

Mainstream Families with Children

with Special Needs:

A Qualitative Study of the Process of Coping

by

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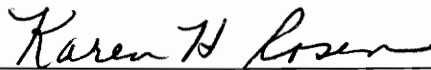
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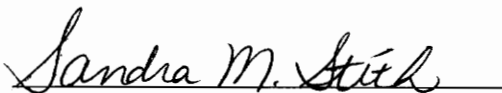
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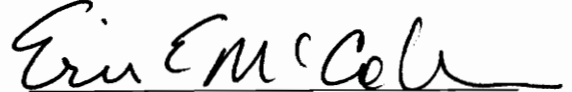
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NEEDS: A QUALITATIVE STUDY OF THE PROCESS OF COPING**

by

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Family and Child Development

(ABSTRACT)

This study examines the coping process of families with children with special needs. The purpose of the study was to develop a detailed description of the coping process of families who appear to be coping well with children who have physical disabilities.

A multiple-case study qualitative research design was selected to allow for the unique stories of each family to emerge as they illustrate the complex nature of the coping process. A contextual stress and coping theoretical framework guided the study. Participants were recruited from a preschool program that mainstreams children with special needs. A pool of ten potential participants was identified by a selection team consisting of six

school staff members. Five families were selected and interviewed using the theoretical sampling procedure outlined in the grounded theory approach developed by Glaser and Strauss. Data analysis followed this same procedural model.

The study revealed the ongoing coping process to be an iterative cycle of events, perceptions, behavior, and personal growth. This process was found to be influenced by the core concept of shared traumas as they are evidenced in the themes of initiation to special needs, boundary defining events and everyday reminders. An additional concept of the mastery process of the interaction between perceptual and behavioral components, included cognitive coping processes, faith, boundary definition and external systems management style. Finally, the phenomenon of personal growth and change in world view was observed.

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Finally, I want to thank the families who participated in this study. It is their stories, told from the heart, that serve as inspiration and education for families in the future.

TABLE OF CONTENTS

I. INTRODUCTION	1
Statement of the Problem	1
Significance of Study	4
Theoretical Framework	10
II. Literature Review	16
Introduction	16
Stress Research	16
Impact Studies	21
Negative Impact Studies	21
Family Strengths and Positive Impacts	27
Research Related to Coping	30
Stage Theories and Chronic Sorrow	32
Qualitative and Longitudinal Studies on Families with Special Needs Children	34
III. METHODS	59
Design of the Study	59
Description of Participants and Selection Process	61
Data Collection	69
Measures	71
Unit of Analysis	73
Data Analysis and Interpretation	74

IV. RESULTS	77
Introduction	77
The Story	82
Core Categories	83
The Andrews Family	91
The Brown Family	105
The Conway Family	119
The Donahue Family	131
The Edwards Family	146
Summary	167
Figures and Tables	168
Figure 1	168
Figure 2	169
Table 1	170
V. DISCUSSION	171
REFERENCES	182
APPENDICES	191
APPENDIX A	192
APPENDIX B	195
APPENDIX C	198

CHAPTER I

Introduction

Statement of the Problem

The last two decades have brought about radical changes for disabled individuals. Public Law 94-142, the Education of All Handicapped Children Act of 1975, has altered dramatically basic educational programs. Revised and retitled the Individuals with Disabilities Education Act (IDEA) in 1990 with revisions in 1991, the new P.L. 102-119 has put in place additional rights and responsibilities for individuals, their families, and society as a whole. Psychological barriers of fear and ignorance are crumbling. Public awareness of disabled individuals has grown to a new level of acceptance. Our language reflects this change with the use of terms like "special needs," "disabled" and "physically challenged" rather than "handicapped." Even popular television shows include disabled characters who are portrayed as likable and admirable individuals. Accessibility to public buildings has become law. Ramped entryways and facilities that accommodate their needs are replacing physical barriers that once made independent living almost

impossible for physically challenged people.

However, with all these changes in societal perspective there is one area that has seen very little growth. Within the therapeutic community there remains a pervasive and specific bias against families with special needs children (Beavers, 1989; Byrne & Cunningham, 1984; Turnbull, et al., 1993; Turnbull & Turnbull, 1990; Wikler, Wasow, Hatfield, 1983). With very few exceptions most literature on research which seeks to examine the impact of special needs children on family functioning does so from a pathological perspective (Bristol, Schopler & Gallagher, 1988; Flagg-Williams, 1991; Goldberg, Maracovitych, MacGregor & Lojkasek, 1986).

Clinical intervention and research with the families of developmentally disabled children have consistently focused on the problems, stresses, and inadequacies of these families . . . Study after study has been done to determine whether the presence of a mentally retarded child in the family is associated with increased rates of alcoholism, depression, physical illness, or divorce (Wikler, et al., 1983).

This linear research approach assumed that such families are subject to high levels of stress which cause psychological impairment among some, if

not all, family members (Byrne & Cunningham, 1984). In addition, the family as a system or a functional whole has rarely been the subject of study (Crnic, Friedrich & Greenberg, 1983; Seligman & Darling, 1989; Turnbull, Paterson, et al., 1993).

The assumption that dysfunction and family stress is omnipresent has been set down as the foundation from which to work with these families. Therapists have been oriented to this perspective by decades of research and literature that focus on the pathology and the seemingly unavoidable array of specific dysfunctions that often surface in families with special needs children (Flagg-Williams, 1991; Turnbull, et al., 1993; Wikler, et al., 1981, 1983).

It is the intention of this study to go counter to past research trends and to focus on the strengths of families with disabled children. The purpose of this study is to examine how families who appear to be coping well, cope with physically disabled children. The study focuses on the development and significance of coping strategies as a process over time. It builds a detailed description of the experience of families with children with special needs. The research objective is to clarify some of the strengths in families with special needs children and to hear in their own words how they describe their

coping processes and how they believe these processes were developed.

Significance of Study

It is generally agreed that the impact of a child with special needs is not restricted to that child alone. Clearly other family members will feel the effects to some degree or other. What is not clear is the reciprocal nature of the relationship and influences between children with special needs and their families. For example, in the case of retarded children, their satisfactory level of emotional development may be more dependent on the families' responses to them than to the extent of their disability (Crnic, et al., 1983). Even with the acknowledgment that families play an immeasurable role in their disabled child's development, there is much greater emphasis in the literature on the reverse impact, of the child on family and almost no research on the family as a whole (Berger and Foster, 1986; Turnbull, Paterson, et al., 1993).

Although researchers continue to desire quantitative measurements and controlled circumstances which aim to reduce complexity, the end result may be of questionable value. The bulk of literature on family stresses as it is

associated with families with children with special needs is both limited in its scope and inconclusive (Kazak & Marvin, 1984; Turnbull, et al., 1993). As mentioned earlier, there are repeated studies that focus on the problems and extraneous stresses associated with a disabled child. A review of the literature shows that not only are the studies frequently at odds with each other, but they do little to inform the theory or the practice of professionals who work with families with special needs children.

Recently there has been a call from professionals and parents alike to expand research designs so that families with special needs children participate in a more active role (Tunali & Powers, 1993; Turnbull, et al., 1993). Participatory research involves the participants in the planning and development of research questions. It involves the collaboration of researchers, family members, service providers, and theorists. The participatory process "seeks to combine scientific knowledge and experiential knowledge to enhance quality outcomes." Some researchers who prescribe to these research methods indicate that there are concerns about the nature of family research in general (Turnbull, et al., 1993). One of many areas of concern is that family research generally provides greater benefits for

researchers than for the families and the service providers who work with those families. Research findings are generally not available to the vast majority of families and even if they are accessible, the level of abstraction and complexity may prohibit many families from comprehending them.

Finally, in defense of participant-driven research Turnbull and her colleagues note that, "Theorists and researchers are rewarded academically for generating theoretical and empirical knowledge, yet, by contrast, families tend to rely on practical and accessible information and the personal experience and insights of 'veteran families' who have had similar experiences" (p. 7).

In contrast, this study is designed to tap into those "veteran families," with the intention of not only coming away from this collaborative process with greater insight into how families that appear to coping well operate, but also with some practical descriptions of this process. The synthesis of these narrative accounts will be useful to a variety of disciplines as well as to families with children with special needs.

Historically, research is oriented towards the individual child rather than the family system, it pays attention to the pathology rather than the

strengths, and is narrowly focused on isolated characteristics rather than on the complex processes which enable families to manage and even thrive under unusual circumstances. This study proposes to look at families that appear to be coping effectively and apparently have found a way of living which takes advantage of resources and strengths over time to produce a competent and healthy day-to-day life.

There is little research focused on coping and resiliency in families with children with special needs. The process with which these families do cope and in particular those families who cope well has gained little attention (Byrne & Cunningham, 1985; Trachtenberg, 1992). When researchers find evidence of competency and strength among families with children with special needs they often disregard it as denial or research error (Wikler, et al., 1983).

Kazak and Marvin (1984) make a strong point for adopting research methods designed to elicit participant responses which focus on strengths and competencies. They believe that the utility of this approach for clinicians is critical. Successful, adaptive functioning in families with handicapped children has not received sufficient attention. In their well intentioned efforts

to document areas of difficulty in families with handicapped children, researchers have sometimes neglected to describe ways in which differences may indicate successful family functioning within a different but not deviant family structure. The implications of this for clinicians are most critical: If they are not aware of the range of adaptive family functioning, intervention efforts will be narrowly conceived and possibly fail to capitalize on family strengths (p. 68).

Research directed towards the investigation of competencies is particularly well-suited to therapy models which build on competencies and solutions (Berg & Miller, 1992; Walters, Carter, Papp & Silverstein, 1988; Waters & Lawrence, 1993). The highlighting of family competence will enhance therapists awareness of potential competencies in two ways. For families who display competence, an increased awareness on the therapists part can only add to a more productive outcome. For families who appear to still be seeking areas of strength, the therapist can guide them towards areas of competence and help to develop them.

Researchers have not only called for more studies which focus on families who are managing well but also for research methodologies which

lend themselves to a more narrative style. The topic of family strengths and the evolution of those strengths seems to lend itself to qualitative investigation. Field based research which yields reports from the families themselves in their own words may be of the greatest value (Reiss, 1989).

Featherstone (1980) articulates the value of hearing the voices of participants:

Writing in the first person, mothers, fathers, sisters, and brothers tell the story of their own experience with disability. Each of these writers knows in intimate, sometimes heart-rending detail how it feels to live with a particular handicapped child. They know the strains, the fears, the hopes, and the compensations. . . . The strengths and the weaknesses of the first-person accounts mirror those of the professional literature: Every book I have read has helped me to taste someone else's pain and joy and to feel the textures of another life; none has compared one family's experience with that of another, or fitted it into larger perspective. . . . We cannot generalize from these accounts to the larger population of parents of handicapped children. But if we read with sympathy and an occasional dash of skepticism we can learn a great deal about the way certain human beings have felt in particular situations (p. 8).

This study aims to identify general themes which highlight the strengths of families with handicapped children in the hope that this approach will be useful and enlightening to therapists who work with these families. It is through the eyes and words of the parents as they present themselves, that clinicians may gain the greatest insight to the coping processes of families

with children with special needs.

Finally, it would be of true significance if studies such as this one could reverse the common bias against families with children with special needs. The resulting information may place family therapists in a position to move from the traditional expectation for dysfunction and disabling stress toward the perspective of anticipated family strengths and coping skills that can be further enhanced by therapy.

Theoretical Framework

Using the theoretical framework of general systems theory, this study examines how families with a child with a physical disability cope with the unique stressors associated with the disabling condition. A system may refer to a relationship, a nuclear family, or an organization. In systems theory, as it is applied to families, the focus is on the relationships and the process by which these relationships develop (Becvar & Becvar, 1988). A systems perspective is based on a foundation of assumptions which include reciprocal causality, the holistic nature of a living system, and a respect for the contextual backdrop of family life (Becvar & Becvar, 1988). The disabled

child himself and the mother-child relationship are the most commonly studied units in the literature on disabled children. But, by definition both of these subsystems are only "dependent fragments" of the larger family unit (Bowen, 1978). Systems theory suggests that in order to get a more complete understanding of any individual's situation, that individual must be studied within the context of his or her larger system (Becvar & Becvar, 1988; Barber, Turnbull, Behr & Kerns, 1989; Kerr & Bowen, 1988). The subsystems in any family are both coexisting and interrelated. The interactional system functions for all family members not just for the child with the disability (Barber, et al., 1989).

Through personal narrative the parents of children with special needs provide a window into their family's emotional system and help to clarify how they have managed so well. When working in this model it is not necessary to have the other family members present. The questions and manner of thinking about the family's emotional process is sufficient to keep the focus on a family level when dealing with individuals (Kerr & Bowen, 1988).

Another compatible theoretical perspective guiding the study proposal

is a stress and coping theoretical framework. The study of stress and coping in families with handicapped children requires a broad theoretical base from which to pose questions as well as analyze responses. This conventional method of examining stress in families is the ABC-X model developed by Hill in 1949. This model looks at the stressor as the initiating event (A), the family's available resources (B), the family's perception of the stressful event (C) and the resulting crisis (X). McCubbin and Paterson's revisions in 1983, the Double ABC-X model, allowed for more latitude and complexity in terms of analysis and interpretation but is still found to be too restrictive. The resulting data and conclusions from stress theory research are unable to adequately describe the complex nature of a family's coping processes.

Robert Burr (1990) builds on the ABC-X model with an "ecosystem" model which is congruent with non-positivistic thinking of systems theory and which allows for the possibility of more complex analysis and more creative solutions. The ecosystem model regards stress as a process which is a function of the family system and the environment (Burr, 1990). According to Burr, ecosystem theory is holistic in nature and is less concerned with finding the causes of stress and more focused on "discovering processes,

describing interactions, feelings, meaning, purpose and patterns" (p. 7). Just as it is crucial to study the handicapped child within the family context, it is imperative that we begin to examine stressful episodes and coping behaviors as processual rather than isolated and discrete events.

The family's ability to manage stressors will vary on many dimensions. The way in which the family has come to understand their situation and assign meaning to it may be the foundation for their level of functioning (Ashworth, 1987; Burr, 1990; Turnbull, et al., 1993).

Burr writes about stress and highlights the quality of stress as a process rather than a discrete event or even a series of discrete events. Burr's attention to the environment and interaction of stress is particularly appropriate to families with children with special and unusual needs. His conceptualization of stress as a process is as follows: "Stress begins when feedback indicates to the people in the system that their system does not have the requisite variety of rules to transform inputs into outputs that meet desirable standards. In other words, stress, or the process of stress, is when the frequently or usual transformation processes are not sufficient for families to handle life or certain parts of life" (p. 10).

