>
<th>Family Structure</th>
<th>Major Caregivers</th>
<th>Primary Source of income</th>
<th>Educational Level of Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Male age 7, CP and MR</td>
<td>Married</td>
<td>2 parents</td>
<td>Both Full-time</td>
<td>Both College degrees</td>
</tr>
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<td></td>
<td></td>
<td>2 parents</td>
<td>Home health aide</td>
<td></td>
<td></td>
</tr>
<tr>
<td>02</td>
<td>Female age 4, CP and MR</td>
<td>Married</td>
<td>2 parents, 1 sibling</td>
<td>Mom Full-time, Dad Graduate</td>
<td>Both graduate degrees</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 parents</td>
<td>Home health aide, nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>03</td>
<td>Male age 5, CP and MR</td>
<td>Married</td>
<td>Mom</td>
<td>Dad</td>
<td>High School Graduate</td>
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<tr>
<td></td>
<td></td>
<td>5 siblings</td>
<td></td>
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</tr>
<tr>
<td>04</td>
<td>Male age 2, MR and Visual Impairment</td>
<td>Single Mom</td>
<td>Mom</td>
<td>Govt. Subsidy</td>
<td>High School Graduate</td>
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<tr>
<td></td>
<td></td>
<td>Boyfriend</td>
<td></td>
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<tr>
<td>05</td>
<td>Male, twin age 3, CP, Visual Impairment</td>
<td>Mom</td>
<td>Mom</td>
<td>Fiance, 2 Siblings</td>
<td>High School Graduate</td>
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<td></td>
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<td>Fiance</td>
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CP=Cerebral Palsy, MR=Mental Retardation
<table>
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<tr>
<th>Family</th>
<th>Child's Description</th>
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<th>Primary Source of income</th>
<th>Educational Level of Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>06</td>
<td>Female age 4</td>
<td>Married</td>
<td>Mom</td>
<td>Dad full-time</td>
<td>Dad High School+</td>
</tr>
<tr>
<td></td>
<td>CP and MR</td>
<td></td>
<td></td>
<td>Mom part-time</td>
<td>Mom High School</td>
</tr>
<tr>
<td>07</td>
<td>Male age 4</td>
<td>Married</td>
<td>Mom</td>
<td>Both parents</td>
<td>Dad High School</td>
</tr>
<tr>
<td></td>
<td>CP and MR</td>
<td></td>
<td></td>
<td></td>
<td>Mom High School+</td>
</tr>
<tr>
<td>08</td>
<td>Female age 5</td>
<td>Married</td>
<td>Mom</td>
<td>Both parents</td>
<td>High School Graduates</td>
</tr>
<tr>
<td></td>
<td>CP,MR,CHARGE</td>
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</tr>
<tr>
<td>09</td>
<td>Female age 1</td>
<td>Married</td>
<td>2 parents</td>
<td>Both parents</td>
<td>Both College Degrees</td>
</tr>
<tr>
<td></td>
<td>CP and MR</td>
<td></td>
<td>2 siblings</td>
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<tr>
<td>10</td>
<td>Female age 12</td>
<td>Married</td>
<td>Mom</td>
<td>Dad Full-time</td>
<td>High School Graduates</td>
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<tr>
<td></td>
<td>CP and MR</td>
<td></td>
<td></td>
<td>Mom part-time</td>
<td></td>
</tr>
</tbody>
</table>

CP=Cerebral Palsy    MR=Mental Retardation
retardation, and seizure disorders.

Of the children chosen for the study, five are female, and five were male. When this study began, six of the children were preschool or school age and attended a public school program at least part time. Four of the children received home-based early intervention services. Six of the children received gastrostomy tube (G-tube) prior to the interviews, three of the children received gastrostomy tubes prior to the conclusion of this research, one child had his gastrotomy tube removed, and one child continues to eat orally. Eight of the ten families continue to receive some type of home intervention services such as a visiting nurse, home health aide, occupational therapist, or physical therapist.

Because the focus of this study is on gender issues, only those families that had both male and female adults living in the home were selected. Eight of the ten couples are married, while two of the couples are composed of one biological parent and an opposite sex live-in companion. One of the couples divorced during the term of the study. Of the ten couples, seven of the women work outside the home, two of them part-time. At the beginning of the study, one of the fathers was not employed outside the home as he was a full-time graduate student. He was employed full-time by the end of the study. Also, at the end of this research, one of the mothersswitched her part-time status to full time, and one of the mothers who
was not employed became employed full-time outside of the home. Six of the ten families receive government subsidy, such as Title 19, Social Security Income (SSI), or the Supplemental Feeding Program for Women, Infants, and Children (WIC). The other families utilize private insurance to assist with their medical expenses. Table 1 provides a summary of demographic information on the families in this study.

All of the couples studied are Caucasian, with low to middle incomes. Most of the families are from Des Moines and its surrounding suburbs, with two families from a near-by large town, and one family from a near-by small town. One of the families is from a rural area. Seven of the families own their own home, one of which is a mobile home. Three of the families rent.

In one of the families, the target child was an only child. Five families had one older sibling, one had one younger sibling, two families included two older siblings, one family contained one older and one younger sibling, and one family had one older sibling and four younger siblings. Five younger siblings were added during the course of the study (three to one family).

Data Collection

Procedure

Incentives Families were reimbursed $100.00 for their involvement in the study. This included two to four interviews and, at times, a videotaping of the child's
mealtime (five families were selected for videotaping).

**Location**  Family interviews were conducted in their home, at a time mutually agreed upon to facilitate their schedules. This was done to encourage participation by both adults in the home and to avoid adding further stress to their routines. It should be noted, however, that we usually had to go through the female in the home to gain access to the male.

**Interviews**  The initial research team was composed of two faculty members, two graduate students, and two undergraduate students. A third undergraduate student was added during the course of the research project. All members of the research team participated in all aspects of the research with the majority of the data collection and analysis having been conducted by the graduate students and faculty members. All first and second interviews were audio-taped and transcribed for content analysis. Some third interviews were also audio-taped and transcribed, while some third and all fourth interviews were recorded with field notes. A total of 33 interviews were conducted with the ten families over a four year span. Seven of the families were interviewed three times, and three of the families were interviewed four times. Five of the first interviews were with the female only, and five were with both parents present, with two of the five fathers joining near the end of the interview in the latter group. Only one interview of 33 was held with the father alone, while eleven interviews were conducted with the mother
alone. A total of nineteen individuals of the ten families were interviewed in the study. Eighteen were parents or significant others, while one interviewee was a sibling. Approximately 650 pages of interview and field note transcription were generated for this study.

The interviewer was responsible to monitor and guide the discussion, to probe, and to clarify when necessary. An assistant interviewer was present at the interviews whenever possible to monitor the taping equipment, to be sure all areas were covered, and to record field notes regarding the interview process, family dynamics, and ideas for future questioning. The assistant interviewer also had a useful role in furthering credibility by discussing field notes and perceptions with the primary researcher immediately following the interviews.

The primary researcher and author of this study is a forty-one-year-old married mother of four boys, ages nine through fifteen years, one of whom has a learning disability. The researcher has fairly strong attitudes and beliefs about gender expectations and work roles in families, and attempts to model those attitudes in her own family. Due to her child's exceptionality, she also has experience and opinions related to the added stress and work needed to care for children with special needs. Although the author's spouse is involved in caring for the children, meal preparation, grocery shopping, and a myriad of other tasks, the majority of
responsibility for home and child management continues to fall upon his wife.

It is certain that these attitudes and beliefs influenced the interpretation of the data to some degree. Rather than attempting to control for these biases, the researcher acknowledged the presence of the values and beliefs and endeavored to heighten her own awareness of them through discussion with colleagues and through the use of field notes. Following are a few of the values/beliefs held by the researcher:

1. Even in couples who believe their relationship to be egalitarian, work is rarely divided equally.

2. When men participate in child care and domestic chores, the work done has often been delegated to them by their wives.

3. Women tend to identify with their roles as mother and manager of the home and may be selective in letting go of certain tasks.

4. Men often appear to lack knowledge of or appreciation for the work involved in maintaining a home and family, especially when a child with disabilities is involved.

5. Men frequently perceive their primary roles as financial providers for their families.

Protocol

Interview questions The interview questions were designed to be semi-structured, open-ended questions to elicit
as much discussion and information as possible. The purpose of the interview questions was to derive contextually-rich information about the family members' experiences and perspectives. The interviews were begun by asking a "lead question" similar to the following:

1. What is it like for your family to implement a feeding intervention?

If family members did not give the information spontaneously in response to the "lead question", the following example questions might have been asked:

2. What are mealtimes like for your family?
3. How does your family deal with the stress of having a child requiring nutritional intervention?
4. If you could rewrite the intervention to meet your family's needs, what would be different?

Caution was taken to not "lead the witness" in that family members were encouraged to relate their own words. Additional probe questions were asked to elicit description, explanation, and/or clarification of responses. Follow-up questions were formulated in response to informants' comments. For example, if the informant stressed a word or phrase, that word or phrase might be fed back to him or her for clarification or amplification. If the informant's statement was vague or incomplete, informants were asked to state more about that theme. In general, the interviewers followed the suggestions of Spradley (1979) and asked descriptive, structured, and
contrast questions if the informants were not complete in their descriptions. These follow-up questions were generally formulated to follow from comments the informant had already made. In short, the interviewer attempted to be led by the informant, rather than lead the informant in a preconceived direction. All interview questions were developed in such a manner. Following are examples of additional probe or follow-up questions:

1. How are different members of your family involved in implementing the feeding intervention?
2. How does the intervention help you or hinder you in meeting the needs of other family members?
3. What kinds of activities and how much time is occupied in family activities outside of feeding?
4. How much has your work outside the home, or your decision not to work outside the home, been influenced by having a child with disabilities?

Follow-up questions: Subsequent interviews were held with the family members to probe additional topics introduced in interviews with other families and to probe more deeply those issues presented in the initial interview. Although there is no preconceived hypothesis, a protocol for follow-up questions was used. Examples of these questions include:

1. How have the work/social roles in your family been determined?
2. What are the stressors that are unique to your role
as mother/father of a child with disabilities?

3. Are there differences and similarities in the manner in which males and females are included in the intervention process? What are the factors contributing to their inclusion/exclusion?

4. Who makes up your social support network, and what qualities were important in the selection of these people?

5. What impact, if any, does having a child with disabilities place on the marital relationship?

Additional questions were again asked to elicit richer description, explanation, and/or clarification or responses. Examples of these include:

1. Has the way in which you perceive your role as mother or father changed with the birth of your child with disabilities? If so, how?

2. How are your social support systems different than those of your spouse? Whom did each of you turn to for support in the initial stages of your child's diagnosis?

3. How do you and your spouse handle work requirements outside of your regularly scheduled work hours?

4. How are decisions made in your home regarding finances, physician appointments, intervention services, respite care, and so forth?

5. When seeking information or support outside the
marriage, what was your primary need?

Additional examples of interview questions and follow-up questions are included in Appendix B.

**Interviewer training** Another important aspect of the procedure of data collection is interviewer training. Six persons were trained for this study. Brotherson (1993) discusses interviewer training as an essential component in conducting interviews. The interviewer must be able to elicit trust and acceptance among participants to facilitate open, thought-provoking discussion. Good interviewing skills, including listening and thinking at the same time, reflecting the content and attitudes heard, and asking effective questions are important skills for the interviewer (Brotherson, 1993). Confidentiality and ethics are also necessary components to the interview processes. Participants must know that the information they divulge will be kept in confidence. Participants signed a consent form that assured confidentiality to all families. A sample agreement to participate form, consent form, and video consent form is included in Appendix A.

Data collection when interviewing more than one person at a time also calls for management skills (Kreuger, 1988). The interviewer's goal is to elicit as much information with as little participation as is possible. Information must be elicited from the hesitant participant as well as from the controlling one. This task was significant when interviewing
couples, as one was often more dominant than the other, making it difficult to get the other's perspective. Brotherson (1993), in her research regarding focus groups, states, "Moderators must be able to develop rapport, maintain eye contact, handle distractions, anticipate the next question, reflect content and feelings, relate new information to previous information, ask appropriate follow-up questions and remain non-judgmental" (p.12). This information, although intended for focus group research, helped the interviewers conduct interviews with couples and families.

**Revision of protocol**
As the interview process progressed, revisions of the interview protocol and on-going member checks were conducted. Questions were modified to probe emerging themes and patterns as the researchers learned more about the problem. Interviews, as described earlier, were conducted to explore these themes and patterns and to examine those comments that did not seem to reflect the majority of those being interviewed.

**Data Analysis**
Qualitative analysis can be derived through many different methods (e.g. ethnographies, case studies, content analysis) (Brotherson, 1993; Krueger, 1988; Tesch, 1990), but all of these methods share the commonality of reduction of text to its essentials (Tesch, 1990). This process of reduction of text is commonly referred to as classification. However, because we are concerned with the classification of
narrative text, and not discrete objects, the qualitative researcher searches for "meaning units", i.e. a segment from text that has a particular meaning, differing from other segments of the text (Tesch, 1990). To give these "meaning units" a conceptual connection, the researcher needs an organizing scheme.

Organizing scheme

The organizing scheme used in this study was adapted from the work of Renata Tesch (1990). There are seven steps to the process. This process was followed for all data in the larger study, and issues of gender and work roles were focused on for the purpose of this study. The seven steps were adapted as follows:

1. Get a sense of the whole. Transcripts were read and reread by two to three researchers. An initial description of each family that was being studied was developed. This enabled all researchers to get a better sense of the family and facilitated a sense of the family as the data was being synthesized. The video tapes of families also helped the researchers to gain a sense of the whole, especially those families which individual researchers had not interviewed personally.

2. Synthesize the data. Each major paragraph of the data was reduced to its essentials, usually 1 to 2 sentences, which were written on the margins of the transcripts. This was done by two to three members of the research team.
Initial themes and patterns were noted. Appendix B includes a sample of synthesis statements on a transcribed interview page.

3. **Make a list of initial themes.** After becoming familiar with a small portion of the data (2 to 3 transcripts) and noting the themes, a list of initial themes to that point was prepared. Themes that appeared to fall under a particular category were grouped, and the categories were written on a separate list.

4. **Preliminary coding of synthesis statements.** A separate list of the synthesis statements was made, and themes were assigned to these statements as they appeared on the transcripts. Appendix B has an example of how one interview was preliminarily coded. Coding was conducted by two researchers and referenced back to the family and interview transcript pages.

