PARENTING CHILDREN WITH DISABILITIES

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BY

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To my children,

Eric Schoen Johnson

and

Jessica Schoen Johnson,

who show me daily that we all have greater abilities

than we have disabilities

ACKNOWLEDGMENTS

Here I stand at the culmination of my formal education and look back at, what some would call, my morbid fascination with schooling and wonder how I got myself both into, and out of, all this. Who would have thought that the skinny little girl who, as the nuns were apt to comment, "talked too much to the boys," would make it to Ph.D.? Where did this kind of determination come from? there are many who had a hand in it--

My parents, Roy and Marie Schoen, have always believed that I could accomplish anything I attempted. That kind of message does not ever wear off.

My sisters, Roberta Schoen Ravagnani and Mary Ellen Schoen Makkos; my brother, Jeff Schoen, brothers- and sisters-in-law, Bryan and Dee Johnson, and Bonnie and Denny Balcer have supported my efforts over the years.

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ABSTRACT

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The study was a qualitative approach to the parenting of children with physical disabilities. Participants in the study were mothers of preschool and elementary school-age children with a physical disability of mild to moderate degree of impairment and who were mainstreamed into normal classrooms and usual childhood activities such as sports, Scouts, and neighborhood play.

The participants in the study were asked, by means of a nonscheduled standardized telephone interview, what they were doing well and "not well" in parenting their disabled, child, what difficult experiences they had encountered, how they were preparing their child for the questions or teasing of other children, what they were doing to encourage their child's social skills, how they were handling discipline and nurturing issues, and how they were teaching their child new skills. In addition, they were asked to give their overall perception of themselves as parents and to comment on anything they wished to add

regarding the rearing of a child with a disability which the interviewer had not mentioned.

The parents' responses were taped, transcribed, and then analyzed according to grounded theory methodology. The data concepts collapsed into the categories of goals for the child, communicating to the child, interacting with the child, seeking help for the child and themselves, dealing with their own feelings as parents, parental regrets, and advice for other parents. From these categories emerged the core variable, parental straddling, which occurred on three levels: (a) parents were living in the past, that is, the preoccupation with the child's birth, diagnosis, and developmental milestones, and dealing with the day-to-day present, the additional challenges of parenting a child with disability; (b) parents were dealing simultaneously with the child's and their own feelings and issues; and (c) parents were striving for an ideal position of viewing and treating the child and helping him or her see himself or herself as "normal" when the child was not "normal" as evidenced by his or her involvement with therapies, doctors, and special education. The core variable, parental straddling, was diagrammed and discussed as a component of parents' coping with rearing a child with a disability.

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INTRODUCTION

. . . of all the blessings and misfortunes it is our
fate to meet with in life, those connected with our
choice of parents are the most important; nothing in
the world can be matched with them for significance.

Eugen Bleuler
(cited in Anthony, 1985, p. 312)

The critical nature of parenting is thus described by
Bleuler, the famous Swiss psychiatrist who named the
syndrome, "schizophrenia." In recognizing the impact of
the parent-child relationship, he continued, "They
[parents] nurtured his 'heart' so that he could feel
properly; his mind, so that he could think of ways to deal
with his predicament; and his body, so that he would be fit
enough to adjust better" (Bleuler, cited in Anthony, 1985,
p. 312). Parenting, so vital to the development and future
mental health of any child, is no less instrumental to the
well-being of a child with a disability.

When we study about families with disabled children,
we invariably meet with volumes of information on parental
reactions to the birth of a child with a disability. We
hear about denial, grief and mourning, shock and disbelief,
anger, bargaining, depression and chronic sorrow, stress
factors, and, finally, acceptance and adjustment (Eden-

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Piercy, Blacher, & Eyman, 1986; Fraley, 1986; Kubler-Ross, 1969; Olshansky, 1962; Shapiro & Tittle, 1986; Stein, 1983). We rarely hear the more positive terms of family coping, strength, resilience, and growth. We read about the immediate reactions of parents and the events surrounding the diagnosis of the child with a disability (Farran, Metzger, & Sparling, 1986; Halpern, 1984; Lipsky, 1985). We rarely are told about the day-to-day events of rearing a child with a disability or the long-term adaptations of families. We may learn what professionals and experts have to say about parenting a child with a disability. We rarely listen to the words of parents.

Problem of the Study

The problem of the study was to describe the parenting behaviors used by parents of school-age children with physical disabilities. Categorization and analysis of mothers' own words about their care and rearing of their disabled child may lead to the formulation of a theory of parenting which would enhance the development of children with special needs.

Purpose of the Study

The purpose of the study was to elicit information from parents of physically disabled children regarding

their strengths and weaknesses in parenting, their encouragement of the child's social skills and learning, their nurturance and limit-setting or discipline, and general perceptions of themselves as parents.

Rationale for the Study

Current research on parenting children with mild to moderate disabilities is sparse. There is, however, an abundance of studies on parental responses to the birth of children with severe disabilities (Blacher, 1984; Eden-Piercy et al., 1986; Pilon & Smith, 1985), on parental stress, grief, discord, and attitude toward the disabled child (Donovan, 1988; Fraley, 1986; Lipsky, 1985; Shapiro & Tittle, 1986), on young children with disabilities (Bennett & Algozzine, 1983; Hayden, 1979), and, increasingly, on siblings of disabled family members (Edmundson, 1985; Harvey & Greenway, 1984).

Yet, the needs of the many children, whose disabilities are mild to moderate in degree of impairment and who are mainstreamed into "normal" classrooms are infrequently, if ever, documented and discussed. In addition, the needs of the parents of those children are uncharted territory for the nurse-researcher. In clinics and home visits and schools, nurses could assist parents to help their physically disabled child reach his or her

physical, psychological, and social potential. It is difficult for nurses who are in contact with these parents to know what anticipatory guidance to offer about parenting. Is it, as some would assert, impossible to advise without having been there oneself? Nurses and other health care providers need specific and honest information about the parenting processes in families with children who are mildly to moderately disabled. This information will help them in meeting the needs of other parents whose children have special needs.

Many physical disorders have identical consequences, says Stein (1983), regarding development and adjustment; the issues in rearing a child with a physical health problem are parallel, regardless of the nature of the child's condition. The information gained from parents in the present study may be applied across disgnoses or conditions to the rearing of children with other types of disabilities or long-term health problems.

Although we have knowledge of the stages of grieving after the birth of a handicapped infant, we have less understanding of the ongoing process and successful functioning of the family (Kazak, 1986). In fact, we do not even know what is "normal" functioning in the homes of families with disabled children. We need to understand

these families as units coping with ongoing, long-term, chronic illnesses and disabilities (Kazak, 1986). The knowledge gained in the present study of parenting may be used by nurses in their child health practices to offer realistic, adaptive, and hopeful approaches to the care and rearing of children with disabilities.

Conceptual Framework

Each family uniquely experiences the stresses with which they cope; no model can capture those experiences with absolute fidelity (Farran et al., 1986). Yet, models have a great usefulness in helping health care researchers and providers to examine and analyze the events and responses experienced by others and plan appropriate services.

The Stress-Adaptation Model for parents of handicapped children (Farran et al., 1986) is a linear model with three major components: (a) the demands on parents, (b) the capacity to adapt, and (c) the impact or end-state. It is also a stimulus-based and response-based depiction. The model is portrayed below.

Individuals who are in a chronic state, such as those with a permanent disability, periodically cycle through the pathway depicted by the model. A new cycle is triggered each time new events occur that demand changes on the part
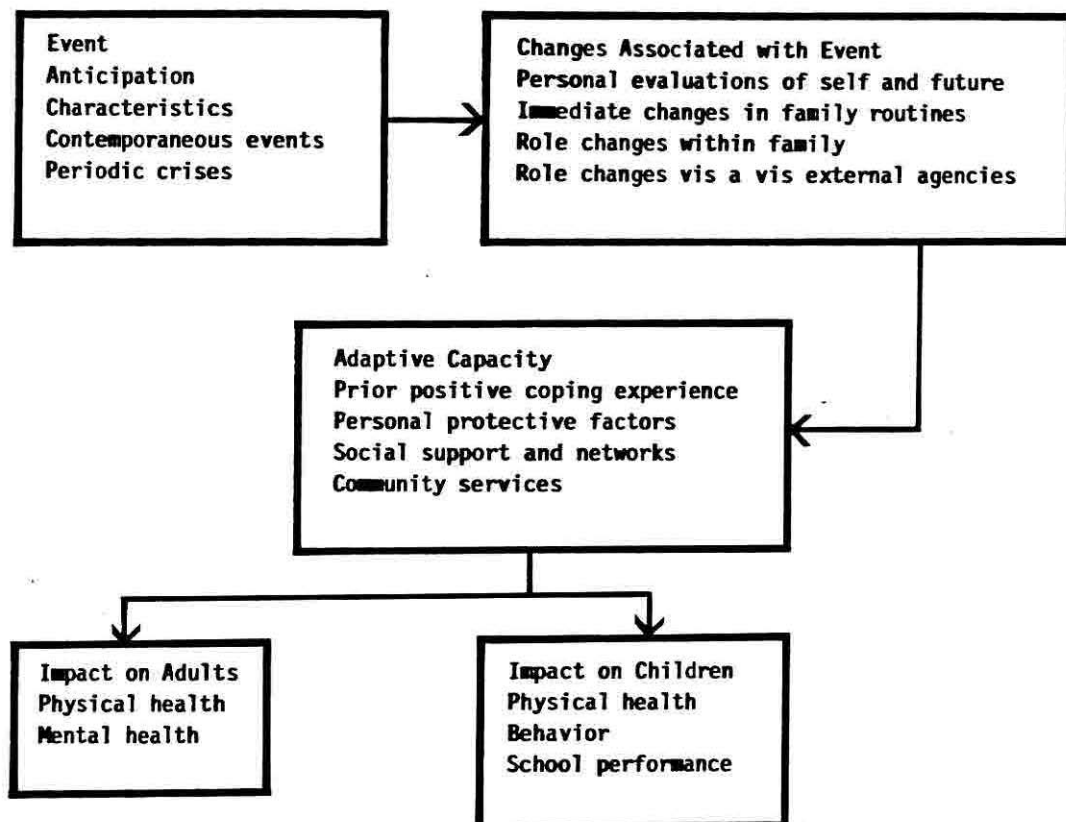
Figure 1. Stress-adaptation model for parents of handicapped children (Farran et al., 1986, p. 145).

of the family. Therefore, although the model is linear and appears to terminate, in that it reaches an "impact" state, it is also applicable to chronic conditions (Farran et al., 1986). The model and other literature regarding children with disabilities, however, do not attend to the long-term coping and daily business of parenting.

The capacity to adapt is not static but must be assessed with each new movement through the cycle. The family's resources are strained by its coping with the child's or other family member's chronic condition. The family's adaptive capacity may also be weakened in the face of new demands (Farran et al., 1986). The changing demands of rearing a child with a disability require that a parent progress beyond the initial issues of dealing with the event itself and the beginning adjustments required by the child's disability to the process of adaptation. For example, a parent may cope well with the demands of a disabled infant, but become overwhelmed by the problems encountered when the child enters the school system or faces rejection from the neighborhood (Farran et al., 1986).

The Stress-Adaptation Model for parents of handicapped children underscores the assertion that the adaptation process for families of handicapped children is an ongoing

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one. Intervention derived from this model can be applied
by trying to alter the demands of the event (e.g., the
diagnosis of the disability) and decrease the number of
changes families must undergo both immediately and
throughout the years, and by assisting at the level of
individual adaptability through means such as parent
support groups and counseling (Farran et al., 1986).

The model, however, does not address those actions and
events which take place between the Adaptive Capacity and
Impact on Children and Adults segments of the cycle. Those
factors, which could be proposed in a new model, might
include parenting behaviors, experiences with peers,
sibling effects, and influences of significant adults such
as teachers.

Assumptions

The assumptions of the study were:

1. Parenting is a responsibility that demands
maturity, diligence, and the acceptance of self and one's
children.

2. The entry of a disabled child into the family unit
is an event requiring adaptations of all family members.

3. The experiences of any family with a disabled
member, while unique to that family, also contain some

elements or threads common to other families with disabled members.

Research Question

The research question of the study was:

How do parents of children with disabilities describe their experiences in rearing a disabled child?

Definition of Terms

Terms defined specifically for the study were:

Conceptual Definitions

1. Disability--lack of competent power, strength, or physical or mental ability, or incapacity.

2. Mild to moderate disability--physical impairment of a minor nature, not severe, extreme, or acute.

3. Parenting--to take care and support up to maturity, or the process of interaction between parent and child.

4. Child--a boy or girl, or a minor person who has not reached maturity.

Operational Definitions:

1. Disability--a physical disability such as a motor impairment caused by congenital static encephalopathy, limb amputation, spina bifida, hearing, or visual impairment.

2. <u>Mild to moderate disability</u>--physical disability which does not interfere with the child's ability to participate in normal childhood activities such as school, Scouts, sports, or neighborhood play.

3. <u>Parenting</u>--the provision of guidance, acceptance, supervision, and valuing toward the child, and satisfaction of the child's needs.

4. <u>Child</u>--an preschool elementary school-age child, in the preschool years through the fifth grades in school, or approximately 3 to 10 years of age.

Limitations

The limitations of the study were:

1. The information gained in the research reflected the experiences, attitudes, and opinions of the study participants and may or may not be generalizable.

2. The questions asked of the participants did not encompass all of the topics which could be covered in a discussion of parenting.

3. The study participants were asked to recall past experiences, resulting in the potential for retrospective distortion.

Delimitations

The descriptions of parenting derived from this study applied to the parents of preschool to elementary school-age children with physical disabilities of mild to moderate degree. The children lived at home with their families, attended school in "normal" classrooms, and otherwise were mainstreamed into usual childhood activities.

Summary

This qualitative research study was an examination of parenting of children with physical disabilities, told in the words of the parents. Although much research highlights the impact of the birth and diagnosis of a child with a disability, parental grief and stress reactions, and the detrimental effects of living with a disabled child or other family member, there is little research about how parents rear a child with special needs. Farran et al.'s (1986) Stress-Adaptation Model for parents of handicapped children, which focuses on the ongoing adaptation process of the family, provided the conceptual framework for the study.

CHAPTER II

REVIEW OF LITERATURE

This chapter will review the literature pertinent to the research topic of this study. The review will discuss parenting and parental attitude, behavior, and styles, parental reactions to the birth or diagnosis of a child with a disability, family issues in the presence of a disabled member, effect of the disability on the child, and parenting of children with disabilities.

Parenting

This section of the chapter will examine parenthood as a stage of adult development, parental empathy, the concept of generativity, parental attitude and behavior, and parenting styles.

Becoming a parent is, for most of us, a unique and important event in our lives. It is an event that is anticipated, imagined, often planned, and even, the subject of our dreams. However, the making of a baby, says Erikson, does "not necessarily imply the emergence of a parent" (cited in Anthony & Pollock, 1985, p. 11). Rather, it is the attribute of generativity that establishes and guides the next generation which hallmarks the development of parenthood. The driving power of generativity motivates

a couple to look beyond the sexual act to the offspring which are created and to the culture which is enhanced. "When generativity fails, parenthood fails, and stagnation results," Erikson continues (cited in Anthony & Pollock, 1985, p. 11). "Concern becomes self-concern that inhibits the development of true care."

This development of true care is termed "parental empathy" by Ornstein and Ornstein (1985). These authors state that parenting, especially parenting of infants and very young children, requires resources that are above and beyond those which we use to deal with ordinary life stressors. Adults who function well in other areas of their lives may, under the pressure of parenthood and as a result of deficits in their own self-development, experience particular difficulties as parents (Ornstein & Ornstein, 1985).

The parent who can immerse himself or herself into the inner life of a child without this threatening his or her sense of separateness and without injecting his or her own needs into the interaction with the child is capable of parental empathy. The essence of parental empathy occurs when parents respond not out of their own needs, nor from a set of rules about how to be a good parent, but according to the needs of a particular child at a particular time in

the child's life (Ornstein & Ornstein, 1985). Although a single parent-child interaction does not usually have the power to determine a lasting impact on the child, each exchange becomes part of a pattern which begins to shape the child's developing sense of self (Ornstein & Ornstein, 1985).

Parental hopes and expectations are continuously conveyed to the child throughout his life, say Ornstein and Ornstein (1985), contributing to the child's sense of self and also to the parents' sense of continuity across generations. The child's selfhood is further defined by the everyday "structure building" activities such as being fed, put to bed, and sent off to school and by the repeated, innumerable merger experiences in which the child merges first with the parent's physical strength, and then with his moral strength and power (Ornstein & Ornstein, 1985).

To learn to relate empathetically with a child, then, parents need the support of their social milieu and the child's affirmation of their parenting (Ornstein & Ornstein, 1985). A child affirms his parents and their parenting abilities by successfully mastering his various developmental tasks; children who, for whatever reason, do not successfully master these tasks affect their parents'

self-esteem to some degree. Infants with health impairments may elicit extremes in caretaker responsiveness from overprotection and oversolicitousness to covert and overt rejection. When a parent feels ineffective in the care of his or her child, parental empathy begins to erode (Ornstein & Ornstein, 1985).

Parenting is a complex of behaviors which require knowing the parents as individuals, as a couple, and as members of a family and families of origin. To understand parenting, assert Anthony and Pollock (1985, p. 6), "one needs to know as much about the parents and what is going on inside them as they go about the work of parenting as one knows about the child who is being parented." The authors further contend that the parents' memories of having been babies once themselves, and of having been cared for, are part of the intergenerational transmission of parental attitudes and behavior (Anthony & Pollock, 1985).

Parenting is an opportunity to continue and expand the development of the adult self; in fact, say Ornstein and Ornstein (1985, p. 194), "the conception and birth of a child 'reopen' adult self-development . . . ." These new events provide the adult with another opportunity to consolidate his sense of self.

Parental attitude and behavior have been characterized by Ausubel (1958) according to several dimensions of the parent-child relationship. These dimensions encompass acceptance and approval of the child, satisfaction of the child's needs, relatedness with the child, stimulation, protectiveness, punishment and control, valuing of the child, and aspiration for the child.

Various types of parenting styles have been proposed by family development theorists. Baumrind (1968) classified parenting styles as:

1. Authoritarian--in which the parent tries to shape, control, and evaluate the behavior and attitudes of the child in accord with a preestablished absolute standard of behavior, stresses the value of obedience of the parent's wishes, and favors punitive, forceful discipline;

2. Permissive--in which the parent behaves toward the child in a nonpunishing, accepting, and affirming manner, consults with the child about family decisions and policies, explains the basis of family rules, allows the child to govern his own behavior most of the time, avoids exercising control over the child, and tries to reason, not use power, with the child; and,

3. Authoritative--in which the parent frequently uses positive reinforcement and infrequently uses punishment, is

responsive to the child's demands for attention but not indulgent, directs and controls the child with an awareness of the child's thoughts, feelings, points of view, and developmental capabilities, demands mature, independent behavior of the child, and frequently explains to the child the rationale behind the parent's disciplinary and other controlling actions.