Finally, Walker's (1985) work on reconceptualizing family stress adds an important component which is the taking note of the importance of the sociohistorical context. This is omitted from prior stress models and seems particularly relevant to today's society with new and aggressive laws for disabled members of our community as well as heightened consciousness about the contributions of disabled citizens. This is a time of change and potential for physically challenged individuals.

This study's interest is in hearing from families who present themselves as successfully accomplishing this process of managing a wide variety of stressors. Those unexamined processes which enable families to operate within the confines of the disabling condition will be looked at through the lenses of the theoretical models mentioned above.

From these theoretical perspectives the research issues guiding the interviews include the following:

1. What are the coping strategies that participants notice they have developed? How have these changed over time? Do they see coping efforts as individual efforts and family efforts? How does this impact the family members? Can participants identify a turning point in their coping actions

when life became easier or required less effort to cope?

2. Is coping the word they would choose to characterize how they, as a family, have weathered the storm? What other ways of looking at adaptive functioning have they identified?

3. What are the resources that families have used? How have they employed these resources? Are they internal and external? Can families recall how they came to reach out or come into contact with sources of support/friends/community services/religious affiliations/extended family/schools/medical professionals and any other source which could be considered an external resource? In terms of internal resources how have those developed? Where did those inner resources come from? How did they acquire and develop those and to what extent have they employed those in other situations?

4. How have their thoughts and perceptions of their family changed over time? How has their narrative about their family changed over time? Are there shifts in thinking as children have grown older? Have attitudes about their child's physical disability changed?

CHAPTER II

Literature Review

Introduction

This study explores how families cope with the challenges they face in raising a child with special needs. The literature on stress and coping as it is associated with families with children with special needs has a long history. Research on the etiology of stress and its many impacts on the family both positive and negative will be presented. This is followed by a review of the research on coping theory and its relation to families with special needs. This chapter concludes with a more comprehensive review of the literature based on qualitative studies of families with handicapped children.

Stress Research

At the outset, there seems to be a consensus in the literature that families with children with special needs experience higher levels of stress than those families who are similar in makeup but do not have special needs children (Agee, Boyce, Innocenti, 1994; Beckman, 1991; Kazak and Marvin, 1984; Leyser, 1994; Turnbull, et al., 1993). Stress in general may be

conceptualized as, ". . . a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and as endangering well-being" (Folkman, Lazarus, Gruen & DeLongis, 1986).

Research on stress associated with families and children with special needs includes elements which are relevant to those families with members whose developmental path differs from the norm. Patterson and McCubbin (1983), outline a variety of sources of stress for families who are faced with chronic illness in their children. Included in this list of potential sources for stress are the following: strained family relationships, modifications in family activities and goals, increased tasks and time commitments, increased financial burden, need for housing adaptation, social isolation, medical concerns, differences in school experiences, and grieving. These sources of stress and many others have been researched and identified over the years. The list of stressors is long and varies from family to family. The stressors come in unique forms and are managed in unique styles as individual families grow and change (Agee, et al., 1994; Patterson & McCubbin, 1983; Tackett, Kerr, & Helmsstedt, 1990).

It is important to note that there is some disagreement in what constitutes stress. Not only between researchers who believe that they can identify sources of stress but within families themselves. For example, the severity of the child's disability may or may not determine levels of stress. Some studies suggest a definite correlation between the severity of the disability and the degree of family stress (Gallagher, Beckman, & Cross, 1983; Noh, Dumas, Wolf, & Fisman, 1989) and other studies suggest no correlation between the two (Boss, 1993; Bristol, Gallagher, & Schopler, 1988). Tackett, et al. (1990) looked at stressors as perceived by children and their mothers and found a fairly wide differential between what the children identified as stressful and what the mothers perceived as stressful. For example, in the category of "Not being able to do what other children can do," twenty of the forty mothers mentioned this as a primary source of stress, but only one of the forty children listed this as a stressor. The assessment of stress is a complex process which is not easily measured or generalized.

Financial concerns are frequently listed as stress points for families with special needs children (Byrne & Cunningham, 1985; Featherstone, 1980; Gallagher, Beckman & Cross, 1983). Financial concerns may include

current expenses associated with the medical care of young children, career restrictions for parents due to requirements for accessibility to medical facilities, loss of a wage earner if one parent becomes the full-time care-giver, and lastly later in life concerns about the care of adult children with special needs (McCallion & Toseland, 1993).

Social factors, meaning attitudes of others, can be a source of stress (Gallagher, et al., 1983). Tackett and colleagues (1990), identified "social variables" as representing about half of the responses for stress by both mother and child. Although the children in this sample had physical impairments it was the lack of acceptance by peers or concern about possible teasing that was the primary stressor. Another aspect of social support which has been widely researched is the importance of informal social support, for example, neighbors, friends, and extended family (Beckman, 1991; Dunst & Trivette, 1990; Gallagher, et al., 1983).

The age of the child with special needs is among the factors that seem to be associated with stress in the family. Many studies have suggested that as age increases the special needs child becomes more difficult to manage (Bristol & Schopler, 1984; Gallagher, et al., 1983).

Difficulty gaining access to resources and information is another element related to the stress experienced by families with children with special needs (Duffy, McGlynn, Mariska, & Murphy, 1985; Gallagher, et al., 1983). In some cases the medical and helping professions increase the family's stress by supplying excessive information, demonstrating an insensitivity to the impact of the initial diagnosis, and by expecting compliance with multiple recommended therapies (Kazak & Marvin, 1984 Roberts, 1984; Turnbull, et al., 1993).

In summary, the resulting stress in families with special needs children has been well researched and documented. With few exceptions the presumption has been that families with children with special needs experience more stress, more symptoms, more of life's hardships in general than families without handicapped children (Harlin, 1991; Kazak & Marvin, 1984; Leyser, 1994). With all this information there is still much to learn about these stressors and how they play out in the day-to-day lives of families.

A wide variety of impacts have been researched and reviewed in the literature on children with special needs and their families (Byrne &

Cunningham, 1985; Kazak & Marvin, 1984). This review will include a discussion of the various findings of impact studies, the concept of coping as it is assessed by various stage models for parental grief, the concept of chronic sorrow, a more thorough examination of several landmark studies which focus on family strengths, and more recent research looking at families from a systemic perspective.

Impact Studies

Negative Impact Studies

There are certain topics which have gained considerable attention in the past twenty years. Included in these are studies on siblings and their adjustment, the marital relationship, maternal depression, and more recently paternal role and family structure.

Siblings of special needs youngsters have long been a source of concern and investigation (Byrne & Cunningham, 1985; McKeever, 1983; McLinden, Miller & Deprey, 1991; Meyer, 1993; Simeonsson & Bailey, 1986). These authors, and many more identify the particular stressors for siblings of children with special needs (e.g., less time with parents, burden of care, family focus on special needs child) and note the possibility of some

benefits (e.g., appreciation of siblings' achievements, pride in helping, appreciation of human values). Some studies suggest that certain sibling positions may be more vulnerable to experiencing negative impact (Byrne & Cunningham, 1985; Crnic, Friedrich, & Greenberg, 1983; Simeonsson & Bailey, 1986). However, within the literature there are inconsistent findings with regard to which positions those might be. Some studies suggest younger and closer in age siblings are at greatest risk for maladjustment (Simeonsson & Bailey, 1986), while others suggest that oldest daughters are under increased strain in families with disabled children (Byrne & Cunningham, 1985). A review of the literature on children with special needs siblings suggests that there is a tendency for non-handicapped siblings to be at risk psychologically (Atkins, 1989).

The marital relationship is a second area of frequent study among researchers who are interested in studying the impact a child with disabilities has upon the family. There is evidence of an increase in incidents of marital problems with fathers being particularly subject to dissatisfaction (Bristol & Gallagher, 1986; Bristol, et al., 1988). The level of mutual support appears to be a mitigating factor in marital satisfaction. Bristol and Gallagher (1986),

identify the indirect impact of a special needs child on the marriage where the increased demands on the mother and the tendency towards a child-focused family reduce opportunities for husband and wife activities. Byrne & Cunningham (1985) report both increased negative measures in marital relationships as well as increased positive measures. Other studies support the notion that the presence of a child with special needs increases marital cohesion and provides the opportunity for more interaction of both a positive and negative nature (Trute & Hauch, 1988).

A third area of interest is the issue of mother's adjustment and resulting stress, depression, and role strain (Beckman, 1991; Bristol, et al., 1988; Konstantares & Homatidis, 1989; Marcenko & Meyers, 1991; Shapiro, 1989; Singer & Farkas, 1989). In general, there is research support for the hypothesis that mothers experience more stress than fathers (Beckman, 1991; Bristol, et al., 1988). Researchers have also learned that mothers of special needs children experience a wide variety of impacts such as depression, social isolation, difficulties with self-perception and a sense of competence, and negative effects on their own health. There is some evidence that there is a correlation between mother's age and their perceptions of their children's

behaviors; and, evidence that older mothers (over 36 years of age) manage stress better and with fewer problems (Konstantares & Homatidis, 1989). Regardless of employment status, mothers tend to perform most of the household work and child-related tasks such as tutoring, driving to therapies, interacting with specialists, etc. (Marcenko & Meyers, 1991; Shapiro, 1989). Not surprisingly, mothers have traditionally been the primary source of information for research studies on children with special needs.

In the past decade the complementary role of the father has become increasingly popular as a topic of interest in studies of families with disabled youngsters (Bristol & Gallagher, 1986; Bristol, et al., 1988; Goldberg, Marcovitch, McGregor & Lojkasek, 1986). Older studies tended to focus on fathers' psychological adjustment and personality variables which are impacted by the presence of a child with special needs (Cummings, 1976). More recent studies tend to take a systemic perspective which allows for more flexibility in thinking with regard to a father's impact on the family as well as vice versa. These studies indicate that fathers are in fact less involved with the day to day care of their disabled children even more so than control group fathers of normal children (Bristol, et al., 1988). Fathers do

contribute to positive adaptation in an indirect way by being supportive of the mothers (Bristol & Gallagher, 1986). However, fathers tend to report less distress and more control over their lives than do mothers, yet the fathers report receiving less in the way of support both formal and informal (Goldberg, et al., 1986). It is possible that, although fathers appear to spend less time with their disabled children than do mothers, it is the father's attitude toward the child and the situation which sets the tone for the family (Meyer, 1993).

Finally, the family as a whole has been the focus for some theorists who are interested in the impact of the child with special needs on broader family issues such as family structure (Parker, Hill & Goodnow, 1989), family boundaries (Roberts, 1984), social isolation (Slater & Wikler, 1986) and child abuse (Burrell & Sexton, 1994). Impacts on family structure include the parental subsystem taking precedence over the marital subsystem and parentification of non-handicapped siblings. Boundary ambiguity may occur where the family's external boundaries become less clear-cut when professionals and outside sources play a critical, insider- role in the disabled child's development (Boss, 1988; Featherstone, 1980). At the same time

internal boundaries within the family social network may become overly rigid and social isolation may occur as a result of the medical and/or behavioral difficulties of the child with special needs which impacts negatively on the family system (Featherstone, 1980). For example, families with severely impaired children may not be as readily included in family gatherings or neighborhood parties and those social events which include parents only are equally difficult to attend due to difficulties and cost of finding competent child care for their disabled child. Social isolation builds on itself and families can find themselves with few outside interests other than those that are associated with the disabled child (Duffy, et al., 1985).

The incidence of child abuse among families with children with special needs is estimated to be higher than the average. A recent study on the potential for child abuse as it is related to increased stress, found that the mothers of children with disabilities tend to be at increased risk for child abuse potential (Burrell & Sexton, 1994).

A review of the impact studies reveals a multitude of methodological shortcomings. As Roberts (1984) noted, the literature on disabled children and their families tends to be either "self-report" or traditional research. The

self-report personal accounts provide in-depth and across-time observations, although biased and the traditional research varies in consistency. For example, some studies compare children of different disabilities to one another, others compare children of vastly differing ages, others compare severe disabilities to control groups with no disability but with little attention to other variable differences such as socioeconomic status or parental age.

Of those studies which included a control group and held other variables constant, there were little or no significant differences between control group outcomes and study subjects in some or all of the areas of study (Abbot & Meredith, Crnic, et al., 1983; Kazak & Marvin, 1984; Morrison & Zetlin, 1988). In general, these studies and others have found that families with children with special needs are more alike than different from other families and that added stressors of any type have an impact in family adjustment, marital satisfaction, or adolescent perceptions of family life.

Family Strengths and Positive Impacts

Many families with special needs children make satisfactory adjustments (Bristol, 1987; Darling, 1983; Trute & Hauch, 1988; Tunali &

Power, 1992). And, in fact, some research indicates that there is an increase in family satisfaction (Kazak & Marvin, 1984; Wikler et al., 1983; Leyser, 1994). Until recently there has been little evidence that researchers are interested in examining those strengths or willing to believe that true strengths were possible. Commonly, those areas of strength that have been identified were disregarded as flukes or insignificant (Wikler, et al., 1983). Wikler and her colleagues assert that the continued bias by professionals to view families with special needs children as families who are necessarily dysfunctional, prevents clinicians from tapping into existing strengths and seeing opportunities for growth. They advise mental health professionals to pay attention to the resulting strengths and to build on those strengths rather than dismiss them as denial or research error.

Where some research mentions strengths as unexpected by-products of a study and the primary focus is on some other aspect of family life, there are studies which bring the recognition and identification of strengths to the foreground. For example, Abbott and Meredith (1986), found significant differences on two items of the Family Strength Scale when comparing 60 parents with retarded children to a group of 60 parents of intellectually

normal children who were similar in family configuration, parents and children's ages, income, and other demographic variables. Parents of retarded children were found to be less critical of family members and they had fewer persistent family problems.

The importance of family strengths as a springboard for intervention are outlined by McCubbin and Huang (1989), in their research examining the critical family strengths which contribute to the overall health of children who have Cerebral Palsy. The study examined the relationship between the severity of the CP child's impairment for 130 two-parent families, stressors and demands, resources and capabilities of the family system, and the health outcomes for the child. They found that family type (as assessed by the Typology Model of Adjustment and Adaptation) as well as coping patterns and strengths of both parents were critical factors in assessing the child's progress.

Among articles looking at family strengths and the interplay of strengths and demands, it appears that researcher interpretation of findings are less clear cut, more descriptive and presented in context. For example, it is not uncommon to find a marital pattern of a very involved mother and a

somewhat distant, career-driven father in families with children with special needs. Rather than assuming this is a dysfunctional pattern and necessarily detrimental to family members, from a strength perspective this pattern would be viewed as an adaptive strength among families who face special challenges/demands where more parental specialization is a healthy strategy (Kazak & Marvin, 1984).