5. **Add new data and continue to refine themes.** Throughout this process, data collection and analysis occurred recursively and simultaneously. As new transcripts are added to the analysis process, steps 1, 2, and 4 were repeated as the researchers noted if the current themes were adequate to address all new data. As new themes emerged, the researchers returned to the previously coded synthesis statements to see if those codes still held to that theme. At times more than one code was needed to describe data if the content was too rich to fit in one category. For example, this synthesis
statement fit into two categories, gender and control. 
"[daughter] directs the relationship with Mom by telling Mom what to do. J. doesn't do this with Dad."

6. **Perform a preliminary analysis.** All synthesis statements were then listed by theme. The content for each category was identified and summarized. While looking at content, each area was examined for commonalities, differences, and confusions and contradictions. At that point, the research team determined if the organizing system needed any revisions.

7. **Return to the whole.** The researchers returned to the initial family descriptions to get a sense of how the content analysis fit each family. A case study was then developed for each family using examples from the content analysis of transcripts that provided documentation and quotations to supplement the themes. This seven step process initially identified gender and work roles as major issues in nutrition intervention for families with children with disabilities. Continued analysis was repeated by part of the research team focusing on issues of gender and work roles.

**Indicators of Rigor**

There are four indicators of rigor, according to Guba & Lincoln (1981), which they term "aspects of trustworthiness". They are: credibility, transferability, dependability, and confirmability.
Credibility

Credibility is the assurance that the data belong to the subjects and are not the biases of the observers, and that we have an accurate understanding of the perspectives of those we interviewed (Brotherson & Goldstein, 1991). Several aspects were used to assure credibility: multiple methods, multiple researchers, and member checks.

Multiple methods  Multiple methods are used to triangulate data, as several methods are more convincing than a single method. The methods used in this study were interviews, participant observation, videotapes, and field notes.

Interviews were done with both mother and father (or live-in companion) when willing and available, and at times included siblings and/or extended family members. Interviews were tape recorded and transcribed whenever possible.

Interviews were performed by two researchers in order to safeguard the credibility of the study. The second researcher was able to concentrate on the interactions of the parents with their children, with each other, and with the research team, data which may have been missed by the primary interviewer alone. Participant observation gave researchers insight into the family beyond their stories. For example, one father and mother discussed the father in very peripheral terms. However, in observing this family, the mother paid very little attention to the child, while the father initiated
and supervised a tube feeding of the child and held the child after completion of the feeding.

Videotapes of the families were taken during meal times in order to observe the feeding of the child with disabilities. Like the participant observation process, the videos were very helpful in allowing several participants from the team to add their observations. Not all of the researchers were able to meet each family individually. The videotapes were used to help team members who did not participate in particular family interviews to better know and understand those families.

Field notes were kept in two different methods. First, individual interviewers could jot notes immediately following the interview regarding their impressions, possible themes, and thoughts for follow-up questions. A second method included the taped discussion between the interviewers regarding the same topics. This method enabled interviewers to record and discuss their perceptions before they were forgotten. Refer to an example of field notes in Appendix B.

These multiple methods allowed the researcher to cross-check the data, obtaining information in one method and probing for more depth in another. Survey data was also collected on all interview participants. This data was used to cross-reference data obtained from the interviews. The survey instrument used is included in Appendix A.
Multiple researchers

The use of multiple researchers helps to limit the bias of one researcher. A team of researchers interviewed, coded, and analyzed the data. Different perceptions and interpretations were noted and discussed until agreement was reached. The research team consisted of professionals from the areas of nutrition, child development and disabilities, and marriage and family therapy. Two researchers, not necessarily the same ones that participated in the interview, reduced the transcripts to synthesis statements. The synthesis statements were then coded, and those statements were checked for agreement by a different team member.

Member checks

In order to check the credibility of the findings, some participants from the individual interviews were chosen to participate in a member check. This study utilized the follow-up interviews as primary member checks. Data taken from individual family interviews was analyzed and reduced as described above. The "essentials" or themes regarding gender were then presented to the family members to check for fit.

Eleven participants representing seven families were selected for follow-up interviews to check their perception on the accuracy of the summary of the individual interviews. A summary of the themes and categories that were found in the analysis of the interviews was shared with the participants of the member check during the interview. Member check
participants had the opportunity to expand on or to clarify their responses. Participants were invited to offer further input on any topic, especially the fit or lack of fit with the conclusions of the research. These responses were then used to modify the findings of the data, to confirm that the reality created was one that was shared by the researchers and the participants. In this study, the member checks confirmed a shared understanding of the issues by the research team and the participants of the research study.

Participants were chosen for the member checks based on the following: balance of those working outside the home versus those not working outside the home; involvement of the father in the home; age of the child; willingness of the members to participate; and the identity of the previous interviewer. Because there were several interviewers involved in the gathering of the data, the researcher had not always had personal contact with each family. The researcher found a "face-to-face" interview to be very helpful in gaining a deeper understanding of the family and its perspectives, and therefore, included those families in the member checks.

**Dependability**

Qualitative research has been challenged on its ability to maintain stability and consistency of data, while recognizing the emergence of the data and the design. Three methods are used to address dependability in this study: peer debriefing, multiple researchers, and process audit trail.
Peer debriefing  Two forms of peer-debriefing were utilized in this project. One method was outsider peer debriefing. In this form of peer debriefing, the researcher discussed data analysis with a peer not directly involved in the project to get an untainted opinion (Brotherson & Goldstein, 1991). Another application of peer debriefing which was employed was collegial peer debriefing. Researchers discussed the data with each other after interviews and analysis sessions. Biases, interpretations, areas of void, etc., were discussed and documented.

Multiple researcher  This method was discussed earlier but was used as a dependability check as well as a credibility check. A problem associated with multiple researchers as a dependability check is the consistency of the researcher while allowing for the evolving questions (Brotherson & Goldstein, 1991). To address this problem, the researchers were trained regarding question format, family interview protocol, and format for data analysis.

Process audit trail  An audit trail was kept to review notes, tapes, and transcripts to be sure acceptable research practice was followed. This trail included evolving protocol questions, discussions between researchers, rules and guidelines for analyzing the data, and categories and themes as they emerged in the data. Examples of the audit trail are included in Appendix B.
Transferability

Qualitative research is not intended to develop truth statements or to generate universalities, but rather to generate rich descriptions of respondents and settings so that others can determine how the data are useful or fit their particular situation. This study utilized contextual description and purposive sampling to enhance the transferability of the study.

**Contextual description** Information needs to be included regarding the makeup of the families, the types of disabilities involved, the working status and marital status of the couples, and particular family dynamics. Knowledge of how these families' lives and circumstances are similar and different from others that will be studied in the future is critical in designing a research study that might utilize these findings. The case studies are very helpful in giving a richer description of the family than can sometimes be gained from the use of only reviewing transcripts and cross-cutting themes.

**Purposive sampling** Participants are chosen for their knowledge and experience regarding the subject being studied. The greater the diversity of the participants being studied, the greater the depth and breadth of perspectives being reported. This allows the researcher to utilize a variety of experiences and perspectives to the understanding of a more general context or event (Brotherson & Goldstein, 1991).
Reporting

Confidentiality is a key component in qualitative research. Participants have often allowed researchers into very intimate aspects of their lives, and this needs to be respected through keeping their anonymity. Names have been altered to help preserve each family's anonymity. This information will be disseminated to other professionals and to parents through journal articles, presentation at professional organizations, speaking engagements, and presentation to classes.
CHAPTER FOUR: RESULTS

This chapter tells the stories of ten families with children with disabilities, first through case studies, and then through an examination of cross-cutting issues. The families are all located near a major metropolitan area of Iowa, some from the inner city, some from nearby suburbs, others from large towns, and one from a rural area. The income levels range from low to upper middle class, and the education levels of the parents range from high school diplomas to graduate degrees. Although these factors and also the diagnoses of the children are quite different, the families' experiences with work roles, social support systems, employment, daily routines, lack of privacy, and the expectations they hold of themselves as parents are quite similar. The ages given in these family stories are from the initial interview. The following are their stories.

Family Stories

Family story one

Chad, who is seven years old and is an only child, is severely mentally retarded and has cerebral palsy. He lives with his mother and father in a large, two-story home in a midwestern town of about 50,000. The child's bedroom and a bathroom, large enough to accommodate a wheel chair, is on the main level. A large ramp, which was partially funded by the family's church, facilitates access from the driveway to the deck. The family's income is in the $30,000 - $50,000 range.
Their son's medical expenses are paid by their two insurance policies and by medicaid. Chad attends a local school in a self-contained classroom.

Chad's mom and dad are both professionals, employed full time outside the home. Initially, Mom planned to stay at home with Chad until he was more independent, and then return to work, part time. Mom found that Chad's care was so involved and overwhelming that she needed to return to work for her own peace of mind. This was a very difficult decision for both his parents, and Chad's mother viewed herself as a failure for being unable to care for Chad on her own. Both parents' employers are flexible about hours required to deal with crises/problems related to Chad. However, his dad's job is more self-directed. If needed, he can rearrange his schedule or bring his work home with him, but hiring a nurse is their first option when Chad is ill.

Chad is fed solely by G-tube. He receives four feedings per day and is fed continuously at night. At birth Chad's oral feeding skills were adequate but began to deteriorate at six months. Parents dealt with constant problems with breathing, refluxing, and respiratory infections. A tube was placed at about 18 months, which was viewed as a temporary measure at the time. Chad continued to have reflux problems until the parents made the decision to stop feeding Chad orally and to have surgery (cardiomyotomy) to correct esophageal problems that were causing him to reflux.
Chad is unable to walk, crawl, sit up, or even turn himself. He is able to raise himself up on his elbows and hold his head up. Chad is not able to communicate verbally, but his parents are able to interpret his sounds, eye movements, and smiles.

Both his parents split direct care of Chad, but his mom is responsible for nearly all of his indirect care. Mom admits that her husband is much more capable of taking care of Chad than he lets on when she is home. His mother felt a need to be involved in Chad's care when she was home, and she really needed a break from him, so in order for her to have some respite away from these responsibilities, she and her husband have devised a schedule of alternating Chad-care nights.

The couple rely heavily on friends and their church for support as their relatives are unable to help. Dad has found support from his colleagues at work as his work involves children with special needs. Mom also receives emotional support and understanding at work, but she states she initially received the majority of her support from close friends. They are each other's closest support now, but this was not always the case. The couple experienced tremendous marital strain with the overwhelming demands of caring for their child. They also were at odds over whether or not they would be able to care for their child at home. Chad's parents separated for a period of time, but they feel their marriage
is much stronger now than it has ever been.

All decisions made by Chad's parents regarding Chad's care, are based on his quality of life and a sense of spirituality. Chad's parents continually struggle to determine which changes they make may improve or detract from his ability to enjoy life to his fullest capability. Chad is now ten years old, and the family is expecting a new baby. Future decisions regarding possible placement of Chad will again be very difficult for this family.

**Family story two**

Ellen was age four at the date of the first interview. Ellen and her parents live in a single-family dwelling in a midwestern community of approximately 45,000. The family income is in the $30,000 - $50,000 range. There was one older sibling at the first interview, but another child was born to the family during the course of the study.

Ellen is diagnosed with cardiomegalovirus (CMV), cerebral palsy, seizure disorder, is visually impaired, and has dislocated hips. Abnormalities were not noticed until age two months, at which time tests revealed that she lacks an occipital lobe.

Before receiving a G-tube, Ellen was fed four times a day, each feeding taking 30 minutes. Parents stopped feedings at that time regardless of completion. The decision to place a gastrostomy tube was based on: 1) Ellen did not enjoy food/oral feedings; 2) severe dehydration, malnutrition,
deterioration followed hip surgery, 3) parents did not want to lose an opportunity for financially assisted home-based waiver of care; 4) other financial considerations - formula for G-tube is paid by insurance but would not be if used for oral feeding, 5) the family hoped for decreased family stress and frustration.

Since the G-tube, there has not been a change in Ellen's alertness, but Mom feels Ellen lost ground after her hip surgery. Ellen has fewer colds and ear infections, and weight has increased dramatically since the G-tube, which has improved her health status but has made her more difficult to handle, physically. Ellen has a fundaplication but continues to vomit daily. She now receives pumped tube feedings at 4:30 a.m., receives a feeding at day care, a feeding at school, in addition to those received at home. Ellen receives Reglan, Tegretol, Phenobarbital, lactulose, and is on antibiotics about 50% of the time. Her formula contains ingredients which require special handling. A specially made wheelchair cost $4,800.

Both parents are professionals and work full time outside the home. During the initial phases of the research, Ellen's father was completing his graduate studies, taking many of his courses at night, and was at home more often to accommodate sick days and crises. When looking for a new position, Ellen's Dad turned down a good offer because the company did not feel it would be acceptable for him to miss work due to
his child. Because Ellen has required much medical attention, both Mom and Dad feel they try harder to be exemplary employees when they are at work.

A home health aide comes in three nights a week to help with bathing. The family also employs a nurse to take care of feedings and medication after school and on weekends. Although Mom appreciates this help, she states this is a problem for the rest of the family regarding privacy. Ellen's care is very expensive, due to her medications, special formula, equipment, and in-home services. The family relies heavily on health benefits offered through the parents' employment, and have turned down other job opportunities based on that factor. The family also receives assistance from Home Based Waiver, Family Support Subsidy, and Medicaid funds.

Mom states that her husband was not always so involved with child care. When their first child was an infant, he worked out of town. Now they agree that the direct child care is split about 30% - 70%, with Mom doing the major share. Mom also does 100% of the indirect child care. Dad's role is more play-oriented, and he has used his expertise to adapt switches and toys for her.

The couple relates that most of their social support comes from their immediate family and from co-workers. The family has had difficulties with extended family members being unable to accept Ellen's disabilities. This has caused a strain on family relationships. Although they don't entertain
in their small home, the couple feels they have more opportunity to go out and spend time as a couple than most, due to their home health providers.

Originally, the couple had planned to place Ellen outside of their home at about age nine or ten years. However, with the birth of their young child, they have decided it is important for him to get to know his sister, so that he will feel more invested in shared decision-making with Ellen's older sister when they are adults. Ellen's mother initially believed that "it would take a nervous breakdown" to place Ellen in outside care, but now believes that they will be ready to accept that phase of Ellen's life when the time comes.