The differences in child behavior with these three parenting styles are striking. The children of authoritarian parents tend to be conflicted-irritable, moody, apprehensive, unhappy, easily annoyed, and vulnerable to stress. The children of permissive parents tend to be impulsive-aggressive, frequently out-of-control, and have trouble inhibiting their impulses. The children of authoritative parents, however, tend to be energetic-friendly, socially competent, approach novel and even stressful situations with curiosity and interest, possess high levels of self-reliance, self-control, and cheerfulness, and have friendly relations with their peers (Baumrind, 1968).

This section of the review of the literature has discussed the emergence of parenthood as a stage of adult self-development, the concept of generativity, the development of parental empathy, the importance of parental

self-awareness, various dimensions of parental attitude and behavior, and different parenting styles and their effects on child behavior.

Disability in Children

This section of the chapter will discuss the research findings and writings about the issues surrounding the presence of disability in children. These include parental reactions to the birth or diagnosis of a child with a disability, family issues and problems resulting from the presence of a disabled member in the family, and effects of the disability on the growing child.

Parental Reactions

The birth of a physically handicapped child should be regarded as powerful information, compelling the family to reorganize, and most frequently challenging the parental couple, the siblings, and the extended family (Cirillo & Sorrentino, 1986). In this section of the review of the literature, the reactions and responses of parents to the birth or diagnosis of a child with a disability will be discussed.

The formulation of Kubler-Ross' (1969) "stages of grief" based on her work with the dying is applicable to parents of the disabled child as they move through the

denial that their child is disabled, anger that this event has happened to them and their child, bargaining with a Higher Power to remove the disability in exchange for some conciliatory behavior of the parent's depression over the event and its implications for the child and the entire family, and acceptance of the reality of the situation, with its implied adjustment to the new circumstance. More recently, however, many authors (Blacher, 1984; Eden-Piercy et al., 1986; Fraley, 1986; Halpern, 1984; Stein, 1983; Tynan & Fritsch, 1987) tell us that family members do not progress smoothly or in an ordered sequence through the stages of grieving or adjustment.

When the child is diagnosed with a disability, the parents are in an emotionally vulnerable, and perhaps a shock, state. They are suddenly facing a radically altered future (Halpern, 1984). Parents may feel angry, cheated, guilty. They don't want to hear or believe what they're told. They will often want a prognosis, predicting possible futures for their child. They will want to know what to do next (Halpern, 1984).

To cope with his or her own stress regarding communicating the diagnosis of disability to parents, physicians often withhold their own personal views of prognosis, attempt to keep the discussion technical and

factual, attempt to control the time allotted to the interview, provide information in incremental amounts, and generally lead parents into it (i.e., the diagnosis) gently. Parents, on the other hand, want a clear, simple explanation of the meaning of the child's diagnosis, a prediction of possible futures for the child, advice on what to do next, opportunities to ask questions of the physician, a warm and sympathetic listener for their concerns, and, most importantly, time (Halpern, 1984).

In 1962, Olshansky coined the term "chronic sorrow" to characterize the parents of mentally retarded children. Through the phenomenon of chronic sorrow, the parents must deal with the issues of loss and disappointment on an ongoing, often unresolved, basis. In a study of parents' reactions to the birth of premature children, Fraley (1986) found that parents responded in ways similar to the feelings associated with the death of a child or the birth of a child with a disability; these included feelings of loss, intense longings for the desired child, resentment of the cruel blow life has dealt, and guilt evoked by the dead, disabled, or premature child. Fraley (1986) also labeled this experience of recurrent parental grief, at the premature birth of the child and periodically throughout his growth and development, "chronic sorrow."

Common parental responses to the birth of a child with a disability or chronic health problems include a sense of personal failure and inadequacy as parents, wondering what they might have done to prevent the disorder, and fantasies about possible causes of the disorder (Stein, 1983). At critical developmental stages in the child's life, the parents are confronted with the ways in which their child's functioning, needs, and future potential differ from those of their peers.

In one Hispanic parent group, Pilon and Smith (1985) found that some of the parents' emotional reactions to the birth of their severely disabled child had religious bases. These religious orientations included stoicism and fatalism ("It's the will of God"), guilt for the presence of the child's condition, and thankfulness for the challenge the child gave them.

In a study of 77 parents' of young children (18-128 months of age) with severe disabilities such as spina bifida, mental retardation, and autism, Eden-Piercy et al. (1986) discovered that content analysis of the parents' reactions led to a three-category model, not stages, of reactions. The first category, shock-guilt-despair, symbolized the emotional disorganization of the parents and was marked by comments like, "I can't believe I gave birth

to this child," "This is the biggest tragedy of my life,"
"I cry a lot and feel hopeless about my situation," "I hate
when people stare at my child," and "Why has this happened
to me?" The second category, refusal-denial, was
identified by parental comments such as "I don't believe my
child is severely handicapped," "I'm sure he's just a bit
slow and will catch up," and "I believe my child will one
day be normal." The third category, adjustment-recovery-
acceptance, was noted when parents made comments such as "I
know my child will never be cured," "When people stare at
my child, I know they're curious and unaware," "I am
involved in advocacy efforts on behalf of my child," and
"Taking care of my disabled child will broaden my
life--make it rich and purposeful" (Eden-Piercy et al.,
1986, p. 289).

Are the "stages of adjustment" real?, asks Blacher
(1984). The body of literature about these stages suggests
that many authors are describing similar phenomena using
different terminology. Blacher (1984) also proposed three
groupings to describe parental reactions to their disabled
child:

1. Initial crisis responses--including shock and
denial, feeling detached and bewildered, shopping for a
"cure," and denying the reality of the handicap. When the

anesthetic of shock wears off, the parents enter the second stage.

2. Emotional disorganization--marked by anger, disappointment, guilt, blaming self and others for the handicap, grief with its concomitant physical symptoms and detachment in relationships, loss, sorrow, and low self-esteem. These emotional reactions occur even when the parents are intellectually aware of the handicap.

3. Emotional adjustment or reorganization--a very gradual process of adaptation in which the parents become less anxious and more comfortable with their situation and develop unique attachments to their child, of acceptance in which the parents accept their child as well as others and themselves, and advocacy orientation in which they channel their energies to solve realistic problems for their child and family and for other disabled children and families.

Two problems with the "stages" model of parental reactions identified by Tynan and Fritsch (1987) are that (a) the definitions of stages are often confused and poorly justified, leading professionals to develop overgeneralizations or misleading expectations of parents; and that (b) the model is not supported by research on adjustments to other aversive life experiences. It is known, for example, that an individual's emotional

responses may not build to a final state of adjustment or acceptance.

Blacher (1984) decries the lack of writing about the positive reactions and adjustment of parents with a disabled child, the birth of descriptive or data-based articles about parents of handicapped children who adjust to the situation realistically and smoothly. For example, the "shopping behavior" of parents, which is so often labeled a sign of denial of the child's disability, may actually be a positive approach to finding appropriate services (Blacher, 1984).

Many variables influence parental reactions to the birth or diagnosis of a disabled child. These factors include the family's socioeconomic status, availability of support services, the presence of other children or a spouse in the home, prior information about the disability, religion, physician attitude and interaction with the parents at the time of diagnosis, availability of support persons or social networks in the community, single-parent versus two-parent home, previous births of nonhandicapped children, and actual physical appearance or winsomeness of the disabled child (Blacher, 1984).

This section of the review of the literature has discussed the topics of the reaction of parents to the

birth or diagnosis of a disabled child, the stages of
adjustment or acceptance to the presence of disability in a
child, and the factors which influence the parents'
responses to the birth of a disabled child.

Family Issues

Parents and other family members of disabled children
face a variety of issues in learning to adapt their lives
and their goals for the family. Two of the basic problems
they encounter are learning about the techniques of the
child's health care or therapies and coping with the
inherent emotional stress, such as guilt and denial,
accompanying the event (Pilon & Smith, 1985).

Several family characteristics affect the family's
adjustment to a disabled child in their midst. These
characterisitcs include:

1. Family size--families which are larger tend to
adjust more readily to the presence of a disabled child,
because there is a greater number of people to absorb the
burden of extra work, on the condition that there is enough
money to support the large family.

2. Socioeconomic status--middle-class or higher
status families have more options for outside resources to
assist the child with a disability, but they also may have

problems in adjusting their high expectations for the child.

3. Religion--the birth of a handicapped child precipitates a theological crisis for many families.

4. Parental attitudes and expectations--the degree of acceptance of the parents is usually mirrored in the degree of acceptance of the siblings (Powell & Ogle, 1985). The ease or difficulty with which parents and other family members cope with the disabled child is affected by certain characteristics of the child; these include caregiving demands, temperament, and responsiveness of the child (Beckman, 1984). Donovan (1988) also found significant differences in maternal perceptions of family stress between groups of families with a mentally retarded child and those with an autistic child. The families with an autistic child reported that they experienced greater levels of stress and diminished coping abilities than the families with a child with mental retardation. These findings suggest that the more pervasive the impact of a handicapping condition on development, i.e., the greater the number of areas of functioning impaired, the more stressful the disabled child is on family life (Donovan, 1988). Kazak (1986) supports this belief that the most troublesome types of stresses for families of disabled

children are those that are regarded as persistent, long-term, and lacking a clear solution.

The consequences of a child's physical disorder or disability on family life are typically described in terms of the initial emotional response which includes the financial, physical, social, and psychological stressors (Stein, 1983). Each family member, to compound the family crisis, moves through the stages of shock, denial, anger, and sadness at different rates, in different order of responses, and undergoes different levels of intensity and timing of exacerbations. Ideally, in time, they achieve a reestablishment of equilibrium and family reorganization (Stein, 1983).

Turnbull, Summers, and Brotherson (1986) have identified stressors arising from the developmental stages and transitions in families with a mentally retarded member. Many, if not most, of these stressors are likewise applicable to the family with a disabled child. In the childbearing stage of family development, for example, the family is involved with obtaining an accurate diagnosis, informing the siblings and extrafamilial subsystem, locating services, seeking to find meaning in the handicap, and establishing new interaction patterns within the family. In the school age stage of family development, the

family is concerned with adjusting emotionally to the
educational implications of the handicap, dealing with the
reactions of the peer group of the child, participating in
IEP conferences, arranging extracurricular activities, and
clarifying a personal ideology on mainstreamed versus
specialized placements. Issues of concern during the
adolescent family stage of development include adjusting
emotionally to the chronicity of the handicapping
condition, dealing with peer isolation and rejection,
future planning for vocational development, identifying
issues surrounding emerging sexuality, and dealing with the
physical and emotional changes of puberty (Turnbull et al.,
1986).

In fact, Stein (1983) points out that the ordinary
events of life bring with them a greater-than-normal
impact. Ordinary occurrences such as a vacation may
require a good deal of planning for the disabled or ill
family member. The financial and emotional costs may be
extensive; there may be hopes of finding a cure. There may
also be secondary economic burdens, due to lack of energy,
as a worker and/or homemaker. Family members may try to
"make it up" to the disabled or ill child. The family may
experience fatigue and tension. They may sense an absence
of social support as friends and neighbors feel

uncomfortable about what to say or do and pull away. They may tend to "baby" or overprotect the disabled child. Siblings, affected by society' negative attitude toward the handicapped, may take on extra family responsibilities and become intermediaries between the disabled child and the world (Stein, 1983).

The siblings of a disabled child function as his or her socialization agents. But they are likely to have ambivalent feelings of anger, love, jealousy, and guilt toward the disabled child. While parents demand that siblings protect the disabled child, their playmates may shun the child (Powell & Ogle, 1985). Edmundson (1985) lists the concerns of siblings of disabled children as: expression of emotions and issues; guilt, anger, ambivalence, and personal identity; self-help, information-gathering, and advocacy; dating, marriage and children, and genetic counseling; care of aging parents and handicapped siblings; lack of recreation programs, residential care for adults, respite care, and professionals who understand; and guardianship. The sibling literature, however, says Kazak (1986), is inconclusive and sometimes contradictory; there are no observational studies of family interaction studies regarding the role of siblings to disabled brothers or sisters.

The sources of stress in families with a disabled child are many. The child looks different. The dream of a "perfect child" is shattered. A greater amount of attention is spent on the disabled child. Routine caregiving is more difficult than that needed by a nondisabled child. The family has to deal with society's attitudes toward the handicapped. Frustrations and humiliations occur. Self-esteem of family members diminishes. There is little time for siblings. Spouses have little time together. Friends become uncomfortable and drift away. The family avoids social situations. There are fewer rewards for being a parent. The parent-child relationship may be disrupted. The reactions of relatives may be distressing. The family may lack specific information about the disability.

A study of the needs of 24 families with young (under 2 years of age) children with developmental disabilities was conducted by Kornblatt and Heinrich (1985). The families repeatedly revealed a lack of knowledge and utilization of existing community services. Community services, also termed family support services, are defined by Castellani, Downey, Tausig, and Bird (1986, p. 71) as "services other than those basic residential and vocational/habilitative services that people with

developmental disabilities require for normal community living."

In a sample of 148 married adults, Ferrari (1986) found that the parents of chronically ill children perceive a lesser amount of social support than do adults who parent children without illnesses. Of that sample, fathers of children with illnesses were least likely to perceive social supports in their environment. The type of illness proved to be a significant factor with parents of diabetic children perceiving the lowest level of support (Ferrari, 1986). This finding raises the question whether social supports respond when the need appears great, and when the need does not appear great, such as with children with less severe disabilities or chronic illnesses, social support to parents decreases. Families with disabled children often feel socially isolated from their extended family and friends. This isolation may be seen as the result of rejection of the child or may result from the parents' decreased receptiveness to support as they work through their reactions to the child's birth or diagnosis and reestablish their roles (Kazak, 1986). In a study of 50 Mexican mothers of physically disabled children (mean age, 8.2 years), Shapiro and Tittle (1986) reported that the mothers perceived a lack of help with their disabled child

from friends and neighbors and that people responded to them differently because of their disabled child.

Parent support groups, such as Pilot Parents, helps to diminish this isolation by providing a form of assistance that professionals cannot offer--another parent who understands (Iscoe & Bordelon, 1985). As a result of these parent peer support groups, parents have become better health care managers for their child, as measured by the child's weight, hospital usage, use of the educational system, and self-ratings of parents (Pilon & Smith, 1985).

Physical disability has also been identified as a risk factor in child abuse. Due to methodological flaws of the studies on this topic, however, White, Benedict, Wulff, and Kelley (1987) found that the linkages between childhood disability and the risk of maltreatment are supported, but not confirmed.

There have been a long history and abundant interest in circumstances that are potentially deleterious to the well-being of families, but limited attention to successful family coping. We are moving toward the realization, says Donovan (1988), that stress can result in family distress, but it can also result in more sophisticated family functioning if resources and coping skills are sufficient. Kazak (1986, p. 267) concurs, adding that our past methods

of looking at families with a disabled child has been a
"deficit approach" to families. For example, an important
concern of the family's has been the long-term care of the
handicapped child, but research hasn't addressed how family
resolution of this issue is reached.

Effect on the Child

This section of the review of the literature will
examine the effects of disability on the child's ego
development and self-definition, socialization, educational
progress, and emotional functioning.

The secondary psychological problems which may
accompany a physical disability can become the primary
handicap for a disabled child (Kazak, 1986). "For the
child with a visible physical difference, the presumption
is one of incompetence or lack of ability," says Stein
(1983, p. 58). Being thought of as incompetent results in
anxiety and uncertainty in the disabled child, who then
feels the need to prove that he is capable.

Certain characteristics of the disabled child
influence the adjustment outcomes within his own family.
These characteristics include the: child's individual
traits, temperament, and functional behaviors; severity of
the disability; and, age of the handicapped child.
Caregiving demands of the child are based on the severity

of the child's handicap interacting with the family's financial resources. Siblings of the disabled child often experience more difficulties as the child grows older (Powell & Ogle, 1985).

The risk of psychological problems in children with chronic health conditions is increased over those of children who are physically ill or disabled (Stein, 1983). This greater incidence of psychological maladjustment seems to be associated with the severity of the child's illness according to the child and the family, not according to the physician, and with the functional limitations of the disorder (Stein, 1983). Factors influencing psychological outcomes for the disabled child are: (a) characteristics of the child, (b) the disease or disorder, (c) the family, and (d) the nature of interventions. The children at highest risk for the negative social and psychological consequences of a physical health disorder are those whose functioning is at a low level and whose condition is not visible (Stein, 1983).

Negative perceptions of the disabled child's psychological state are commonplace. In a study of 50 Mexican mothers of disabled children, the mothers reported that their handicapped child was less well-adjusted, in

terms of mood, behavior problems, fears, and peer and
sibling relationships (Shapiro & Tittle, 1986).

Harvey and Greenway (1984) undertook a study of the
self-esteem of 20 preadolescent children with physical
disabilities and disorders and their siblings nearest in
age. Impressionistic assessments of the children with
orthopedic handicaps, cystic fibrosis, spina bifida, and
congenital heart defects were those of depression,
withdrawal, and poor self-image. The contributing factors
to these assessments appeared to be the children's poor
physical health, lack of social acceptance, and consequent
paucity of contacts outside the home. Compared with the
nonhandicapped children in the study, the physically
handicapped children had a lowered sense of self-worth,
greater anxiety, and less integrated view of self (Harvey &
Greenway, 1984). The results were not affected by the
disabled child's school placement of being mainstreamed or
in a special school. Neither was the disabled child's
diagnosis a factor in the findings of the study (Harvey &
Greenway, 1984).

Each of us has a need to determine who we are and
define our role in society and our identity as individuals.
The family is instrumental in helping each person establish
his or her self-identities. In a family with a disabled

child, members may thwart self-expression and development by discounting the chronically ill or disabled child's potential and limiting his activity or by overprotecting him. On the other hand, a family may not limit hopes and expectations and view the individual as a person and as a child first, and as someone with a special need secondly (Goldgarb, Brotherson, Summers, & Turnbull, 1986). Some family members report that they are able to recognize the strengths and positive contributions of their disabled family member: "She has taught me to be more accepting of differences in people," "He helps me not take life so seriously," "I have learned to let each person reach his potential," and "She is simply a wonderful person-- disability or no disability" (Goldfarb et al., 1986, p. 43).