The brief overview of the literature on impacts, stressors and strengths in families with children with special needs clearly indicates that there is a wide variety of findings. It behooves professionals who work with these families to resist making assumptions about family functioning based on dated stereotypes. In addition researchers and clinicians alike must be willing to avoid drawing simplistic conclusions and take the time to interpret their findings within the context of each family's relationships.

Research Related to Coping

The relationship between stress and coping is of great interest to family researchers. Coping seems to be a universal aspect of parenting in general

and in the case of parenting special needs children the process of coping is of particular interest.

Coping as a process refers to, "the person's cognitive and behavioral efforts to manage (reduce, minimize, master, or tolerate) the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person's resources" (Folkman, Lazarus, Gruen, & DeLongis, 1986, p. 572). In the case of the child with special needs, the family's coping and adjustment is affected by a number of variables. These include the nature of the disability, the time of its onset, the family belief system, the affective responses of family members, the structure of the family, and the interaction of the family with extended family and other larger systems within the community (Friedrich, Wilturner & Cohen, 1985; Patterson & McCubbin, 1983; Roberts, 1984). The meaning associated with the birth of a disabled child and the subsequent expectations about the child's development effect the levels of distress and subsequent coping abilities (Affleck & Tennen, 1993, 1991). Research indicates that individuals who perceive some control over illness related stressors tend to feel less helpless and more inclined to take active coping measures which improve their

circumstances (Affleck & Tennen, 1991). Marital satisfaction and general family success in overcoming problems are significant predictors of coping in families with mentally retarded children. Further, the relationship between parent problems and behavior problems with the child is seen as bi-directional, with the parents' difficulties contributing to the behavior problems of their children, and vice versa (Friedrich, et al., 1985).

Stage Theories and Chronic Sorrow

One set of theoretical models which shed light on the coping process for parents with children with special needs are the stage theory models. Using Kubler-Ross's (1969) classic research on the mourning process of the death of a child as a framework many theorists have applied this stage model to parents of children with disabilities. Many believe that parents will pass through predictable stages of adjustment before resolving their grief. In her literature review of 24 different stage theories, Flagg-Williams (1991) reported that most of the theories could be summarized using a three-phase model. Briefly, these include stage one of shock and denial; stage two which includes a wide range of feelings associated with disorganization such as

shame, ambivalence, anger, disappointment, hopelessness, and guilt (siblings in this stage may react with jealousy and resentment); and stage three which is considered a point of resolution or acceptance where the family attains an organized sense of how to cope with the realities that the special needs child presents.

The stage theory model has been widely applied and continues to be revised to include a wholistic perspective. For example, grieving has important biological, intellectual, emotional, behavioral, and spiritual aspects and may be a source of personal well-being (Bristor, 1984; Ellis, 1989).

Educators have developed revised stage models that focus on teaching objectives designed to support the families emotional task as they pass from one stage to the next (Anderegg, Vergason & Smith, 1992). However, there remains debate about the predictability and sequence of these stages.

Theorists and parents alike warn clinicians against using interventions based solely on this model (Flag-Williams, 1991; Hanline, 1991; Roberts, 1984; Stone, 1989).

The other side of this debate is the concept of "chronic sorrow." This phenomena was first addressed as a therapy issue in an article published in

1962 by Simon Olshansky, a psychiatrist working in a children's clinic. His recommendation to therapists and social workers was to accept chronic sorrow as a natural, rather than neurotic, response and to anticipate the return of parental grief at various points throughout the child's and parents' lifetimes. Wikler, et al. (1983), conducted a research study that supported the hypothesis that chronic sorrow seems to be "a normal reaction to an abnormal situation." These scholars suggest that professionals and specialists treat it as part of the grieving process and a coping strength rather than working from a belief system that views grief as time-bound, eventually evolving into ultimate acceptance.

Qualitative and Longitudinal Studies on Families with Special Needs Children

Research which is designed to examine family strength, as it results from coping with disabled family members, is still qualitatively different from research which looks at families who cope effectively in spite of their disabled youngster. It is the unusual research project that can conceptualize and sustain the required effort of an exploratory investigation where the methods and personal interest match the complex nature of the subjects'

experience. Two of the most comprehensive examples of such research are Ethel Roskie's research on the Thalidomide children born in Quebec, Canada in the 1960's and Ray Barsch's research on parenting handicapped children in the Milwaukee area in the early 60's. Both books offer longitudinal information and qualitative analysis of data gathered from personal interviews, observations and medical assessments.

In an effort to examine and understand the Thalidomide phenomenon as it existed in the province of Quebec, there was a fair amount of research done on the children themselves and their health and rehabilitation. Roskie became interested in the mothers' experience and believed that this maternal-infant bond played an important role in the child's eventual adjustment. The research team adopted the guideline that the study would be "descriptive and non-judgmental." This was a deliberate orientation in direct contrast to the majority of the previous research on families with disabled children. Roskie comments, ". . .after thirty years of trial [traditionally oriented research on family dysfunction as it is associated with handicapped children] it has borne remarkable little fruit either in increasing our understanding of precisely how and why things go wrong in the mother-child relationship, or in helping to

right them. In fact, a recent review of literature (Neff and Weiss, 1965) states categorically: "We know less about the actual dynamics of family reactions to disablement than about any other aspect of the problems of handicapped persons (p. 797)" (p. 16).

Roskie identified a wide variety of stressors including physical, psychological and social isolation, mothers' anger and guilt, marginality and dual identity for these children who were perceived by society as "monsters" yet were deserving of home care. Among the 20 mother-child dyads, Roskie noted the complexity added to family life as its members interact with the larger social world. She found that her original hypothesis that the child's development is a function of the relationship between mother and child, was conceptually insufficient. The descriptions of impact, coping and adjustment inevitably included a third party. That third party was represented by any number of entities. These included doctors, nurses, hospital social workers, hospital rules and regulations, friends, family, schools, neighborhood, and even abstract ideas such as societal norms and values. Roskie states, ". . . this third entity could not be considered simply as the background against which the mother-child relationship took place; on the contrary, our data

strongly suggested that society (in its various representations) played as vital a role in shaping the meaning and course of events as did the mothers and children themselves" (p. 288). She identified the triangle which we have come to know so well in family therapy circles and places her findings in a contextual framework with a process orientation.

Roskie found these children and mother teams as varied as any other group. She noted the common experience and critical role of a third party in the development of the mother-child bond. In addition, she noted that mothers' responses to questions on the developmental history of their maternity indicated the lack of a developmental framework in which to understand how their children were developing and in predicting how they might continue to mature. This lack of a framework was a source of anxiety and stress for the mothers and was reflected in their difficulty to relate the present situation with their past experiences and future expectations. They insisted that their experience was lived on a "day-to-day" basis and Roskie notes a failure to develop a sense of time or change over time in terms of identifying a defined sequence or pattern. For the mothers, the most anxiety provoking questions raised by their children were those that sought to link the

past with the future such as, "Mummy, what was I like when I was born?" or "Mummy, what am I going to be like when I grow up?" Roskie identified this "lack of continuity" (developmental framework and meaningful certainty sequence of development) as a basic element of stress and elaborates on the many levels of impact for the mother-child dyad (societal, child, mothering). She concluded with a poignant summary recognizing that the past and future do play a role, ". . . This was a maternity that sometimes appeared to be dominated by the shadow of a traumatic past and by an ambivalent mixture of fear and hope about an uncertain future" (p. 279). Because it was so difficult for the mothers to integrate their experience and their expectations the primary focus for the child became the day-to-day life of the present.

This study did not yield a cohesive theory of the "maternity of a handicapped child" as the researchers had hoped. What it did provide was a new perspective on the maternal relationship, expanding it to include the societal impacts and consequently revealing the complexity and individuality of each family's relationships as they encountered the biases, prejudices, support, or encouragement from their communities at large.

Ray Barsch wrote Parent of the Handicapped Child in 1968 and his

efforts to capture the essence of family life and parenting styles remains a landmark work. This study was conducted over three years, with middle class parents of children between the ages of four and ten who had a disability in any one of the five following diagnostic categories: cerebral palsy, organic (neurologically impaired but no neuromuscular deficit), Mongoloid, blind, and deaf. Although the samples were not evenly represented (ranging from a high of 63 subjects in the organic population to a low of 20 subjects for the deaf and blind populations) a total of 177 mothers completed the full interview sequence. The first phase of the study included a series of self-administered questionnaires, tests, and a variety of scales. These were completed in a small group setting where mothers were oriented to the goals and nature of the project and given two sessions to complete the forms. The second phase was a series of clinical interviews lasting three to four hours and scheduled simultaneous with their child's therapy visit to the center. Fathers were invited to participate and the researchers found that they had the most success when mothers were used as allies in recruiting fathers. Ultimately, 73% of the available fathers participated in the study.

The interview was structured in three phases with the first portion

primarily devoted to routine questions regarding infancy and background information. The second segment included questions relating to recent practices in relation to feeding, sleep, toileting, play, etc. Parents were asked to compare such practices with other non-handicapped siblings and to begin to comment on their own and their spouses efforts to modify, develop, and accommodate the disabled child's needs. The third portion of the interview focused questions about current practices and personal feelings relating to the daily life management of their child as well as their thoughts about the child's sex behavior, expectations for the future, and their own feelings of adequacy.

Researchers found that the parents were very cooperative and the personal interviews, (conducted by a medical social worker, male and a clinical psychologist, female) proved to be dynamic, and in some cases therapeutic opportunities. Over the course of the personal interviews the parents came to trust the relationship with the researcher and became more self-revealing. Barsch comments that in hindsight the decision to forgo audiotaping was a bad one. Interviewers felt that much was lost in the data analysis process by not having access to the parents' verbatim responses. Researchers unexpectedly found themselves privy to the parents innermost

thoughts and concerns and felt a struggle to balance the protocol for the study with the therapeutic experience for parents. Researchers found it difficult to code a response and prepare it for statistical analysis suspecting that not only was information lost, but the subtle differences in meaning as well. The research design had underestimated the impact of the personal interviews finding parents more willing to contemplate and talk about their experience in ways that took them away from the interviewers' specific questions. Barsch notes that the parental expression of need and obvious appreciation for a sounding board and the opportunity to systematically talk about their child's day to day life won out over the strict procedures of the research format.

The study looked at differences among the categories of disabilities, but for this purpose the general observations and impressions are most relevant. Among the general findings are the following: 1) the majority of parents are inaccurately represented as guilt-ridden, anxiety-laden, overprotective, and /or rejecting; 2) there was no evidence that the parents had buried themselves into a social isolation as a result of having a handicapped child (Variability in social networks and number of outside interests were related to differences in personal style rather than the presence

of a child with special needs.); 3) in general, there was a tendency towards similarity in child-rearing practices among the five groups with only scattered evidence of variations due to the nature of the child's disability; 4) the child-rearing practices employed with the disabled children did not differ significantly from those used with their siblings; 5) parents generally seemed to be uninformed about modifying their language in keeping with their child's actual ability to understand and process receptive language (The parents seemed to give their child credit for understanding more than was actually the case.); 6) siblings tend to accept the sister or brother with special needs and don't exhibit significant negative attitudes or behaviors; and, 7) in general, the mothers and fathers were in agreement on their responses to questions about child-rearing practices (Minor disagreements were noted as not significant and those that did display open arguments and hostility were in the minority.).

Barsch concluded with an impassioned plea for communities to provide special-education trained parent counselors for parents of children with special needs. He suggested a three-prong approach with the primary relationship being the counselor as member of the special education team in the school system. Secondly, the counselor might be associated with

preschool programs and community clinics and finally the counselor role may be integrated into the maternity ward of local hospitals. The good news is that this has come to pass.

More recent research on families with children with special needs indicates an increasingly complex and systemic view of these families.

Articles which focus on family strengths and coping look at the patterns of family life as a dynamic, as changing overtime.

Trute and Hauch, 1988, looked at families' positive adjustment to the birth of a developmentally disabled child. The study took place in the Province of Manitoba Canada and the subjects for the study were associated with the child development center which serves as the central testing and assessment resource for that Province. Their study looked at 36 families who were identified by a coordinating social worker and staff pediatricians as satisfactorily adjusting to the child's disability. Both groups used a brief rating scale based on three criteria: 1) family adjustment, 2) child emotional stability, and 3) child's developmental progress. A personal two hour interview was conducted with each family and involved both parents. The intent of the research was to conduct an exploratory survey which would

produce basic descriptive information about families, ones who had adapted well to the birth of a developmentally disabled child specifically taking into account the multi-levels of the families' social ecology. A wide range of standardized measures were used to assess the families' adjustment, depression, child's temperament, social networks, and the degree of disability.

The children included in the study had a mean age of three years, 64% of them were males, 44% of the them had multiple handicaps and 33% were diagnosed as Down's Syndrome. Twenty percent of the children were identified as severely disabled. The temperament inventory revealed the children to be equivalent to infant norms on levels of soothability, significantly lower than the norm in attention span and persistence and activity level. The children were rated by their mothers as being more sociable and of lower emotionality than the norm.

The parents/primary caregivers were characterized by the following demographics: average age of the mother was 32 and of the father was 35; all families consisted of one mother and father with the exception of one single-parent; 44% of the mothers and 60% of the fathers had gone beyond high school; 54% of the mothers were full-time homemakers, and 11% of the

mothers and 91% of the fathers were employed full-time; and, a range of family income was represented with the largest percentage being in the \$30,000-\$39,000 range (31.4%).

Mothers showed no differences in self-esteem when compared to normal ranges and 82% of the mothers showed no, or minimal, signs of depression.

The spousal subsystem was rated as no different from the norm on levels of quality, satisfaction with spouse, and perception of affectional expression. However, the survey did indicate increased levels of dyadic cohesion and significantly lower levels on dyadic consensus. This was interpreted to mean that the couple was "tightly bound " as a marital dyad but that they frequently disagreed on family issues. However, they were able to discuss and negotiate alternative ideas without threat to their marital commitment.

The family system measures revealed findings which in large measure corroborated the screening professionals impressions that these were strong families who identified themselves with family strengths. The participants' average scores on measures of family adjustment were significantly higher

than those obtained from normative families in the areas of affective expression, involvement and consistency in family values and norms.

Demographic variability in income, number of children, age of child and degree of disability was assessed with the finding revealing little correlation between any of these variables and overall family functioning.

In general, the social networks for these families were small in number, intense in association and used for specific purposes. Friends and family members were sought out for advice and emotional support but only family members were used as ongoing resources for respite and actual hands-on care. Friends tended to not know each other and provided association and activities which did not center on the disabled child.

Trute and Hauch concluded that the birth of a disabled child is a family issue that is most effectively addressed with the whole family system in mind. They advise clinicians to pay close attention to the marital relationship, social network functioning and coping strategies of the parents as individuals and as a cohesive team.