**Family story three**

Jimmy, age five, is the second oldest of six children. The other siblings, two girls (oldest and youngest, and three boys are age six years, four years, two and one half years, one and one half years, and four months). Jimmy was born two months premature and weighed 3 1/2 lbs. He was diagnosed with cerebral palsy at age 1 year. Jimmy is unable to sit unassisted or crawl on his hands and knees and is unable to feed himself. He is able to communicate verbally and make most of his needs and wants known. Jimmy attends an integrated preschool, where he works on a computer to enhance his communication skills.

Jimmy's father is a factory worker, earning between
$20,000 and $30,000 per year. He works 12 hour shifts. This was a job change to a position of lesser responsibility that the company requested he make due to home life interferences with his job. Jimmy's mother is not employed outside the home, and has opted to home-school all the couple's children. She and her husband are frustrated that they are not also able to home-school Jimmy.

The family lives in a double-wide mobile home, which the family likes due to its open floor plan that is wheelchair accessible. Mom and children have very little social interaction outside the family except at church. The family religion is based on fundamental Christian belief, and this strong belief system plays an important role in all aspects of this family's functioning.

Control is a very important theme in this family. Mom and Dad believe that Jimmy uses eating as an area in which he can control others. Parents also state that Jimmy "controls" by bed wetting and encopresis. Family style is quite regimented: no food is allowed on the table until after prayers; children have assigned seats at the table; children line up according to age to use the bathroom and wash hands; privacy is strictly enforced between boys and girls. Routines are described by Mom as "stressful" and "full of tension", especially mealtimes.

The family receives very little social support, especially Mom. The only time Mom leaves the home is to go to
doctors' appointments, to go to church each Sunday, and to go to the grocery store once each week. Even these trips are never without children. Dad states he is very sympathetic of stress Mom feels, as she parents alone for 13 hour stretches. Dad enjoys his contact with co-workers and feels it is very beneficial for him to be able to release his frustrations by talking at work. He therefore, "allows" Mom to talk on the phone to receive social support from others.

This family is extremely family focused. Parents have very traditional gender expectations of selves and of each other. Dad has made some sacrifices regarding his career to enable his philosophy of family first.

**Family story four**

Jerome is age two years and has been diagnosed as developmentally disabled with profound mental retardation and visual impairment. Jerome's mother, age 22, is divorced from Jerome's biological father. Jerome has visitation with his father one time per month. Living in the home with Jerome and his mother are his biological sister, age three, and mom's live-in boyfriend. At the beginning of this study, Mom's younger sister also lived with the family. The sister was injured when a 1300 pound pop machine fell on her, and she is paralyzed from the waist down. There is some uncertainty about the permanence of the disability and her prognosis. She uses a wheelchair and has weekly physical therapy, the information from which she brings home and suggests be utilized to keep
Jerome's muscles toned. Jerome's mother found her sister to be a support to herself and to Jerome, believing that Jerome's aunt shared something special with him due to their disabilities. During the course of this research, Jerome's aunt moved to another state.

Jerome's mother was unemployed at the beginning of this research study, but was working full time outside the home at the study's completion. The family continues to receive financial support services. They also receive home intervention services from a dietitian, a teacher, and several occupational therapists. Mother provides the majority of Jerome's care, receiving intermittent help from her boyfriend and a few family members. No formal respite care is presently available, due to lack of funding. Mother has discussed her need for respite care with Jerome's biological father, but is unwilling to trust his care to him, feeling he is "too lazy". Jerome's mother rejects the idea that her ex-husband may be separating emotionally from Jerome, despite the fact that Jerome's father has openly stated that Jerome will be gone soon.

Jerome's feeding problems have been a source of stress or worry for his mom for some time. He was hospitalized for placement of a G-tube just prior to participating in the research project. Prior to G-tube placement, family members frequently participated in his feeding, which could take up to two hours a day. After placement of the G-tube, Mom reported
help with feeding only two times in six weeks. A four-hour feeding routine was established during hospitalization, which Mom adapted to her own schedule upon their return home. Jerome is fed separately from other members of the family and is expected to play quietly, near the table as the family eats. Jerome's mother believes that the feeding tube made a tremendous difference in Jerome's behavior and responsiveness. She states that "it's as though he came back to life."

Jerome's mother relies on extended family and her boyfriend as her primary social support system. She also has friends at work, but is unable to socialize outside of work due to her responsibilities at home. She often feels overwhelmed by the pressures of caring for a child with disabilities, but she is thankful for his continued successes.

Jerome's mother believes she has adjusted to life with Jerome. She takes the advice of professionals and adapts that advice to her perception of Jerome's and of the rest of the family's needs. Mom states she "worried all the time" about Jerome before having the G-tube placed. She worried he might not live and that he might be in distress and not be able to communicate his need to her. The G-tube has made the worries surrounding Jerome's care and prognosis significantly less stressful for her. She sums up Jerome's situation as, "It's life. Jerome is Jerome. You take care of him any way you can."
Family story five

Dusty, age three years, has developmental delay, visual impairment, cognitive, speech, and eating disorders. He and his twin brother had intracranial hemorrhages at birth and have cerebral palsy. He functions at the ten month level and is able to get around on his own by crawling and pulling himself up to furniture. Dusty is currently receiving physical therapy and occupational therapy services.

Dusty's mother is divorced and newly engaged. Her fiance, who is very involved in the children's care, has lived with Mom and her three sons for one year. The oldest boy is six and the twins are almost three. The family lives in a two story home which they have rented for the past nine months. Mom is not employed outside the home, due to the amount of time and energy required to care for her children. Her fiance works nights, and their income falls between $10,000 and $20,000. Mom's ex-husband lives out of state and still has phone contact with the oldest child, but he wants nothing to do with the twins and pays no child support. She left him because he threatened the lives of the twins, and she didn't feel they were safe if she was ever away from them.

Dusty, who was hospitalized for the first seven months of life, and on a nasogastric (NG) tube for a lengthy time after that, wouldn't suck from a nipple, and had a dysfunctional gag reflex. A G-tube was placed at six months and was in for about one year.
Mom reports that bonding was difficult in the hospital as
the nurses would take him from her as soon as he cried. The
medical staff did not want her to start bottle feeding, but
she did so anyway at home. She also started him on "mushy
foods" on her own. The doctors had placed a button G-tube for
feeding, but as Mom had succeeded at getting Dusty switched to
oral feedings, the doctor removed the button. Dusty's mother
reports that "feeding was a nightmare." Dusty resisted all
foods, sometimes holding food in his mouth for one half hour
before spitting it out in a corner of the home. It often took
two to three hours to get two bites of food in.

In September of his second year, Dusty had surgery to
repair a hernia. A tube was placed again to bring his weight
up. Again, Dusty's mother was advised by the nursing staff
not to try any oral feedings, but the surgeon told her there
was no physical reason he could not eat, so she persisted.
The hernia repair made a dramatic difference in his ability to
eat. However, self-stimulation behaviors are problems now, and
Dusty also is suffering from oral sensitivity and must be fed
sandwiches etc., on a fork. The goal is for Dusty to be able
to feed himself.

Finances are not perceived as a problem for this family,
as the twins are covered by SSI and WIC. Dusty's
hospitalizations are more infrequent, and sicknesses have not
been as severe as in his infancy. He is not on any special
diet and can eat the same meals as the family. His diet is
supplemented with extra calories and Pediasure, which presents an issue regarding equality with siblings. In order to deal with this, Mom often increases fat and caloric content in all three children's meals.

Mom states she is very stressed all the time as Dusty's problems have an emotional component (attitude) to them as well as the physical disabilities. This makes it more difficult "because you can't fix it."

Mom finds time for herself after the children are in bed. She does not have much social life other than with her fiance. Friends used to call on her, but she had so many difficulties with her children, that she felt too distracted to entertain guests. The family utilizes respite care on weekends occasionally, so the couple can have some time to themselves.

She sees the issues of child care as family issues affecting her fiance, too. Both adults share the work and the fun of the family. Dusty's mother and her fiance agree that he has better control of the children than she. It is the couple's wish that he will be allowed to adopt the twins after they are married. Mom is hopeful for Dusty's future. She states, "We never say never. We just take one small goal at a time and work on it until we get it."

**Family story six**

Reba is a four year old female with a diagnosis of cerebral palsy and seizure disorder. Her mental disability falls in the severe category. Reba lives with her mother, her
father, a thirteen year old sister, and a sixteen year old brother in a small, three bedroom ranch, which the family owns. Reba's weight was 24 pounds at our first visit.

Dad is a full time carpenter, but his work is seasonal, so finances are tight. Mom works part time at a grocery store. Although the family depends on both these incomes, their work schedules place more stress on them both with "less time to do what needs to be done." The family makes too much money for financial aid (about $32,000 annually) but struggles to keep up with their bills and medical expenses. There is often not enough money for the extras like pediasure and high calorie puddings that have been recommended by the dietician.

Reba was on an apnea monitor early in life, due to her irregular breathing patterns. When Reba was two months, Mom became concerned about her "arching backwards" and felt there were times she had stopped breathing, even though the monitor would not sound. After several incidences, the child was hospitalized at age two months and diagnosed with a Dandy Walker cyst on the cerebellum. At that time, Reba's parents were informed that their daughter would be delayed in walking for one to two years, and the belief was that her disability was in the mild to moderate category. When Reba was fourteen months, her parents learned that she had cerebral palsy and that her disability was actually moderate to severe. She is unable to walk, talk, sit up, use her hands, and swallow normally. Mom believes there were some signs that something
was wrong early in her pregnancy and also in the delivery, but she does not feel that any of her doctors were concerned when she reported these signs.

Prominent issues for this family are a need for control; a lack of information, "I just didn't understand ..."; mother's need for normalcy; and the parentification of the female sibling. Reba previously attended the Early Childhood Special Education program, but she now attends Smouse School. Transportation to school was difficult at first, as Mom would not allow Reba to ride the bus.

Reba sleeps with Mom every night as Reba wakes easily due to her movements. Mom believes Reba sleeps more restfully with her by her side. Dad has slept on the couch in the living room since Reba was a toddler.

Reba's mother also feels strongly that her family will never put her child in residential care. It is her responsibility, and that of her children, to care for this child. Respite care is also available to this family, but Mom has been unable to find help with which she feels comfortable. She believes that physicians and staff could have helped more by alerting her to possible complications and problems. She had no knowledge that there may be difficulties in eating and therefore was not responsive to signs of a swallowing disorder. "I didn't know it, so I didn't look for it. They asked me how she ate, and I said, 'Oh, just fine.' I mean, she liked to eat and she coughed, but I didn't think anything
about it, because I didn't know that there could be a problem in that area."

It was a surprise to Reba's parents when the staff and physicians at the University Hospital recommended a G-tube. Reba had been evaluated at the hospital in hopes of finding a way to better control her extensive movements. A swallow study showed that Reba was aspirating her food. Reba's parents were quite dissatisfied with the surgery as her movements became worse and the family was confined to the couch to do tube feedings, but eventually Reba and her family settled into the routine. Now Mom states she can see big improvements from her increased nutrition and weight.

Mom calls her older daughter "Reba's first mother." Mom depends on her to care for her child often and says, "She can read her like I read her. She knows what to do just like I know what to do, and I feel bad about that for her ...". The older sister misses school at times to help with Reba.

Except for the assistance she receives from her older daughter, Mom cares for Reba alone. Even though Dad may be home for long periods of time due to seasonal layoffs, his work around the home or with Reba does not increase. Mom is also responsible for all the indirect child care tasks, such as scheduling and keeping doctor appointments, communication with professionals and teachers, shopping for and maintaining clothing, and has decision-making power regarding Reba's care and educational program. Dad has all the decision making
power in other matters of the home. For example, Mom is in charge of paying bills, but must have her husband's authorization regarding how much is paid on each bill.

Mom initially received some help and support from her sisters but does not feel she can call on them to help any longer. She has friends at work, but she does not socialize with anyone outside of work. She feels that social support groups are not helpful, as "no one else has a child or problems like mine."

Dad, who was never interviewed, also has no social life outside of work. Mom reports that her husband gives up doing things with his brothers to stay at home. "I don't know why, if it's because of guilt or if he wants to be here."

The family also feels extra stress from their inability to get out with their daughter. She does not like to sit in her wheelchair and is difficult to manage due to her uncontrollable body movements. Mom and Dad don't ever leave the house at the same time, even to attend events in which their other children are involved. Dad has taken Reba in the car by himself only one time since she has been born. Mom stated, "I guess I chose to just suffer along, with feeling trapped and not being able to get out. I guess I chose that over letting a stranger take care of her."

**Family Story Seven**

This case study requires some prefacing remarks. Over the course of this study, this family divorced, drastically
changing the support structure and work roles in the family. The author will attempt to tie this information together without losing the sense of the family before or after the divorce.

At the first interview, Tony was four years old, and had been diagnosed shortly after birth with cerebral palsy. This disorder was caused by problems in delivery causing him to remain in the birth canal for an extended period of time.

The family of four includes Tony's father, who quit school when Tony was born to own his own business, Tony's mother, who is an insurance claims processor, Tony, and his six month old sister. Tony attends school in a nearby community. In the initial phase of the research, Mom took the youngest child to the sitters on her way to work, and Dad remained with Tony until the bus picked him up. After school, the school bus took Tony to a sitter for a 45 minute wait until Mom collected both children after work. Tony, now age seven continues to have limited arm and head movement and makes slight attempts to communicate verbally with his parents.

When Tony was one year of age, the school suggested a G-tube since oral feedings took over an hour and Tony was "picky" about whom he would let feed him. With the birth of the baby, family time was reduced, and Tony's condition had worsened considerably. Mom and Dad consulted their physician who wanted to implant a tube and close the esophagus at the
same time. The parents felt that this was too permanent a move to make at that time. Also, feeding time was a family, social time, even though it could take up to one and one-half hours and had to be done before they ate their own meal. A gastrostomy tube was placed one month prior to Tony's fourth birthday. Parents felt that they were not at all prepared for what to expect with a G-tube. Mom had gone back to work three days before the tube was put in and had a seven week old baby at home, who went to stay with Grandma. Dad was not at the hospital much, leaving that responsibility to Mom.