Families are also a major source of affection for their members. Some families find that the presence of a disabled member unites the family with a strong sense of closeness, belonging, and a heightened appreciation and love for one another (Goldfarb et al., 1986). If, however, a disproportionate amount of time is spent caring for the disabled child, the siblings may feel neglected and have unmet affectional needs. Blaming interaction between

parents causes them to withdraw from each other (Goldfarb et al., 1986).

Our society is not at ease with those with handicaps. Relationships and social interactions with the handicapped often remain at a formal level. Negative stereotyping attitudes are learned early in life; they lead to barriers to interpersonal relationships, discrimination, and devaluation of the physically impaired (Stein, 1983). "One specific task that a child who is physically different must master is how to break through and make others comfortable enough to allow for social interchange," says Stein (1983, p. 58).

After finding that retarded students reported significantly more school loneliness and isolation than their nonretarded counterparts, irrespective of mainstreaming in school, Luftig (1988) recommended teaching the retarded child to use and generalize appropriate social strategies by means of social skills "coaching." The coaching which would consist of social concepts instruction, opportunity for practice of social skills, rehearsal of appropriate behavior, and feedback may also be applicable to children with physical disabilities (Luftig, 1988).

A study of the communication which takes place about chronic illness, i.e., hemophilia, prompted Oremland (1986, p. 222) to write, "To be perceived as different becomes a social risk--a risk greater than potential risks inherent in certain kinds of peer participations." Since social participation is beneficial for development, parents and health professionals are encouraged to assist with the disabled or ill child's social functioning in school groups where the parents are not present. In addition, the structuring of small friendship groups help disabled children experience a heightened sense of belonging with their peers (Oremland, 1986).

Socialization has its importance and its problems for the disabled child and his or her family. For many families, going out in public and dealing with the stares of strangers and questions from friends are sources of stress. Siblings of the disabled child may become embarrassed in social situations. Parents may become angry over the insensitivity of others and jealous of the opportunities that most people can enjoy that their loved one cannot (Goldfarb et al., 1986). Sometimes, however, families feel left out of the social mainstream or even isolate themselves because of their anger, resentment, or embarrassment. The rewards of social relationships with

the disabled are the benefits from learning to give of ourselves to another (Goldfarb et al., 1986).

Stigma or social rejection is a possible outcome which the family of the disabled fears, and is more likely if the person has a behavior problem or visible symptom that draws unwarranted attention or pity (Goldfarb et al., 1986). Stigma can also increase as a disabled child grows older, leading to greater isolation for the family. This may occur because the family is so preoccupied with its problems surrounding the disability or illness that it has little opportunity to develop outside interests on which to base friendships.

The child's educational and social success in coping with the disability depends greatly on the attitudes and feelings he brings along into the educational setting from the family experiences (Sigel, McGillicuddy-DeLisi, Flaugher, & Rock, 1982). The child's success, then, depends on the parental belief systems and expectations about the child's prognosis and the degree to which the parents facilitate the child's cognitive development. On the other hand, the family can overemphasize the child's educational development to the exclusion of meeting other needs. One child's response to the constant stimulation and therapy at home was an explosive, "I'm just a kid. You

can't therapize me all the time. I get enough at school. I don't think about my handicap all the time like you do!" (Goldfarb et al., 1986, p. 71).

Despite major changes mandated by PL 94-142 and Section 504 of the Rehabilitation Act of 1973, assuring that programs receiving federal funds don't discriminate against the handicapped, there have been no significant evaluative studies of the effects of mainstreaming (Kazak, 1986). Today, though, parents act as advocates for their disabled children in the educational system, rather than the schools advocating for the welfare of children (Kazak, 1986).

This section of the chapter has discussed disability in children. The information presented has included parental reaction to the birth or diagnosis of a child with a disability, family issues which accompany the presence of a disabled member, and the effect of disability on the growing child's psychological, emotional, social, and educational development.

Parenting a Child with a Disability

This section of the review of the literature will discuss the issues specific to parenting a child with a disability. The particular stressors and challenges to the parents of a disabled child, the adaptation process

employed by parents as the child's needs change, and the support services helpful to parents will be described.

Past research studies of families with a disabled child have focused on parental attitudes such as acceptance/rejection patterns, perceived discrepancies between special, normal, and ideal children, perceptions of the child's adjustment, overindulgence, overprotectiveness, and authoritarian control (Sigel et al., 1982). Rarely is the family studied as a unit.

Physical disorder in a developing child occurs in a dynamic and everchanging context; the problems faced by an ill or handicapped child and his or her family depend on complex interactions between the child's physical condition and his development (Stein, 1983).

Parenting, says Bennett (1986), is a difficult, complex, and demanding task for which many people are inadequately prepared. How much harder, then, is it to be the parent of a disabled child? Although there is no precise answer, Bennett (1986) proposes that it is N times as hard, with the N factor including:

1. Screening the child's environment--a difficult task which involves balancing protection of the child from dangers against maximizing learning, fun, and satisfaction.

2. Deciding what the child needs to learn, when and how to learn it--whereas all parents ask, "Have I done the right thing?", parents of disabled children ask, "Have I done enough? Have I done all that I could?"

3. Continuing to provide constant supervision and help for a longer time than that needed by children without disabilities.

4. Putting an extra strain on the marriage due to the complicated decisions and additional attention needed by the disabled child--deciding what is best for a child is a source of friction to any marriage; this is experienced to a greater degree by parents of disabled children.

Higher stress levels in parenting a child with a disability are thought to be related to frustration and helplessness, the characteristics, temperament, and needs of the child, severity of the child's handicap, unusual or additional caregiving demands, an intense degree of commitment to the child, lack of respite care facilities, and lack of perceived support services (Tynan & Fritsch, 1987). Parents are also confronted with contradictions. On the one hand, parents are told that their response to their handicapped child will determine the child's future motivation, ability to tolerate frustration, and acceptance of limitations. On the other hand, parental behavior

designed to encourage and stimulate the child is called denial of the diagnosis, overprotection, encouraging dependency, neglect, negating the child's future and care needs, forcing excessive demands on the child, or being too punitive toward the child (Lipsky, 1985).

The adaptation process for parents is not a time-bound experience of grief and eventual adjustment. It is, according to Blacher (1984), chronic sorrow with various periods of stress and sadness over time. Parents have a lifelong need to make continual adjustments and readjustments to one's disabled child. The feelings of guilt, sadness, anger, and disappointment never totally disappear but stay on as a part of the parents' emotional life--unresolved and contradictory feelings. Parents experience positive feelings in a step-by-step movement (Blacher, 1984).

Often parents are very committed to the child's development and future well-being. This may occur in accordance with the parents' beliefs about the future of the child. If parents believe that with proper education and home training the child will actualize his potential, they will value and make every effort in that direction (Sigel et al., 1982).

Parenting a child with a disability means striving toward the goals of retaining the integrity of the child as a human being and providing the child with opportunities to participate in his or her family and society as completely as possible (Stein, 1983). Within these broad goals, families work to help the child and members adjust to the condition, confine the effects of the disorder, maximize the health and potential of the child, buttress self-concepts, focus on assets rather than deficits, enhance coping strategies, and minimize the handicap and its secondary sequelae (Stein, 1983).

To counteract the tendency to overprotect or spoil the disabled child, parents are encouraged to include the child in important lessons in living such as the normal give-and-take with peers (Stein, 1983). Ways to accomplish this are by expecting the child to complete some of the household chores, allowing him to work out normal sibling squabbles, and participation in neighborhood and after-school activities. Social interaction with other children and social feedback from them contributes, ultimately, to a sense of self-worth. Inadvertently, parents may deprive their disabled child of these experiences out of their desire to protect him from being "hurt" by the world (Stein, 1983). Melton (1972) believes that, more than

anything, parents of disabled (in this case, brain-injured) children want their child to blend into the group of other children, thus demonstrating acceptance by others.

Limiting jealousy and competition among siblings in a family with a disabled child is discussed by Powell and Ogle (1985). Some of their suggestions include balancing the responsibilities of siblings, recognizing each sibling as an individual, providing time with each sibling, talking about the positive characteristics of each child, and recognizing each child's accomplishments.

Bennett (1986) offers several specific suggestions to parents of disabled children:

1. Get the best expert advice you can find, use it, and also use your common sense.

2. Develop realistic and specific goals for your child's present and future.

3. Don't continually "second guess" yourself or your spouse, rather give your well-developed plans a chance to work.

4. Spend a reasonable amount of time and effort working with your child.

5. Reach out to other parents, for working together by means of support groups for parents and other advocacy

activities will result in better services for all disabled children.

A common error is expecting too much or too little of the disabled child. Expecting too little of the child limits his experience and heightens his dependency; expecting too much places both parents and child in a situation of needless and avoidable frustration. Whether parents set goals unreasonably high or low for the child, they are probably acting out of legitimate concern for the child's well-being. On the one hand, parental desire to protect the child from overwhelming and potentially dangerous experiences may motivate parents to lower expectations for him. On the other hand, parental concern for maximizing the child's development may stimulate parents to raise their expectations (Bennett, 1986).

Bennett (1986) also encourages parents of disabled children to acknowledge that they are both a parent and a person with needs and satisfactions. "There has to come a time," says Bennett (1986, p. 51), "when you say, 'Yes, I have done all I could. Yes, I have done enough'." Guilt and excessive worry do not help the disabled child; instead, it detracts from the sense of satisfaction derived from being a parent and from parenting effectiveness.

Sometimes, though, parents have trouble separating disability-related from non-disability-related issues in families (Goldfarb et al., 1986). The tendency to attribute the cause of family problems to a member's illness or disability can be a dangerous lure and a trap for families. For example, it can distract from the true source of a problem, camouflage the number of useful solutions, and limit a family's ability to maximize its strengths and development (Goldfarb et al., 1986).

It is easy to locate a variety of manuals and other written "helps" for parents which explain everything from how to play with your disabled child (Lange & Zieher, 1985), to how to teach social skills to your disabled child (Rule, Morgan, Innocenti, & Stowitschek, 1986), to behavior modification techniques to manage the behavior of a disabled child (Tynan & Fritsch, 1987). These kinds of roles and demands put on parents of disabled children are different from those of non-disabled children. Allen and Hudd (1987) call these new roles, "professionalizing" parents. The amount, level, and quality of parental involvement in parents of disabled children are not only expected to be greater, but it is more difficult for these parents to refuse to become involved. These roles include functioning as the educational decision-maker, advocate,

teacher, case manager, and program evaluator (Allen & Hudd, 1987). They suggest that health care providers need to individualize parental expectations according to the parents' ability and willingness to take on new roles and family needs.

The professionals working with the family of a disabled child often lack a genuine family orientation and, instead, focus their interventions on the child alone. What is needed is the skill to engage the family in an ongoing treatment program based on the needs of the entire family system (Kazak, 1986). Perhaps, when professionals begin to treat parents as valued, contributing members of the health care team, parents may view professionals as a source of support. Such collaboration would encourage disabled children or adults to reach their potential and the family system to maintain as much equilibrium as possible (Lipsky, 1985).

Where does family support come from? In her story of her son's life with uncontrollable seizures, Joyce Metzger (Farran et al., 1986) points to the many strengths in her own family-love, health, emotional stability, financial security, and education--even before her son's disorder manifested itself. "My heart cries out for families lacking any one of these at the onset of hardships such as

ours," she writes (Farran et al., 1986, p. 158). "In this 'special parenthood' every faculty is put to ultimate testing; each needs support." Her career provides a new perspective and Metzger (Farran et al., 1986, p. 161) claims, "Life is not only to give of oneself, but it is also okay to take for oneself. This balance voids my feelings of self-denial and self-pity."

Religion did not always provide a source of solace for Metzger; neither does it automatically comfort other families with a disabled member. After quoting 1 Corinthians, 13:4 "Love is patient, love is kind . . .", Metzger (Farran et al., 1986, p. 160) confesses,

> Trying to comprehend our situation--even the doctors and clergy didn't understand--brought everything but passivity, patience . . . . I did not have kind feelings . . . . I was irritable. I was touchy. I was jealous and envious of 'normal' families. I did hold grudges. I did have resentment.

Intense feelings are normal in intense situations, but how often are the parents told that? Are they told that their experiences are understandable and okay? Often the provision of support becomes more difficult when the family cannot identify or articulate their needs (Brower & Wright, 1986).

The positive side of parenting a child with a disability, according to Bennett (1986), is that the parent can take a great deal of credit for the child's progress,

since his development is crucially dependent on the parents' efforts and care. For example, ordinary things in a child's development are not taken for granted. Siblings may learn important things about living with and loving a disabled child. Rather than look upon the child as a failure, we are extolled to think of the disabled child as a success, the parents' success, the medical world's success, and his own success (Melton, 1972).

Summary

This chapter has examined and discussed the literature dealing with parenting, disability of a child, including parental reactions to the birth or diagnosis of disability of a child, family issues in the presence of disability of a member, and the effects of disability on the growing child, and parenting a child with a disability.

CHAPTER III

PROCEDURE FOR COLLECTION AND
TREATMENT OF DATA

The study uses the grounded theory approach to the
investigation of parenting children with disabilities.
Through interviews with parents of preschool to elementary
school-age children with a mild to moderate level of
physical disability, data were gathered about the parents'
perceptions of the problems they have encountered along
with their accomplishments.

Setting

Parents were interviewed via telephone contact.
Subjects were selected from school records of the
Grapevine-Colleyville Independent School District,
Department of Special Education, in Tarrant County, Texas.
This suburban school district of Fort Worth and Dallas,
Texas, serves over 7,000 students and is composed primarily
of middle to upper-middle income families. The Special
Education Department of Grapevine-Colleyville Independent
School District provides services to children in early
childhood, elementary, middle, and high school programs
(Appendix A).

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Population and Sample

Participants in the study were mothers of physically disabled, preschool to elementary school-age children whose disability is of a mild to moderate level of impairment and who are mainstreamed into usual childhood activities. Participant selection was nonrandomized and proceeded according to ability to meet the criteria of the study.

Protection of Human Subjects

The study conformed to the criteria of the Texas Woman's University Human Subjects Review Committee guidelines established in accordance with the Department of Health and Human Services regulations, and approved by the Human Subjects Review Committee (Appendix B). The participants received a description of the study, an explanation of its purposes, procedures of the study including information about audiotaping the telephone conversation between researcher and participant, benefits and discomforts, an offer to answer any questions about the study, and an explanation of the anonymity of each participant and freedom of each participant to withdraw from the study at any time (Appendix C). Agreement to be interviewed by the investigator and signed consent form were recognized as consent to participate in the study (Appendix D).

Instrument

The instrument used in the study was a nonscheduled standardized, or focused, interview in which certain types of information are sought from all participants, but the particular phrasing and the order of questions are redefined to fit the characteristics of each respondent (Bernheimer, 1986). The assumption in this approach is that for the meaning of a question to be standardized, it must be formulated in works that are familiar to those interviewed. In addition, no fixed sequence of questions are satisfactory to all respondents. The most effective sequence is determined by the subject's willingness and readiness to discuss a topic (Bernheimer, 1986). The focused interview is particularly compatible with qualitative methodology, because it provides a framework within which respondents express their own understandings in their own terms (Bernheimer, 1986). A telephone interview contributes to the validity of the study by reducing the awkwardness of a face-to-face interview and allowing parents to respond to sensitive questions with greater accuracy and honesty in describing their feelings (Eden-Piercy et al., 1986).

Validity

A naturalistic approach to research has an inherent validity (Stern, 1985). The grounded theorist is present to observe and record the conversations of the interview. While quantitative researchers value data that are consistent or stable as indicated by the researcher's ability to replicate or reproduce the findings, qualitative researchers are deeply concerned with the validity of the findings and interpretation (Bernheimer, 1986). They want to understand the participants' frame of reference. Therefore, the grounded theorist makes no attempt to remove himself or herself from the scene (Stern, 1985).

However, a serious concern related to qualitative research is the lack of strategies to determine the validity of measurement. For that reason, certain strategies for examining the validity of qualitative measures will be followed such as weighting the evidence, making contrasts and comparisons, checking for representativeness, using extreme cases, and looking for negative evidence (Burns & Grove, 1987). Continuous data analysis enhances the validity of the research; discontinuities, contradictions, and other puzzling features of the data are further assessed in the field (Stern, 1980).

The interview questions were presented to three experts in the fields of child and family development and the care of physically ill and disabled children and their families. The opinions of Dr. Denise Billage, Director of Child Life and Child Development at Texas Scottish Rite Hospital for Crippled Children, Ms. Sally Francis, Director of Child Life and Child Development at Children's Medical Center, and Ms. Barbara Short, RN, Child and Parent Educator, Texas Scottish Rite Hospital for Crippled Children, all of Dallas, Texas, were sought and incorporated into the parent interviews.

Reliability

Although the grounded theory method cannot be replicated, reliability is established by asking the participants in the study to evaluate the findings (Stern, 1985). The researcher asks the participants, "Is this how it is?" "Does this describe the problem?" The participants, says Stern (1985), are the real experts. They are the most reliable judges of the reality of their situation or the problem under study. The factors discovered in the study can be tested. A test-retest procedure takes place as the study participants are asked whether what was true for other participants was true for them (Stern 1985). This took place in the study when

the participants were asked, at the end of the study, to verify the findings.

Data Collection

The value of either qualitative or quantitative methods is determined by the research question being asked (Bernheimer, 1986). In the present study of parenting children with disabilities, the qualitative approach with its search for an understanding of human behavior and events and its valuing of "disciplined subjectivity" (Bernheimer, 1986, p. 224) is appropriate. By this means the investigator deliberately enters the informant's world of purpose, meaning, and belief, and suspends her preconceptions to focus on the parent's perceptions.

Qualitative methods do not employ quantitative or numerical measures. Typically relying on observation and interviews, qualitative methods use a flexible or modifiable approach to data collection (Walker & Avant, 1983). Qualitative methods are also intent on understanding the context of behavior and might ask, "What things are going on?" What are the forms and variations of the phenomenon?" (Bernheimer, 1986).

The form of research does not begin with a hypothesis, but rather with a tentative assumption or assumptions about the phenomenon being studied. Its emphasis is on

discovering new concepts and theories rather than testing preexisting ones. The hypotheses are generated only after observations are made in the field (Bernheimer, 1986; Stern, 1980). Data are classified and analyzed concurrently, according to emerging themes, linkages, and other associations. The actual words of the subjects, or anecdotal notes, constitute the major substance of the study (Oremland, 1986; Stern, 1985).