Tunali and Power (1993), have developed a cognitive theory of parental stress and coping based on Maslow's hierarchy of needs. They

developed a new way of thinking about families with disabled children as they acquire their basic needs in an environment that includes special needs children. They look beyond the so called "predictors" of successful coping (i.e., active seeking of information, strong family social support network, good organization, etc.). They consider the psychological strategies that family members use as part of the coping process. Theories on coping suggest that prior to an observable coping response the individual under stress goes through a three step process -- definition, appraisal and evaluation of the supposed stressor.

The authors propose that families with disabled youngsters use a "redefinition" process as part of their coping repertoire. For example, Maslow identifies the need for belongingness, affiliation, and acceptance as one of eight basic human needs. Families with children with special needs may find themselves less socially acceptable, less intimate with friends and extended family and more isolated from the general community. Tunali and Power hypothesized that parents who confront this interference may use a redefinition or reappraisal process in the face of a situation that cannot be changed. Reappraisal of a need for acceptance and belonging may mean a

shift in the level of importance put on nuclear family activities. Family activities would be considered of greater value than any outside affiliations and support would be sought within the family rather than from external sources such as neighbors or friends. Evidence of high levels of family cohesiveness among families who cope well with disabled children supports this notion.

A pilot study using a semi-structured interview process and various questionnaires with mothers of 29 autistic children and a control group of 29 matched mothers and children was conducted to test the authors hypotheses. The focus was on mothers' need definitions and career orientations. The authors literature research on autistic children indicated that mothers of autistic children have less opportunity and freedom to pursue a career and due to the unusual nature of the handicap and are less able to find childcare . The results indicated that when compared to mothers of non-autistic children the mothers of autistic children placed less emphasis on career success and a greater emphasis on the belief that mothers should stay at home with young children. In addition they tended to spend more time in leisure time with extended family, placed less emphasis on others' opinions about their child's

behavior, and showed a greater tolerance of ambiguity. Results showed that the more the mothers displayed these characteristics the greater degree of life satisfaction they reported. Researchers concluded that threatened by life circumstances, the degree to which this redefinition occurs is positively associated with life adjustment.

Tunali and Powers discuss these findings as they relate to clinical settings. They urge therapists to work with families in developing patterns and belief systems which highlight their strengths and make the most of their unique resources rather than relying on conventional therapeutic assumptions based on families without special needs children.

Two studies have looked at families of children with special needs or fragile medical beginnings (preterm infants) over time. Beckman and Pokorni's (1988) research looked at families of 44 preterm infants to determine if there were changes over time in the amount of stress and support. Primary caregivers were interviewed at four intervals between the child's ages of 3 and 24 months. The interview procedure included several questionnaires which were completed by the primary caregiver (in all cases mothers) to measure stress. In addition to survey data, researchers collected

observational data based on videotape of 15-minute interactions between mother and child. The observers conducted a semi-structured interview to assess subtle aspects of the home environment that may influence development.

The study was designed to determine if there were significant differences over time in the impact of preterm infants on their families and it was hypothesized that there would be a significant decrease over time in the amount of stress reported by parents. The study also looked at the relationship between social support and stress levels and sought to identify factors that would predict family stress over time.

In general, results indicated that family stress does change over time; however, changes in stress were specific to the child-related problems at specific ages. The authors concluded that professionals working with families must be aware of the complexity and individual nature of stress and support systems. They noted that an understanding and recognition of stressful events differs dramatically from one age to another and that families needs change over time. They encourage more longitudinal studies adding to the knowledge and understanding of families as complex systems.

Yona Leyser (1994) looked at strength and adaptation in Orthodox Jewish families with a disabled child. This study is a four-year follow-up to a study conducted in 1986-1987 in Israel. The original study found that although there were many hardships of various types and degrees most families were indeed coping with the situation. The most recent study was designed to measure changes over time, utilization of psychological and environmental coping resources, and overall adjustment. Eighty-two families of children with moderate to severe developmental disabilities participated. Parent interviews (mothers only in 90% of the cases) by social workers familiar with the schools, a child competence measure, and a teacher rating scale were used. Results indicated that over the year period mothers experienced decreases in stigmatization and negative impact from having a disabled child and increases in overall adjustment and in time to spend with their other children. Very little change was noted in perceptions of the time needed to care for the disabled child or in perceptions of the child's behavior problems. The overall rating of the social worker also indicated a significant improvement in adjustment over the five year period. There were also some changes in the use of resources with some increasing, (talking with neighbors,

friends, school personnel, discussions within the family, and contact with grandparents) and others decreasing (consultations with health care workers, therapists, the rabbi and other parents of special-needs children). Parents' responses to questions about the future included an increase in parents' hopes for an independent life for the child and a decrease in hopes or expectations for the sons to become biblical scholars (as were most of the fathers).

Although this population was unique in many ways, Leyser found that most families experience similar types of daily hardships and stressors and used strategies which are comparable to those reported by families with special-needs children in other cultures. She concluded that with the passage of time and changes in family life-cycle, many families continue to cope and to live as normally as possible while continuing to experience major hardships and stressors associated with the care of a disabled child. Leyser urges future research to include fathers and to use a longitudinal design where the impact on families and strengths of families can be assessed over time.

Two final sources which are particularly relevant to this research are Jeanette Beavers' work with non-clinical families in the Dallas area in the 1980's and Ann Turnbull, et. al.'s, book entitled Cognitive Coping, Families

and Disability (1993). Both focus on health and strength in non-clinical families with handicapped members.

Jeanette Beavers 1989 article, Physical and Cognitive Handicaps, appears in Lee Combrinck-Graham's Children in Family Contexts: Perspectives on Treatment. Beavers' study was part of a longitudinal, cross-sectional study of families with children enrolled in urban public school district special education programs in the Dallas area. Working from the assumption that these were "ordinary families with an extraordinary task" the research was designed to learn about coping from parents who were at varying stages over the course of a five year period. In addition, this study adopted the stance that "the family is the expert on its own experience, both good and bad, and the handicapped child is both part of the problem and part of the solution (p. 194)." The study began with 85 families of pre-schoolers who were just entering the program. These families were interviewed each year for 5 years; new families were added with special attention to families who had children at critical transition points such as early teen years or early adulthood.

The researchers used a structured interview augmented by a 10-minute

period of family play or picture drawing during which the interviewer was not present. Each hour-long session was videotaped for later analysis and for the family to see if they wished. Analysis was based on the Beavers Family Assessment model of Competence and Style (Beavers, 1977). This assessment measures family structure, boundaries, the distribution of power among members, family members autonomy, clarity of communication, ability to negotiate, feeling expression, overall mood, and conflict resolution. All observations are interactional and focused on patterns producing two continuums; one of competence ranging from least to most capable and one of family style (families tendency to pull members inward emphasizing closeness and loyalty or push them outward with emphasis on assertiveness, emotional separation, and independence) with the more desirable styles being in the middle of the two extremes. Family members were also asked to complete self-reports and to suggest advice to other families.

Findings directed towards family therapists include advice for efforts to free families from constraints and misconceptions about the nature and cause of the handicap and to use the motivations, problem-solving skills, and values of all family members. Once again the authors warn professionals to look

beyond pre-conceived assumptions and to have respect for the unique ways that these families handle their special situations. If not, professionals may become part of the problem rather than part of the solution.

The most current and comprehensive source of information on families with disabilities is the book on cognitive coping edited by Turnbull, et al.(1993). This book contains a thorough collection of opinions, experiences, and research findings from a wide variety of contributors. The book is the by-product of a 1991 conference which gathered a cross-section of professionals and parents in an effort to discuss, define and share experiences of families with developmentally disabled members. The Beach Center on Families and Disability at the University of Kansas and the Center for Children with Chronic Illness at the University of Minnesota sponsored this conference.

The editors propose that families have the potential for active adjustment and can take advantage of this when faced with stressors. Cognitive coping is defined as "thinking about a particular situation in ways that enhance self-esteem, feelings of control, and sense of meaning." They recognize that people use different types of cognitive coping strategies. For

example, they make favorable comparisons of their situation to others; for example, concluding that a child with Down's Syndrome is in some ways less challenging than a regular teen who will be faced with peer pressure for alcohol and drug use. Or they may find positive benefits from an event or choose selectively to ignore negative aspects; for example, concentrating on the positive contributions of the disabled family member to the greater unity of the family unit. Another cognitive coping strategy cited is attributing a meaningful and self-enhancing cause of the event; for example, families may decide that a person has a special purpose in life. Having a sense of control or influence over the event is another cognitive strategy. For example, a family may believe that they have a critical role in selecting educational opportunities for their child, thus reducing their feelings of helplessness. Finally, humor can help; for example, families may find inappropriate behavior in public places humorous thereby transforming a potential embarrassing situation into a laughable one.

Each one of the chapters is well-suited for inclusion in this study due to the conferences overall orientation on health and success in families who have members with developmental disabilities. The authors are individuals

who participated in the 1991 conference. They are parents, service providers, theorists and researchers in the field of families and disabilities. Well-known names such as Hamilton McCubbin and Pauline Boss contribute their theories and relate them to the coping styles and success of parents with children who have developmental disabilities. Researchers and service providers from a variety of clinics and centers of study report their current findings and models of working with these families. The chapters written by family members themselves are well written and inspiring while they offer a fairly realistic description of family life at different life stages.

The final section of the book is devoted to a summary of the participatory process itself as it unfolded during the conference and as a model for future research. Interestingly, although life has changed for individuals with handicapping conditions and public access and acceptance have at least become more politically correct if not personally genuine, the recommendations by parent participants and researchers who have come to recognize the complex nature of family research are similar to those made for decades. They include the familiar concerns of ethical practices; attention to diversity; the assumptions, nature and intent of the research questions;

concerns about measurement of research variables and the dissemination of findings written in usable fashion to audiences who will directly benefit from the data.

In summary, there is an abundance of literature on families with children with special needs. Studies on the impact of disabled children on their siblings, their parents' marriage, family structure and many others fill the journals of education, nursing, social work, and family therapy. The studies that focus on linear causality are contradictory and for the most part inconclusive. Studies focusing on family strengths are more useful when practitioners can apply the research findings to assist families in making the most of their own competencies and personal resources.

There is little recent research approaching families from a less deterministic perspective where the complexities of life's events are studied in context. The current interest among some family researchers to include family members in the research process as both participants and analysts will help to set an agenda for future research that will contribute more positively to families with children with special needs. This study hopes to follow that trend.

CHAPTER III

Methods

Design of the Study

This study explores the issue of how families with physically challenged children cope. Understanding that the act of coping is a process with both cognitive and behavioral features, the primary aim of this study is to build a descriptive profile of families' coping processes over time.

A multiple-case qualitative design was used to build a detailed and comprehensive description of the coping processes of participants who are parents of children with physical disabilities. Qualitative research methods of inductive analysis and the grounded theory approach (Strauss, 1987) were used iteratively with the interviewing process to interpret the data as well as to guide future interviews.

Qualitative methods are more appropriate than quantitative ones in eliciting, organizing, and interpreting the complex and multi-layered system of a family. Like systems theory, qualitative research emphasizes social context, multiple perspectives, individual differences, circular causality, and holism (Moon, Dillon, & Sprenkle, 1990). The qualitative method invites the

researcher to focus on the participants' perspectives, using those perceptions and verbal descriptions as the data itself and as a guide through the complexity of the data. Although there is an abundance of research on families with handicapped children, the predominant interest has been the measuring of negative impacts on the family rather than on the family's own active coping responses. Grounded theory allows for more abstraction in reported data. At the same time it is the concrete elements of daily life, as recalled by the participants, which will make up the data. The open-ended nature and narrative style of the qualitative interview allows for that process of new understandings and previously unrecognized patterns to emerge (Strauss, 1987).

In summary, the exploratory multiple-case qualitative design seems to be most suitable for the research problem examined in this study. A qualitative design allows for flexibility and creativity which may be the same attributes used by participant families that allow them to cope so successfully. The abundance of data from quantitative research could certainly be complemented by the richer, descriptive nature of a qualitative study looking at coping and strengths. On a number of levels this is a good fit and offers

the most potential for results which are informative and useful.

Description of Participants and Selection Process

The participants for this study were recruited from a private nursery school program which mainstreams children with special needs. The school administration approved this study and agreed to participate and to have the school serve as a research site. The researcher has been a staff member for seven years serving as an educational consultant to the special needs population and to the school as a whole. The families were "graduates" of this program who have school-age children (ages 6-12). Each family has a child with a physical handicap that either has been or is currently considered as moderately disabling and that was identified within the first year of life. Each of these families has sought a mainstreaming placement for their child in a regular nursery school setting.

A list of 19 alumni, consisting of those students with a wide range of moderate physical handicaps who have attended this school in the past eight years, was distributed to each member of a six-person selection team. The selection team consisted of two long-time administrators of the school, the researcher/consultant, and three classroom teachers, each of whom have been

on staff for a minimum of eight years. These six individuals represent many years of teaching and hands-on experience. Within this group a variety of educational disciplines are represented, these include credentialed specialties in Early Childhood Education, Early Childhood Special Education, Human Development, and Mainstreaming Practices. Independently, each team member reviewed the list of alumni and selected a maximum of ten families who he/she believes adapted fairly well. Their selection assessments were based on their own recollections, school records, and personal impressions of each family's coping abilities. A pool of ten potential participant families was created from those which appeared with the greatest frequency on the six lists. From this pool, a total of five families that appeared on at least four of the lists were contacted directly, one at a time, to ask about participation and schedule the research interviews. The selection process was modeled on a theoretical sampling procedure where potential participants are selected depending on the current progress and direction of the prior interviews (Strauss, 1987). For example, after finishing the first joint interview (Case 1) with a family of an eight year old girl who has three older siblings, I knew that I would like to interview a family with a similar aged son with a different

birth order and fewer family members in an effort to compare and contrast what I had began to hear about coping from Case 1. Cases 2, 3 and 5 provided me with that gender and family size diversity and got me wondering about cultural influences. Case 4 was selected, in part, because of the mother's ethnic background. Theoretical sampling allows the researcher to develop a rationale for the sequence of data collection whereby both differences and similarities work in tandem to reveal patterns (Gilgun, Daly, & Handel, 1992).

These five families shared a common lifestyle, socioeconomic status, and level of education. With one exception, each family is a two-parent family (one single mother) with the current marriage being the first and only marriage. Each of the four fathers work full time in a professional capacity and each of the five mothers work in a professional capacity; three full time and two part-time. The families' annual incomes are considered to be in the upper-middle class range with all but one family reporting a family income exceeding \$75,000. The parents are a highly educated group, among them they share two bachelors, three masters degrees, two advanced degrees, and two doctoral degrees.