Tony presently receives oral feedings of blended fruit and baby food meats. His tube feedings have been reduced from five times daily (at our initial interview) to three times daily and a nighttime continuous feeding. Mom is largely responsible for Tony's tube feedings and tube care. Dad is not comfortable with tube feedings, but has helped with one of two oral feedings per day. Tony's oral feeding skills have improved since the tube was first suggested. Mom feels this would have been lost if they had agreed to the tube at age one. Mom says accepting the tube at age one would have meant accepting Tony's disability, which she had not yet been ready to do.

Family support has been generally positive except for one grandmother. Other support for Mom has come from friendships through child care providers and support groups. Mom reports that many of her previous friends were not comfortable being
around Tony, so she has not pushed it.

Dad had a very difficult time accepting his son's disability. Tony's mother, in our final interview, explained that she believes that her husband felt guilty, that he had only prayed for a son, not for a healthy son. She also shared that Tony's father had lost all his faith in God, and finally believes there is no God. Rather than spending time at home, Tony's father retreated to his store and spent many hours tending to his business. These hours led to more hours away at night entertaining clients, which eventually led to problems with drinking, gambling, and extra-marital affairs. Eventually, Tony's parents decided to divorce.

Tony now lives with his mother, younger sister, and his father's sister. Mom opened her home to Tony's aunt as a mutually beneficial situation. Tony's mother benefitted from the extra live-in help, and Tony's aunt benefitted from the free room and board. This arrangement also allowed Mom to pick up an additional part time job, two to three nights per week.

Tony's mother states that both her employers are very flexible, allowing her to make up work on other days of the week. She also adds that she only leaves work if Tony really needs her, and then works 200% when she is there.

Tony's father sold his business and has recently started a new job. Although Mom has requested that he seek a second part time job to help with finances, Dad states his employer
prohibits him from doing so. Tony's dad continues to be rather frightened by his care, and spends time with him only occasionally. He does pick up his daughter every other weekend, which gives Mom some respite. Mom notes that he recently spoke of wanting to give her a break by taking Tony for a while, giving Mom hope that perhaps he is beginning to understand.

Tony was on Social Security, but he no longer qualifies. He is on the waiting list for the waiver program, but does not anticipate any help from that source in the near future. Insurance pays for all medical expenses, and Tony's parents were able to build a new home with the money from a settlement with the physician.

**Family story eight**

Jennifer's family consists of her father, her mother, and her brother, age 6 years. Dad works full time as a truck loader and Mom works full time as a communication specialist. Their yearly income is between 30,000 to 49,000 dollars. The family receives financial assistance through the Family Support Subsidy, but does not receive SSI or Medicaid. Both parents have benefits, which they pay an additional $100 per month to maintain. The family lives in a modest three bedroom home in a rural town. Both parents' families are involved in Jennifer's care.

Jennifer is age five and was diagnosed with CHARGE syndrome at five days old. CHARGE has a variety of disorders
(e.g. defective retina and optic nerves, heart defects, blockage of nasal passages, mental and physical retardation, and abnormalities of the genetalia and of the ears) that can be associated with the syndrome. Jennifer has several of them. She had many medical problems when she was born and had to have surgery as her nasal passage was blocked. When Jennifer was one month old, the physician realized that she had swallowing problems, and it was at that time that she had a gastrostomy tube placed. It was not until she had the G-tube that her parents were able to bring her home from the hospital. The family was very focused on the worry of losing their daughter for the first two years of her life.

During this time, Dad and Mom pulled away from each other. Mom became the primary caretaker for Jennifer, while Dad spent time working in order to keep up with the medical expenses. This situation created a lot of stress on the marital relationship. Their six-year-old son spent time with his grandparents when Mom needed to be at the hospital with Jennifer.

Jennifer became involved in the Early Childhood Education Program when she was a toddler. She attends a special classroom half days at school and is mainstreamed for the remainder of the day. Mother reports that Jennifer is constantly getting into trouble at school, hitting and hurting the other children. The school often calls to have her sent home due to loose stools and eating problems. This is a
constant battle for the family.

Jennifer's feedings have increased from five to ten times per day at the initial interview to 10 to 14 times per day at the last interview. It takes approximately five minutes to feed her and an average of two minutes to prepare food. Generally she is fed lying on the floor and is fed alone. On occasion Mom or Dad will blow into the tube in order to speed up the feeding process. Both parents and a grandmother are involved in the feeding process. The family feels that they are providing adequate nutritional needs for their daughter. When the study began, she weighed 20 pounds. A child her age should weigh around 45 pounds, according to the National Center for Health Statistics, and her weight is approaching that level now. The parents have noticed that Jennifer is more alert and active right after eating. She becomes bored quickly, and physically tugs on her parents until they feed her again. This means she is fed each hour throughout her waking hours. She is able to sleep through the night.

The family does not find feeding her with a G-tube stressful. What they find stressful is the thought of orally feeding her. Jennifer recently had an evaluation to determine if oral feeding was possible, and the results indicated that physically Jennifer could orally feed. At this time, Jennifer does not want anything to do with oral feeding and refuses to participate. This becomes stressful for the parents and is a challenge that they know they will eventually have to
overcome.

Dad was home when their older child was an infant and helped out with his care, but Mom is responsible for most of the direct and indirect child care. Mom schedules doctor's appointments and tries to facilitate her schedule, but on occasion, Dad will need to take Jennifer to the doctor. In that case, Mom calls the doctor after they return to get the information first hand, as she doesn't rely on Dad to relay the information accurately. Dad does do some entertaining of Jennifer over the weekend, and will pitch in when his wife "has had it." The older son can usually tell when Mom is close to her limit and will find Dad or will run interference on his own. Mom states she is very jealous of her husband, as he "putts around" all he wants, can always accomplish the things he wants to do, and he only has to get himself ready when he goes to work. Mom is thankful for her job, which she says she has in order to keep her sanity.

Mom states she has had a need for social support as this is such a rare disorder; they had very little idea what to expect. Mom receives her social support at work with a co-worker she can confide in. She also values her husband's family who are so accepting of Jennifer. The family travels about 100 miles round trip each week to spend a few hours with his family. The men work on their trucks, and the women visit and care for the children.

Dad denies any need for social support now or at the time
they received the diagnosis. Dad insists he and his friends and relatives only talk shop. He has never needed help dealing with his feelings regarding Jennifer's disability. Dad remarks, "No sense in getting tight - she could drop dead tomorrow."

**Family story nine**

This family is composed of mother, father, and their three children, at the beginning of this study, were age six, age four, and age 13 months. Rhonda, at 13 months, weighed 15.9 pounds. She had gained only two pounds since age six months. Rhonda was not diagnosed with cerebral palsy until after she turned two years of age, which caused much concern and confusion for her parents.

The family resides in a large, midwestern city. They live in a new, split-level single family dwelling, which they own. The parents are both employed full time. Dad is a financial consultant, working from an office in his home, and Mom is a research analyst. Their annual income is approximately $48,000. The family receives some financial aid, but it was unclear from which program.

When Rhonda was thirteen months of age, the family still had not received a diagnosis for her, and their concern at that time was that Rhonda's development was significantly delayed. They began testing at a local hospital when Rhonda was six months of age. At that time, the feeding process could take up to an hour for Rhonda, during which time she
would consume only one to two ounces of formula. The local physician recommended letting Rhonda "grow out of" her delayed development and suggested a course of physical therapy. The family pursued the idea of further consultation and testing, despite resistance from their insurance company and delays in getting appointments. Swallow studies indicated Rhonda was refluxing and aspirating.

Dad did not consider the placement of the G-tube an extreme measure. He stated that the procedure was fairly simple, and it insured that Rhonda received the nutrition she needed. Dad stated in their initial interview,

My thing with nutrition is, I want to do something, and I want to do it now, because if we find out five years from now that we should have done it a month earlier, that her brain didn't develop properly, or something like that, I'm going to have to know that for the rest of my life. On the other hand, if you put it [G-tube] in, and she doesn't need it, and everything goes fine, you know, what have you lost? Other than, she'll have a scar.

The family receives emotional and child care support from Rhonda's maternal grandmother who lives about two hours away, and from a babysitter they have learned to trust. Dad's mother and great aunt (a nurse) have encouraged the family to be aggressive in their search for answers for Rhonda. Other family members and friends have continued to offer suggestions and encouragement for the couple. In addition to the support
of their family and friends, Rhonda also receives support services in her home including nutrition intervention, physical therapy, occupational therapy, and a preschool teacher. A health aide takes care of Rhonda in her home each day while her parents work.

Regarding social support, the couple states it has telephone numbers of support groups for parents of children with cerebral palsy, but have never felt they need them. Mom states she has close friends at work whom she can confide in and also enjoys getting out to her aerobics class once a week. She doesn't socialize with friends outside of work much as there is just too much to do at home.

Dad, on the other hand, gets out with his friends frequently as he is involved in several service clubs and organizations, none of which involve children with disabilities. Dad expressed his need for something else in his life besides the focus on disabilities. These are also groups that continue to support his business.

The impact of Rhonda's delay and feeding problems on the couple's marriage has more to do with the amount of time it takes to care for her than in differences in philosophy. Both parents are heavily involved in their careers and in raising their family. They see the G-tube as a way to successfully manage Rhonda's nutritional inadequacy and the time problem created by her difficulties in feeding.

The couple has been attending doctor visits for Rhonda
together, since they both see different issues that need to be addressed during visits. They share household tasks, including the feeding of Rhonda, and feel free to tell each other when they are stressed and need help. Dad seems to take the lead in decision-making and is usually more vocal about family needs and perceptions. Mom is responsible for most direct child care tasks (Dad has never bathed or diapered Rhonda), but he does occasionally help with tube feedings, bottle feeding prior to the tube, and transporting/caring for older children. Mom is also responsible for all indirect child care tasks.

When it comes to missing work for sick days with their children, both say it is Mom who will take off work. Although Dad is at home, he does not receive any benefits or income for missed work since he is compensated through commission. His wife, though, has a lenient employer and has five weeks paid vacation per year that can be used for any reason. Dad will take time off in emergencies, though, or if he has no appointments scheduled.

The couple's goal for Rhonda is to keep her home as long as is possible. Both state that their life is not centered around her or her care. They are careful to involve their other children in as many activities as the children are interested in and consciously avoid their resentment of Rhonda.
Family story ten

It is interesting to note that none of the interviewers or the members of the interdisciplinary team have ever seen or met the father in this family. We tried but were unable through any means to gain access to him. Mom would not allow him to be interviewed in person or on the phone and filled out the questionnaires for both of them.

Allison is a twelve-year-old female with cerebral palsy and seizure disorders. She lives in her home with her mother, her father, and her fifteen year old sister. She has severe mental and physical disabilities. Allison is unable to speak, crawl, walk, sit, or feed herself. She hears well and tracks objects slowly. Her family feels she is able to understand some commands, such as when to open her mouth for the doctor, and that she responds well to all family members.

Allison's parents have been married for 22 years, and both work outside the home, Mom working part time in the school cafeteria. The family income is between $20,000 and $30,000. Insurance is covered by Dad through his employment, and Allison is covered by Medicaid. The family owns a small two bedroom home with its only restroom/bathing facility in the basement. This is significant, as Mom needs to carry Allison up and down the stairs in order to bathe her.

Mom reports that the family works hard at maintaining family activities with and without Allison. The family went through a difficult time with Allison's older sister, which
caused strain to the relationship between them. Mom feels she and her husband are now much more conscious of the needs of a sibling of a child with disabilities.

Babysitting services have been provided through a private agency and are paid for by Title XIX and waivers. Health care expense has not been a factor for this family due to the subsidy. Prior to the placement of the G-tube, some extended family members were supportive of Allison's care and would keep her overnight occasionally. Since the placement of the G-tube, Allison's mother reports she is "back to square one." The babysitter is not yet qualified to feed her, and relatives have been unwilling to assume responsibility.

Prior to placement of the G-tube, feeding was a long, encumbered process. Each of her three meals and three snacks took 30 to 45 minutes to feed. At the initial interview, Allison weighed 37 pounds. The specialists and nutritionists wished her weight to be in the 50 pound range, but her pediatrician cautioned her mother that 50 pounds could cause heart problems. Mom is more comfortable keeping her weight at 40 to 45 pounds. The school Allison attends has encouraged Mom to use a cup at home for liquids, but Mom uses a syringe as she is concerned that Allison won't get enough fluids. Mom feels that professionals question whether she is really meeting Allison's nutritional needs. Professionals and physicians pushed for the G-tube, which she fought as long as she could.
The decision to have a G-tube was a major one for this family. To Mom, tube feeding is very closely tied to issues of normalcy for her child and to Mom's definition of a "good mother." The issue of normalcy is very significant for this family.

Responsibility for feeding Allison rests mostly with her mother. Allison's sister helps out with feeding at times, but both she and Mom agree that Allison eats best for Mom. Allison's father does not feed her "unless he absolutely has to," but prior to the G-tube, her aunt, her grandma, and the babysitter could get her to eat. Following the placement of the G-tube, Allison was fed every four hours for six weeks. Due to Dad's work schedule, Mom was solely responsible for these feedings.

The decision to place the G-tube was made following testing at a large teaching hospital. Allison's maternal grandfather was to accompany Mom and Allison for the testing, but he had a stroke the night before, so Allison's dad went with his wife and daughter. By 4:00 p.m. of the first day, the physicians were "pushing" the family to hospitalize Allison that afternoon, put a tube in, and have a button added in two weeks. The family refused to decide that quickly, consulted with their surgeon in their town, and were scheduled to discuss surgery three weeks after that visit. Mom, although reconciled to the tube feeding after that consultation, was still holding out for SOME oral feeding.
Mom noted, though, that they were now aware of the seriousness of the situation. She stated the most positive aspect of the hospital visit was her husband's attendance, which led to his involvement and support.

Mom has no time to socialize outside of her family, other than her part time job. When Allison is ill, it is Mom's responsibility to take time off from work to care for her. Her supervisors know Allison and always offer to cover for her when she must leave work. Mom's life appears to be completely centered around her two daughters and their needs. Placement of Allison is not an option to either Allison's mother or to her sister. It is understood that when Allison's mom is no longer able to care for her, it will become her sister's responsibility.

**Cross-Cutting Themes**

After analyzing the data, several themes, or cross-cutting issues became apparent. This section of the paper defines these themes and discusses the significance each has when examining the similarities and differences among the families. A family systems framework is used to organize these themes.