The study, employing a grounded theory method, is a form of naturalistic or field research. Field research is characterized by:

1. Interviewing or participant observation in which the researcher is the primary "instrument" of data collection.

2. Data collection and analysis take place in a natural setting where variables are studied rather than controlled.

3. Examination of the data precedes the development of the researcher's multiple tentative hypotheses.

4. Many propostions are studied at once.

5. Data collection and analysis occur simultaneously.

6. Concepts, propostions, and middle-range theories are developed (Wilson, 1985).

In grounded theory methodology, everything is data (Stern, 1985). Its basic assumption is that not everything has been discovered yet. It involves a factor-searching or factor-relating approach which looks at the processes, not the static conditions, of a situation or occurrence (Stern, 1985). The grounded theorist concurrently gathers, examines, codes, and analyzes data. As the data collection, coding, and analysis proceed, the investigator formulates and links hypotheses together and is eventually able to present an integrated theory which explains the problem under study (Stern, 1985).

The 10 mothers who were the participants in the study will be asked to discuss their parenting experiences with the investigator. The questions asked of the parents included:

1. What have you done (or are you doing) well in parenting or raising this child? And how have you done that?

2. What have you done (or are doing) "not well" or wished you could do differently with this child? How would you do that?

3. What were (or are) the most difficult things you've encountered in raising this child? How did you handle them?

4. What have you done (or are you doing) to prepare him/her for the questions or teasing of other children?

5. What have you done (or are you doing) in these areas of parenting--

(a) developing social skills/getting along with others

(b) limit-setting/discipline

(c) nurturing/affection

(d) teaching new skills and awareness

6. Overall, how are you doing as parents?

7. Is there anything else about parenting your child with a disability that you would like to say, and that I haven't asked?

The parents' responses were recorded by means of audiotaping and then transcribed. A sample transcript of an interview with a participant is found in Appendix E. When necessary, parents were asked to repeat, clarify, or explain their responses. To obtain accurate data, the interviewer reflected the words and apparent meanings back to the parents and asked for feedback.

Pilot Study

Three parents representing different families of children with physical disabilities were interviewed by telephone in the pilot study. Two of the children, one boy and one girl, have motor impairments of the extremities

(cerebral palsy), and the third child, a boy, is legally blind. All three of the children met the criteria of being in preschool or elementary school, and being mainstreamed into usual childhood activities including school and extracurricular activities (Scouts, soccer, gymnastics) with nondisabled peers.

Although the investigator deliberately began the interview with a "positive" question, i.e., "What have you done well as parents?", she was surprised at the hesitancy of the parents and the encouragement they needed to start answering this question. The responses began with a pause, "I guess . . ., " and "I don't know, probably . . . ," but then the interaction picked up in spontaneity and seeming interest. In fact, the investigator believes that this placement of the first question helped set the stage for the desired underlying mood that the parent is the expert on the topics of her child and how to rear the child. The parents included in their responses encouraging the child to accept and be proud of himself or herself, have a high degree of self-esteem ("He doesn't see himself as having a disability, although he knows he has a problem with his arm" and "She sees herself like everybody else, she thinks she can do anything"), and interact well with other people, and not giving special treatment or catering to the child.

The parents did not hesitate in responding to the question about what they had done "not well" or would do differently. They said that they "give in a little more than they should" to the child, should be a little firmer with him or her, and one mother said she should have obtained special therapy for the child sooner.

What were and are the "difficult things" about parenting the child? Parents unanimously recited stories of other children "picking" on, bullying, or making fun of the child, their worry about the child and his or her safety, and critical or "ignorant" statements made by relatives, neighbors, teachers, and other adults.

How have the children been helped to explain their disability? One mother said her visually impaired son "does not like to admit it. If we're out in public and he stumbles a lot, I'll hold his elbow, and he says, 'Don't do that. People will think I'm blind.'"

In response to how they have helped the child learn social skills, the parents answered that they role model social skills for the child within and outside the family, invite other children over to their house for playmates, expose the child to other children, both handicapped and not handicapped ("We want him to know that there's nothing wrong with being handicapped") at the family's church, in

the neighborhood, and in school groups. One mother said, "I'm more worried about her getting along with others than she is. She handles it real well."

Parents were not in agreement about whether they disciplined their disabled child differently than their other children. One mother said, "She is not favored. We use the same kinds of discipline as the other kids get." Another mother said, "We discipline him a lot different, I guess because he's the youngest and because of his handicap."

All three parents saw their disabled child as more affectionate, although they tried to be equally as nurturing with the siblings. Said the parents, "He's more affectionate that way. He likes that more than the other one." "He wants to be held." "He doesn't know a stranger --that's another fear." "She's naturally more affectionate. We developed a closer bond, she and I."

The question about teaching new skills revealed some information about the child's determination to try new things and practice until they are mastered, and about the frustration involved.

Overall, how did the parents think they were doing? "Struggling," responded one. "Well," said another, "but it's always something. There's always something new coming

to face and deal with." "It's hard to be a parent nowadays of any child," said one mother, "but especially a handicapped child." When the investigator asked if the parents wanted to add anything else about their parenting experiences with a disabled child, none responded with any additional comments. During the phone interviews the mothers were asked to clarify and validate their experiences as needed.

Treatment of Data

The grounded theory method of research consists of the following steps:

1. Collecting empirical data including coding and categorizing data.

2. Concept formation.

3. Concept development by means of reduction, selective sampling of the literature, selective sampling of the data, and emergence of the core variable.

4. Concept modification and integration by means of theoretical coding and memoing.

5. Production of the research report with its presentation of substantive theory and examples of filed data (Stern, 1980).

The protocol of Chenitz and Swanson (1986) was employed to analyze the data. By means of this protocol,

the hundreds of bits of data were grouped as responses to the questions asked of each participant in the study. These data were not coded because of the articulateness and clarity of the respondents' answers, but clustered into concepts in the concept formation stage of analysis. The researcher looked for and attempted to identify the processes, as recommended by Stern (1980), and applied a system of line-by-line analysis as the data were received.

In the concept development stage of analysis, the framework began to be generated from the data and low-level categories, seemingly unconnected to each other, were discovered (Corbin, 1986a; Stern, 1980). In this stage of analysis the categories began to cluster and collapse into each other on the basis of obvious fit, and the core variable emerged.

Concept modification and integration take place after identifying the core variable and hypothesizing a conceptual framework (Fagerhaugh, 1986); Stern, 1980). In this stage the emerging theory is further integrated and delimited (Stern, 1980. Finally, the research report was prepared. This analytical process was applied to the data found in the interviews of the parent-participants who discussed their experiences in parenting a child with a disability.

CHAPTER IV

ANALYSIS OF DATA

The data of the study will be analyzed in this chapter. A description of the sample and the findings of the study will be presented. In the concept formation stage of analysis, the data derived from the participant responses to each of the study questions will be presented. In the stage of concept development, the discovery, definition, building, and clustering will be discussed. In the stage of concept modification and integration, a diagram of the core variable of the study and the main categories will be proposed.

Description of Sample

Mothers of physically disabled preschool and school age children were the participants of the study. Six of the children of the study participants were female; four were male. The ages of the children ranged from 3 years 6 months to 9 years 5 months. The mean age of the children was 5 years 4 months.

The diagnoses of the physical disabilities of the children included; 3 children had cerebral palsy; 1 child had Apert's syndrome; 1 child had growth hormone deficiency and a craniofacial anomaly; 2 children had spina bifida;

1 of whom also had hydrocephalus, dislocated hips and clubfeet; 1 child had a spinal cord injury, leaving her with right-sided weakness; 1 child had a visual impairment; and 1 child had a hearing and speech impairment. All of the disabilities were classified as mild to moderate degrees of impairment. Eight of the children lived in a home with both parents; two of the children lived with single mothers. Seven of the children had siblings also living in the home; three did not have siblings.

Findings

Qualitative research begins with guiding questions, not preconceived hypotheses. Clearly conceptualized and articulated research questions form the essential structure which guides data analysis and interpretation. The intent of qualitative research is to understand more fully some aspect of human experience and to communicate that understanding to others (Ammon-Gaberson & Piantanida, 1988). The intent of the study was to understand the processes involved in parenting a child with a physical disability.

Grounded theory methodology is designed to generate, rather than test, theory. It moves from inductive, arising from the data, to deductive; that is, formulating

hypotheses, and back to inductive thought, returning to the data for verification (Corbin, 1986b; Stern, 1980).

The grounded theorist concurrently gathers, examines, codes, and analyzes data through a system of constant comparison until the study generates a number of hypotheses. The theorist does not, however, impose a theory from other studies onto the present study (Stern, 1985).

Concept Formation

In the stage of concept formation, the grounded theorist begins to label, hypothesize, and cluster data (Stern, 1985). The first strategy leading to discovering, defining, and building categories is to transcribe the data exactly and break it down into bits and pieces (Corbin, 1986b). The responses of the participants to the questions of the study led to the definition and development of data concepts.

Doing Well in Parenting

Some segments of the responses of each of the participants to the questions, "What have you done, or are you doing, well in parenting or raising your child with a disability? How have you done that?" follow:

1. We've given her a lot of self-esteem. She is not really aware of the fact that she has a disability. We've never told her that there's anything that she cannot do. We were much more aware of things that she accomplished. Everything that she does well is given so much praise. We say, "Gee, (Child's Name), that's a good job and we know you worked hard on that. You did a good job." It's my job to do the work (to worry about her and what she can and can't do) and her job to be the kid.

2. What we've done well is helping her to cope with the way she is, explaining to her, you know, that's she's like this and some kids could be worse off, some kids are worse off than she is. We've let her know that we love her just the way she is. We try to raise her just like we do the other kids. We try not to treat her different. Try to explain to her and tell her she shouldn't be depressed. We're glad that she's here and there are children that are worse off than she is.

3. We've tried to give him a good sense of self-esteem. Praise him for things that he does, and giving him a lot of love and affection. By validating his feelings. Not pretending that his problems don't exist if they do. We've been willing to ask for help. It's important for him to have a sense of self-worth and that he realize that he

is a valuable human being, has intrinsic value and worth,
irregardless of what he may or may not accomplish in life.

4. Just making sure that he has all the medical . . .
that he needs, like taking him early to an eye specialist.
Keeping up with every problem or having everything
investigated.

5. I try my best to ignore the disability as much as
possible so that my son doesn't feel he's any different.
And I try to teach him and his twin sister not to make fun
of other children who might have disabilities, no matter
what they are, because they're just different; they're just
a little different, but not worse or try to make them feel
uncomfortable with themselves, not to be real self-
conscious about their disabilities. And push them to do
the best they can. They can still do everything that other
kids can do.

6. Just letting her be the same as other kids, pretty
much, you know. Just not make her feel like she's
different. When she was little, we didn't make a big deal
of it, we didn't point it out to her and whatever she
wanted to do, you know, like, what the other kids had done,
as much as we could, let her do the same things. The same
rules applied for her--that was another thing that made her
feel the same, not different.

7. She was super before and since the accident. It's really not anything we've done. She has never considered herself, uh, disabled. Basically, we don't use it (the term, disabled) around her. We really don't look at her as disabled. We're just so grateful that she can do what she can. We have a lot of regrets and, you know, and it's, it's tough but she, she doesn't feel it, you know.

8. We just treat her like we do our other two children. We don't treat her really any differently. We don't love her less or anything like that. We don't do anything less with her, we don't let it inhibit our activities, we take her with us. We have her involved in physical therapy and occupational therapy, and also have her enrolled in the special education system to help prepare her further for her education.

9. From the very beginning, trying to get answers. How can we make things better, how can we make him more normal, or more average? At three months we started with the Mobile Training Unit for infant stimulation, and they taught me and I taught Dad what we were supposed to be doing. At three years we started with the Early Childhood Program. We feel like we've done everything possible to benefit (Child's Name).

10. I'm trying to treat her just like I treat my 11-year-old daughter that does not have a handicap. I demand the most from her that she can do. If there's something she can't physically do, then that's different. But if she can physically do it, then she does it. I set very, very high goals for her. I push her. She gets mad at me a lot, but I push her.

Doing "Not Well" in Parenting

Some of the responses of each of the participants to the questions, "What have you done, or are doing, "not well," or wished you could do differently with this child? How would you do that?" follow:

1. I find myself getting more frustrated at what she can't do rather than what she can do and that bothers me. Because I was never like that before. (Tells story of comparing her child's drawing with another child's drawing). I said, "Hey it's a lot better than what (Child's Name) can draw." And that bothers me. I wish things like that didn't bother me.

2. Maybe not exposing her too much, you know, like to scary pictures on TV, that thing. She loves that stuff. She loves to watch it, but she won't sleep at night. I still have times that I wish I'd raised her, that I could have raised her closer to, like closer to God, you know,

like Sunday school and church and stuff like that. To have faith in the Lord and to know what the Bible is all about.

3. The thing that I wish that I had done differently is to lighten up at points, personally, because I have a tendency to be a perfectionist. To have not taken things so seriously at different times in his life. I need to lighten up. We're a family, first.

4. Probably handling his discipline problems. Maybe being stricter like I am with my other son. I'd change that. Be a little bit more stricter with him first.

5. Oh, I babied him too much. I took a lot of his own personal responsibilities on myself. Dressing, eating, bathing, things that he should be able to do for himself, I did. The worst thing I did, was treat him like he could not do these things. I just babied him too much. I was feeling sorry for him and feeling sorry for myself. And, oh, God! Why did this happen to me and my child? He's very bright, and that sort of thing. I think we were caught up in a depression, a real depression-type situation for about a year or so. And, of course, at the expense of my healthy child, his sister. The worst thing that I did, was to feel so sorry for him and feel so sorry for myself for so long, when it wasn't necessary. You have to go on.

6. I wish she was a little more independent in the way of, particular, gettin' herself dressed, and, uh, doing things for herself like gettin' herself a drink or snack or something like that. I wish that I was a little better with that, in being more firm, about having her do things, and being more consistent with lettin' her work with it until she gets it done rather than, you know, takin' over when it's the last minute and doin' it for her.

7. No. Cause, she's just been so easy.

8. In all sincerity, I can't really think of anything. Because, at this point, we have done absolutely the best that we could do up to that time. I sincerely feel that both my husband and I have done the best that we could do. I don't feel at all guilty, I don't feel that we're doing anything wrong. I strongly feel that.

9. No, I don't have any regrets. He's so happy and he's so content and when I see that, I say, "I wouldn't do anything different."

10. Basically she's still spoiled rotten. I work all the time and my hours are crazy. That's probably the thing I regret, not spending as much time with her as I'd like to. I don't have enough hours in the day to keep up with her. Sometimes I'm too tired and say, O.K., I'll carry you this time. Give me your crutches.

Handling Difficult Encounters

Some segments of the responses of each of the participants to the questions, "What were, or are, the most difficult things you've encountered in raising this child? How did you handle them?" follow:

1. When she was younger, when she was a baby, the expectations of other people, of -- like my neighbors, "Is (Child's Name) sitting up yet?" But there was no pressure from my close friends and family, they were very aware and very tuned in. "Oh, your child is 15 months old, and she's not crawling yet?" Your know? And I guess some self-pity. I've never pitied myself before about it and I'm really bugged that I'm beginning to pity myself. Why should I pity myself? I'm not the person going through it. It's her, and I don't pity her because I don't think --that's one thing we've never done, we've never pitied her because we thought that if she got pity, that was going to blow it for her. She'd always be the poor, little, handicapped kid.

2. That's the only thing she tells me, but she's having trouble in school, you know, with the kids and stuff, I'm sure, she'll tell me. You know how they hint around at something like, "I wasn't like this," or, "I had

to be like this." And that hurts me, too, you know, because I'm hurting for her.

3. The most difficult thing in raising him has been to come to terms with my own feelings. Um, to separate my own issues from him. Ah, when we come upon people who say thoughtless things, or cruel, and that hasn't happened a lot, but it has happened at times, ah, I hurt for him, and I'm immobilized at times, I can't think of anything to say, and so it's been hardest for me, is to separate my own feelings, and be able to be there for him, to be a role model. That's one of the most difficult issues for me, because I love my child and it hurts to hear people say something stupid. Realizing that he can handle his own feelings. The other thing is the medical issues, because he's had so much surgery, that's a reality in our life, and he's going to experience difficult pain, and giving him the support he needs. And the other issue, of course, is education in school. It's just real difficult to know what to do, what action to take, and yet what to let go of.

4. And you have one that has a reading disability, it's really hard to, it's probably the hardest thing right there, dealing with that. I'm tempted to say, "You know that word, you've seen it," you know. But you cannot do that. You have to be very patient, not be critical. Even

when the word's blown up, he doesn't always recognize the word.

5. The most difficult thing I've had to to deal with is being understood and understanding him. It's just very frustrating to the parent, I'm sure it's very frustrating to the child that he cannot get his point across to his mother. It just breaks your heart. Because you sit here and have to watch this child go through this transformation just because he cannot make himself understood.

6. These are all for me, really. (Child's Name) is just beginning to have problems with, uh, feeling different, and worrying about that other kids know about, uh, her handicap and stuff. It was really difficult for me when she started to kindergarten and I knew that she'd be in with all the other kids (she'd been in classes with disabled children). I remember in particular that the kids, before they started kindergarten, they had to walk across the stage at a kindergarten orientation, or whatever they called it. And I was worried that she wouldn't be able to climb the stairs, you know, by herself, or that she might fall or something like that and, and she did just great. She had no problems with it at all, but I remember that being a hard time for me, anyway.

7. She absolutely hates her AFO brace, especially last winter when it was cold and painful. So for the winter months she did not wear it. But I think now she may be, she's aware of it, you know, last year she, you know, kindergarten, you know, the new school and the, you know, she was not paying any attention to the brace and I think now she is aware of it. And that she's different, and the peer pressure and the questions, you know, she's had and I think that's a lot of it and so we don't wear it. It's not helping her that much and the doctor said, if you want to wear it, she can wear it, if she doesn't, that's fine, too.

8. I don't think I've ever said this to anyone else, but there were times when, after I found out where, um, oh, I almost just didn't want to pick her up and hold her. Those were just fleeting moments, you know. I never held those views, there were just moments where I almost had to detach myself emotionally just a little bit in order to deal with it. I'm not proud of it. Sometimes people say you're an extraordinary parent, but you're not. You have no choice. You have the situation it's just like anything else in life, you have to make the best of it. We're just making this as normal as possible, and, you know, I really don't think of her as different. She has some special needs but she's, she's gonna' be fine when she grows up.

9. The most difficult thing, is his case, is having to deal with the surgeries. We've gone through so many and there's so many more to face. Worrying and being concerned that he is pleased with himself, as an outcome of all these craniofacial surgeries.

10. Outside of the fact that she requires a lot of time off work, all day visits to the hospital, my biggest frustration is with the medical world, not (Child's Name). She's having "spells" now, and it's frustrating that no one knows what's wrong. She requires a lot of time and attention, and as a single mother, I don't have a lot of time and attention. Sometimes our time together is sitting in a doctor's office. And she takes away a lot of time that I could spend with my other daughter.