Each of the families reside in a large urban area in a Mid-Atlantic state. The mothers' ages range from 36 to 47 years and the fathers' age range is from 37 to 52. There were three girls and two boys ranging in age from 7 to 12 and grade levels first through sixth. The number of children per household ranges from 2-4. Each of the five children has a physical disability of severity to be considered in the moderate range. Among the children there is a wide range of disability however. Although each of the children is independently mobile, for several of them the use of a wheelchair or leg braces is required at this time or may be in the future. None of the children have cognitive impairment. Each child is mainstreamed in an age appropriate class.

The families were contacted using a procedure discussed in the next section.

Procedures

Qualitative interviewing begins with an interest, curiosity, or unusual phenomena which the researcher may observe or take notice of (Marshall & Rossman, 1989). The qualitative approach allows the researcher to be flexible and adaptable, yet focused on the topic of the inquiry.

As mentioned earlier the participants were recruited from a nursery school which mainstreams special needs children. As is common with qualitative research, a few cases were studied rather intensely, and the findings will generalize to theory rather than to a specific population. The families selected were initially contacted by phone in order to introduce myself and to briefly outline the focus of the research study as well as the procedures, audiotape process, and requested time commitment. Each of the five families who I spoke to were interested in participating and had an opportunity to ask questions and voice any concerns prior to the first interview.

I made every effort to acquaint the participants with the qualitative process and to be available for any questions or concerns. It is in the best interest of all concerned that a collaborative and trusting relationship be established. Although the study focuses on strengths and competence some aspects of family life were difficult to talk about. At no time were participants expected or encouraged to continue a dialogue which was upsetting. The researcher made it clear that the participants had the freedom to respond in any manner they choose and to discontinue the interview if

necessary. Although I was prepared to refer participants to outside therapists if they requested that or I had concern about the impact of the interview, this was not necessary. Most participants reported that they found the interview process less upsetting than they anticipated, more helpful and an overdue opportunity to think about their own perceptions in a calm and thoughtful way.

At the outset of the first interview the couple was asked to read and sign an informed consent form describing the basic study purposes and design, confidentiality, and their right to withdraw from the study at any time (Appendix A). Each of the five families was interviewed twice. Interviews took place in families homes and offices at mutually agreed upon times. Although each of the joint interviews was scheduled for one and one-half hours, most tended to run over the two hour mark. Individual sessions ran about 75 minutes. I met with a single mother twice for two hours each time.

In order to collect the bulk of the data as efficiently as possible, interviews were conducted with parent(s) only. However, questions were directed toward the entire family, taking special consideration to include circular questions which highlighted subsystems in the family that were not

actually present in the interviews.

The first interview included a period of what is commonly called in the Family Therapy literature "joining" (Minuchin, 1974). At this time the researcher asked for family background information including the following: brief demographic data such as participants' age, gross income range, and occupations; the handicapped child's specific disability; the family structure (siblings and household members); and, a brief description of the family's daily routine.

At the outset of the interview the tone of cooperation and partnership was established. These are essential characteristics of the qualitative method where the participants serve as describers and co-interpreters (Becker, 1986).

The remainder of the interview followed a semi-structured design using questions as a guide (Appendix B). Research questions which are open-ended and fueled by curiosity and an unknowing stance may produce data which is richer, more descriptive, and ultimately more useful to parents and professional alike. Some of the questions prepared ahead of time were used and others were eliminated after the first interview with the first family. As the participants responded new questions came to mind and new themes

emerged that were carried over into later initial interviews replacing and augmenting the prepared list of questions. My approach was to pose questions or topics in as open-ended a way as possible and to follow the participants lead. Initially, my interest was whatever seemed important to these families. I adjusted my questions to the topics that surfaced as meaningful within the context of the interview itself. By the fifth and final conjoint sessions I had abandoned more than half of the original questions.

The second interview provided the researcher the opportunity to interview both the mother and the father, individually. The individual sessions were helpful in broadening descriptions of certain aspects of family life by offering a binocular perspective. Several couples spoke about the same period in their lives or critical event, but in very personal ways which helped me to conceptualize their experience more completely. Even though I was consciously trying to avoid this I found myself favoring the mothers in the joint interviews and unwittingly directing more of my questions to them. Fathers' perceptions and rationale for decisions were of great interest to me and it was necessary to separate the couples before I realized how caught I had been in dialoguing with the mother. Second interviews tended to be more

structured where questions were constructed ahead of time to clarify prior comments or bring in new themes which had been evidenced in other interviews. In addition, the use of a verbal summary of the first session's themes and the researcher's interpretations of the interview data was helpful in lending some beginning structure to the second interviews. For participants who requested it, a synopsis of the research findings will be provided.

Data Collection

All interviews were audiotaped. I also maintained a journal and used memoing techniques throughout the data collection process. A research journal serves as a tool for tracking reactions to the content and process of the interviews (Becker, 1986). In addition, it provides an avenue for the researcher to reflect upon the subtleties and emerging themes which surface as the data becomes richer. My journal efforts were somewhat inconsistent over the course of the interviews and analysis. Initially I was quick to enter thoughts and impressions after each interview or phone contact. As the weeks passed I became less reliable but I found those earlier entries interesting as I reviewed them for the data analysis process. Many of my first

impressions about the participants and this process were way off base and I could see that my initial biases and impatience to get started were interfering with my own thinking. Perhaps the most useful aspect of the journal was that it provided me with a place to record my own personal reactions to this study and to de-toxify some of what I was hearing.

The memoing technique was more readily used. Memos are speculative comments made by the researcher including thoughts on common aspects and speculations about the possible theory and the relevance of emerging findings to existing bodies of research (Gilgun, Daly, & Handel, 1992). Typically, memoing occurred in my car right after an interview, while listening to an audiotape, or while reading literature on families with special needs children. But there were many random times when I found myself thinking of the participants' experiences and being reminded in some way of a old thought or happening upon a new one which was quickly jotted down for further consideration.

The names of the participants will not be used in the reporting or analysis of this study. Pseudonyms are used throughout the study to protect the privacy of the participants and anyone to whom they referred. In addition,

participant's careers and some other identifying characteristics have been altered. As the interviews were transcribed the pseudonyms were assigned and typed directly into the written transcript. The researcher, her research advisor, and the transcriptionists were the only people with access to the raw data. Each of the three transcriptionists signed a pledge of confidentiality statement (Appendix C). The raw data will be destroyed when the research project is completed.

Measures

The major vehicle of data collection in this study was the semi-structured, in-depth interview (see Appendix B). The interview questions and themes guided the inquiry in this study were developed during the process of reviewing the literature on coping and families with handicapped children. The questions were intended to elicit the richest, most thorough and detailed description of the participants' life experiences, perceptions, and beliefs regarding their family system. The original questions and most of those that developed out of the on-going interviews tended to fall into four major categories: perception of the handicap, its meaning and function in the family; descriptions of day to day events; the identification and utilization of

resources both internal and external to the family; and parents perception of changes over time. Questions were open-ended and the researcher was flexible in order to allow for the broadest possible avenue of dialogue and narrative to develop. Qualitative research begins with wide ranging inquiries and develops through the collaborative process of the interview into more focused categories. As stated above, research questions based on anticipated avenues of interest were modified during the interview process as new and unexpected themes emerged (Marshall & Rossman, 1989). As participants shared their stories the researcher redirected questions and probed for the most complete description and clarity of meaning to unfold.

In a qualitative study, the researcher may be considered an instrument of data collection (Moon, Dillon, and Sprenkle, 1990). It is my own interest and professional experience in this field which drew me to this topic and this type of collaborative research. Experience in the field of special education has prepared me to deal with clinical clients who have children with special needs. This is both an advantage and disadvantage. It is my hope that my prior background enhanced my ability to build rapport and a sense of trust with the participating families. Knowing that prior knowledge can potentially

contaminate a researcher's ability to sustain an "unknowing stance" I followed the format outline by Becker (1986). She encourages researchers to write down or discuss their implicit knowledge of the research phenomenon in order to bring the pre-understandings to the forefront of awareness and guard the researcher from imposing them unwittingly on the participants. In addition this process sensitizes the interviewer to the difficulties the participants may encounter as they attempt to describe their own experiences. In an effort to monitor my own lens I continued to record the changing awareness of my biases and preconceptions using the journal. This process brought me to a richer more complete understanding of the phenomenon, all the while guarding against hasty conclusions and preconceived judgments. In addition, regular discussions with my research advisor helped in considering alternative perspectives.

Unit of Analysis

The unit of analysis for this study was the families with handicapped children. Although the research was conducted with the parents only it is the family system, as the frame of reference and meaningful context for the

participants (Becvar & Becvar, 1988).

Data Analysis and Interpretation

Data analysis in qualitative research is an ongoing, iterative process where data is collected and analyzed simultaneously (Moon, Dillon, and Sprenkle, 1990). The constant comparative method as outlined by Strauss (1987), is a systematic process where data incidents are named (coded) and organized into categories. Codes from current interviews are checked against previously coded data. New codes, themes, and possible new categories emerge as the data is analyzed across cases. This iterative process allows for more diversity and depth within each case, as well. The core categories which emerged "earned" their way into the final draft by the systematic analysis of the data (Strauss, 1987).

The data collected came from transcripts of the recorded interviews. The data consisted of 14 transcribed interviews representing four conjoint interviews of approximately two hours each, eight individual sessions of approximately one hour each, and two, two-hour interviews with the single parent. A total of approximately 20 hours of taped interviews were

transcribed and roughly 300 pages were coded for analysis. The taped interviews were reviewed and analyzed to refine certain concepts and to begin to extract patterns of action and meaning from the recorded interviews. As the data collection and analysis proceeded, the constructs emerged, taking shape as distinct patterns which were recognizable within the descriptive narratives of the participants. The first two interviews yielded over one hundred codes. The data were coded and categorized with the assistance of Ethnograph (Seidel, Kjolseth, & Seymour, 1988) a computer program designed for the analysis of test-based data. Each interview was coded and compared with previous interviews in an effort to fully represent all aspects as well as to comprehensively organize the categories with respect to one another. This process was a tedious and time consuming one where earlier interviews were re-coded as new categories and salient themes emerged. At the completion of the coding process the number of codes was reduced to fewer than twenty with four core categories identified.

The additional data for analysis included my journal notes, memos, and mental notes from weekly meetings with my research advisor which made their way into the working notes of my journal. In an effort to clarify my own

thinking on several issues I conducted informal interviews (10-15 minute chats) with four adults who happened to have school -aged children. The discussions that ensued and their willingness to "think out loud" was very helpful.

The final report describes my interpretation of the experience of the participants as richly as possible using a summary of the coding analysis in combination with illustrative fieldnote quotations. References to relevant literature sources will be included to further validate the descriptive, participant-driven narrative (Strauss & Corbin, 1990).

CHAPTER IV

Results

Introduction

This research study was undertaken to develop a better understanding of the complex nature of coping in families with children with special needs. The five families I met with offered me an inside glimpse of their lives. Whether we met in their homes or offices, the personal flavor and heart-felt honesty of their experience was evident. No two interviews were alike yet each of the parents talked about themselves, their children, and their families in ways that came to sound familiar. Each family found unique solutions to their own problems and challenges but the larger theme was one of an ongoing process where parents' experiences, perceptions and behaviors interact to provide the framework for healthy adaptation.

Each one of the couples made a point to say that they did not see themselves or their child as being defined by the disability. As our conversation became more specific however, it was clear that at critical times their child's disability has been a point around which the family has been

organized and major decisions have been made. It was almost as if the presence of a disabled child lent a built-in narrative to the larger family story. (See Figure 1)

Unlike the concepts presented in the stage theories discussed earlier which are linear and static, I began to see a process which was iterative, and could be conceptualized as a continuous figure-eight with many levels and interchanges. (See Figure 2) Somewhat like a child's erector set of a multi-leveled highway which requires you to loop through one end in order to carry you up at the other. The figure-eight is conceptualized with one loop representing perceptions and the other loop representing behaviors. The events which set this process in motion may be thought of as lying at the interchange in the center. Additionally, there are ramps which elevate the track and these represent the **personal growth** and shifts in world view that some families reported. Just as the toy track is made up of curves, some of which are more treacherous and require more skill to negotiate successfully, so too is the path and process of a family's coping with a child with special needs. Each of the five first interviews began with the parents telling me about the starting point of their **initiation to special needs**. In the case of

Robin Andrews that starting point was a slow, piecing together process that occurred over many months. With Shelley Donahue it was clear at the moment of birth that she would need special emergency surgery as an infant and be facing some long term physical challenges into the future. The Andrew's and Donahue's paths on this figure-eight track of events, perceptions, behaviors and personal growth occurred at different speeds and with differing momentum. But each family described the process of coping behaviors that took them from perceptions about their child and the potential impact of the disability to the daily experiences of living with and caring for their child and back again to perceptions and the meaning making process of coping.

Each case study begins with a section describing the family as a whole by introducing the reader to the family members and adding a personal impression of the participants as I saw them. This section is followed by the Findings section which integrates the core categories with the families' stories using the participants own words, transcribed from their interviews verbatim. These highlight my interpretations and create a more meaningful story that conveys the complex and unique nature of each family's process. A case

study format is used to illustrate the interaction between the **shared trauma** events and the parents' perceptual and the behavioral coping processes as they demonstrate the theoretical concepts which emerged from the data.

Telling the birth story or initial event story seemed an important place to start for each couple. For some the telling lasted as long as 30 minutes and the impacts of the those early days reverberated throughout the interview. These stories were central to the larger stories of family coping and the construction of meaning. They set the stage and provided the background to appreciating where the parents are in their thinking today. As the stories unfolded themes of ambiguity, family congruence, faith, and confrontation lent richness to the description of the event-perception-behavior sequence of coping that is the focus of this study.

The next section begins with a summary of the "The Story" which is a brief, generic, description of how these families are mastering the process of parenting children with special needs. Next is a description of each of the core categories that emerged from the analytical study of the transcribed interviews. Finally, a portion of each of the stories of the 5 families is presented in case study format to illustrate how the major constructs are

demonstrated in their lives. Reference to existing literature embellishes the case studies and establishes theoretical support for the contextual story. Each case study begins with a brief introduction to each family. Verbatim quotes from each parent are intermingled throughout the case studies to add clarity and depth the concepts being illustrated.

The Story

The story is about how parents with children who have a wide range of moderate physical disabilities are mastering the job of parenting. These parents do the "normal stuff" of parenting but with a heightened sense of purpose and intentionality. The events of their stories are both alike and different but each contain the elements of shared traumas and the challenges of coping with unanticipated events. Each family in their own way came to terms with their child's disability. Some called it "making peace," one father called it "realistic recognition," and others reluctantly use the word "acceptance." Through an iterative process between the domains of experience, perception, behavioral responses, and personal growth the families master and constantly re-define the parental role. The use of behavioral responses (e.g., boundary definition and external systems management) interwoven with the perceptual responses (e.g., cognitive coping, a common understanding of the disability, and faith) assist each family in mastering the job of parenting in their own unique style. This process is not time bound but rather an unfolding, experiential and meaning making process that changes over time.