The Family Systems Framework is based on the recursive interactions between child and family characteristics, family interactions, and family perceptions, which, in turn, contribute to functions, or outcomes. The outcomes generate the recursive motion once again, as the work done by the
family members influences the family perceptions and the family interactions. Table 2 lists the cross-cutting themes.

**Child and Family Characteristics**

The child characteristics that were most salient were the severity and demands of the disability. The family characteristics that were most salient were size and socioeconomic status (SES). The following are the cross-cutting themes identified for child and family characteristics.

A. **Severity of the disability increases work and role demands for mothers.** All of these families experienced different types and levels of disability, and these differences affected other areas of family functioning. In these families, as the severity of the disability increased, so did the work demands placed on the mothers. The following statements, made by mothers in the study illustrate the types of demands they faced. The parentheses indicate the family from which each quotation was taken.

"She required suctioning and medication around the clock. Some medications you don't give with food and she would be eating every three hours. We had to alternate food with medication, so we were feeding her all the time." (mom, 8)
Table 2. Cross Cutting Themes Identified in Families

<table>
<thead>
<tr>
<th><strong>Child and Family Characteristics</strong></th>
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<tbody>
<tr>
<td>A. Severity of the disability increases work and role demands placed on mothers.</td>
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<tr>
<td>B. Additional children can positively influence both parents.</td>
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<tr>
<td>C. Disability can lead to financial hardship.</td>
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<th><strong>Family Perceptions</strong></th>
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<tr>
<td>A. Both mothers and fathers expressed a need to perceive their family and child as normal.</td>
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<tr>
<td>B. Parents have a need to perceive control in their lives.</td>
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<td>C. Parents persevere to define quality of life.</td>
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<th><strong>Family Interactions</strong></th>
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<td>A. Many fathers withdrew emotionally and physically from the family.</td>
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<td>B. Both husbands and wives experience positive and negative influences on marriage.</td>
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<td>C. Disability influences employment, especially for mothers.</td>
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<td>D. Husbands and wives use different social support.</td>
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<tr>
<th><strong>Social Roles and Family Work (Functions)</strong></th>
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<tr>
<td>A. Mothers are responsible for medical care.</td>
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<tr>
<td>B. Mothers perform the majority of child care, and fathers &quot;help out.&quot;</td>
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<tr>
<td>C. Mothers are responsible for the organizational component of caring for children with disabilities.</td>
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<tr>
<td>D. Mothers are responsible for advocating for children's needs and rights.</td>
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<tr>
<td>E. Fathers perceive their role as financial manager and leader.</td>
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<tr>
<td>F. Mothers are gradually being worn down.</td>
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The mother of the child with CHARGE Syndrome, complained that her child's demands continually interrupted her time, which often resulted in Mom losing her patience.

"She can't pay attention to anything for very long, so she gets bored. She just follows me around, getting right up in my face, and won't leave me alone until I feed her. I feed her every hour on the hour, and sometimes she wakes up at 2 o'clock in the morning and won't go back to sleep. She can't be left alone." (mom, 5)

Severe communication skills can also be very frustrating to family members. This mother, whose child is severely disabled with cerebral palsy and mental retardation, discussed the demands placed on her because of her daughter's lack of communication skills.

"My role is to keep them happy and to make things easier for them. For her, it is to keep her comfortable, to entertain her, and to figure out what she wants. It's so hard when she's ill, and I don't know what's the matter. I need to think for her, to know if she's unhappy and why." (mom, 6)

The demands of caring for a child with disabilities rarely ends when the child's parents retire for the evening. Whether or not the child's parents are employed outside the home, continued sleep interruptions take their toll. One mother's story exemplifies this situation.
"He [husband] usually doesn't go to bed until around midnight, so it works okay for him. If she is continually vomiting, it is frustrating. Once she starts in the night, it's hard. She just wants to keep doing it over and over. Two or three in the morning is usually when I get up with her. That's really hard, especially when I have to get up several times with her." (mom, 2)

The parents of the 12 year old child with cerebral palsy and mental retardation do not tag team their four hour feedings. Their daughter was on a feeding schedule which required her to eat each four hours throughout the day and the night. Because Dad worked at 4:30 a.m., he did not participate in any feedings.

"The first six weeks I was run down, getting up at 2:00 a.m. for her, then at 4:30 when my husband gets up...then again at 6:00 for her....At first when she got up at 2:00, she just stayed up, because she went to bed at 10:00 and had that four hours of napping...If she stayed up, [I] had to stay up." (mom, 10)

B. Additional children can positively influence both parents. The number of children in the family often appeared to positively influence the way in which parents perceived their parenting skills, positively impacting their self image. This was true for all families with siblings except one. As one father noticed, the other children sometimes served as a distraction from too much emphasis on
the disability. Family life was centered around normalcy for the rest of the family. Siblings were encouraged to participate in all activities, and care was hired for their child with disabilities. Dad stated, "Having a normal child in each gender helped to not make R. a problem." (Dad, 9)

The literature suggests that older children (larger families) may alleviate some of the work and time demands placed on families with children with disabilities (Trevino, 1979). Of the eight families in the study that had older siblings, two participated in caring for the child. However, only three of the ten families had siblings over the age of twelve. Of the three, the two that helped were female, and the one that did not was male. Following are examples of the roles these teenage siblings took in their families. Additional children positively affected mothers only if they were older female siblings.

"R's older sister helps to care for her whenever she is home, and sometimes even misses school to help care for her. Mom states, "She thinks she's R's mom." However, R's older brother "...doesn't have much to do with helping with anything around this place!" (mom, 6)

Family 10 also has an older teenage daughter. She is very close to Mom, helped to feed her sister orally before she had a G-tube, and has also missed school to help care for her sister. "I help Mom take her downstairs and give her a bath. In the mornings when Mom is taking Dad to work I get
her ready and help Mom." (Sibling, 10)

C. Disability can lead to financial hardship. All the families but one talked of financial hardships or financial implications of parenting a child with special needs. Often, this financial hardship was a burden felt more keenly by mothers. Three of the mothers discussed the need to take on part-time jobs because of the financial demands of the disability. One mother, who already worked full-time outside the home, took on a second part-time job when she needed to replace her vehicle. She explained,

"I needed to pick up an extra eight to ten hours per week to cover expenses. The car died on me, and with J. being the way he is, I needed a reliable vehicle to get him and all his stuff around in." (Mom, 7)

Another mother explained her increased demands this way.

"I have a part-time job to try to help out financially, but it is so stressful. It makes it worse, because there's less time,... because we don't have enough time anyway. Because it's just too hard." (mom, 6)

Socioeconomic status sometimes determines whether or not a child has the supplements, supplies, and equipment needed. One family admitted they were unable to provide the proper nutrition for their child.

"It's expensive. I think...six cans of the liquid is anywhere from seven to eight dollars. And the pudding, might be about five [dollars] or so for four little cans.
And if you give her one or two cans a day, it gets expensive, so I haven't had any pudding for a while."
(mom, 6)

Another mother discussed the high costs of accommodating their environment to fit the needs of their child.
"We'd like to put a bathroom in on the main floor, so we don't have to carry her down the basement to bathe her, but we can't get any funds to remodel our house, and we sure can't afford it on our own." (mom, 10)

Middle and upper middle income families appear to be the hardest hit, financially. Following are examples of two such families.

"I have tried to get assistance for her, and we can't get it. We are just barely over the line of being eligible, but we're not wealthy enough to handle it on our own. And it's, hard. I mean it has drained our savings account down to nothing." (mom, 6)

"You are talking about $2,500 per month. Even paying 20% of that a month would be difficult if we were talking about moving to a different state where we would lose the waiver and have to change insurances. We would really have to check it out before we could accept another job." (mom, 2)

Lower income parents, appeared to have their needs (regarding medical care) met more adequately. This mother of three small boys, two which have significant special needs,
told of her lack of worry regarding medical expenses and equipment.

"Everything he needs has been paid for. I just had to have a wheelchair made, and it was paid for. I don't have a dime in medical expenses, thank God." (mom, 5)

Family Perceptions

Each family discussed their needs to think about or perceive the disability. Some families had similar views; some did not. The following are the major themes identified regarding family perceptions.

A. Both mothers and fathers expressed a need to perceive their family and child as normal. Perhaps the most common of the themes is that of normalcy. Many of the families expressed a need to define their child, the disability, and their family, as normal. For fathers, the issue of normalcy was focused on practical issues; for mothers, the issue was focused more on positive self-identity.

"We have previously decided to operate on the principle of providing C. the most normal life possible. We could, but do not, put medical issues in a supreme position. We have C. at home rather than in a nursing facility where he would receive 24-hour oversight. We send him to school and take him into other settings where he could be exposed to illness--unnecessarily..." (dad, 1)

Other families, especially mothers, tended to define normalcy around eating.
"The trouble that it was to [orally] feed her was abnormal. It was a lot of work. It was extremely frustrating. So getting away from that was getting back to normal." (dad, 2)

Five of the nine mothers who had experienced G-tube feedings with their children not only defined normalcy for their children as being able to eat orally, but also defined the role of a good mother around that construct.

"I can identify with [feeling a failure as a mother]. That's a good way to put it, that's what a mother does for her young child, that kind of feeding. I remember even though I knew it was irrational, feeling like a failure that this kid is not being fed properly.... This is not natural; it's a very unnatural decision to make." (Mom, 1)

Having a normal mother-daughter relationship is critical to this mother, and that involves feeding her orally.

"A big thing is, because my daughter can't walk, talk, sit up, she can't DO anything normal. The closest thing I have to normal with her is feeding her. I don't want that taken away." (mom, 6)

Placement of a G-tube placed the mother-child relationship at risk in this mother's perception as well.

"I just feel like I can feed her and I want her to eat normal foods. I don't know about tube feedings. I don't know if they can grind up meat and put it down in that
tube or if it is all fluids or what. But I just want her to eat the hamburger and mashed potatoes like a normal person. I don't want to put her in the corner and tube feed her. I feel that's my motherly duty to feed her."

(mom, 10)

This same mother was so ingrained in her role of orally feeding her child, that it took her some time to adjust to the G-tube feedings.

"It doesn't really bother me now. It did right after surgery. I thought, look at all this free time I have. Am I doing something wrong? Am I supposed to be doing something else?" (mom, 10)

Yet one more mother agreed that normal meant to eat orally.

"I was so stressed out. I didn't know what to do. This was the one thing I believed a child was supposed to do, was to eat." (mom, 5)

Some families described a need for convenience as being part of a normal life. Families had so many inconvenient aspects to their lives, that this issue became quite important. One father remarked on his perception of convenience associated with G-tube feeding.

"You can always stop at Quik Trip and get a pint of milk. Just give her straight milk; it's not going to give the full nutrition or calories she needs for four hours, but it will get us by." (dad, 8)

The mother of a twelve-year-old daughter with cerebral
palsy and mental retardation agreed,

"It's just, I could hook her up and feed her and go on and help with supper and get other stuff done, instead of one of us doing supper and one of us feeding her." (mom, 10)

B. Parents have a need to perceive control in their lives. Control, or the lack of it, is another common theme in families with children with disabilities. One family had a difficult time with their belief that their child with disabilities was attempting to control them through his refusal to eat. Parents attempted to retain control by sending him away from the table, which may have contributed to his malnourished state.

"Dad is his preference for feeding. When he is there, he will be stubborn in order to get Dad to feed him....that's the only way he can get our attention sometimes, or control us. It does get frustrating. Trying to deal with that frustration so that he doesn't miss a lot of meals because one of us is tense." (mom, 10)

The parents also felt the child tried to control them through incontinence.

"He is potty-trained. That's how he controls [us]. He gets upset at us, and he won't try and hold it. He will just let it go." (mom, 3)

Control in this family was not just related to the
children, however. The father alluded to his authority over his wife's habits in the following excerpt from the transcripts.

"[Knowing that] I need to communicate with somebody, it helps me to allow her [wife] to talk on the phone to people. She needs an outlet." (dad, 3).

Several families discussed their lack of control, especially with physicians and professionals. This mother received conflicting instructions from professionals.

"The doctor said to get her up to 50 pounds. Who are we pleasing? Her, or all these nurses? Now are we going to have problems with her heart because of too much fat around it? I have to deal with that. I have to cope with the dietitians. I am caught in the middle, and I have to try to please everybody." (mom, 10)

This father's fight for control was not with physicians or professionals, but rather with the bureaucracy of the insurance companies.

"I had called them and said I wanted to take her to ... and they basically said, well, let's try this first and this. You know, just kind of stretching things out, I guess. And I was very disappointed with that. And I think on the other side, if we didn't have any insurance at all, you could have just picked up and gone to ... and got it for free to begin with. You try to do what you're supposed to do and they are kind of working against you."
I don't like to take the insurance and abuse it, but...we had a baby that needed immediate attention and she wasn't getting it. And it wasn't the doctors' fault." (dad, 9)

C. Parents persevere to define quality of life. Still other families defined quality of life as the most prominent theme for their family. This was true for both mothers and fathers. Some parents defined quality of life as it pertained to their own lives. Some described it as it pertained to their children with disabilities. This family's view involved quality of life for themselves and for their children without disabilities.

"Over the last year, more for quality of life, we have focused on [older sibling's] education and our pride in her accomplishments. Seeing her excel has really enhanced our quality of life." (mom, 2)

This father spent a great deal of time and energy pursuing the definition of quality of life from his child's perspective.

"Is he basically rational, despite significant mental retardation? If he is rational, what implications does that have for how I interpret him and act toward him? Does he have a basic drive for mastery and dominion? What can he master? Is reinforcing the impulse for mastery a more meaningful objective than seeking to develop functional skills? Does he have the capacity to appreciate beauty? If so, how can I help develop that capacity?" (dad, 1)
This mother persevered for her son's quality of life, often battling with professionals.

"The nurses had the attitude that he is going to be on the tube for the rest of his life. I said, no, he is not. I don't want him on this tube. I don't find that it's healthy for him, and I don't like the looks of it. Now he is on all oral feedings, and they took the tube out." (mom, 5)

Many families have redefined their perception of the disability as well as their roles with their children. In his perseverance for purpose, one father asked these questions.