Preparing for Others' Questions and Teasing

Some segments of the responses of each of the participants to the question, "What have you done, or are you doing, to prepare your child for the questions or teasing of others?" follow:

1. She's already had one incidence. And I said, "You were doing your very best, weren't you?" and she said, "Yeah, you know, I was trying real hard," and I said, "Well, as long as you're doing your best, it's not up to anybody to say you're doing bad, because I know and you

know you're doing your best." She tells kids that her
muscles are weak. And she's real funny, because she'll
say, "When I was born, I came out too early and I was
really, really sick." She learned that explanation from
me. She asked me if she was handicapped, and I said, "Yes,
to a point, you know how you have to go to therapy, and
wear a brace."

2. We have talked to her about that, but you know
her, she does it on her own. We has explained it to her
and she explains it to them the way we have explained it to
her. She just tells the kids that she was born like this.
She'll tell them that her feet were twisted when she was
born because she had a disc missing out of her spine and
the doctors straightened it out as much as they could, and
she don't have as much strength in her legs. She tells
them that. You know, cause they ask, the first thing are
kids going to ask is, "Who broke your legs?" So she is
going to say to them, "Didn't nobody break my legs. I was
born like this."

3. Surprisingly enough, the things that I would have
thought would have upset him are not the things that upset
him the most. Again, it's separating my feelings from him,
you just have to take it one situation at a time, and
realizing that if I don't have the answer then, that I can

ask for help. I believe my husband and I are going to role
model for him through our response, not over-reacting,
helping him to realize when people make statements, that's
about them and it's not about him. And he had some
counseling when he was in the preschool program. My
husband and I have both practiced with him. To practice,
to pretend he is himself and then pretend he is the other
child.

4. I just tell him to explain why he doesn't see as
well as they do, and not to get upset, or . . . or want to
fight back at 'em, or anything like that, to explain to
them what your problem is. And we had a program at the
library that he got up in front of the children and got to
explain to them his impairment and, uh, he also got to show
them some equipment that he works with.

5. I've only had to deal with this once, but if I see
child making a comment to (Child's Name), I'll go to that
child myself and tell the child what is wrong with (Child's
Name). You take the child by the hand and say, "Look
there's nothing really wrong with (Child's Name), he just
can't hear, and it seems to change their attitude a little
bit, the child's attitude. Once a little girl wouldn't
play with him and didn't want him near her because he
talked funny. And he came running to me in tears, the

first and only time he's ever done this, I just told him to ignore her, that she was the one who was stupid because she couldn't understand. And it was her problem and she was the one missing out because she would not play with (Child's Name).

6. We talked about that just the other night. She had asked something about the other kids, and some of them tease her, or say something that makes her feel bad. It seemed like she was more concerned that the other kids knew that she was handicapped and she was kinda gettin' onto her brother because the kids'll ask him, you know, they'll ask him what's wrong with her. She kept sayin' that she didn't want him to tell them that she's handicapped or has some problem with her muscles, and I asked her what she would rather he say, and she said she didn't know, but it seemed like that bothered her. I told her that, you know, that different people have, everybody is different in some way or another, and that this is the way that she is different.

7. The teacher brought me in last year. There were some questions, 'cause the kids were asking, "What is that brace?" and stuff. We've talked to her and, but not at any great length or anything, you know. She says, "I had an accident. It's an AFO brace, "but they don't know what that is, you know. She probably heard me tell, maybe tell

some people, about her accident. And going to all the
doctors, we've had to answer a lot of questions, and so
she's heard what we've said. She'll just say, "Well, I had
a spinal cord injury, you know, and I have to wear an AFO."
It's like that's enough.

8. That's something that we really have not run into.
We've run into other kids, or people in stores wondering
about a special chair she was sitting in, and we've been
real open with these children. We've answered their
questions because, of course, they're going to be curious
and they're going to want to know. I always do say, of
course, that she's basically no different than you, that
she just has this special chair that helps her sit
properly, or her equipment helps her walk so she can be
more like the way you walk.

9. That's a real burden on my mind. He hasn't really
encountered that yet, that he has let me know or that I've
noticed. (Relates that she was heavy in grade school and
dealt with it by making jokes about herself.) As long as
he feels good about himself, what others do or say will not
destroy him and I try to reinforce that every day. The way
we treat him, building a strong inner being within himself.
My husband and I try to load him up with confidence. He

has a lot of confidence in himself, he likes the person he is.

10. I really haven't dealt with it at all. I've thought about it, but I haven't figured out exactly what I'm going to do. I don't talk to her at all about being different because I don't want her to think that she's any different. When she comes to me with it, I'll deal with it. For now, I don't want her to think she's any different, or special. Or has to be treated different. My older daughter has some problem with it, gets tired of explaining her sister, why she's like she is. She tells them she was born with a hole in her spine and they sewed it up. And she's got some paralysis in her legs and she's doing the best she can.

Developing Social Skills

Some segments of the responses of each of the participants to the question, "What have you done, or are you doing, in the area of helping your child develop social skills/learn to get along with others?" follow:

1. When she was very young, she started school or special therapy, but these were all children with handicaps. Then we moved to Texas and we were in a neighborhood of nothing but kids. I just encourage her to get out there and play. I've gone to the parents of the

children and told them her situation, so the parents have answers for the kids. The kids don't even see her anymore as a kid with a handicap, she's just a kid.

2. (Child's Name) has lots of friends, so she just goes and starts talking to people. And she just likes to talk. I guess she gets that from my husband, he's real friendly. She'll go up and talk to anybody. She has friends in the neighborhood that we don't even know.

3. That's been to expose him to other children. It's still hard because of the all the problems he has, to allow him. Right now we're in an older neighborhood and there are not a lot of younger children. We've almost had to make situations where he could interact with other children. He goes to Sunday school. And I did some preparation with the Sunday school teachers and his teachers and baby-sitters. So that they'll be aware of the fact that there are some limitations but that he's going to be okay. I think it's important, too, that (Child's Name) have a peer group of children, that have similar problems to him, like a support group.

4. Just to be around other children. And, church activities, anything that has other children around, you know we've had them over to our house to play, and, er, if they have questions, we answer them. One of the hardest

things for children to accept, is that he gets close to them. And touches them.

5. They've been at day care a lot. I haven't really done very much with that, in helping him to develop social skills with other children, because his twin sister has done that for him. She mothers him a lot, sometimes she tends to over-mother him. He doesn't seem to feel out of place with other children at all. He just runs right up and joins them, and you know, he'll talk to them. He's not embarrassed to talk to other people.

6. She's just real easy to get along with. She's not, uh, selfish or doesn't seem to have problems in that area so much. It's more of her basic personality that she's just, I don't know, gets along and plays well with other kids.

7. Nothin' different. Nothin' at all, because she just has fit right in, you know, we haven't changed anything. She's gotta lead a normal life and that's one thing we've tried to do is, not prevent her from doing anything that she, you know, that's not over her limits.

8. She's always, always been around other children I take her to a Kid's Stop. We live in a neighborhood with a lot of children, and when I work I generally take her to

child care facilities where she's around other kids. She's
very social little thing.

9. He runs and plays well with others. But not
sitting down and playing with Lego blocks with others,
things like that are difficult for him. He plays with the
neighbor kids. As far as keeping up with kids his own age,
he runs fine but real slow. He has no finger joints, but
he can't do what kids his age can do. If he can't do it,
he watches the other kids.

10. We don't have a problem with that. She's a very
sociable little girl. She hugs everybody she sees. Now,
these kids around here, they got her spoiled. They put her
in her chair or on a wagon, and take her everywhere to
play.

Handling Discipline

Some segments of responses of participants to the
question, "What have you done, are you doing, to discipline
or set limits with your child?" follow:

1. Nothing unusual.

2. I do her the same way I do my boys. And when she
don't clean her room, she don't go outside and play with
her friends. We discipline her like the others.

3. This is probably my weakest area. I have probably
spanked him once or twice, just a pop on the rear, and

that's been totally ineffective. I don't know if it's because he's had physical pain... Separating him is the worst punishment you can do because he loves to talk and he loves to play. A lot of things you use with regular kids are still the things that I have to use for my own child.

4. I don't feel like I've handled it good. I think privilege taking away from him has meant more than anything, has helped him.

5. Now he's spoiled because of what I've done personally, and other people also. It's very difficult to discipline him, ah, but one reason is sometimes I'm not really sure if he understands what he's done is wrong. I don't like to do a lot of physical punishment, because I don't believe it works. We try the corner or send him to his room by himself, that sort of thing.

6. It's been the same as with her brothers. We've tried not to make special allowances for her, at least, obviously, you know, to say that we're doin' it. We've been pretty consistent in keeping the rules the same for each of them.

7. She's an easy child to discipline. Very easy. Yeah, very easy. She got the citizenship award last year in kindergarten.

8. Yeah, it is different. Somewhat different just simply because I'm dealing with a different child. And I wouldn't say it's as much her physical problems as much as her emotional little self.

9. My husband and I have said, from day one, if we want him to be a normal, happy child, we've got to treat him normal, and we have, from day one. He's so headstrong, that I try to distract his attention to something else. I'll say, "I bet (Child's girlfriend's name) is brushing her teeth," and then he'll brush his teeth.

10. She's 50 times more headstrong than my other child. If she's not going to do something, she's not going to do it. The thing that works the most with discipline is "Time Out." She loves to talk and is very social and she hates "Time Out." I try to enforce the same rules as I would do with my other daughter I try to treat them the same. She has to pick up her toys.

Nurturing and Showing Affection

Some segments of the responses of each of the participants to the question, "What have you done, or are you doing, to nurture or show affection to you child?" follow:

1. We're a real affectionate family. I mean it's hugs and kisses all the time. Maybe I'm more loving, more

affectionate towards her, more hugging of her just because
I know that there could have been the chance that I didn't
have her.

2. She tells us all the time that she loves us and
she has such good parents. She says, "And I love my
brothers, too, even though I don't think they love me."
But they do, you know how boys are and everything.

3. I believe that if she had not been born with any
problems that we would still probably show the same kind of
affection, . . . we have always tried to be very nurturing
with him. Telling him we love him, of course, and hugging
him, you know, giving him physical affection. I think it's
just real important because it's so tied in with sense of
self-esteem.

4. I don't feel like we've treated him any different,
and you know, he seems to be more affectionate, he just
wants to sit up, you know, under you. We've never tried to
treat them any different as far as affection is concerned.

5. Most of our time together is after dinner, about
an hour, and we just sit on the couch. I'm in the middle
and they're on each side of me, and we read, or they talk
to me. I devote that time just to them, because I'm so
busy all the rest of the time. Sometimes I feel that I'm
not really the mother, I'm the baby-sitter in the house.

It's very important to me, that we develop this, a very strong personal relationship where they feel they can just talk to me.

6. She's a little more affectionate than the other two, and I think maybe that might have to do with the time that we spent together when she was, uh, goin' for therapy. It was just she and I usually, you know, and I just think it kinda' brought us a closer bond.

7. I'm sure that we, you know, probably picked her up a lot more than, you know, there was like 6 weeks that we could not hold her and, uh, that's tough. She's a very hugging, loving child.

8. Oh, we're a highly affectionate family, and there's been absolutely no difference between her and my other kids.

9. He's extremely affectionate. Loves hugging. Of course, we're always hugging and kissing. He'll say, "Oh I love you. I need a hug." Of course, my husband and I are very affectionate toward each other and (Child's Name) is a part of that, too.

10. She's never been the type of child to just sit in your lap, even when she was a baby. She'd rather just lay on the couch, as to have you hold her. Now she sleeps with

me, just like my other daughter did, but clear on the other side of the bed.

Teaching Skills

Some segments of the responses of each of the participants to the question, "What have you done, or are you doing, to teach your child new skills?" follow:

1. When she was smaller, she and I really did a lot of that stuff every day, and the skills that I know was to help her improve her fine motor. Now I felt like I could finally let down a little bit. And now instead of working on special things like that, we just work on the regular that any kid needs to learn. Math and reading.

2. We've done plenty of teaching her, you know, to play new games and to do things for herself. And so she put her shoe on yesterday all by herself. And I learned her -- I showed her how to take a bath, too.

3. I guess that began from day one, ah, teaching him any kind of skill and self-help skill. I try to walk him through it, I try to not only tell him how to do it, but show him how to do it. He can take all day doing something if he's not motivated. I really am a big believer in infant "stim" and early childhood programs, . . . because he's far surpassed anything we were told when he was an infant.

4. When he was smaller, we used to have to take him
to a lot of unfamiliar areas to get him not afraid to do,
like going to the park was a big scary deal for him, or
like going across a bridge that he wasn't for sure, 'cause
he couldn't see that well. Now he works with a mobility
specialist.

5. They're always telling me what to do or how to do
it, you know, to get him stimulated and make him want to
play, and that sort of thing. So, after awhile, you tend
to rely on these people too much. You start to think
they're God. I think his sister helps him a lot more in
that department than I do. Because she's with him all the
time, and she is the one who has taught him how to interact
with other children.

6. I don't really remember doing very much of that.
She did a lot of that sort of thing at therapy in Dallas,
they do toys, you know, and things like that.

7. There's been a lot of teaching because, uh, we'd
drive back to Dallas four days a week, and to pass the time
for her, it was just -- it's always been a game. And
sitting there in the hospital, we read and we, you know, we
did so much

8. In some respect, I bet, I've been a little less
active with her, but I think that is considering the fact

that she's my third baby. I've become busier. And I've started working. I relied on her to be a little more independent in playing with herself than I have with my other kids.

9. He learns very well by just watching. He learns most of his activities by just showing him something, just show him and he never forgets anything. And if he can't do it with his hands, in the position you showed him, he'll turn it around till he can do it, maybe he'll turn it upside down to do it.

10. She's had that independent, "I-can-do-it-myself" attitude all her life, and I don't really fight it as much as I did with my older daughter, because she needs it. I never really, I don't work with her that much. Basically, she picks things up real quick when she wants to, and loses interest real quick. It has to be her idea.

Overall Perceptions of Parenting

Some segments of the responses of participants to the question, "Overall, how do you think you are doing as parents?" follow:

1. I'm almost taking this as a compliment to myself and to my husband, I think we're average parents, and I mean that in the good sense. Overall, we see ourselves as parents of a normal kid, and that's exactly how we do.

2. Well, I think we're doing pretty good, you know, but, the older they get, the more they understand what life's all about. We doing the best we can, we get depressed, too, like she does. We just try to go on and live every day.

3. It's like you get one problem worked out and you think, okay, we're going to coast for a while and then something new comes along. If I can't do it, you know, I'll ask for help, because I sure don't know how to do this deal.

4. The best we can. Some days you feel like you're doing great and other days you feel like, what did I do wrong? I guess we'll know when he's grown, huh?

5. I guess I'd have to be in the middle. They're basically good kids. So I'd have to say I'm in-between, I'm kind of a moderate mother. I'm not a really exceptional mother, but I'm not a real yucky mother, either.

6. I think, you know, we do pretty good. I kinda like the way she is developing and, uh, things that we're doin' with her.

7. I think we're doin' great. You know, she's just easy, everthing's going as well as expected.

8. I feel real good about the direction (Child's Name)'s taking. I honestly don't know how we could mentally, physically, emotionally, do anymore than what we're doing. I, I don't think it could be possible.

9. Oh, gosh, I hope all parents feel guilty, because I'd hate to think I was the only parent who feels guilty. There are days when you just don't feel good about what you've done -- we should have read a book together or something. But overall, though, I'm proud of the way his Dad and I have handled his disability and have made his life as normal as possible, what we have control over, I'm extremely proud of (Child's Name), he makes me smile many times a day. I feel we've done a real good job. I hope that I'm not kidding myself.

10. A lot of time I don't think I'm doing very well, which doesn't have anything to do with her handicap or anything, just in the fact that I'm never home. But dealing with her handicap, I think we're doing that pretty well. Most of the time, I don't think of her as a handicapped child, I think of her as (Child's Name). I try a little bit harder to put that into her, you're not any different than anybody else.

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Parents' Additional Comments

Some segments of the responses of each of the participants to the question, "Is there anything that you'd like to say about parenting or raising a child with a disability that I haven't asked or mentioned?" follow:

1. I think that the person on the street thinks that a parent of a handicapped child is near a saint. Well, hell, you'd do the same thing if they were your child is what you want to say to somebody. I did what I had to do for my kid, and I don't see it as any different as any other parent fighting for their kids. But it's just down to the situation, they had normal kids and I didn't.

2. Kids being like that, you know, handicapped and everything, they don't think that they're going to be able to be something when they get older, not be able to do anything. I'm talking about like getting a job or something. And there's one thing I'd like to say, you know, you get tired of doing things, you know, I'm talking about like catheterizing herself. And people shouldn't be embarrassed to take their kid places, you know, about their condition.

3. Whenever something new happens with us, I have to grieve a little bit. It's like I have to back off for a minute and feel that pain, and then I can come back. The

awareness of that has really helped me a lot. We've come a long way in general, in terms of society's attitude toward handicapped individuals or people that have--that are different in some way, and I, that is a very frustrating area for me. Our children have intrinsic worth and value as human beings.

4. We had to let him be a normal child. Even the normal children in normal classes get hurt. But I've got to let him go. He's got to be a kid. That's probably the hardest thing for people that have handicapped children. You have to accept a lot, too. You have to face up to it. It's there and they just wasn't doing it to be mean to you. Because you want your child to be normal.

5. What has disappointed me the most is that there are not programs in this area for hearing impaired children, or other children who have severe speech impairments. Yes, (Mom's Name), your child is disabled, but he's not disabled enough to get this schooling that he needs. It was very difficult to sit through the ARD meeting we just went through and not just throw all those papers in their faces and get up and walk out.

6. I think that it makes it easier if you have kind of a, a group of people that have, have that in common with

you that they have, uh, a child with a handicap or a problem that is similar, you know, to your child.

7. This is still awful new to us. It's just really, it is, you know, it's been hard emotionally, but everything else, she's made it real easy. And there's not a whole lot of people we can talk to about it. You start talkin' and they quickly change the subject. That's, that's been hard. When people say, "Oh, think how bad it could have been," I want to say, "Yeah, it could have been worse, but she is damaged, you know," and that was tough, I really was bitter for a while. I know I'm grateful for what she can do, but I want her back the way she was. I'm selfish.

8. There are definitely times when you kinda resent the situation because it's more difficult. I mean, it's not always wonderful. You have those moments where it's just, it kinda wears you out. Most of the time you're not even that much aware of it, everything's so normal and you're involved in your own little . . . . You do run into situations where you realize that they are different and that it's gonna take a little longer.