Core Categories

The results led to the formulation of three core categories which in combination provide the conceptual framework for this description of the **Mastery Process** of coping in families with children with special needs. The three categories are **Shared Traumas**, **Coping Processes** and **Personal Growth**. (See Figure 3)

Shared Traumas

The category of Shared Traumas includes the challenges these families face. The challenges vary in degree and may be conceptualized on a continuum of severity from fairly minor (a peer teasing episode, late for school) to very major (traumatic birth, prolonged court trial, death of a grandparent). The three themes that seem to have the most significance to Shared Trauma are **initiation to special needs**, **everyday reminders** and **boundary defining events**.

The first event, marking the families' **initiation to special needs** in two cases was the birth, in another two it was delayed development and ambiguous diagnosis, and in one case it was an accident. The initiation to

special needs varied in duration and intensity but for each of the families it brought a period of **instability** and varying degrees of **ambiguity** about the diagnosis and prognosis of their child's disability.

Everyday Reminders are common occurrences for families with special needs children. They include events like finding no access ramps when you take your wheelchair-bound child to a movie theater or a "complement" from a parent of your child's school friends that makes it clear she was surprised by the abilities of your "different looking" child. They are usually ignored or regarded as simple set backs but each of the families in this study talked about these kind of events and their varying ways of managing them.

Boundary defining events are the subsequent events which bring with them the capacity to restructure the system in some fashion. They may be secondary crises to the **initiation to special needs**, like major surgeries or court trials. They may be a series of **everyday reminders** which are seemingly minor events but symbolic of larger issues like a weekly visits to a sick child's bed from grandma. Whether major or minor they have the impact of marking the boundary for the family in a way that makes it clear who is in

and who is out.

Each of the challenging events which are categorized as **Shared Traumas** impact the family system and require a response. These responses are conceptualized under the category of **Coping Processes**.

Coping Processes

The Coping Processes are made up of **Perceptual** and **Behavioral** components. The distinction between Perceptual and Behavioral components is an illusive one. They appear to go hand in hand where the figure eight spiraling between perceptions of events and behavioral responses each contribute to the meaning making process of coping.

Perceptual

The **Perceptual** concepts and themes include the following: **family congruence, cognitive coping strategies, and faith.**

Family congruence relates to the "sense of harmony" present among the family members definition of the stressor, appraisal of the stressor, and their world view (values, beliefs, expectations) (McCubbin, Thompson,

Thompson, and McCubbin (1993). Families where the parents are in agreement about the meaning of the disability, share a joint view of its impact on their family system, and have common values tend to have a high level of congruence. In this study families evidenced varying degrees of congruence and reveal some changes over time in their level of congruence.

Cognitive Coping Strategies include thoughts and cognitive processes which enhance a sense of well-being. The strategies include the following: **attributing cause and meaning to the disability** ("Although we'll never know, I believe it was the doctors fault" or "We had this child because God believes we are up to this challenge"), **assigning a special purpose to the child** ("God has a special purpose in mind for him"), **construing benefits** ("Her awareness of her disability makes her more sensitive to others"), **making favorable comparisons** ("Dealing with the wheelchair is hard but it would be much worse to have a child who couldn't communicate"), **redefining events** (assigning new value and importance to events), **normalizing** ("Everybody has troubles some are just more obvious than others"), and **perception of control** over the events ("I cannot take him home

from the hospital but I can make sure he has the best medical care").

Faith includes the practice of a personal spiritual faith or participation in organized religion. Participants's perceptions and beliefs in the existence of a knowing God enhanced their coping behaviors.

Behavioral

Behavioral concepts are the active responses by individuals to their perceptions of events. The two most significant themes are **boundary definition** and a **continuum of external system management styles**.

Boundary Definition is considered a phenomena which may be overt or covert but achieves the same goal of clarifying who is "in" and who is "out" of the family circle. Boss (1988, 1993) talks about boundary ambiguity in families and notes the high level of stress associated with the diseases such as Alzheimer's which leave family members physically part of a family but psychologically not available. This study found a variation on the theme, where the boundary defining process is extended more to the perimeters of a family than the internal operations. It was evidenced in families in two ways. First, through a phenomena of extended family members who either clustered

in and came to be part of the crisis (boundary defining event) or stayed away separating themselves physically and psychologically from the crisis.

Second, by the parents of the special needs child marking the boundary in an effort to maintain some control and follow their own plan free of conflicting beliefs and advice. Those who are "in sync" with the parents perceptions become central to the family in the time of crisis. Their thoughts are welcome and depended on. Those who are challenging and critical may be defined as outside and not sought out as advisors or support.

External Systems Management Styles appear as a continuum where by parents ways of managing outside systems (medical, school, therapeutic) vary from the extreme of the **Confrontive Questioner** to the other extreme of the **Compliant Consumer**. Each parent used a variety of styles along the continuum depending on the context of the contact with an outside system. In addition, changes over time as needs change, or perception of needs change occurred. Some parents used a style that was close to one end of the continuum for medical interactions but closer to the other for the child's school setting. Other parents standardized on a style that was closer to one end than the other. And one parent seemed to be most comfortable working

in the mid-range of **Managing Partner**.

The **Confrontive Questioner** lacks faith in the those external systems and relinquishes as little control over their child as possible. They do what they can to limit their involvement with other systems and collect as much information as possible on their own prior to any major interventions.

The **Compliant Consumer** goes along with all medical or other professionals' advice with few questions or suspicions. They follow-up on each referral and look to the "experts" for decisions.

The **Managing Partner** tends to infiltrate the system by allying themselves with the professionals. They make deliberate choices about physicians, teachers, even coaches who they can build a relationship with in order to provide a favorable result for their child. Managing partners are interested in working with the professionals and forming a partnership that allows them to make any final decisions but enables them frequent access to the expertise of the professionals.

Personal Growth

Personal Growth is the third component which appears conceptually

as an integral part of the figure eight spiral leading one to a higher level. This category could be thought of as a paradigmatic shift or a second order change (Watzlawick, Weakland, and Fisch, 1974). Personal Growth represents a **change in world view** and a change in self in reference to others. It could be considered a move toward differentiation (Bowen, 1978) with the impact of a perceptual change resounding through the system by the resulting behavioral changes of the individual. As an individual becomes increasingly differentiated they are more adaptable and less likely to absorb the emotionality surrounding them. An increase in the differentiation in self brings an increase in one's ability to maintain a high level of thinking in difficult situations (as opposed to reactive emotion).

With personal growth comes a structural and foundational change in an individual's understanding and a behavioral shift in relationship to the family system. The manifestations of personal growth are both a result of and a contribution to the **Mastery Process**. The change in perception and behavior on a personal level feed back into the figure eight spiral by enhancing the effects of that adaptive coping process.

The Andrews Family

The Andrews household bustles with children's activities. With four daughters, Kelly (16), Mary (14), Melanie (12) and Robin (8) there is a constant hum of discussion about carpools, school events, church commitments and sporting schedules. The youngest daughter, Robin, has unspecified generalized hypotonia which significantly affects her motor skills and balance making both large and small motor activities a challenge. Robin can walk and even run with an unstable gait but she still uses training wheels for her bike and her parents report that the paper and pencil work associated with second grade is a challenge. Mike Andrews works nearby in a management capacity for a mid-sized local organization with many community ties. Although he frequently works evenings and regularly attends obligatory social functions, he is very involved as a coach and volunteer for each of his four daughters sports teams and other extra-curricular activities.

Jane Andrews works a half-day job in a nearby clinic and seems to be the daytime "on duty" parent who provides most of the after school care and chauffeuring associated with parenting in the 90's. Over the years Robin's

condition has required physical therapy several times a week and it was not uncommon for Jane and at least one of the other girls to spend the afternoon at a local clinic or hospital. In addition Jane has encouraged each of the girls to take music lessons and participate in organized sports so a weekly routine of 4 music lessons, 6-10 athletic practices, 4-6 games, and a host of school and church activities keep this family hopping.

Both Mike and Jane spoke about sharing responsibility for the girls' schedules although Mike admitted that Jane does the lion's share on the weekdays and he, "knows better than to expect dinner on Wednesdays" which is a particularly hectic day. Both parents wonder if the girls are over extended and realize that the pace of their lives may be too much, but they make a deliberate effort to preserve some informal family time most evenings and they coordinate and maintain an elaborate system for trying to please everybody.

The Andrews reside within a mile of Mike's parents' home and the childhood home of Jane where one of her five siblings now lives. The girls attend the same parochial school that Jane and her siblings attended a generation before. The combination of community in the school, church, and

neighborhood is an often mentioned source of support for the Andrews. I got the impression that they give as much as they get from their association with the larger community. One gets the feeling that Robin's disability is a sideline issue for this family and that her sisters' activities, as well as her own, keep this family in the mainstream of life.

Both Mike and Jane were cooperative in our meeting schedules, they worked our interviews around their jobs and over the lunch hour. Their flexibility and long established system of working together was evidenced in their interviews and the ease with which they talked to me and with one another.

Findings

The story of Robin's birth and ensuing physical delays illustrate the concepts of **initiation to special needs** and **ambiguity**. Robin's birth was an emergency C-section and she had several cyanotic episodes in the hospital but there were no other early indications that her development would be anything other than normal. Jane's pregnancy was uneventful and her three older daughters were fine. However, before long both Jane and Mike began

to notice that, "Robin wasn't developing at the rate that she should have." As they reported, "We pressed our pediatrician on it to send us to somebody to have her checked out." This is a commonly occurring sequence of events with families whose special needs child has a delayed diagnosis. It is frequently the parents who are the first to notice that something is awry. In the Andrews' case they were not willing to let their concerns go unattended or to be put off by the doctor's reassurance that it was probably nothing to worry about. Significant delays in motor development were evident by the time Robin was five months old, but it was over a year before they had a definitive diagnosis. Jane describes the event of **initiation to special needs** and the accompanying **ambiguity**.

I think our pediatrician definitely saw that there was a delay and I think he thought it was maybe a little too soon to descend on, and we just - - well it's great if you go and they say, "Hey, there's not a problem." but you know if there is a problem it's better to get on this now that to wait, it's definitely to the benefit of the child.

Mike spoke about that early period of searching for medical information and a cause for Robin's apparent delayed development. His comments below illustrate the cognitive coping strategy of **redefinition** that occurred in order for them to get on to behavioral coping strategies:

The hardest thing for us was trying to get an analysis or diagnosis of the problem. It's funny, you put a lot of energy into solving the problem. She obviously had a problem so what you do is you solve it. So you put a lot of energy into solving it and then you come to a point where you figure you have to split between trying to solve the problem and help the person.

Seligman and Darling (1989), discuss trouble spots in the normalization process for parents with children who have special needs. It is easy to hear in Mike's words how his initial focus was on finding the cause (solving the problem). During the **initiation to special needs** period his response was the following: initial event (the unknown cause), the perception (believing the cause is highly important), and the behavioral response (**Confrontive questioner** style which led Mike to track down hospital records and develop his own theory about a possible milk allergy). He **redefined** the importance of the cause in order to shift his energy from "finding a cause" to "getting the help Robin needed." Jane also wondered why, but was very clear that she had done nothing wrong or different with this pregnancy than the others and her focus from the beginning was on getting help for Robin. For Jane the event was the same but her perception differed (she knew she was not responsible and did not put a lot of value in finding the cause) and her

behavioral response was to pursue medical tests and assessment of Robin's current functioning in preparation for the future rather than to look back at the past.

Seligman and Darling (1989), note that a delayed diagnosis contributes to the **level of ambiguity** and can be a major roadblock for families.

Ambiguity is a well-known stressor (Lazarus & Folkman, 1984) and is a potent aspect of the period of **initiation to special needs** when there are many unknowns. It is at this point when families can become discouraged and perceive that they have no control over their child's health and future. It is typically a time for parents to ask themselves, "Why Me" and to spend time trying to make sense of their circumstances. This grappling with the disability and unknowns is part of the meaning making process of coping. It is a beginning of a perceptual change using the **Cognitive Coping Strategy of attribution of cause and meaning** which assist families in gearing up and going forward into an active response. When I asked Jane and Mike about their assertiveness with doctors and how they might have left things up to fate, Mike's response was the following:

We did talk about that at times and I think our concern always was that

we weren't being aggressive enough. But it was something we talked about and actually, in the early stages I sort of always wanted to know why and Jane was much better at saying, "Why doesn't make a whole lot of difference now." She was more concerned with how we would take care of her. . . and we need to know what we're going to do next. And so, in that way we were kind of in agreement that more aggressive was better but it was a different way of seeing it.

Mike's comments illustrate the concept of **family congruence**. Their different ways of perceiving the event might have been a road block for moving ahead. As it played out their differing approaches were not a big obstacle and both of them were in agreement about the behavioral response required.

Research tells us that active coping measures are generally more productive than passive ones (Lazarus & Folkman, 1984) and this held true for the Andrews. They may have come from two different points in trying to make sense of Robin's condition but they were in complete agreement when it came to what to do about it. McCubbin, Thompson, Thompson, & McCubbin's (1993) work on family appraisal and functioning, discusses the concept of congruency as an important aspect of healthy functioning in the face of stressors. A family's paradigm (a model of shared beliefs and expectations shaped and adopted by the family) is evident in the way they

respond to unexpected events. Families with similar definitions and resulting appraisal and coping strategies are high in congruency and have a smoother adaption phase in this normalizing process. Over and over again the Andrews shared stories which illustrated their flexibility and willingness to work through their differences in order to accomplish their goals. Mike recalled a familiar story which highlighted this:

One time we were supposed to go to Cunningham Falls and I got home late so we had a late start and nobody wanted to go anymore. Their friends were doing something and they all had complaints. But we all got in the car, headed off, rode around the block and parked back in front of the house. It was Jane who said, "All right I tell you what we'll do, get the tent and we'll spend the night at Cunningham Falls." I was thinking, "You guys are jerks for not being as enthusiastic as I am." I was mad and she was like, well it's lost, and she was right, so why not shoot the three-pointer.

Mike and Jane do argue about his tendency to over-schedule and to try to do too much. He has many interests and impressed me as a high-energy person. When this personal style is matched with his ambitious efforts to **normalize** Robin's role in the family it sometimes backfires.