"Why should I give my heart and my time to a child who has such severe limitations and who will likely die at an early age? Why should I want him to live if he's going to experience such difficulty in life?...What can I do to encourage him to take an interest in life - to find life worthwhile despite his difficulties? What kind of person do I want him to become? In what ways can he become the child I had originally imagined - in what ways is he already?" (dad, 1)

The mother of the seven-year-old boy who was brain-damaged during labor shared how she has persevered to define quality of life with her son.

"Sometimes it comes back to me, your child could be up and running around. It will dawn on me, and I will step back and say well, I've got a little boy that loves me,
and like any other mother with a child, I want to be with him. I have to accept what I have, and what I have is good." (mom, 7)

Family Interactions

The findings in this study support that having a child with disabilities in the family can impact every other level of the family system. Several themes were identified in these families that demonstrated the impact on interaction between the child and the family subsystems, as well as with the family and its larger external systems. The following are these themes of family interaction.

A. Many fathers withdrew emotionally and physically from the family. The child's interactions with his or her parents initiate the recursive cycle of interactions within the family. A father who is detached from his child may devote himself to his work in hopes of avoiding his responsibility, have an affair in hopes of being supported and understood, or withdraw socially. All of these choices impact his other relationships. Eight of the ten fathers studied withdrew, at least initially, from their children with disabilities and, in some cases from their families as well.

J's mother was very angered by his father's response to his birth, at which time his disability was obvious.

"His father wanted to get rid of him. He didn't deserve to live, and when he did, he wanted to just put him up for adoption. He even threatened to throw him in the
This mom explains her stress around her husband's distancing from his daughter.

"We bought more toys so we didn't have money for a divorce. The hardest thing for him at first was accepting. Then I would get mad because I couldn't understand why he couldn't accept it. My thing was, we've got to do everything for this baby, because we are not going to have her for very long. His was, I can't do it because we're not going to have her for very long." (mom, 8)

This mom has been distressed by the child's father's continuing lack of involvement, now that their son is age five.

"I just wish if he didn't want to, if it is too much to handle, just tell me. I wish he wouldn't lie to me. I know he is lying....There were a lot of times...and he would call and tell me things so he wouldn't have to come and pick him up." (mom, 4)

T's mother, now divorced from his father, was unable to cope with her husband's avoidance of their son and his problems.

"My husband was already running from the condition when our son was born. I always had to pick up the pieces. He threw himself into his business, working long hours, and when he wasn't there, he was going out with
customers. He began drinking, gambling, and having affairs. He was never home. It was really overwhelming." (mom, 7)

Of course, not all the fathers withdrew from their children's disability. Two fathers were involved and supportive from the beginning, while four of the remaining fathers were able to form close relationships with their children as time passed. Following is an excerpt from the story of a mother who perceives her husband's relationship with their daughter in that way.

"He has always loved handicapped kids, and he has the patience. In fact he is real close to her. He will come home and pick her up and play with her and they still romp. They still have the father/daughter relationship there. She looks forward to him to come home and romp with him every night." (mom, 10)

None of the mothers in this study withdrew from their children as a means of coping with the disability. Mothers who were full-time care-takers for their children appeared to feel more satisfied with the relationship they had with the child than those who were not. One mother who worked full time outside the home explained how difficult it was for her to develop a relationship with her daughter.

"At 3 o'clock in the morning...when that was the only interaction with her I had, because I was working all day, then I had to come home and play with [her sister]
and help with dinner, then to wake up with a child in the middle of the night who did nothing but cry, that was very hard." (mom, 2)

B. Both husbands and wives experienced positive and negative influences on marriage. Some couples in this study felt their marriage was stronger due to the child's disability, while others felt that their marriage was not able to tolerate the strain of the added demands. One couple noted their increased communication, which they felt was a positive influence of having a child with disabilities.

"We communicate so much better than we did before, mostly because we have to. It's mostly around schedules and educational programs, but we really spend time communicating." (Mom, 2)

One mother, who received almost no help from her husband, directly or indirectly related to child care, noted her relationship was much stronger after the birth of their daughter. Many of her descriptions of her marriage involved the word trapped, and she summarized their relationship as feeling cemented in the marriage. The child did have a very direct relationship on the couple in that she and her husband had not shared a bed for several years.

"I sleep with R. every night in my bed. Her movements were always waking her up, and she wasn't sleeping well. The only way I could calm her down and get her back to sleep was to hold her arms down. This way she sleeps a
little better....He sleeps on the couch in the living room....He has since she left her crib..." (Mom, 6)

Another couple described the positive influence on their marriage as it related to team work.

"I think we've had to work together a lot more, as far as doing things with her and doing things with the kids...he'll take the older two and play with them and keep them busy while I'm feeding her or trying to get things. I think we've had to work more as a team." (mom, 9)

In seven of the ten families, wives described their relationships with their husbands (or significant others) as satisfactory, but discussed negative influences on the marriage in terms of wanting increased involvement from their mate, either emotionally or in the form of direct assistance.

"My husband feels he doesn't do enough, but he doesn't know what or how to do it. I tried to tell him how to help, but he never followed through. I guess he never really wanted to know." (mom, 7)

This wife discussed how the demands of her daughter's condition influenced her need for assistance from her spouse. She wanted some respite from the responsibility of putting her child to sleep each night, but was not able to ask her husband.

"My husband goes to work in the morning, and I feel bad. I mean, as it is, he doesn't get much sleep [on the
couch]...but there are times at night that I wish I could go, and somebody else could put her to sleep. But I can't expect him to when he has to get up earlier than I do." (mom, 6)

This woman addressed how her jealousy of her husband's freedom negatively influenced their marital relationship.

"He puts around when he wants; he's able to spend time at his grandma's; he can get all the things done that he wants to; he only has to get himself ready when he goes to work; and I can only take time to get groceries."

(mom, 8)

C. Disability influences employment, especially for mothers. The child with disabilities has a major influence on parental employment outside the home. All ten of the families believed that having a child had a significant impact on either one or both members' employment. This was especially significant for mothers. Seven of the ten mothers interviewed worked part-time or were unable to work outside the home at all, due to their child's needs. One mother discussed her inability to work due to her children's needs,

"The doctor appointments in the past and in the future, there's no way an employer would tolerate the time off I would have to take. Emergencies at 2:00 to 3:00 in the morning. I don't even consider working until the kids are in school. I might not even be able to then." (mom, 5)
Mobility is another way in which the disability can affect employment. Couples with a child with disabilities may not be as mobile as those couples without. Five of ten couples stated they had no choice but to stay at their current employment due to the possible loss of health insurance benefits, while one couple changed jobs and geographic location to upgrade those benefits.

"We were faced with the option of moving to ... and not being reimbursed for increased expenses and having our health insurance dropped because E. was too costly. I was offered a position here, which had no preexisting condition on the policy... We decided to jump." (mom, 2)

Couples were also very cognizant of work-permeable boundaries. Of the eight wives employed outside the home, six would expect to be the one to take off work with their child. The other two wives shared that task equally with their husbands. All six of the above wives reported that their employers were very flexible. All of the men reported they would get off work in an emergency, but all but two expected their wives to go first, for a variety of reasons.

"She gets five weeks off per year with pay. I am strictly commission, so it makes much more sense for her to take off work than it does for me." (dad, 9)

One of the fathers learned his employer was not as sensitive to the needs of his family as he had believed.

"My husband's boss told him it was okay to put his child
first. Then he came to the hospital to help me after I had been there with her for one week [out of town] by myself. He'd been back to work just one week when he got laid off. It kind of made us wonder." (mom, 6)

All of the professional men brought work home with them, and one of the men working a blue-collar position did as well, but none of the women brought work into the home from the office. All of the women expected their home lives to transgress the boundaries of the office, while only two of the fathers found that would be acceptable in their positions. One of those fathers was employed in academia, while the other was employed in a human service agency.

D. Husbands and wives use different social support.

Four husbands reported their most significant form of social support were relationships at work, and two men reported their relationships with their wives. One husband stated his major source of support was individual friendships (which he met through his child), one described extended family members, and it was not clear what type of support one of the men preferred (family 10). No wives selected work relationships as their most significant form of support. Two wives selected individual friendships, four selected their husbands, two selected organizations/support groups, one described extended family members, and one wife had no support system, other than her teenage daughter. Her husband also did not spend time away from the home, and apparently had no significant support.
Mom stated, "If my husband does take time outside of work, I resent him for it." (Mom, 6)

Extended family played a notable role in the lives of these families. While only three of the families received support from both their extended families, four families counted on one of the extended families for support, and three families received no support from extended family members. Even those families which received no support from their extended families, felt their relatives made an impact on their families.

"His parents were very against the G-tube. They felt like we should just let her die. My family is just the opposite extreme. They really push E. to excel, [saying] I should take her to more therapy...I say, why don't you just be a grandmother? Why don't you just be [my] mom?"

(mom, 2)

Social roles and family work (functions)

This section discusses the major themes identified regarding the type and amount of work done by both parents in a family with a child with disabilities. Females continue to be affected more significantly with both direct and indirect child care responsibilities than do males.

A. Mothers are responsible for medical care. The medical aspect of the child's disability is often left to the mother, as was the case in this study. Much time is spent in the hospital with children with severe disabilities, and in
these families, it was most often the mothers who stayed with the children in the hospital. Mothers were also the ones who scheduled and took the child to doctor appointments and relayed information back to the husbands. The following examples illustrate the increased responsibility mothers bore for their children's medical care.

"He [father] didn't go to visit her an awful lot. To get him to visit her, it was like I had to go with him. I had to quit my job to stay with her...we still had a baby at home...The hardest thing was, I couldn't be at the hospital 24 hours a day like some of the other moms, and you get the feeling that the doctors and nurses look at you like, 'How can you leave this baby who needs you?', when you have a baby at home that needs you, too." (mom, 8)

This single mother also complained that her child's father did not share the responsibility for his care in the hospital.

"The last time he [child] was in the hospital, I don't think he [father] went there once. The time before that I think he was up there twice. He [child] has been in the hospital four times. Sometimes I stayed over night, but it was really hard because of my three year old at home." (mom, 4)

The father in this family neither spent time at the hospital nor cared for the new infant, born just seven weeks prior to his child's hospitalization. The baby was passed between
family, babysitters, and grandmas.

"Well, I...she [wife] basically took care of him herself. I went down [to the hospital], so she could come home, but I pretty much wasn't there." (dad, 7)

In this study, two of the mothers had a medical background, so it seemed a logical choice for their husbands to defer to their judgement, to have wives attend doctor appointments, and to have wives seek medical information. However, in eight of the ten families, moms were solely responsible for the medical component of child care. In two families, mom and dad shared the medical information component. In one family, parents shared the search for information and the actual doctor appointments, and in no instances, was the father solely responsible for medical information or physician appointments. According to one mother, her doctor indicated that was a common experience for him.

"That's one of the things our physician said one time. When the mom and dad both come in, my immediate reaction is fear and feeling threatened. If both of them are there, something must be wrong. I guess I never realized that. They are really used to dealing with moms." (mom, 2)

Another mother was elated, when, by chance, her husband found it necessary to accompany her to an important medical appointment after twelve years of sharing a child with
disabilities.

"He was there with me and he seen it all. He was like me, they are not going to put the tube in. Instead of me being there and coming back and him saying, oh, they just told you that because that's what they want....The Lord worked in mysterious ways....I think he is starting to get involved in it, and he's wanting to know, too." (mom, 10)

B. Mothers perform the majority of child care, and fathers "help out." Mothers also do the majority of direct child care and family work. Even in situations where wives perceive their husband as doing his share, they are perceived by themselves and by their wives as "helping out" their wives.

"My husband is very willing to stay home and take care of the kids. He did not do so with the first child, but I was making more money when E. came along, so dollars became a factor in this change. Despite the fact that he came from a very traditional home, he is willing to help out at home." (mom, 2)

This husband also helps out at home, but he is not very good at it.

"He might try to help hold her hands [while I feed her], but you catch him watching TV, and he's not paying attention to what he's doing." (mom, 6)

Many wives find, as the following excerpt will show, that the majority of the daily tasks of child care continue to fall on
their shoulders.

"He will hold her while she's being fed, but he won't prepare her food. He'll change diapers if he has to, and once in a blue moon, he'll dress her. He's never made it to an appointment, and he's taken her in the car by himself only once." (mom, 6)

Another father, who considers himself, and is considered by his wife, to have an egalitarian relationship, boasted about the fact that he has never changed his daughter's diaper, nor has he ever bathed her. Speaking of his wife's time, this father stated,

"Well, it [the child's disability] really is time consuming. I really try to stay busy working, every minute I can. So I'm either...outside or making phone calls, or I've got some paperwork to do. I guess this has put more demands on her time, with the kids." (dad, 9)

Mothers complained that they continually felt obligated to their husbands for their help. As one mother put it,

"Sometimes, I feel resentful because he'll do the same things I do all the time, but when he does it, I should thank him or feel indebted." (mom, 1)

This wife felt guilty for not rewarding her husband enough for his help.

"I neglect to tell him often enough that most dads wouldn't spend time, especially with J. being who she is.
Most dads wouldn't pick her up from school, pick her up from the babysitter, and have her hanging around until I get home from work." (mom, 8)

C. Mothers are responsible for the organizational component of caring for a child with disabilities. Mom's role not only involved more of the direct child care and family work tasks, but it also involved more of the organizational component. It's not just the organization of schedules and medications that consumes the mother's time. Singer, (1995) notes, "Homemaking still requires cooking, cleaning, laundering, transporting children, and caring for family members with illnesses and disabilities.... along with taking the child to medical appointments, attending school meetings, and arranging child care" (p. 15). This mother used a rigid regimen to enable her to organize the needs of her children and to facilitate the needs of her husband.

"They have pajamas on and are ready for bed. Then they eat, so all I have to do is change diapers, go potty, brush teeth, and then they are in bed. That way...he can come home and sit down, and eat while I do the rest of the diaper changes and that type of thing. Then, while he puts them in bed, I work on cleaning the kitchen."

(mom, 3)

Regarding her daughter's medication and schedule, one mother organized a system to keep herself, and anyone else who might care for her child, aware of her daughter's needs.
"To keep it straight, I just had to put it down on paper and keep it on the side of the refrigerator. Every time I walked by it I would check it. I had all the medications on index cards, the dosage, what times I gave them to her, what the side affects were, and what to watch for." (mom, 8)

Another mother also assumed the responsibility for organizing her daughter's needs to be sure her child had consistent care. "We developed a book that has all of the procedures, exercises, what we want done, and how we want it done. That's made me feel better. I don't know if it has helped them,... but it has made me feel better about what happens in the house." (mom, 2)

D. Mothers are responsible for advocating for children's needs and rights. Mothers tend to advocate for the rights of their children on a daily basis and with a variety of individuals. They may be more involved in this process than their husbands as mothers often have more contact with the professionals, the school, and the physicians.