9. It's, um, it's probably the toughest job in the whole world, but it's also the most rewarding that there is. I think, time and time again, how much it hurts and the hurt never ever, ever, ever will go away, you just

learn to cope with it. You hate that he has to go through
what he has to go through, but you want him to be the
person he is and everything, that he is physically
disabled, makes him who he is. And you have to take it all
in one bag. You want every person on the street to see him
like you do.

10. Actually, all of this that has gone on so far
bothers me more that it bothers (Child's Name). To her,
it's a way of life. But to me, it's total frustration.
She's amazing, and all these kids I've met at the hospital,
I don't know how they do it. I guess because they have to.
My advice to other parents: make yourself clear. And talk
to the doctors. You are the best advocate your child has.
Your job is to force them to get your child the services
she needs. As long as you have information, you can deal
with it. Sometimes you feel like you can't deal with it
anyway. But if you know what's going on, it's a little
easier. Something we don't cope with around her is money
problems, but that's everybody's problem.

Concept Development

Categories, said Stern (1980, p. 21), are "simply
coded data which seem to cluster together." They are
abstractions of phenomena observed in the data (Corbin,
1986b). The data were assigned to categories according to

obvious fit. Seven categories emerged from the data; these included three which focused on the child, three which focused on the parent, and one which comprised help-seeking for both child and parent.

The three categories which focused on the child were setting goals for the child, communicating to the child, and interacting with the child. The three categories which focused on the parent were parental regrets, dealing with the parents' feelings, and parental advice for others. One category dealt with seeking help for the child and the parent.

The concepts which made up and collapsed into these categories were:

Goals for the child--self-esteem, self-confidence, child not being conscious of his/her disability, close bond with the child.

Communicating with the child--praise, explain disability, express gladness at having child, express love for him/her as he/she is, validate child's feelings, belief that child is valuable and has intrinsic worth, reinforcement that child's doing the best he/she can, view of child as child first and not as disability.

Interacting with the child--high demands for child, "push" him/her, practice explanation of disability and use terms

understandable and usable to child, show affection, treat like any other child, discipline according to needs of child, working with/teaching child, exposing child to other children and encouraging interaction.

Parental regrets--"babied" child too much and too long, pitied child, pitied self, not enough time for the child.

Dealing with parents' feelings--frustrated at what child can't do, self-pity, take self too seriously, emotional detachment at times, recycling of grief, own fears, worries about child's future, problems with amount of time away from work, avoiding over-reaction, resentment, events which upset parent don't necessarily bother the child.

Parental advice for others--you rise to the occasion, fight for services for your child, be an advocate, your child has intrinsic worth, let the child try new things, find a support group, there's frustration, resentment, depression, and bad days ahead but also rewarding, happy times, things may bother you more than the child, you're only a parent not a saint.

Seeking help for the child and parent--asking for help, attending to medical problems and physical and occupational therapies, realizing what are the parents' feeling and issues and separating them from the child's, facing the medical problems, treatments, and surgeries.

The densification and saturation of these categories became clear as further data collection produced no additional concepts within the categories. Searching for the relationships between the categories and placing conceptual order on the categories involved returning to the research question. What are the parenting behaviors used by parents in their rearing of a child with a disability? When attempting to pull together the central idea or phenomenon under study, Corbin (1986a) urges the analyst to locate the two or three main categories which may be unrelated processes and then abstract them to a higher level. Through review of the field notes, trying out different story lines, and talking over the data, a main pattern emerged--the parent was straddling two positions on three levels:

1. The parent was dealing with her own issues and feelings and simultaneously she was dealing with the child's issues and feelings.

2. The parent was striving for an ideal position of viewing and treating the child as "normal" and helping the child see him/herself as "normal," but at the same time, and in reality, as evidenced by special equipment, ARD meetings, therapies, the child was not "normal."

3. The parent was living with one foot in the present and facing the additional tasks and responsibilities of the present, and with the other foot in the past, as noted by the myriad of exact detail in each parent's "story" and frequent reference to past events such as the child's birth, diagnosis, and developmental milestones and triumphs.

Concept Modification and Integration

Further modification of the parent's straddling behavior developed by diagramming the core variable and other categories. Laying out the theory in the form of a diagram, says Corbin (1986a, 1986b), enables the analyst to visualize the logical flow of ideas and determine if vital points in the argument are missing. The diagram of straddling behavior follows. The concepts entailed in this diagram are of lower and higher order and, therefore, understandable to lay and professional alike, and important criterion according to Corbin (1986b).

Summary of Findings

Participants in the study, mothers of preschool and elementary school age, physically disabled children, responded to interview questions regarding their parenting of a child with a disability. They described what they

were doing well and "not well" in rearing their child,
difficult experiences they had encountered in parenting the
child, and what they had done, or were doing, to prepare
the child for the questions or teasing of other children.
They also discussed their parenting behaviors in the areas
of limit-setting/discipline, nurturing/affection,
encouraging social skills/getting along with others, and
teaching new skills, and their overall perceptions of
themselves as parents. In addition, they were asked to
comment on anything else about parenting a child with a
disability that was not mentioned by the interviewer. Each
interview lasted 40 to 65 minutes and the participants
talked freely about their experiences.

The participant responses clustered into the general
categories of setting goals for child, communicating to the
child, interacting with the child, seeking help for the
child and parent, parental regrets, parental advice to
others, and dealing with the parents' feelings and issues.
A core variable of straddling living in the past and the
present, dealing with their own and the child's issues and
feelings, and trying to parent the child as though he were
"normal," when, in reality, he was not "normal" and
required that the parent provide special care or

adaptations for him. A diagram of straddling behavior of parents of disabled children was proposed.

This chapter has discussed the analysis of the data. It has presented a description of the study, the findings of the study, and a summary of the findings of the study.

Figure 2. Straddling behavior of parents of disabled children.   106

Parental Straddling

Past

Present

Parents' Issues
. and Feelings

Child's Issues
and Feelings

Child as
Normal

Child as
Disabled

Regrets
Seeking help
Giving advice

Goals for Child
Communicating to Child
Interacting with Child
Seeking Help for Child
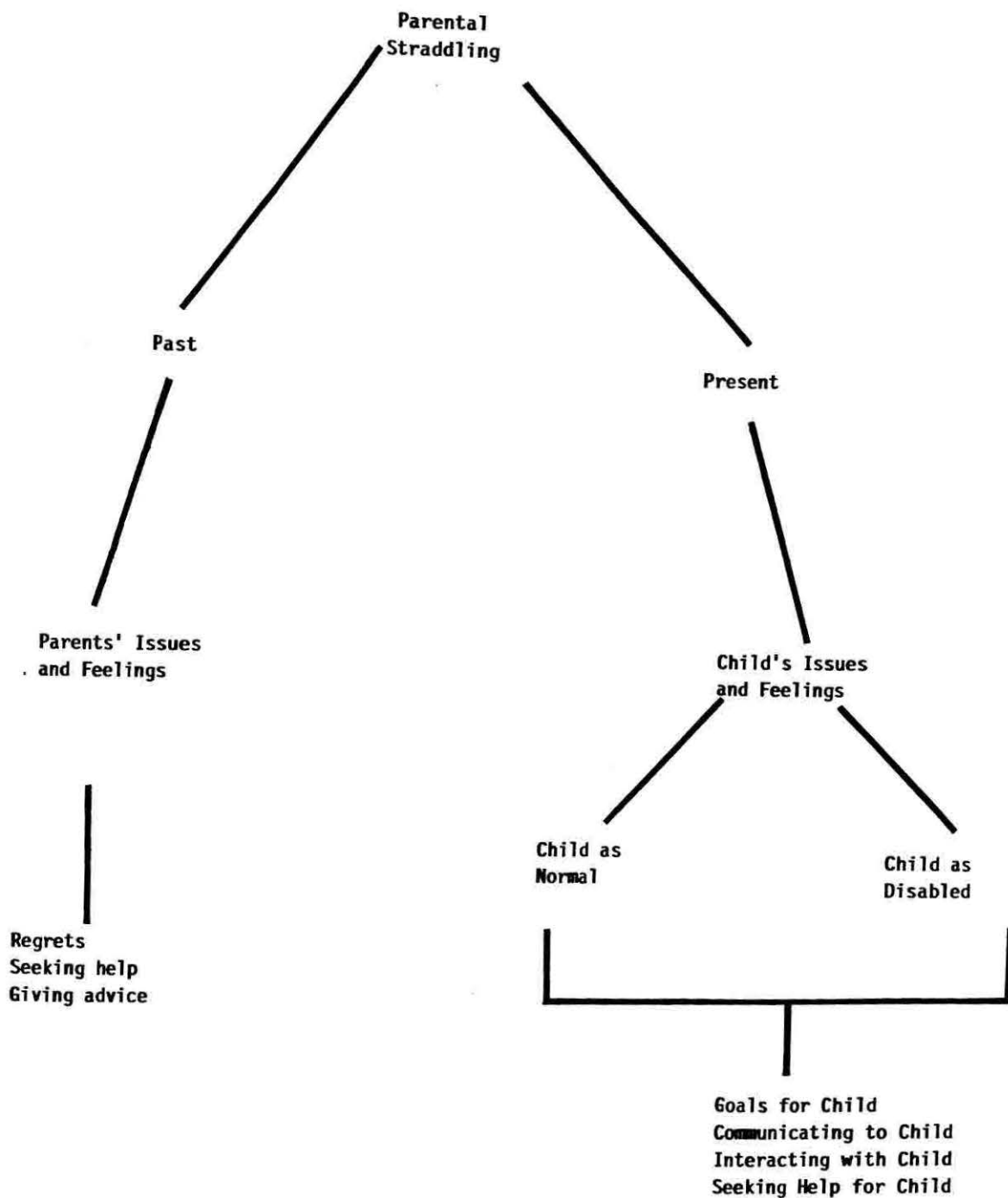
CHAPTER V

SUMMARY OF THE STUDY

The problem of the study was to describe the parenting behaviors used by mothers of preschool and elementary school age children with physical disabilities. This chapter will review and summarize the study problem, the findings of the study, the conclusions and implications of the study results, and recommendations for further study.

Summary

This research was a qualitative approach to the study of parenting of mildly to moderately physically disabled children of preschool and elementary school age. A nonscheduled standardized, or focused, interview was used to elicit information from the participants about the parenting of physically disabled children. Specific areas addressed by means of the interview included what the parents thought they were doing well and "not well' in parenting their disabled child, difficult experiences they had encountered in parenting the child, and ways in which they had prepared their child to respond to the questions or teasing of other children. They were asked to describe their parenting in the areas of encouraging social skills/

getting along with others, nurturing/affection, limit-
setting/discipline, and teaching new skills, and their
general perceptions of themselves as parents. In addition,
they were asked to comment on any other issue related to
the parenting of a child with a disability which was not
mentioned in the interview.

The participants in the study were mothers of
physically disabled, preschool to elementary school age
children whose disability was in the mild to moderate range
of impairment. Parents were selected from the school
records of the Grapevine-Colleyville Independent School
District, a suburban school district of Fort Worth and
Dallas, Texas, according to the child's ability to meet the
study criteria. The focused interviews took place over the
phone and were then transcribed. The data from the
participants' responses were then treated by means of
grounded theory methodology.

Discussion of Findings

In the review of the literature, no study was found
regarding the parenting of children with mild to moderate
physical disability. Therefore, the present study will be
discussed on its own merit. While no specific statements
were found to be similar to the findings of this study, a

few general statements, particularly about nurturing and loving the child, resembled statements from the literature.

The concepts, categories, and core variable which emerged from the data demonstrated the concerns and daily issues of the parents of physically disabled children. The core variable, straddling behavior, gave substance to precarious balancing of these parents on three levels of parental functioning. These three levels of straddling emerged as: (a) working out the dilemma of trying to view the child as "normal" and help him to see himself in that manner when, in fact, he is not "normal" and the parent must be engaged in a variety of activities designed to secure special services for the child; (b) dealing simultaneously with the child's and the parent's issues and feelings; and (c) living in the past and the present, as evidenced by the parents' frequent references to the past and the richness of detail regarding past events including the child's birth, diagnosis, and developmental milestones.

Straddling may be thought of as a precarious leaning from one side of a position to another based on the concurrent emergence of both child and parent needs. The behavior evidenced by the parents in the study may not be applicable to all parents of disabled children because agreement to participate in the study meant that the parent

recognized that the child has a problem, some type of disability, and was willing to discuss it with an interviewer.

The study of parents' involvement with the past is not typically seen in the behavior of parents whose children do not have a disability. These parents, however, could, and did recount the exact moment at which they learned of the child's disability; the precise day, month, and year at which their child reached a particular milestone; and how that achievement relates to the milestones of normal children. They related many details of various events in the child's development, such as who was present, what everyone did and said, later thoughts about the event, and comparisons of the child with other, non-disabled children. In addition, they failed, except in one instance, to discuss the child's future, and the hopes and dreams for the child in the future. One mother, the mother of the oldest child in the study, a 9-year-old girl with spina bifida, expressed her concerns about what the child's employment opportunities would be when she grew up. She recounted that she and her husband had explained to their daughter that there were jobs available for the handicapped.

Conclusions and Implications

The hypotheses developed by qualitative research are grounded in the data of the study, and thus those hypotheses can help bridge the gap between theory and practice (Bernheimer, 1986). This study was designed to look at the "relatively uncharted waters" discussed by Stern (1980, p. 20), which was the examination of parenting behavior used by mothers of preschool to school-age children with mild to moderate levels of physical disability. This form of research, the grounded theory approach, is particularly well-suited to nurse-researchers because it allows nurses to capture the complexity of problems and the richness of everyday life which makes up a great part of nursing practice (Corbin, 1986b). The concepts derived from the data develop into categories which are, in turn, the building blocks of theory (Swanson, 1986).

The present study indicates the need to add the core variable, parental straddling, to the adaptive capacity part of the Farran et al. (1986) Stress-Adaptation Model for Parents of Handicapped children.

The diagram of the core variable, straddling behavior is depicted on page 106. It is a beginning model for parental behavior with small children. Further research

using this model will lead to its refinement. The Stress-Adaptation Model for Parents of Handicapped Children (Farran et al., 1986), discussed in the conceptual framework of the study, has been modified to include the variable, straddling behavior, in the adaptive capacity segment of the model (see page 113, Figure 4). Straddling demonstrates a way of picturing the parents' attempting to fulfill, simultaneously, roles which may not be readily reconciled.

The concept of parental straddling displays the concurrent acts of leaning one way or the other which parents of disabled children adapt. Poised between the past and the present, with minimal attention to the future, the parent struggles to support simultaneously both the child and herself, the child's caregiver. She strives to move toward the ideal position of treating the child as "normal" and attending to the special needs of the child. Studying the model, the nurse or other service provider can begin to visualize the complexity of the parent's situation.

The uncertainty of the child's future, drawn from the lack of discussion of the topic, may demonstrate that the parents' focus is on the day-to-day coping and survival as a family with a disabled member. Many parents mentioned
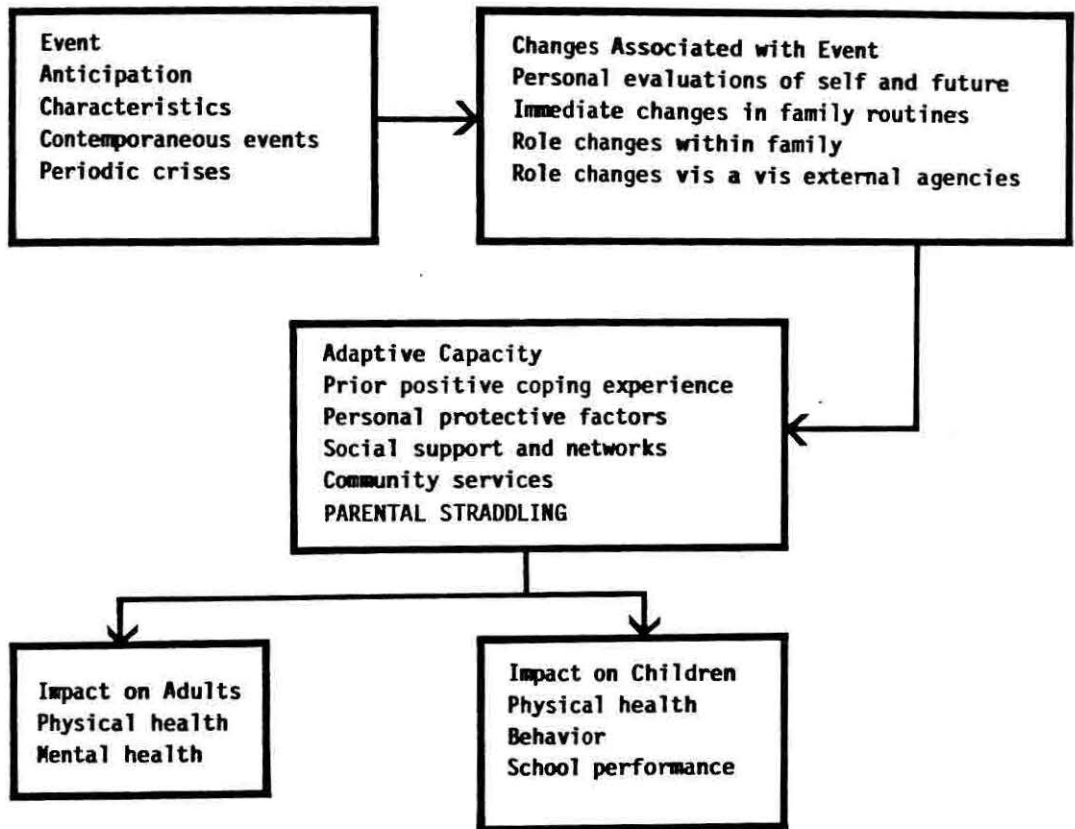
Figure 3. Modified stress-adaptation model for parents of handicapped children (Farran et al., 1986, p. 145).

that, "It's always something," indicating that they were never sure what was coming next to challenge their coping behavior as a parent. (Farran et al., 1986) also discussed this issue and stated that the health care and education systems work against preparing the parents for the child's future.

Many parents also discussed that only a parent of a disabled child could grasp the feelings of heartache, resentment, guilt, failure, and fear which they experienced. They seemed to be trying to communicate that professionals in the fields of education and health care needed to appreciate their needs and the needs of their child and families.

Nurses in obstetric, pediatric, and community health settings are in ideal positions to prepare parents for their often difficult-to-balance roles and responsibilities. Parents' straddling behavior can be explained and its possibilities for positive direction can be assessed with parents of disabled children. Nurses can assist parents to examine their own priorities in rearing their child and the behaviors which are likely to lead to their stated goals. The findings of the study may help nurses and other providers of services to families of children with disabilities to understand and appreciate the

roles and tasks which parents are trying to fulfill and reconcile. Further nursing research is needed to determine optimal approaches to family needs when a member has a disability.