I took Robin and Melissa bike riding in the Fall. Robin still needs training wheels, and Melissa was supposed to do something else but I convinced Melissa to come with us and I thought the toe-path would be great for her. [As we rode] It wasn't working well for Robin, I thought she just wasn't concentrating well, so I said let's go further. It was a

lousy ride for Melissa and a demoralizing situation for Robin but I kept at it. It was Melissa who kept saying "Let's do something else" but I kept at it. Typical me, I had my position and it was going to be fun and they were going to feel successful at it. I think we ended up going to my parents house or going to 7-11 or something so we made up a little bit for it, but it definitely goes in the loss column.

It seems clear that Mike continues to refine his perceptions and beliefs (**redefinition**) about Robin's ability by checking them out in the real world, assessing their usefulness, and creating new ways of thinking about Robin's disability and his own role in how that is manifested in daily life. This is the figure eight spiral of event-perception-behavior which this study describes.

He and Jane believe that part of their job is to support their daughters' efforts to try anything. The Andrews' family tradition is one of athleticism and fast-paced activity. The Friday night basketball games and Saturday soccer games are a family ritual as are the bike rides and beach trips. Rituals are themselves symbols of tradition and provide group stability and social order (Imber-Black, Roberts, & Whiting, 1988). This is a clear strength for this family and a resource which they put to good use. Mike and Jane see Robin as a full-fledged member of the team. But, they are aware that their desire to include her and her efforts to keep up are achieved at some cost.

One of the things that's hard for her, in terms of negotiating, is there is so much that she wants to do and sees others do whether it's playing soccer or b-ball or if they want to go to Annie's house down the street, and need to be back in five minutes, well she can go but she can't be back in five minutes. She could run but by the time she got there she'd be pretty tired and couldn't run back up with the rest of them. Things like that. So for her I think the hardest thing, for her and for us as parents, as a family sometimes is to know when to push her and when to try and accommodate for her and it's very hard to discern lots of times.

. . . With the other kids it's hard for them to know when to rush her, and the pact of our house is such that everyone is running and saying, "Let's go, let's go, let's go." That's not good, we've got to start earlier, and the pace of the house at this age is generally to run in and out and for her that's not the best pace at all.

Jane and Mike have continually adapted their perceptions

(**redefinition**) about what's important and their behavioral responses as they learn from that spiraling process what's best for Robin. Jane is more apt to take a firm stand against too many commitments and too much stimulation. She has been the "voice of reason" on several occasions when Mike was ready to sign the girls up for one more team or head off to hike the most difficult trail. Since Robin's arrival Jane has redefined some of her beliefs to hold some attributes of family life in higher regard than others. Where "being ready to go to school on time" and "getting yourself dressed" used to be Jane's priority in the morning it is now, "getting off to a good start." Robin's

low muscle tone contributes to her slow start in the morning, her disorganization, and resulting bad mood if she's hurried and yelled at. Jane talked at great length about their efforts to make a change in the morning routine so that Robin would have "a good start." That may not include getting herself ready or being exactly on time but the more important element for Jane is starting her day with a good attitude.

Tunali and Powers (1993) discuss the concept of "**redefinition**" in their work with families with handicapped children. They propose that families redefine behavior patterns that were formerly thought of as ideal and find alternative ways of satisfying their needs. Where Robin could not comply with those earlier measures of success she can, with her family's help and adjustment, meet the requirements for "a good start."

The Andrews family is an outgoing and cohesive unit. Their involvement extends to their social support system which includes the church, school, and neighborhood. Both Jane and Mike said that they could have used more support from their extended family but, they have certainly found it in their other social support systems. Mike talked about their style and rationale for involvement:

These days you know to make sure your kid gets looked at favorably or gets at least involved and gets a fair shake is to make yourself indispensable. . . .and I think we're both pretty good at that sort of thing. . . . Not being the hovering parent but you know, you try to coach if they need one or be sure to get to know the coach and find out their name and what they're interested in and offer to help.

This **managing partner** characteristic has carried them into active leadership roles in the PTA, the church, and community service projects. For each of their children they have made themselves indispensable at one time or another basing their involvement on a "quid pro quo" understanding with these "systems" that by donating so much time their kids will get special treatment.

The family's sense of belonging to a greater community is highly valued. So too is the acceptance of their daughter by her peers and her siblings' peers. Jane and Mike both laugh about how Robin's sisters stick up for her and say, "Nobody's going to mess with Robin cause we're all there [at school]." Everyone in the family seems to agree (**a high level of family congruence**) that Robin's disability should not limit or label her and Jane talked about how each of the girls will take Robin's side with anyone outside the family. She also noted that they have their own fights within the family

just as one would expect in a house full of kids.

Mike and Jane are sensitive to the impact on Melissa of Robin's disability. They make a point to provide time for Melissa, who is the closest in age and overly attentive, to have time without Robin.

I think Melissa goes places with Robin and it is almost to Robin's detriment as much as her own. She continually says things like, "Robin look out and Robin be careful." And she worries about her. Less now than before . . . sometimes we try to send them to different camps. It's not good for Melissa because she's worrying about her. And it's not good for Robin because she has to learn to deal with it herself and she can't have her sister there.

Jane has had a lot of experience with siblings having grown up in a large family. She talked about her siblings and how some of them have developed closer relationships than others. Jane told an extensive story about a beach trip with her brother's family which should have been relaxing and fun for everyone. Instead, it turned into a week of non-stop bickering among cousins, ending with hurt feelings and exhaustion for Jane. She believed that Robin's special needs were highlighted in the presence of her cousins who were unaccustomed to dealing with Robin day in and day out, and proved a handicap to her more than ever. Jane made the comment that she would "never do that again." This became a **boundary defining event** for their

family and has led Jane to renegotiate (**define the boundaries**) her shared time with her siblings when Robin is included. Mike and Jane are both inclined to vacation more on their own and to make it clear that Robin will be considered of equal standing at family affairs.

Mike and Jane Andrews provided a good beginning to my foray into the world of research with families who have a child with special needs. Their strong family presence was reassuring for me and provided a good backdrop for the other families I would meet.

The Brown Family

Mark and Winnie Brown live with their two adopted daughters, Kayla, (7), and Suzie, (2 1/2), in a two-story brick house on a tree-lined street which is as close to suburbia as city-living allows. They moved recently from a high-rise apartment complex and were still settling in the day I arrived for our first interview. Mark works as an Economist with a government agency. Winnie who has worked as a health care professional for 24 years talked about her upcoming retirement this spring where she plans to try out "just being a mom."

Of the five families I interviewed this couple's telling of their story struck me as most poignant. At nine months of age Kayla was accidentally burned in a bathing incident with a baby-sitter. After several days in critical condition in the intensive care nursery she began a long and slow recovery period which included many early surgeries, hospitalizations and intensive home health care.

Although Kayla's disfiguring scars have healed over and her secondary surgeries are much less traumatic than the first series of painful grafting

operations, her parents still shudder as they talk about the fear of coming so close to losing their long awaited and much loved baby girl. Kayla's long term physical disability will be minimal with the primary impact being appearance impairment. But both parents, and especially Winnie, seem emotionally raw when it comes to discussing Kayla's recovery and the occasional discomfort of peer curiosity or bad manners. Winnie's concerns for today quickly became worries about the future where she anticipates many potentially awkward situations for Kayla.

Unlike the Andrews this family had organized themselves around the disabling accident and recovery of their daughter. Her regaining health and well-being became the defining issue for these two parents as well as her maternal grandparents who arrived from out of town faithfully each weekend for months.

Today the Brown's no longer see Kayla's scars as her most important characteristic. The six years since her accident have brought many joys as well as a few sorrows to this family but over all they see themselves as "typical parents of a first-grader" whose biggest concerns these days are whether, "she's reading on grade level." Mark told me that they "no longer

have to cope, not like people with children who will never get better." He believes that they were lucky in some ways and gives much of the credit for Kayla's successful recovery to Kayla herself for being such a "strong and winning kid" who was a "fighter."

When I first called Winnie to see if she and Mark would be interested in participating in this research she immediately agreed, suggested the following day as a possible first interview date, and went on to talk for 30 minutes about the particulars of Kayla's accident and how she sees the impact of that today. Even over the phone it was easy to hear the agony of those early days and, what I came to see as, the process of resolving the grief and trauma of this terrifying period. Mark's matter-of-fact manner complements Winnie's emotional intensity. He is much less passionate in his responses and tends to report his memories and impressions of those many months as though he were reciting a sequential list of events for the record. Still, his choice of words and observable pride when Kayla or Suzie would walk through the room or skip past on the sidewalk outdoors calling, "Hi Daddy!" indicated to me his deep connection to these girls.

The adoption of Suzie has been part of the healing process for this

family. Kayla's participation in the adoption and enthusiastic acceptance of her big sister role has been a joy for these parents. In spite of their different approaches (or perhaps to some degree because of them) Mark and Winnie have managed the early crisis and come through with a stronger bond than ever. Their devotion to their children and attentive participation in play was a pleasure to witness.

Findings

Mark and Winnie Brown were on an even keel in the course of their life. With the adoption of a wonderful baby girl whom they had waited for seven years they finally had the family that they dreamed of. Their **initiation to special needs** came in the shape of an unfortunate accident with critical results. Unlike the other families in this study whose children were born with a disability Kayla's accident interrupted an existing family schema of normality (which they had longed for) and turned this family inside-out. As we hear their story and their growth it is easy to see the progress Kayla has made, the adaptations that Winnie and Mark have put in place, and the slow but steady return to a routine life.

It seemed clear to me that they cannot say "it's over" because they are still in the process of righting themselves, and Winnie suspects that this may last a lifetime. But most of the trauma and fear is over and they have returned to a point where Kayla's injuries do not play a role in their day to day lives.

Although Kayla's remaining disability is, for the most part, a difference in appearance it is almost impossible to describe the severity and medical implications at the time of the accident. Briefly, the story started in this way: At nine months of age Kayla was being bathed in a kitchen sink by a trusted baby-sitter who cared for her each day. She sustained water scald burns over 60% of her body due to a faulty faucet which flashed on with exceeding hot water. A police investigation determined that this indeed was a mechanical fault. She was in the intensive care unit for two months. She went through six skin graft operations, extensive physical therapy for several years, and as an infant and preschooler had malformed joints, muscular damage and delayed motor development. Winnie and Mark carried out a rigorous routine of daily exercises which were painful for Kayla and traumatic for her parents.

Winnie talks about the trauma of the **initiation to special needs** where

she was getting a lot of signals from the doctors and the **ambiguity** of the unknown prognosis was almost intolerable.

Agony. It was just sheer terror for sixty days. Sheer terror. I was too afraid most of the mornings to call the hospital, I just couldn't pick up the phone. I had Mark do it, cause I didn't want to hear what they had to tell me.

At this point in our joint interview Mark dutifully recited the hospital phone number and told about how would dial in first thing every morning and get the report on her condition. This couple experienced the **shared trauma** in a way that brought them closer together. Mark shared his thoughts on the impact the accident and hospital stay:

I think it's fair to say that we, if anything we grew closer during this time of crises. The literature will tell you, I'm told I don't read it myself, that a crisis like this causes real strain on lots of marriages but that just didn't happen for us. We went everyday to our girl's bedside and I don't think of it as a coping mechanism, I think of it as something that just happened, that the three of us just grew through this awful event and this awful aftermath. I guess that's coping.

Mark tends to be more upbeat and optimistic **construing benefits** of a closer marital relationship as an outcome of this very stressful period. Winnie sees all the potential rough spots and worries about what might happen next but they are united in their understanding of their role as parents which

provides a high sense of **family congruency** and reduces the stress in critical times. In addition to their working together they also learned to specialize and back up one another when things just got too hard. Winnie's medical background prepared her to deal with the doctors over the course of the first two to three years and Mark admittedly took a back seat to her knowledge and expertise. At home however, Mark was very much a part of the day to day medical care for his daughter. Winnie stated:

There were some days when she first came home, that I just could not bear to do the exercises cause I couldn't stand the pain, to see her crying. Mark would do it. We had to trade off.

The impact of the **shared trauma** for this family spilled over to the next generation. Both Winnie and Mark remarked about the strong bond between Winnie's parents and Kayla and see this as a direct result of the injury and crisis period that they shared. Where some families with special needs children experience disruption and cut-off from extended family the Browns enjoyed tremendous family support. The accident itself was a **boundary defining event** with Winnie's mother and father being drawn inside their family unit.

We were for better or worse brought together and not torn apart by the

whole thing. . . . One of the things that impressed me the most was this way of how they latched onto Kayla. When you think about it here was a couple who were only dimly aware of what adoption is all about and kind of gave us a funny look when we said we were going to do it. They showed up with a funny look when Kayla was a few days old and looked into the cradle with a funny look because they thought the baby would look funny because it was adopted. This was their mindset coming down the road. But once we got her, and shortly after she was injured they were as heroic as any grandparents have ever been. They made this 500 mile round trip every weekend. She was having an operation every week and there was no fun to be had. They were just there to provide support. I have not read any of the social research but just from the lay point of view it's obvious now that there is an extra bond.

Throughout the next few years of recovery Mark held fast to his belief that this was all going to work out for the best. Literature on the benefits of positive illusion (Baumeister, 1989; Brown, 1993) suggest that individuals who assess their predicaments as slightly better than probability or evidence can justify tend to have reduced stress and high degrees of adaptive coping. In addition to Mark's analytical and systematic approach to Kayla's recovery his continual optimism and energetic faith in a positive end result helped to keep this couple going. He frequently made the point that Kayla's situation was better than many other children and used the **cognitive coping strategy of making favorable comparisons** to keep up his spirits.

As we went through this torture I had a inner vision that this was going to have a good result. I wanted to get through to that next point. I'm not sure if we had a child with something much worse, what I think is much worse, that I would have been content with it all. We were plenty depressed as it was, we lost weight and all that stuff, but we had this glimmer down the road and support from parents, so that was in play there. And it worked out that way, she got better, she was a trooper, and we were troopers, and we did what we needed to do.

Winnie was not so certain about all of this. In her own way she searched for some understanding about Kayla's injury and tried to make sense of it. Her medical background played an important role in her pessimism and kept her uncertain and feeling out of control. Doctors' errors that she witnessed caused her to be even less able to put her faith in the technology of medical practice. Although she questioned each surgery and consulted daily with the doctors she did not put her greatest energy into the external systems management. She moved up and down the continuum using the **compliant consumer** stance early on when they felt they were at the mercy of the specialists and the **confrontive questioner** stance at later stages when they had regained some **sense of control** over Kayla's recovery process.

Winnie's energies turned instead to her **faith** in God and the spiritual tradition of prayer. She found that support in that arena had the greatest

impact.

. . . faith in God and the ability to pray. I remember when Kayla was in the hospital people would call and say, "Can I make you muffins? Can I bring you soup? What can I do?" And the only thing that helped was there was a nun at the hospital. She was the only person throughout the whole hospitalization who I looked forward to seeing. A social worker would come and stand at the foot of the bed and try one of these silent routines, probably because as a health care person I know she was trying to elicit some responses. . . I knew what she was up to and I thought, "I don't need this!" Get out of here. But the nun was the person I looked forward to seeing. . . . She represented the only thing I thought that could turn this around. The only thing that could save Kayla. I really felt that it was in God's hands.