"Because I have had to do the majority of the advocating for E., I have become a much stronger person. It has increased my ability to advocate for myself and for my other children, and I am much more assertive than I used to be." (mom, 2)

This mother gives an example of how she advocated for her child's health care needs.
I can only buy 'That's just J.' for so long. Then I changed doctors. I went on a manhunt. I would call them up and ask what their interests with special needs kids are, if they care for kids with gastrostomies.... I went to meet the doctor...and saw if they want to give the doctor's attention that I need. (mom, 8)

Fathers were more likely to spend time advocating for their children's needs when their wives needed their assistance in dealing with individuals or bureaucracy.

"We were upset with the school because they didn't want to spend the time during the day to fight with oral feeding. Well, we're not going to do this [G-tube] just to make it convenient for the school." (dad, 7)

E. Fathers perceive role as financial manager and leader.

Dads' role encompassed some tasks that supported the caring for the child, even though it was not direct involvement. Dad often perceived his role as the financial manager or leader for his family. The following are examples of this.

"My husband has last say in all financial decision. I fight for my way, but I never get it. I pay the bills, but he gets to decide how they get paid, even if I don't agree." (mom, 6)

"The husband is ultimately responsible for the overall leadership of the family....So it's not the wife trying to take the dominant role. The ultimate responsibility of the child's education, car repairs, and food, the
husband is really supposed to take the responsibility for. (dad, 3)

F. Mothers are gradually being worn down. The needs of the child with disabilities, and thus, the needs of the child's family, change over time. With every developmental stage will come new stressors. The child who does not learn to walk, does not go to school, does not learn to drive, and does not leave home at age 18, will present a new challenge to his or her parent, and a renewal of the grieving process. It may also bring on a repeat of the avoidant behavior if the parent has not yet dealt with his or her grieving of the disability. Along with the child's change over time, the adult will continue to grow and change. Children will become too large to be lifted, and parents will become too feeble to lift them. This section will illustrate how these changes gradually wear down mothers, the child's primary caregiver.

"I'm so physically and emotionally tired now. There are days when I sit and cry, because I don't know how I can stand any more. And I worry about the future. I'm getting older, and she's getting bigger. I feel like I don't have as much patience because I'm tired all the time. I feel like I just have so much on top of me, so much stress, and I have to rely on her [older daughter] so much. The dependency never stops like it does with my others" (mom, 6)

Six of these ten families are already looking toward out-
of-home-placement for their children. Of the remaining four, one has been removed from his home, one family will not consider out-of-home-placement, and two families have not yet decided what their future might hold. This decision has been very difficult for those families who have made the decision, or are continuing to struggle with it.

"She was having constant vomiting, things really changed drastically in a short amount of time...I felt like I couldn't handle it much longer. I really felt like she was at risk for out-of-home placement...back then, at 3 o'clock in the morning, saying I can't do it anymore, we need to call a social worker. I can remember doing that several nights." (mom, 2)

This wife is very sensitive to her husband's feelings about placing their child, but is also feeling very worn by her son's care.

"I believe I will be ready before he [husband] is to let him go [to placement]. But things will go much more smoothly if I let him initiate that process. I trust that he has my well-being in mind enough that he will not let that go too long."
CHAPTER FIVE: CONCLUSIONS

Summary

The purpose of this study was to examine the relationship between gender and family and child characteristics, to see how gender influences family perceptions and interactions in families of children with disabilities, and to examine how gender influences social and work roles (functions). These results support other findings that suggest that child care is still the responsibility of women.

This study identified many common themes or cross-cutting issues in families of children with disabilities. This section will address conclusions made about those commonalities.

Child and family characteristics

This study found that the severity of the disability increased the work and role demands placed on the mothers, which supports the findings of Bailey, et al. (1992) and Schilling, et al. (1985) that when a child with disabilities is in the home, child care and house work take much more time. As mothers were the primary caregivers, their role demands increased commensurate to the severity of the disability. Mothers experienced role strain due to the increased interruptions and great demands placed on their time, preventing them from completing other role-related work. The results of this study support the literature (Bristol, et al., 1988, and Young & Roopnarine, 1994) in that this other work
(cleaning, laundering, cooking) is generally not assumed by the husband, and therefore, does not alleviate this additional role strain caused by the severity of the disability. Mothers also suffered from sleep deprivation, caring for their children with disabilities throughout the night, and maintaining their other responsibilities in the morning (caring for husbands and other children).

Additional children can have a positive affect on the family. This study supports the conclusions of Powell and Ogle (1985) which suggested that additional children may help to fulfill the parents' expectations for achievement. Trevino (1979) found that the availability of more family members to absorb chores and work related to the disability may contribute to this positive affect on the family. This study supports Trevino's conclusion only when it is applied to older female siblings. In this study, female siblings were significant supports for their mothers in the provision of direct and indirect care for the younger sibling only if the older sibling was at least thirteen years of age. It would be interesting to examine the roles of adolescent female siblings of children with disabilities to see if the role performance of these two teens is characteristic of their population, and if they would continue to emulate their mother's roles in provision of care for their siblings at the expense of their own needs. Certainly, by the end of this study, these two adolescents were beginning to show the role strain that is
characteristic of mothers.

All the families in this study noted that having a child with disabilities can be a financial hardship for the family. This study reinforces the need for financial reform in distribution of aid to families of children with disabilities. Lower income families felt that their medical needs were met adequately. Upper-middle income families felt the financial implications in restrictive job mobility and insurance limitations. These findings indicate that middle income families often have difficulty qualifying for needed subsidies, but do not have the necessary financial resources to independently manage the needs of their children. As Singer (1996) notes, "Pressures to cut costs have led to increased reliance on unpaid family help to care for vulnerable people" (p. 5). In most cases, this unpaid family help is mothers. This is significant when viewed in terms of Schor's (1992) research, in which surveys showed that "70% of all working women still perform all or most of the work at home" (p. 15). With this fact taken into consideration, the financial hardships on families of children with disabilities become keenly appreciated by women.

Family perceptions

It seemed helpful for the families in the study to organize themselves around their perception of the disability. In some families it was intentional, and in others it was not. The need for normalcy was the most unifying theme in this
group of families. Over half of the mothers in the study, who were faced with decisions regarding feeding tube placement, had a need to maintain a sense of normalcy in the mother-child relationship, and in each of those cases, the relationship was defined by the child's method of eating. This information could be beneficial to therapists, nutritionists, and early interventionists, as they experience resistance from mothers regarding feeding tube placement.

Quality of life was another major theme which families used to organize their perceptions of the disability. It was common for families to search for meaning, either for their own lives as they were impacted by their child with disabilities, or for meaning in their child's life. Quality of life for the child usually included keeping the child at home for as long a period of time as was possible, which, in turn increases role strain for mothers.

Family interactions

A significant theme regarding family interactions in these families was that of the father's withdrawal. Eight of the ten fathers in this study distanced themselves emotionally and/or physically from the child and from their wives at the time of the diagnosis. It is unclear if all the fathers withdrew due to the disability, or if some may have withdrawn due to the tension in the marital subsystem resulting from the disability. It is possible that the fathers did not perceive themselves as having withdrawn, but may have felt shut out by
their wives, as some of the mothers assumed a rather exclusive relationship with their child. It is also possible that mothers assumed a strong role identification through the tasks they performed for their children and were hesitant to let go of that role, consequently giving up an aspect of their identity. This seems unlikely in this study, however, as there was more than enough work, and mothers did not complain about husbands not doing work well enough. The mothers in this study appeared to be open to any assistance from their spouses.

Perhaps this withdrawal was due to different communication styles used by men and women. Men tend to internalize their feelings, while women tend to be much more verbal in expressing their feelings. Certainly, traditional role models, life experiences, and the media might have influenced men to be strong and silent, while women have been conditioned to express their feelings and emotions.

Certainly, this finding indicates the need for therapists and early interventionists to be sensitive to signs of stress in the marital subsystem, as well as a need for supportive services to enable couples to work through and understand these very different coping strategies of mothers and fathers. As Kazak and Marvin (1984) noted, how effectively this experience is shared can lead to marital disharmony or to a stronger marriage. Grieving mothers needed the support of their spouses at the very time the grieving fathers were
turning inward. This would support the need for marriage and family therapists to be involved as part of the early intervention team.

A child with disabilities influences employment, especially for women. This study supports the conclusions drawn by Kandal (1988) regarding the double burden women face, that even though they are an integral part of the work force, women are still made to choose between career and family. The mothers in this study reacted differently to employment outside the home. As Shelton (1990) found, maternal work force participation can influence different families in different ways. For some mothers, working outside the home added more stress, while for others, it provided a break from the caretaking demands.

Structural buffers negatively influence role strain on women. This study supports the notion of asymmetrically permeable boundaries as discussed by Pleck (1989). The study also supports the research findings of Traustadottir (1991) that the family's needs were expected to spill over into the mother's employment, but not in the father's. Fathers were more likely to be penalized at their work if they were unable to manage their families. This boundary is permeable in the opposite direction for fathers. They may take their work home, displacing their family time, but mother's work may not intrude in her responsibilities to her family.

Conclusions regarding the differences in social support
between husbands and wives did not always agree with the literature. The different support-seeking style mentioned earlier (men withdrawing, women seeking comfort) is congruent with the way women and men discuss their social support systems and preferences. In this study, men preferred their relationships at work as their primary support system, although this appeared to be fairly nonsubstantive support, while wives preferred their husbands. This does not support the literature which suggests men rely on their wives for intimate support (Krause, 1993), and women tend to rely more on their friends and organizations (Harris & McHale, 1989; Krause, 1993; and Schilling et al., 1985).

Social roles and family work (functions)

Hospitalization is a common occurrence for children who are severely disabled. This study indicated that medical situations, including medical appointments, surgeries, and hospitalizations were mainly the responsibility of the mothers. The fathers in this study may have made occasional visits, but mothers were the mainstay of care.

This finding is congruent with the literature. LaRossa (1988) differentiated between involvement and responsibility. Fathers in this study appeared to be involved, but not responsible. Responsibility is still the mother's role. Women are responsible for not only the direct child care demands, including feeding, grooming, guiding, nurturing, and transporting, but also for the indirect responsibilities,
including scheduling appointments, shopping for food and clothing, laundry, maintaining records, meeting with professionals, and maintaining the child's environment. At the same time, many mothers are employed outside the home, and are attempting to coordinate the roles of mother, wife, and working woman. The result appears to be that women are becoming worn out.

It was surprising that although, few of the men in the study actually performed significant child care or family work, their wives perceived their role favorably in several instances. This coincides with Traustadottir's (1991) findings that if husbands satisfy the wives' definition of supportive, both parents will describe their marriage as being good, and working well as a team. According to Traustadottir (1991), husbands must "...provide financial support,...be supportive of the mother's dedication and devotion to the child and her caring work, and...take [an] active part in discussing the options and making decisions about the child's educational program or other services" (p. 221). The fathers participating in this study were not bad fathers. These fathers cared deeply for their children, were concerned for the well-being of their families, and were involved. They saw their roles as supporting their wives emotionally and supporting their families financially, but they did not perceive their role as taking responsibility for doing the work. Unfortunately, this does little to alleviate mothers'
role strain. As Leslie, Anderson, and Branson (1991) found in their study of 60 couples regarding responsibility for children,

The physical help husbands offer when women increase employment time may only minimally benefit women. Certainly, the assistance is helpful, but without truly taking responsibility for children, freeing women from solely having to anticipate needs, remember schedules, and so forth, men's contribution may do little to relieve the strain women feel. A true indication of shared parental roles may be an equalization of the parental strain men and women experience as they take responsibility for their children (p. 209).

Implications

Technological advances in the medical field have caused tremendous changes in the makeup of our population. Not only has this new technology lengthened the life span for the persons with long-term chronic illnesses and for older adults, it has also sustained life for infants, who years earlier, would have had no chance at survival (Singer, 1996). These advances have also precipitated serious issues which will surely impact mothers. Some of these issues, which were noted by Singer (1996) are:

Medical technology has improved survival rates but increased chronicity; the main location of care has moved out of hospitals and into homes....; [and] pressures to
cut costs have led to increased reliance on unpaid family help to care for vulnerable people. (p. 5)

Many mothers will be sandwiched between two generations, providing care to both the young and the elderly. If either of the two populations happens to have disabilities, the role strain will be exacerbated, and the wearing down process may occur much more quickly. These issues raise theoretical questions of ethics and morality that must be addressed at some point in the future and will have great societal implications. What are the long term implications for children with disabilities and public policy regarding institutionalization? Is there a level of disability at which point a child should not be brought into this world? If so, who should make that decision, the legal community, the medical community, the religious community, or the parents?

Children of poverty level wage earners are at greater risk than the rest of the population for being chronically ill or disabled (Perrin & MacLean, 1988). Another segment of the population that is at greater risk for experiencing disability and chronic illness is children born to teenage mothers. By the year 1995, 20 per cent of all children were poor, partially due to a drastic rise in teenage pregnancy (Blankenhorn, 1990). Cadman, Boyle, and Orford (1988) noted that children with chronic illness born to two-parent homes have a 1.5 times the average risk of developing emotional problems. However, the child with chronic illness born to the
poor, single, teenage mother is at 14 times the risk for
developing emotional problems. Policies must be formed to
address these special populations' needs, and creative types
of support needs to be available to help the mothers providing
the parenting.

It is important that marriage and family therapists and
other professionals working with families of children with
disabilities understand their special needs and circumstances.
They must be cognizant of the child and family characteristics
and family perceptions and values in order to gain a more
accurate perspective of the issues with which the family is
dealing. Professionals must also be aware of the special
burdens mothers, and possibly their teenage daughters, face in
dealing with a child with disabilities, and of the role strain
that is a part of that process. They must also be aware of
the stress on all the members of this population, the couples,
the siblings, and the individuals. This enormous stress may
suspend the developmental needs of every individual other than
the child with disabilities. Future research might address
the long term affects on these persons, particularly siblings,
to determine if they lag behind developmentally, and if so, to
see if they ever catch up.