Recommendations for Further Study

Future study may be directed toward the fathers of physically disabled children or at the mother-father dyad in these families and their blended expectations and parenting behaviors. The discovery of straddling between trying to see the child as "normal" and carrying out activities which show that the child is not "normal" may be further investigated in terms of the child's perceptions and how the parents perceive their balancing of their foci.

It would also be interesting to conduct a study similar to the present one with the parents of teenagers with disabilities. The adolescents' age would urge the parents to look at the future in terms of job preparation or additional education.

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APPENDIX A

Agency Permission

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE _____ Grapevine-Colleyville Independent School District _____

GRANTS TO _____ Barbara Schoen Johnson _____

a student enrolled in a program of nursing leading to a Doctoral Degree at
Texas Woman's University, the privilege of its facilities in order to study
the following problem.

Parenting children with disabilities

Dissertation/Theses signature page is here.

To protect individuals we have covered their signatures.

APPENDIX B

Research Review Committee Form

TEXAS WOMAN'S UNIVERSITY
P.O. Box 22939, TWU Station
OFFICE OF RESEARCH AND GRANTS ADMINISTRATION
DENTON, TEXAS 76204

HUMAN SUBJECTS REVIEW COMMITTEE

Name of Investigator: Barbara Schoen Johnson   Center: Denton

Address: 1408 Whispering Dell   Date: 10-24-88

          Southlake, Texas 76092

Dear Barbara Johnson

      Your study entitled   Parenting Children With Disabilities

___

has been reviewed by a committee of the Human Subjects Review Committee and appears to meet our requirements in regard to protection of individuals' rights.

    Be reminded that both the University and the Department of Health, Education, and Welfare regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. these are to be filed with the Human Subjects Review Committee. Any exception to this requirement is noted below. Furthermore, according to DHEW regulations, another review by the Committee is required if your project changes.

    Special provisions pertaining to your study are noted below:

_____The filing of signatures of subjects with the Human Subjects Review Committee is not required.

_____Other:

  X No special provisions apply.

                                        Sincerely,

                                        Chairman
                                        Human Subjects Review
                                        Committee at Denton

cc: Graduate School
     Project Director
     Director of School or
       Chairman of Department

APPENDIX C

Explanation to Subject

TEXAS WOMAN'S UNIVERSITY

September 28, 1988

Dear Parent,

My name is Barbara Johnson and I am a nurse and a graduate student at Texas Woman's University conducting my dissertation research on the topic of children with mild to moderate physical disabilities. I am interested in how parents rear a child with a disability and whether that is similar to, or different from, how they rear other children who don't have physical disabilities. I also have a personal interest in this topic.

I want to know, for example, what parents think they have done well, and what they've had trouble with, in parenting this special child. An example of a question which I ask in my study is, "What do you think you have done well in rearing or parenting your child who has a disability?"

My study involves talking with mothers over the phone about these topics and being audiotaped during the conversation. The information is entirely confidential and is reported when the study is complete as group information, not as any individual's responses. No person can ever be identified from the final research report. All

consenting participants will receive a copy of the findings of the completed study.

Your child's school district has given me permission to contact you and ask if you will participate in the study by agreeing to talk with me on the phone for about 30 minutes to 1 hour and have our conversation taped. Later, I will look at your responses and other parents' responses for those issues that come up repeatedly.

This is an important study because it may give nurses and other health care providers some information about living with and raising a child with a disability which we can use when we work with and teach parents like you. If you don't want to participate, your child's services from his school district will not be affected in any way. If you do wish to participate, you may still decide to withdraw from the study at any time and no reason needs to be given. You will not receive any monetary compensation from either Texas Woman's University, your child's school district, or me. However, if you wish, I will send you a copy of the findings of the study when it is completed. In those findings you may discover some useful information, such as some positive ideas about parenting, to you and your family.

Please return the attached Permission Form in the addressed and stamped envelope to me as soon as possible. If you wish more information about the study, please call me at (817) 481-6301, or the Director of Special Education for Grapevine-Colleyville Independent School District.

Thank you for your help and cooperation,

Barbara Johnson

1408 Whispering Dell

Southlake, Texas   76092

APPENDIX D

Consent to Participate

TEXAS WOMAN'S UNIVERSITY

Denton, Texas

CONSENT FORM

I have read a description of the study about parenting
a child with physical disability and its purposes. I
understand that my phone conversation with the nurse-
researcher will be audiotaped. An offer has been made to
me to answer any questions about the study. I understand
that my name will not be used in any release of the
information and that I am free to withdraw from the study
at any time without giving a reason. I understand that
services provided by my child's school district will not be
affected in any way by whether or not I agree to be in the
study. I understand that all consenting participants in
the study will receive a copy of the findings of the
completed study. I understand that no compensation will be
provided to me by the University, my child's school
district, or the researcher for participating in the study.

_____   _____

Signature   Date

TRANSCRIPT OF INTERVIEW WITH
PARTICIPANT #3

B.   The first question that I have is one of those
            kinds of things that I discussed with you in the
            explanation which is, what you think that you have
            done well in parenting or raising your child, and
            how you've done it or how you're trying to do it.

Mrs. C.   I think the thing that I've done, that I feel the
            best about is trying to give him a good sense of
            self-esteem, ah, and the way I've done that, um,
            is by of course, my husband and I both praise him
            for things that he does, um giving him a lot of
            love and affection, and by, um, let me see how I
            want to say this, by validating his feelings...

B.   Um-hum.

Mrs. C.   And being honest with him about his feelings.

B.   Um-hum.

Mrs. C.   Not pretending that his problems don't exist if
            they do. And, ah that I feel really good about,
            um, it's been a long process for us and, uh, it's
            been hard at times, but I think that you know
            we've been willing to ask for help if we didn't
            know the answer to questions, or we didn't know
            how to respond, and uh, I think that's the most
            important thing in the development of a child over
            academics or any other area, that you have a sense
            of self-worth and that he realize that number one
            that he is a valuable human being, that he has
            intrinsic value and worth, irregardless of what he
            may or may not accomplish in life, and I feel real
            good about that. So I guess if I name one thing,
            that would be the most important thing that we've
            done and I believe that he does feel good about
            himself, and uh, and is a happy child, and that
            I'm very pleased about.

B.   And, he is seven.

Mrs. C.   He will be soon.

TRANSCRIPT OF INTERVIEW WITH
PARTICIPANT #3

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          that would be the most important thing that we've
          done and I believe that he does feel good about
          himself, and uh, and is a happy child, and that
          I'm very pleased about.

B.   And, he is seven.

Mrs. C.   He will be soon.

B.   He's almost seven.

Mrs. C.   Right.

B.   He's going to be seven in a couple of weeks.

Mrs. C.   Um-hum.

B.   And you mentioned to me that he has a growth
          hormone deficiency.

Mrs. C.   Right.

B.   Okay, and a craniofacial problem, because you have
          been talking about support groups that you're in.

Mrs. C.   Right.

B.   Okay, um, what, now this is a hard one too. What,
          now, what have you done, can you think of anything
          that you've done that didn't turn out well, or
          something that, something that didn't go well, or
          you wished you could do differently with your
          child? And if that is true, and it may not be
          true, but if it is true, what would that be?

Mrs. C.   The thing that I wish that I had done differently
          is to lighten up at points, personally, because I
          have a tendency to be a perfectionist, and uh, I
          want to do it right, and I want to be the perfect
          parent, and if I, in looking back the one thing
          that I believe that I would change is to have not
          taken things so seriously at different times in
          his life. It's like an extreme position, it's
          good to be aware of resources and to be attuned to
          what's going on with my child and to be educated
          in terms of his medical condition, but on the
          other hand, I've had wonderful support of people
          to remind me that he is a child, and I that I need
          to lighten up, we're a family, first.

B.   Um-hum.

Mrs. C.   And that's hard.

B.   Um-hum.

Mrs. C.   When you've got so many things going on,
           educational, medically, socially, you know etc.,
           so I think if there were one thing it would be
           that, that I would just perhaps have not taken
           things quite so seriously as I did, because they
           all worked out.

B.   Um-hum.

Mrs. C.   In the long run, and it would have been less
           stressful for me.

B.   Um-hum.

Mrs. C.   Okay? So that's all I have to say about that.

B.   That's great. Thank you. What do you think are
           the most difficult things that you've encountered
           in raising (Child's Name)?

Mrs. C.   Ummm. Okay, the most difficult. Ah,...okay I'm
           thinking of several, let me start, I'll try to
           make it the most difficult and go down the list
           from there. I believe the most difficult thing
           in raising him has been to come to terms with my
           own feelings.   Ummm, to separate my own issues
           from him, for example, in socialization. Ah, when
           we come upon people who say thoughtless things or
           cruel, and that hasn't happened a lot, but it has
           happened at times, ah, I hurt for him, and I'm
           immobilized at times, I can't think of anything to
           say, and so it's been hardest for me, is to
           separate my own feelings, and be able to be there
           for him, to be a role model. Um, that's the one
           of the most difficult issues for me, because I
           love my child and it hurts to hear people say
           something stupid.

B.   Sure.

Mrs. C.   Um, again, I've had to ask for support and help on
           that, we've, he's been in a play er...he's worked
           with a counselor at the school he went to at
           pre-school who did some role modeling with him and
           had another child come in and they talked about
           some of the issues, and uh, and we've been
           instructed on things we can suggest that he say in
           response. And in validating his feelings, that

those things are painful, but they're going to happen, so that's been one of my most difficult was realizing that he can handle his own feelings.

B. Uh-huh.

Mrs. C. And I can't live for him, he's going to have to develop his own technique, and we can give some suggestions and advice, but that's been real hard.

B. Oh, yes.

Mrs. C. The other thing is, um, the medical issues, because he's had so much surgery, dealing with the fact that that's a reality in our life, and he's going to experience difficult pain and being able to be there for him, um...and giving him the support he needs, and um...not feeling like we have to be alone, we can ask for help, and you know, I guess we have to take care of ourselves number one, in order to be there for him. Um...and then the other issue of course, is education in school, which is just an on-going process.

B. Um-hum.

Mrs. C. And it's so difficult when you have so many opinions and you have your own gut feelings and you know right now I'm going through something that I have a strong feeling about, um...but yet, I can see the other side too. And it's just real difficult to know what to do, what action to take, and yet what to let go of.

B. Um-hum.

Mrs. C. That kind of in-between and not operating in extremes in terms of, I'm just going to take him out and move him, we're going to move, you know, and going no...no...no. That's not reality today, what can we do to work with it? And looking at the positive as well as realizing there are some things that we need to work on. So, I would say those are the three areas, that I have the most trouble with personally. That's the most challenging.

B.   Um-hum.

Mrs. C.   That's all that comes to my mind right now.

B.   Fine. This relates, this question relates exactly
          with something you just said, and so, you've
          already touched upon it. What you have done or
          what y'all are doing to prepare him for other
          children's questions or curiosity or even teasing.

Mrs. C.   Uh-huh. Well, again, asking for help. I've been
          to parent groups where we've discussed that issue,
          uh, in the pre-school he was in, we had those of
          us whose children were graduating had several
          parent meetings where we discussed those topics.
          Ah, asking for help from parents who have been
          there, and that can share their experience. Um,
          and the things that have worked for them. Ah, ah,
          that has been real helpful. Ah, also,
          surprisingly enough, the things that I would have
          thought would have upset him are not the things
          that upset him the most.

B.   Uh-huh.

Mrs. C.   So then again, it's separating my feelings from
          him, its as if you just have to take it one
          situation at a time, and realizing that if I don't
          have the answer then, that I can ask for help, and
          that, because things will happen again, or similar
          things, and then the next time maybe I'll have
          some information. Because I believe my husband
          and I are going to role model for him through
          response, not over-reacting, ah, helping him to
          realize when people make statements that's about
          them and it's not about him. You know, it's their
          issues that they have not worked through, and that
          he is still valuable and important, but be honest
          with him again about the fact that he does look
          different, his voice sounds different sometimes
          than other children, um, and that those things are
          going to come up. And yet, they don't have to
          immobilize him or keep him from reaching the goals
          that he wants to reach. And it's real hard, it's
          just real, real hard. Ah, so let's see, and then
          as I mentioned earlier, he had some counseling
          when he was in the pre-school program, and it's an
          issue that I've discussed with the teachers and

staff at the school he's in now. And, ah, I'm pushing for some perhaps in the future peer counseling, ah...he's integrated right now, I thing that's real important. I can't over-protect him.

B. Uh-huh.

Mrs. C. He's got to be able to experience those situations. Ah, as I said earlier, things that upset him may not be what I would think would upset him. Ah, because some children, because he does look different, and he wears glasses, and children had asked him a question about his eyes or something, I can't remember what it was, but what he got angry about is someone asking him to take his glasses off. And that infuriated him. And that's not what I, would have upset me.

B. Right.

Mrs. C. But that's his response.

B. Right. That's what upset him.

Mrs. C. My husband and I both have practiced with him, when the situation has come up, that someone angers him, and he really doesn't, because of his other disabilities, it's hard for him to come back with a spontaneous response, so we suggested, well next time perhaps you could say this. Then we had taken him to a neuro-psychologist for evaluation when he was five, before he got back in the school system. So he talked to us about socialization and the problems he would have because of learning disabilities and his social interaction and his social perceptions are different. So one of the things he suggested was, that we can't just tell him, we have to let him practice and experience it, and that's been real helpful for us.

B. To practice.

Mrs. C. To practice, to pretend he is himself and then pretend he is the other child. And use different, use other techniques to respond to those kind of situations, for example, if a child wanted him to take his glasses off, we suggested he say, "No, these are my glasses, and I don't have to take

them off. These are mine." But, we had to
pretend, you know, he can't even, we had help him
just assert himself, and formulate the words, so
we practiced with him being that child, and using
a strong voice. And right now, in his class, his
integrated Special Ed class, his teacher is
working with him to say "No" to children and to
set boundaries because he tends to be more
passive.

B.   Uh-huh.

Mrs. C.   And the interaction with other children, so he's
working with him on that. So, I'm sure there are
other things that we've done, but thats some
examples of things we've worked on till now.

B.   And those are great examples. Everything you're
saying is just feeding, it's like you wrote this
questionnaire, because everything you're saying is
feeding into the next question. I mean
it's,...you're just prompting me along because the
very next thing I was planning to ask you which
you just began answering was, "What have you done,
what have you and your husband done, to increase
his social skills to help him get along with other
children, or adults?"

Mrs. C.   Right. Well, I've pretty much answered quite a
bit of that, and that's been to expose him to
other children, ah, that's an area I still have
trouble with and you know, I...I certainly, they
are not still perfect. But, it's still hard..ah,
because of you know all the problems that he has.
Ah, to allow him, because it still hurts me.

B.   Uh-huh.

Mrs. C.   It still hurts my husband, so we have to just act
as if...and go ahead and allow him...

B.   As if...it's not bothering you. Act as if...

Mrs. C.   Well, right, act as if it's not bothering us, but
at times, but then I think at times we have to be
honest with him about our feelings. Um, something
happened this week, oh, it wasn't about
socialization, it was about he had some blood work

B.   Uh-huh.

Mrs. C.   And then nine times out of ten he's just fine and
            he's had a wonderful time.

B.   Uh-huh.

Mrs. C.   But, it's, it's still real hard. Um, so I think
            that's been the most important thing is just
            exposing him to other children, and also I've had
            to do some preparation like with Sunday School
            teachers and with other people, to let them know
            that, you know, um, what his developmental level
            is and the fact that he can do a lot of things and
            he understands everything and he has fine motor
            problems, but he may be slower in doing some
            things, but that kind of prepare him, um, with
            teachers or with babysitters that he's stayed
            with, that maybe are new or whatever. So that
            they'll be aware of the fact that there are some
            limitations but that he's going to be okay, and
            ah, so I guess that's kind of the preparation that
            we've done. Talked to him about what's going on,
            keep him aware, but try to over-react and allow
            him to be in those kinds of situations. And, then
            apply the other things if a problem comes up. You
            know, then we could talk to him about it. I feel
            real good about the fact that he tells me about
            what is going on. If he's upset or if he's sad,
            you know, he's at a point where he can pretty much
            decide what feeling he's having. If he's angry or
            whatever we can talk about that, and I can
            validate his feelings and um, then he can go on
            about his business. And what's so neat is,
            usually it's something has upset him, he can talk
            about his feelings, he can express his anger and
            then he's just fine.

B.   Uh-huh.

Mrs. C.   He can go on to the next step. Ah, because he had
            a problem with a child in his class last year,
            that had a severe behavioral problem. And, ah, so
            we talked to him about how to deal with it, and
            finally we reached the point where we had to take
            other action, because the problem was so severe,
            um, then I had to go, you know, talking with the

teacher and the Director of Special Ed and some changes were made.

B.   Uh-huh.

Mrs. C.   Um, so it's real hard, when to let go and when to know that you've got to go ahead and do something else. And another thing we worked on is, if he's having a problem with other children, um, to ask for help and I'm trying to teach him that part of helping yourself is to ask for help, if you can't, if you cannot do it, if you're getting nowhere with the child who is harassing you, or whatever, that sometimes you have to ask for help.

B.   Uh-huh.

Mrs. C.   You can't deal with it yourself, so that's been another one of the things that we've used. And like I say, I'm real open to anything new that comes along, you know.

B.   You'll try it, huh?

Mrs. C.   It's like you get one problem worked out and you think, okay we're going to coast for a while and then something new comes along.

B.   Uh-huh.

Mrs. C.   So, if I can't do it, you know, I will ask for help, because I sure don't know how to do this deal, so anyway, I mentioned I think yesterday that we're having a parent, I mean a kind of a seminar parent-group thing come up in November, and it's going to be on socialization and psychological ramifications of having a growth hormone deficiency and being smaller than other children. So, I'm hoping I'll get some information there.

B.   Uh-huh.

Mrs. C.   Ah, oh, one other thing, and this is really important about this, I think it's important too, that (Child's Name) have a peer group of children, that occasionally he be exposed to children that

have similar problems to him, like a support group.

B.   Uh-huh.

Mrs. C.   I think that's really important. I think it's important that he be mainstreamed, but also to know that other children, that there are other children that have similar problems to him because I've seen that before with him and it's been wonderful. In the pre-school he was in there were two other children that were growth hormone deficient and that had to have shots like him, and that...they said they'd never had that happen in that school before, but it was wonderful, because one of his best friends, um, was also taking shots. And, that really made a difference for him to know he was not alone.

B.   Not the only one.

Mrs. C.   That's right. And that they even saw the same doctor, so when he went in to get blood work, I could say, you know, this other child has...he had to have this done too and it hurts him, and he cries, too. And you know, and he knew that and that was wonderful!