Perhaps the most important implication of this study is
that a result of the wearing down of mothers over the life
cycle might be the return to earlier institutionalization.
This study indicates that mothers are burning out from the
unremitting stress levels associated with the caretaking responsibilities of a child with disabilities. If this is true, it will have far-reaching implications for our society. The trend from the last 35 years has been away from institutionalization, and toward family and community involvement. However, the types of services that the recipients need do not appear to be readily available. Mothers need the availability of respite services, early assessment, diagnosis, and coordination of services, and funding for programs to provide in-home support services, so that families can keep their children in their homes. If the choice is to find out-of-home placement, then alternatives to institutional care, such as group homes, need to be more readily available and accessible to all income levels.

Limitations

Because this study included only ten families which lived within a 60 mile radius, the reader must use caution in generalizing any findings. The diagnoses of the children may appear to be quite homogenous, with the majority of them including mental retardation and cerebral palsy, but a wide variety of sub-diagnoses was also evident in the sample.

This study strived to include fathers' voices to the greatest degree possible, however, no men were interviewed without their wives. This is significant, as women shared more openly about their husbands' roles when they were interviewed alone. In six of the ten families, access to the
husbands could be gained only through their wives. Two of the husbands in this study were never interviewed, because the wives would not give permission for the researchers to contact them. In the two families where the husbands were reached directly, they chose not to be interviewed alone. In fact, none of the husbands would even set up the interviews, but always deferred to their wives. This was not ever the case when wives were contacted. Only one of the wives needed to check a husband's schedule, or get permission before scheduling an interview. This proved to be not only a limitation to the study, but also an interesting finding, which supports the findings of McKee & O'Brien (1983) and Linder and Chitwood (1984), who found that husbands and fathers were generally inaccessible for research, that research was dependent on wives as a point of entry, and that wives needed to be won over to give permission for husbands to be approached.

Another limitation is the age of the children involved. The oldest child was age twelve at the initial interview. It would be interesting to study more families with older children with disabilities to see how issues change for the families over an extended portion of the life cycle. It would also be helpful to have more teenage siblings of mixed gender in the sample to more adequately examine their roles in these families.
APPENDIX A. CONSENT FORMS AND SURVEY

Agreement to participate

We are asking a few families to be part of a study sponsored by Iowa State University. This study will examine what it is like for families to feed and provide nutrition for children with developmental disabilities, particularly children with gastrostomy feeding tubes.

If you agree to participate, your family will be involved in a home interview. The interview will take approximately one hour. There will also be a short questionnaire to fill out.

We appreciate the time you would be willing to share with us. Your information is very important for us to understand the experiences you face having a child with a disability.

If you agree to participate, please fill out the bottom of this form and return it in the stamped envelope. Once we receive this letter, we will call to set up a time to meet with you and your family.

AGREEMENT TO PARTICIPATE

_____ Yes, I am interested in participating in the project.

_____ No, I am not interested in participating.

The most convenient time to reach me is ____________________________

NAME __________________________________________________________

ADDRESS _______________________________________________________

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________

TELEPHONE NUMBER(S) ____________________________________________
INFORMED CONSENT

Nutrition Intervention For Children with Disabilities:

PURPOSE: The purpose of this project is to study the feeding and nutrition needs of children with disabilities and their families. The findings will be used to inform the process of developing programs in early intervention in Iowa. The project is being conducted by faculty and students at Iowa State University.

PROCEDURE: Each family is asked to complete a short questionnaire and return the questionnaire in the stamped enclosed envelope. Any questions you have about the study will be answered at all times.

RISK: Family completion of the questionnaire is totally voluntary. The questionnaire presents no risk to you and is intended to be interesting. If there are any questions you do not want to answer, you may decline answering.

BENEFITS: The benefits possible for families include the satisfaction of having their point of view heard and considered in improving services to families of children with disabilities.

CONFIDENTIALITY: Every effort will be made to ensure confidentiality of families. Information gathered on families will be coded and kept in locked files. All information will be destroyed in five years.

I also understand that my participation is voluntary and that I may withdraw at any time.

NAME ____________________________ DATE __________
Video Taping Release Form

Some of the family videos that are being made for this research would also be useful for training purposes. We are asking for your permission to use the video tape of feeding in your family for use in ISU classes and professional organizations. Classes would include Human Development and Family Studies, and Food Science and Human Nutrition classes that are training professionals to work with children with disabilities. Professionals organizations would include such groups as state and national Association for the Persons with Severe Handicaps; The American Association of Mental Retardation; The American Dietitics Association. The video tapes will not be used in any advertising or other media. All tapes will be destroyed in five years.

Your permission to use or not use the family video for training will not effect your participation in this research in any way.

Sincerely,

Mary Jane Brotherson PhD
Assistant Professor

I permit the video taping of my child and family to be shown to professionals groups and ISU classes for the purpose of training.

_________________________  __________________________
Date                      Signature
Parent information on nutritional program

Today's Date ______ Child with a disability ____________________________
Father ___________________ Mother ________________________________
Address __________________ City __________________ Zip Code__________
Estimated Family Income ____________________________________________

Feeding Information
How long does it take to prepare a meal (puree, grind, mash)?______________
How long does it take for you to feed your child one meal?______________
Is your child fed separately from other family members? ______Yes ______No
How many meals a day do you feed to your child?________________________
How many snacks a day do you feed to your child?________________________
How much time per day (total) is spent feeding your child?________________
List the people in your home who are involved in feeding your child:

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How well do you feel the school has successfully met the nutritional needs of your child? (circle a number)

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How stressed are you in meeting the nutritional needs of your child? (circle one)

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<td>no stress</td>
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How helpful are relatives and friends to you in meeting the nutritional needs of your child? (circle one)

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APPENDIX B. PROCESS AUDIT TRAIL

Family interview questions nutrition project

YOUR FAMILY

1. Tell me about your family?
   * Who is in the family?
   * Describe disability of child?
   * What kinds of activities does your family like to do?
   * How many siblings and extended family

WHAT HAVE YOU BEEN TOLD

2. What have you been told by professionals about _____’s disability and feeding and nutrition needs?
   * Physicians
   * Dietitians or nutritionists
   * Occupational therapists
   * Nurses
   * Teachers

NUTRITION INTERVENTION

3. Tell me about what kinds of things you have been asked to do to help _____ with his eating and nutrition and what that is like for you?
   * How long does feeding/mealtime take?
   * Is this easy or difficult for you to do?
   * What kinds of things make it easy or difficult for you?
   * Who else helps with feeding child?
   * How do other people help with feeding?

4. What kinds of things, if any, do you feel are stressful about feeding or nutrition for _____?

5. Could you tell me about any changes you have noticed in _____ since you have tried new things to help his eating and nutrition?
   * Has he/she acted any differently?
   * Has his/her sleeping patterns changed?
   * Has alertness or interaction with others changed?
   * Has amount and types of illness changed?
Nutrition interviews: Debriefing

1. Revisions in Interview Protocol
2. Descriptive data in short case study on each family.
   * child and family
   * school program
3. Content Analysis of cases: initial categories

Issues that may effect feeding and nutrition in families

1. Social Support Network. Describes the extended family and others in SSN (e.g. church). Those networks in place to assist family. Includes both when they are present and missing.

2. Description of Feeding/eating skills. Specifically describes eating and feeding skills that child had or does not have.

3. Description of the Feeding/Nutrition intervention. Includes description of the intervention and its routines. Includes description of snacks, foods fed, how long and where feeding takes place, type of positioning, can the child come into the kitchen.

4. Role and information of different disciplines. Includes what different disciplines tell family and do not tell family, and how they help or do not help with feeding and nutrition.

5. Control issues around feeding and nutrition. Includes child’s control of others and environment through eating. Also includes parents issues of control in feeding.

6. What the family finds stressful. What is stressful for the child and family around the feeding/nutrition process.

7. Fathers roles and issues around feeding/nutrition.

8. Siblings roles and issues around feeding/nutrition.

So you are still able to have the same kind of interactions around the feeding, it's just that you are freer to do other things while you are having that now? [Yes.]

Could you describe a meal for MHHA then? You said you hook her up, what kind of interaction, what is it like for her since she has the g-tube now?

Mom

Sometimes I feel she don't really know that she is eating. She just sits there and it runs in her. She is content. She just goes on and watches television or whatever. I don't really know if she knows what is going on.

LM

So how is that for you? The one thing that has kept her in your eyes as being the normalcy of children is being able to eat. How is it for you with her eating and not really understanding and knowing that's what she is doing?

Mom

It doesn't really bother me now. It did right after surgery. I thought look at all this free time I have, am I doing something wrong? Am I supposed to be doing something else? Now it just comes natural. It's there and we feed her every four hours. It's just another routine I have to get into.

LM

So now that you feed her every four hours do you need to wake her at night?

Mom

At 2 and 6 in the morning.
Sample questions for second interview

What is the current feeding schedule? Changes in diet?

How has [Patient's Name] health been since we saw you in July?

What has the doctor said about [Patient's Name] health, weight?

How are you (Mom) feeling about [Patient's Name] weight, now?

..........................about tube feedings, now?

What do you feel has to happen for the g-tube to be placed?

In our previous interview, when we asked you about your advice to other parents, you suggested that they make the whole process of caring for their disabled child as easy on themselves as possible? .................tell me about how your decision to wait on the g-tube has made caring for [Patient's Name] easier for you?

What will it feel like for you, [Mom], when you know you agree to the g-tube feedings?

What is it that concerns you about the surgery to put in the g-tube?

Tell me about how having [Patient's Name] in your home has affected your relationship with your other children?

..............................your relationship with your husband?

Tell me about the effect [Patient's Name] has had on [Mom] and her friendships with peers?
She's not listening to her own body. She's probably going to end up with some kind of chronic illness, herself; and that will be when she knows.

CM

The turning point.

KL

When she knows.

CM

That was a good question when you asked her that. That was really good. And, but on one level, I think, intellectually, she knows.

KL

Oh, I think so, too.

CM

But emotionally, she doesn't. She is still grieving, still going through that grieving process with her child.

KL

Is that way people react to grief, though, by controlling?

CM

Some of them do, that's one way of coping is to have total control and that fits into why she doesn't want her gastrostomy tube, too.

KL

Exactly.

CM

It's just another stumbling block that she has to overcome, to allow other people in. So, you know, that's kind of how I saw it. She doesn't allow a lot of people in to help or assist her. "But, why did she allow us to come in and interview her? It doesn't fit. I was going to ask her that.

KL

Well, do you remember when Kim first talked about this family. She said she didn't know if she would allow us. Kim wasn't
Sample of preliminary coding

2-3 p.1 PROFESSIONAL/G TUBE: The G-tube decision went much smoother when doctor explained each step.

2-3 p.1 FAMILY INTERACTION: Mom dad and ___ were all present for surgical procedure of GT.

2-3 p.2 OUTCOME/G-TUBE ISSUE: We regret we didn't do it sooner. "Now we regret that we didn't have it done sooner. We are happy that now she is gaining weight she is happier, healthier."

2-3 p.2 G-TUBE: Didn't really bother mom.

2-3 p.2 PROFESSIONAL: Mom remembers all the profs. as helpful during G-tube surgery - everybody explained each step.

2-3 p.3 PROFESSIONAL: Dr. explained how it was going to be done and what was going to happen.

2-3 p.3 SOCIAL SUPPORT PROFESSIONAL: All prof. telling mom she needed it done - she undernourished. Support from others on the parents decision to have GT and this was helpful.

2-3 p.4 DEMO: May 7th 1992 GT was in place.

2-3 p.4 PROFESSIONAL: 8 weeks after surgery - no follow - up yet from any prof. at SMEUSE.

2-3 p.4 OUTCOME/G TUBE: Mom says life after G-tube is much easier. "It's just, I could hook her up and feed her and go on and help with supper and get other stuff done. Instead of one of us doing supper and one of us feeding her. Usually we hook her up about the same time we eat so she still feels involved."

2-3 p.5 GENDER ROLE: Mom says it is much easier now for her - she gets other things done and she eats better and I'm not forcing it in her and I'm not taking all the time.

2-3 p.5 GENDER: Mom thinks she is still - satisfied with mother role - she still snuggles with her before and after feeding.

2-3 p.6 MEALTIME: Mom states that she feels doesn't really know if/when she is eating. ___ seems content with when the GT is hooked up.

2-3 p.6 GENDER: Mom has adjusted to tube and the free time it gave her. "It doesn't really bother me now. It did right after surgery. I thought look at all this free time I have, am I doing something wrong? Am I supposed to be doing something else? Now it just comes natural. It's there and we feed her every four hours. It's just another routine I have to get into."

2-3 p.6 G TUBE/INTERVENTION: Mom feeds her every 4 hours including 2am and 6am.

2-3 p.7 G TUBE GENDER/INTERVENTION: Mom feeds 2x in night - o.k. with mom in 6 weeks they will begin to regulate her or sleep through the night.

2-3 p.8 GENDER MEALTIME: Mom describes getting rundown adjusting to the night feeding - sometimes she was up for several hours if ___ stayed up.
REFERENCES CITED


of young handicapped children. Topics in Early Childhood Special Education, 8, 38-57.


Collaborative involvement with parents of exceptional children.


ACKNOWLEDGEMENTS

It is with heart-felt appreciation that I acknowledge the help of the following persons in the completion of this dissertation:

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I also wish to thank my mother and father for continuing to "parent" my family while I completed school, and especially while I completed this research. I'm sure Mom agrees, "A mother's work is never done..."

My children deserve special thanks for their support, "How many pages do you have left?"; their inciteful questions, "Whose idea was this college thing, anyway?"; their ability to help me to keep a healthy perspective, "My mom's going to be a doctor, but not a real doctor..."; and their tenacity to fend for themselves when the laundry was not done and the refrigerator was empty. Special thanks go to Teague for his technical assistance on the computer. I hope all my sons have learned something about perseverance and the value of accomplishing a goal.

I wish to thank Dr. Harv Joanning for his feedback and edits on the preliminary drafts of this work. I also wish to thank him for his encouragement and friendship as I began this long process. My other committee members have also been very
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Most of all, I wish to extend my appreciation to Dr. Mary Jane Brotherson. She has been my sustenance throughout this process, and I'm not at all certain I would have completed it without her support, encouragement, and friendship. This dissertation is dedicated to her.