B.   Uh-huh.

Mrs. C.   And...

B.   You're not alone.

Mrs. C.   Right, and our craniofacial group, um, at the...we have it at the hospital, and they've got the new, there's a special program in the hospital to help children dealing like, especially in hospitalizations, but they come down, the volunteers and stay with the children while the parents meet, so the kids get to be around other kids that have had operations like them, or that maybe has had similar problems. And I think that's really important as well as mainstreaming that he know that he's not alone, and um, they can support each other. And I, and we're hoping as they grow older and he's only six now, but as they approach adolescence they're going to have special problems at that time and that they'll be able to,

they'll know each other already and they'll be
able to at least say, I understand, and I'm there,
too. And, I know what you're talking about.

B.   Uh-huh.

Mrs. C.   And I just think that really, really important.
So anyway, my mind went blank. I guess that's all
I have to say about that.

B.   Well, in the next part, yeah, is again about these
different areas of parenting, one of them was the
one you just discussed about socialization and
what you've done to help him get along with other
people. And the next one is about discipline and
limit setting. Whether you have to think you do
anything special or different or not different,
than other parents in terms of limit setting or
discipline.

Mrs. C.   Oh, gosh. Okay, this is probably my weakest area.
That I continually work on.

B.   Uh-huh.

Mrs. C.   My child is one that it seems like from talking to
other parents, is either their children are awful,
I mean their behavior is less than what they would
like at school and they're good at home, or
they're wonderful at school and then they let it
all hang out at home.

B.   Uh-huh.

Mrs. C.   Mine is in the latter category, I believe.

B.   Uh-huh.

Mrs. C.   As far as discipline, it's been real hard, for me
um, and I've had to try different things, it's
kind of like I was talking to you earlier, you get
one area taken care of and then something new
comes up. Ah, again, I've had to ask for help,
um, I've tried to be, tried to be as consistent as
I can be, um and that's real hard...

B.   Yes.

Mrs. C. ...to do ah, he gets frustrated easily and in terms of like self-help skills, I get frustrated and sometimes I just go ahead and do whatever, I ... needs to be done, rather than discuss...you know, go around and around about getting his clothes on or whatever. But, I've tried to I have probably spanked him once or twice just a pop on the rear and that's been totally ineffective, the only time I've ever used that is if like, he's going to run out in the street, and I pop him to get his attention, and to say "No". He really knows that that's something that he shouldn't do.

B.   Uh-huh.

Mrs. C. But that's, that has never worked with him, and I don't know if it's because he's had physical pain himself and that's not a...

B.   A big deal.

Mrs. C. ...a big deal. I don't know. I don't like spanking anyway, I was...I just don't like corporal punishment, so I've tried to use you know, time out and rewards, um, and just whatever seemed to work at the time, you know, it seems as the children change in development, then you have to start with something new, and or try something new. Discipline has been difficult, I'm not a real strict parent and I'm pretty easy-going as far as discipline is concerned, so we're not real regimented as a family, and I'm just thinking of like keeping things picked up and toys or whatever. But, ah, I try to set...with (Child's Name) because of the way he processes information anyway, if I'm asking him to do something, I almost have to break the task down into steps and that seems to work better than anything else, if I say, first, we're going to pick these things up and then you'll need to do this, or whatever. And that seems to work best for him, but it took me a long time to figure that out.

B.   Uh-huh.

Mrs. C. Because if I give him a series of tasks, he's overwhelmed then he just won't do anything, and then I get angry, so you know I didn't know what

Mrs. C.   ...to do ah, he gets frustrated easily and in
           terms of like self-help skills, I get frustrated
           and sometimes I just go ahead and do whatever, I
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           long time to figure that out.

B.   Uh-huh.

Mrs. C.   Because if I give him a series of tasks, he's
           overwhelmed then he just won't do anything, and
           then I get angry, so you know I didn't know what

was going on for a long time. But, um,...that's kind of what I've used for discipline. And it's odd that I'm around him more, I know it's not odd...I've heard other parents say that even with normal children that this is a fact, his Dad is not around him as much because he's at work, but when he's there he does it. And that just frustrates me to no end. But,...

B.   Like every other child in the world.

Mrs. C.   That's right. I guess he's just heard me so much he doesn't listen.

B.   It could be the difference in the voice. You know the difference in a man's voice and a woman's voice.

Mrs. C.   I think so too. But, for (Child's Name) I guess just children individual and separating him is the worst punishment you can do because he loves to talk and he love to play, and he's on the go and if I separate him, like he has to go sit for a while, that seems to give him some time to get settled down, and get his emotions under control. Um, and I guess that's an emotion, it's his emotional developmental level anyway. So, I've read books and I've been to groups about discipline, you know and parenting and what I've kind of found is that a lot of the things that work with regular kids are still the things that I have to use for my own child, and so, anyway, I still ask myself on that, because as I said earlier they change, then something new starts and I going...what will I do with this now?

B.   Uh-huh. It's always something.

Mrs. C.   Yeah, it is. It really is. It's always something. So, anyway, I guess that's about all that I need to say about discipline.

B.   What about affection or nurturing? Do you think he's different, or do you do different things with him than other children?

Mrs. C.   Not really, I believe that if he had not been born with any problems that we would still probably

show the same kind of affection that we would if
he were a child without any kind of disabilities,
because we have always tried to be very nurturing
with him. Telling him we love him, of course, and
hugging him, you know, giving him physical
affection, ah, I imagine the thing that would
probably be different in terms of his medical
problems. That we have, when he's had to be
hospitalized or he's not felt well, we've probably
been more conscientious maybe, held him more, you
know, reassured him, I don't know it's hard to say
because he's been my only child and I don't have a
frame of reference. I can't compare him with
other children that I've had, but I'm certain now,
with the hospitalizations his grandparents have
been there and we've all just tried to really
assure him, and be there for him. When he was in
I.C.U. for a month, when he was born and that was
real hard, and you know, when we would go in, I
would try, you know, here he would be with all
these wires and tubes, and any part of his little
body I could touch and pat and I'd talk to him all
the time, and tried to give him what I could in
spite of the limitations because of the
environment and the things that were going on with
him. Um, so that's just real important to me.
And, um, then on the other hand you have to, I
realize that you have to set a limit, then you
have to get it to a point that, oh, how do I say
this?...you have to love and nurture them, and
then they will certainly take advantage of that
too. You have to get at the point when they're
out of the hospital where they can start doing
things for themselves and being responsible for
themselves. Um, someone told me early on, that
you try to re-create the environment in the home
as much as possible in terms of even discipline in
the hospital. And so, when I found that out when
he was old enough, I tried to incorporate that
that would give him a sense of security.

B.   Uh-huh.

Mrs. C.   And, ah...

B.   And that things aren't that different. He's
          treated similarly.

Mrs. C.   Right, and that if he was doing something and I
           disciplined him or I said "no, now you've got to
           do this", and use a firm voice, if I knew it was
           something that had to be done.

B.   Uh-huh.

Mrs. C.   Ah, so anyway that's...it's real tricky.

B.   Uh-huh.

Mrs. C.   And, in fact we're going to a craniofacial group
           this Monday night is going to be in
           hospitalization and what do you do when you get
           home. And, I'm going, because he's going to have
           some surgery this next Spring, and it's been a
           while since we've had surgery, and I need to hear
           some things again, and I hope I'll learn some new
           things.

B.   Uh-huh.

Mrs. C.   So, uh, anyway the subject was nurturing and
           I...ah, like I say, I just think it's just real
           important because it's so tied in with sense of
           self-esteem. And um, so I hope that we've given
           him all that he needs. I think that we have,
           because like I say, I think he has a good sense of
           self-esteem and that he feels good about himself,
           and I just hope he keeps that. My biggest fear is
           as he gets older and the peers, that's one of my
           biggest concerns, and ah, I'm going to be willing
           to do anything it takes to make sure that he keeps
           his sense of self-esteem. That if he gets at a
           point where he's really having some problems, if
           he needs to talk to somebody, if he needs to talk
           to a counselor or be in a support group or
           whatever he needs, I want to be sure he has
           whatever he needs to be able to keep that good
           self-esteem

B.   Uh-huh. And to ask for it if he needs it.

Mrs. C.   That's right. Absolutely. So, I believe that's
           all I need to say about that.

B.   Okay. What about this? What do you think you've
            done, ah, in parenting him regarding teaching him
            new skills?

Mrs. C.   Um, oh gosh, I guess that began from day one ah,
            parenting and teaching him any kind of skill and
            self-help skill?

B.   Yes. How do you interact with him, what do you do
            when he's trying to learn for example, a self-help
            skill?

Mrs. C.   Well, I try to walk him through it, I try to not
            only tell him how to do it, but show him how to do
            it. Uh, because again, with him, the way he best
            learns he needs to really follow through on an
            activity in order to master it. Ah, he's real
            frustrated and I think it's probably largely due
            to the disability when things are hard he'll say,
            "They're hard, I don't want to do it!", and I know
            he's saying it because it's so frustrating for
            him. But, if he'll go ahead and walk through it
            and when he finally learns it he feels so good
            about himself. So, ah, that's...I those are the
            things that I've done to work with him on his
            self-help skill, to try to keep him motivated
            enough so that he'll want to do it, and that's
            been the hardest part is that he not give up in
            frustration, so ah, so one of the things I've used
            is rewards, like in the morning, getting dressed
            is so frustrating, so what I've been trying to do
            most of the time unless we're in a hurry or
            whatever is that he needs to get dressed before he
            comes in and has breakfast or watches cartoons or
            does whatever else he's wanting to do. Because,
            for my son at least, it seems like if we give him
            the right carrot, he goes for it. Ah,...

B.   Like T.V. ...or

Mrs. C.   Right something that he...oh, he can take all day
            doing something if he's not motivated.

B.   Uh-huh.

Mrs. C.   If there's no reason for him personally to get
            anything out of it, but he's motivated like he
            knows that he won't get something until he

finishes whatever task, he can do it in a blink of an eye.

B.   Uh-huh.

Mrs. C.   And the teachers have commented on that at school, too. It's like he has to have a reason to do things that he's doing so that's been some of the techniques that I...that seem to work best with him is to follow-through. And we talk, he has a high vocabulary and I think that's because we've talked to him since he was newborn, and ah, so he, you know we talk to him and explain things and talk about things and I think he's learned a lot that way. Ah, because when he was small, my mother came to stay with us for a period of time, to help me out, till he got to a point to where we could leave him with a sitter, and because I had to go back to work and she's a big talker too. But, she talked to him, even as a small infant and we all did and I think that, that made a big difference. That he got lots of stimulation when he was younger and I think that that's carried through. I really am a big believer in infant "stim" and early childhood programs and I think that that's carried through, you know to the present time, as far as his learning because he's far surpassed anything we were told when he was an infant.

B.   Uh-huh.

Mrs. C.   And so, I think that had a lot to do with it. Ah, in getting him to learn to do new things, and ah, other children motivate him, this has been really exciting in his integration into the kindergarten. Because I've seen some nice progress in his social skills and social interaction, because he does watch the other kids and has learned a lot from other children, and ah, that's been a big motivator, if a certain other child does something then he wants to do it too. So that's how we've taught him a lot of the skills that he has, and he will also, because he's visually impaired he was in the school system since he was three months old he had a visual handicap teacher and a physical therapist come out and work with him and who could help me and teach me how to do some things that I could carry on, so I've had a lot of the support

and instruction on how to do...maybe if this
doesn't work why don't we try this, so ah, those
are some of the things that have helped me out in
working with him to get him stimulated to try new
tasks.

B.   So, you've had a fair amount of help from a lot of
          sources. A lot of resources, support groups,
          teachers, early childhood people.

Mrs. C.   Lots of support, you know. A whole lot of
          support.

B.   You could teach this.

Mrs. C.   Well, no....I don't know if I'm emotionally
          detached enough about that to be able to do
          anything like that, but, and I guess I haven't
          mentioned one other important thing I have had
          contact with a lot of other mothers and that's
          been so important for me in all these areas, for
          someone else that I talked to and ask, "Have you
          had this happen?" And they'll say, "Yes, I'm
          having a problem with it now" and then, or maybe
          they've had the problem and ah, they can share
          with me what works. Ah,...

B.   Uh-huh.

Mrs. C.   And that's been so important for me, too. To have
          like a peer group so I won't...early on like when
          I was working through a lot of the grief and all,
          that I didn't feel so alone, because that's
          just...oh, when your child is born...that's
          different, you just feel, like I felt like it
          didn't happen to anybody else. Nobody understood.

B.   Uh-huh.

Mrs. C.   So, I had, that was really important for me.

B.   To find out somebody did.

Mrs. C.   Oh, I was going to say one other thing, it kind of
          threads through several of the questions you've
          talked about, and that is the grief process. When
          I was talking earlier about ah, my son and for me
          when I'm talking about issues that come up with
          other children, interaction with other children,

things they might say or, or the fact that maybe
he can't play in the same way other children play.

B.   Uh-huh.

Mrs. C.   That, what has happened. When that happens for
me, be it medical or social if it's something new
I'll go into grief again. And, I think that's why
I can't always respond right at the minute.
Sometimes I can, sometimes I can't. Because,
early on I was told that the grief is the on-going
process.

B.   Uh-huh.

Mrs. C.   And it brings the pain up again.

B.   Uh-huh.

Mrs. C.   And so it's like whenever something new happens
with us I have to grieve a little bit. Its like I
have to back off for a minute and feel that pain,
and then I can come back.

B.   Uh-huh.

Mrs. C.   And I can be there and do what I needed to do.

B.   Uh-huh.

Mrs. C.   But an awareness of that has really helped me a
lot in working through medical problems, when we
heard something new like we heard last week, I'm
going to grieve again. And I know, now that I
know that's normal, it's not as bad as it was in
the beginning by any means. But it's still that
process. It's still that little reminder. And,
ah, no matter what area that we're working, and
when new things come up, if it's medical if it's
educational, if it's social interaction or
feelings about, just his feelings about himself,
that comes up again, most of the time. I don't
think that can be overlooked when you're talking
about having a child, you know, with disability,
ah, in any area because it's going to be there.
I'll never be happy again, and I've said that,
I'll never be happy again. And parents at that
point have said, "You will be", and I kept...

B.   You don't think so.

Mrs. C.   No, you don't think so, and I just had to believe
          that what they said was true, I didn't really
          believe it, but I had to keep hearing it you know.

B.   Uh-huh.

Mrs. C.   That's all I have to say about that.

B.   Is there anything about parenting a child with a
          disability that you would like to say and that I
          have not asked or I didn't bring it up?

Mrs. C.   Umm, I don't believe so. The main thing that I
          just wanted to make a comment on you know, was the
          grief, and well, maybe one other thing that we've
          come a long way in general in terms of society's
          attitude toward handicapped individuals or people
          that have...that are different in some way, and I,
          that is a very frustrating area for me. I would
          like to see people have even a more open attitude.
          But, I know it's a process of education and um...

B.   Maybe time.

Mrs. C.   Time, yes time as well and when we were in a ...
          the first parent program I got into it was twelve
          weeks and it was a State School and one of the
          social workers there said, pointed out that we
          were going to be educators and boy, was I mad...I
          said forget it I'm not educating anybody, I can't
          even do what needed to be done on a daily basis,
          but it has been proven to be true, um, that I
          think each of us probably have one little bitty
          part we're doing and ah, I think that it's just
          really important and I love to see, I love to hear
          people speak that are real advocates ah, and that
          are reassure us as parents that we are
          professional and our children have, that they do
          have intrinsic worth and value as human beings,
          and I need to keep hearing that, and I'm real
          grateful for the things that are available now,
          that I know were not available when I was a child.

B.   Uh-huh.

Mrs. C.   So, that's the only other thing I guess I wanted
           to comment on is just that I hope that this growth
           continues in society's acceptance and awareness,
           ah, what really goes on because unless you live it
           you sure don't know what it's like.

B.   And I agree. I mean I agree, I think that that's
           true about living it and that's what helps you
           understand it all. Mrs. C., you have been
           extremely helpful and extremely articulate, I will
           in the process of this study be calling you back
           in about a week or two after I transcribe all of
           your words and say to you, "Is this what you said?
           Is this what you meant? Did I misinterpret your
           words? That sort of thing. And so, you'll be
           hearing from me again. Plus I'll be more than
           happy to send you a copy of the results of this
           final study, if you wish them. I thank you so
           much this has been very, very helpful to the study
           and to me.

Mrs. C.   Okay, well great, I have one other thing, and this
           was for you personally, because you were
           mentioning yesterday that you hoped that this was
           going to be a beginning, actually as I understood,
           part of that educating process is...I have a
           dream. I was sharing this with a friend whose
           also the parent of a child with special needs and
           she, I was telling her that my dream is that one
           day there's going to be a movie, a wonderful
           movie, I don't care if it's on T.V. or if it's on
           at the theatre, but that's really of a family and
           what it's like, my focus at that particular time
           was in terms of working, of what it's like to get
           an education of a child with special needs. But
           also, what it's like in terms of society, I mean
           the issues in your study that you're talking about
           right now, I don't think there's ever been
           anything done like what I have in mind as far as
           the day to day living process and what it's really
           like to work through the educational system, and
           go to ARD meetings IEP's and be told there's no
           money, and all those kinds of things.

B.   And you were there to fight for your child.

Mrs. C.   That's right, and I would love to see that, even a
           documentary done.

B.   Uh-huh.

Mrs. C.   Where people could really understand because they don't. They don't, they look at...they just don't, I know they don't, even this area in this school system. Um, so anyway, if you ever have a place in the future where anything happens I would love to...

B.   Maybe we should do that.

Mrs. C.   Oh, gosh. Well, I think it's a wonderful idea. I mean I'm certainly not a cinema professional or anything like that. But, I would sure give somebody some information.

B.   Well, and what is a professional? A professional is a person who knows something in a very deep way, some sort of specialized knowledge and you certainly have a tremendous amount of highly specialized knowledge. Maybe that's a...maybe that ought to be the next project. A T.V. Show. Yeah, a made for T.V. movie.

Mrs. C.   I just think that would make such an impact, you know.

B.   Because everybody would...

Mrs. C.   On all these other issues in society, and but something well done.

B.   Uh-huh.

Mrs. C.   Not anything to melodramatic, but just really what it's like. I think it would be a great movie.

B.   I do, too.

Mrs. C.   Oh, I've heard so many mothers say "oh, I could write a book".

B.   And they could.

Mrs. C.   I know they can. So, anyway, I was glad to help you and I be anxious to see your results.

B.   I appreciate your help very much. If you think of
         any other questions you can call me back.   I'm
         Barbara Johnson, you'll be getting my phone number
         in the mail, but also, my number is 481-6301.