As Kayla became stronger and moved out into the larger world, Winnie expanded her own interests in regard to Kayla's special needs and became an active advocate.

I've become very interested in child safety issues and with injury prevention, with the department I work in. I'm the liaison with a group that promotes kid's safety. . . it was the kind of thing that happened to somebody else that lived someplace else but now I walk into a coffee hour and I see those coffee urns sitting there and I see the adults holding coffee, whatever it is, and those are issues, like playground issues. . . Kayla and I did some safety advertisements for scald burns and we did a cable television blurb for anti-scald devices. I've done some public speaking on the hospitalized child from a parent's perspective. It gets you into this whole other world.

Some of Winnie's interests and choices may be called part of her

search for mastery and **attribution of meaning**. She has put her talents to good use for the greater community and she is clear that this has been helpful to her as she recovers from the impact of Kayla's accident. As she and Mark recounted the **shared traumas** of the last few years it became apparent that they had been through a lot.

I'm starting to think of it lately, as I was recovering from my own post-traumatic shock and I hadn't thought about that so much, those ages when she was 3, 4, and 5 we were, at least I, was coming out of shock because in that time, we were trying to adopt a second and we did adopt a baby and there was a revocation there, so we had the baby home and the birth mother took it back. There were some pretty significant . . .

Mark jumped into the conversation at this point by adding:

My mother died slowly and her father died suddenly and we lost a baby, we had lot of thins to go through.

Winnie added her thoughts about participating in the interview when I asked her how she sees her parenting job these days:

Hoping, learning, hoping. You know even doing this interview is an example of something that helps me learn about myself and everything. I mean whatever it is you're studying it's giving me some glimpse of how we're dealing with this. In a very indirect or, in other words, by volunteering to do this I put myself in a situation where we'd be talking about it and it gives me feedback whether I want it or not. It gives us a chance to talk about it and put it in a different perspective.

Winnie's struggle to gain a new perspective on the traumatic events of the past is evident in her words. Her behaviors reveal a pro-active approach and the seeds of personal growth resulting from the event and contributing to her own recovery.

At the time Winnie was becoming involved in advocacy issues Kayla entered school for the first time. Mark would usually drop her off and he would frequently be seen standing over the playground fence keeping a watchful eye on Kayla as she made her way into the social circles of a preschool group. Winnie and Mark were reluctant to step back too far out of the protective mode and talked about how they worried that she would be ostracized. They made it a point to talk to each teacher individually in order to make sure that Kayla would get special attention if need be. As it turned out the preschool years went fairly smoothly where she made lots of friends and "became a star" as her dad recalls. Although Kayla enjoyed a successful school transition, the Browns carried that same concern, about Kayla's ability to handle **everyday reminders**, with them to her formal school setting as a first grader and made a very intentional decision about what school might be best. Their choice reflected their perception about Kayla's still vulnerable

status:

We minimize the opportunities for difficulty by having her in places like Grove Park and Oakview. . . where we have access to teachers that are going to make sure there's a caring situation and that if anything flares up, they're ready to deal with it.

The Browns' see their job as "preparation" and "appeal" to other adults in Kayla's world so that their watchful eye can be passed on to whoever is in charge. They now operate most like **managing partners** in the school and social domain.

Our job now is protection. Because the principle exposure, at least in my view, is psychological. If somebody makes fun of her because her legs are scarred and don't look like the other kids, she feels bad. She's still a resilient child and has learned to cope with most of those pretty well but I still want somebody there who can keep an eye out.

We prepare the inbound teacher of what went before, a small thumbnail sketch of what we have gone through with you here, and we say the same old thing, "We're overprotective, you probably won't have to worry about this, just bear with us. But there are times when she just may need [extra attention] this during your tenure and watch so to speak" . . . We prepare the teachers and camp counselors to be on the look out for anybody who gives her a hard time. It hasn't happened yet but we want them to be aware that something like that she may need a little extra TLC.

The Browns found an unexpected "silver lining" when they brought Kayla back to school after a recent surgery and she had to be in a wheelchair

for a while. They were surprised to find :

Among her friends there's an element of coolness in it, she had this wheelchair, she got to be the center of popularity. Her little sister, it's almost humorous, but Kayla's stroller was almost five times as big as hers. She called it Kayla's stroller. We thought that was funny. And she's among friends, there's nobody at school who gives her a hard time and it turns out they are all kind of impressed.

As vigilant as the Browns are they cannot control all the interactions that Kayla encounters in the larger world. There are plenty of opportunities for **everyday reminders**, but they have been able to observe Kayla handling questions and remarks from other children who she doesn't know and are impressed by her ability to begin to fend for herself. It sounds as if they have begun to accept that this will be an on-going process for Kayla which will probably have its ups and downs as she progresses through different stages of development.

This family was brought to the brink of disaster and now enjoys the relative calm of routine life. Winnie and Mark revel in the day-to-day events of what others might consider mundane parenting but they consider it a true blessing.

The Conway Family

Sarah Conway is an articulate woman with many insights and the benefit of a child who is a few years older than the other participants. Sarah Conway is a single parent with a college aged daughter, Sally age 19, and a 12 year old son, Robbie who has a rare visual disorder affecting the eye muscles, which was diagnosed over the course of his first year. This disorder impacted on his development as a preschooler where he was delayed in gross motor skills and quite "reticent and clingy." As a 12 year old he has outgrown those early imbalances and has become a much more confident adolescent whose disability is apparent only when he uses his eyes for specific tasks like reading. (Due to the abnormal ocular control, Robbie must position reading material at a 90 degree angle from his eyes as though he were using his peripheral vision).

Sarah is a professional writer for health related issues working full-time as well as sitting on several boards for her church and children's schools. She also makes a point to participate and assist with Robbie's sports teams as well as any other group he might be involved with. She brings to her

parenting the same determination and attention to detail that she brings to her career.

Sarah and Robbie live in a lovely old home filled with antiques and beautifully decorated rooms. Sally is away at school most of the year but it sounds as though mother and daughter keep in touch fairly regularly. Sarah talked about her extended family with affection but made it clear that they were not supportive when she needed them. Although they grew up in the South her sister lives nearby and is a source of social support today but I got the impression there is some unfinished business between the two of them. Robbie's father is out of the picture all together and she says that she has managed parenthood "completely on my own."

Our interviews together were comfortable and perhaps somewhat less structured. She was able to work from home and with some negotiation, fit me into her work schedule for two morning interviews. Her background in health issues allowed for the two of us to sit in her living room and talk about the theories of this research as well as her own personal experiences. At first she seemed more comfortable talking professionally but as the time went on she was able to identify for herself some issues which impacted on her

coping.

As Robbie has grown up and she has become a more experienced mother she finds herself willing to step back and make space for Robbie to fight his own battles. Recently she has become aware that his peers are noticing his difference and that this may be more of an issue as he enters his teens than it has been as a 10 or 11 year old. She says she sees his visual difference as no more important than his other physical attributes and that for the most part it is simply part of his package, but she realizes that Robbie may have to come to terms with his difference over and over again. She also recognizes the possibility that she too will get caught up in the throw-back to adjusting to his difference in a new context but she is quite clear that she would come to this as a very different person than she was 12 years ago.

Findings

We know now that Robbie's development has progressed beautifully and his visual disorder has become, "just one of many characteristics" (according to his mother) of this pre-adolescent young man. But, Robbie's birth story starts out with an unusual developmental pattern that sent Sarah in

search of an answer.

Robbie was born 4-6 weeks prematurely with no apparent problems other than being a sleepy baby who Sarah remembers having to wake in order to feed. As the weeks passed she noticed that Robbie was not smiling and she recalls being "consciously apprehensive and concerned" about it. Sarah's interest and knowledge in child development led her to suspect that something was wrong. Just as the Andrews found themselves in the driver's seat for seeking out medical advice, Sarah too went to her pediatrician. He also thought there may be a problem and referred her to specialists. Over the next nine months the possible diagnoses of cortical blindness, autism, and a brain tumor were considered, and one by one ruled out. This period of prolonged **initiation to special needs** was a trying time due to marital conflict that predated Robbie's birth, a move to a new city in addition to the **high degree of ambiguity** surrounding the diagnosis and the unusual nature of the symptoms.

It was two years before the doctors were able to rule out the possibility of mental retardation. By that time Sarah had developed a external systems management style of **managing partner** and become a "veteran" at

dealing with doctors and advocating for her son. Early on, as Sarah negotiated the maze of specialists, she sought out professionals who were compassionate as well as competent and placed herself in a position to work with the medical personnel. She talked to me about how the doctors and therapists became her more "natural allies" than her family members who were highly critical of, what they called, her "overprotective stance."

Being an actor. Acting on it is a huge piece, gathering the information, forming the relationships with the doctors. Many families I've talked to hate health care providers. That wasn't my style. I searched the landscape for providers that I could have a relationship with. . .doctors who connected to me as a human being. Finding the professional who didn't infantilize me, treat me like, "mom."

She dug in her heels however and now regards that period as a necessary response at a critical time. This became a **boundary defining period** where her father and sister were identified as outside of the small family circle and to some extent the professional and other families with special needs children were in.

I don't know if that was coping, but I remember that part of my identity became in those years talking about children with special health care needs and I couldn't find information in the traditional literature, as you know those families get written off. This was a huge issue for me at the time. I do think I wanted to be a champion for Robbie and a larger

group of children as well.

Human development theory suggests that, in general, people will strive towards growth promoting behaviors and seek meaning and a sense of understanding from their experience. Sarah's search for mastery involved participation in activities that gave her some **perception of control** over Robbie's situation and her own as the parent of child with special needs. Below Sarah discusses the impact of the event, her perceptions about Robbie's needs, and her active behavioral responses.

I think that it's a major coping strategy to become identified with the special need as advocates, as spokespeople hooking up with other families who have similar experiences. I recognize some of that from that period of time [early years]. At nursery school we started a parent group for those with kids who had some sort of special need. It was good.

Seligman and Darling (1989) talk about family typologies for adaptation and identify the "crusadership model" as one style of interacting with the greater world. Crusadership is characterized as aggressive seeking and increased interest in the disability and its broader implications. Although Seligman and Darling tend to view this crusade approach as "prolonged seekership" and an alternative to normalization, in Sarah's case it seems

highly adaptive and a perfect blending of her personal style and talents.

As a professional with some background in health care she is quick to point out that her personal experiences have greatly influenced her professional style and vice-versa. Sarah worked toward mastery in her own way by looking for allies wherever she could find them and as she said, "searching the landscape" for professionals who she felt took her seriously and allowed her to feel competent. As I see it Sarah's determination to be a champion for Robbie is a symbol of her energy and devotion to her son as well as to professionalism and comradery among parents of children with special needs. She feels strongly about the value of family and peer support.

It was within these parent groups that Sarah learned about many aspects of children with more severe disabilities than Robbie had, at the same time she recognized some similarities among families.

Sarah was the first participant to identify the larger issues of political aspects of funding for handicapped children. She noted the underlying philosophy of our American culture where families who seek help and support are to be pitied. Through hard work, a goal-oriented philosophy, and fine educational opportunities Sarah Conway had achieved a successful

career and financial security. Her "go-getter style" was an attribute in the business world, but she had to come to terms with something that even she could not make right. Sarah and others admitted that this had been a painful process but a maturing one, and one of the positive aspects of parenting a child with special needs.

Sarah's experience as a single-parent may have enhanced her **external systems management style of managing partner**. She was accustomed to making her own way and carried her personal experience with her into other settings (establishing a support group in nursery school, volunteering for high-profile jobs at her children's schools and any and all extra-curricular events where she plays an active supporting role). Sarah's lack of close family support may have been key to her adapted style what she called "manipulation" and I began to think of as managing partner. Like the Andrews thoughts on becoming indispensable to their children's social worlds, she too donated lots of energy to connecting with adults in her children's schools and to becoming a parent with an inside track. She says she believed that she could pave the way for them and in particular protect Robbie, by creating a special bond between herself and his teachers and

coaches. It was a natural strength for her and she used her competent and outgoing manner to achieve this for many years. Her perceived need for Robbie to have protection and her own innate ability to cleverly provide it became a pattern in their family.

Although Sarah disagreed, it seemed plausible that the impact of the **initiation to special needs** may have contributed to the decline of the marriage. Sarah's competent management of that initiation period highlighted the differences between she and her husband who did not share her perception or behavioral responses. The marital distress certainly contributed to a low level of **family congruence** and heightened stress in those early years. As she spoke about how life improved for her and her children after the divorce it sounded as if the re-definition of the marital boundaries resulting in divorce allowed for a higher level of family congruence.

Sarah was one of the first parents to talk about the process of change overtime. She recalled how in the past her approach was to manage Robbie's condition by "leading with the disability" which made her feel that she was protecting him by preparing others for his differentness. Recently she finds herself doing quite the opposite and talks about being "180 degrees" from

where she was a few years ago. This represented the "second order change" associated with **personal growth** which allowed her to make that major shift in her thinking and behavioral responses. Sarah sees Robbie's growth, and more importantly, her own as the primary reason for that 180 degree shift. The process by which changes and recognition come is a complex one. The interaction between the perceptions and the experiences of daily living is a cyclical and continuous one influenced in Sarah's case by passage of time and her own changes in self-perception. She refers to a **change in world view** which encompassed a change in her view of self as Robbie's mother.

I guess what I'm thinking is this goes back to the acceptance issue and that my change in thinking has less to do with Robbie's disability and more to do with me being 12 years older and all the other things that have happened, it's impossible to separate out. My life view is much more realistic than it was. . . less romantic and maybe being [less of] a "good girl" or the kind to keep everybody safe, you just have to get up every day and deal with whatever is on your plate. As a young mother I thought my job was to protect my kids, as an older mother my job is to give them life skills and being protected by their mother is not going to be a very good life skill.

It is easy to hear the progression of change and to compare it with Winnie and Mark Brown's description of their slow but steady efforts to begin to pull back a bit and trust that Kayla will fend for herself. Sarah saw her

changes as a "continually unfolding process." She sees Robbie's visual disability as being a "huge coping issue for him" made up of many **everyday reminders** as he approaches adolescence. The teen years is one period of developmental transition which is marked by a tug-of-war between separation and dependency. Having been through this with Sally, Sarah is well aware of the struggle associated with this period but it still surprised her at first when the struggle became apparent with Robbie. She is clear that she is no longer the lead player and sees Robbie as the person who will make more of the adjustments now.

I think I alluded to this in the beginning, Robbie's feeling about this, let me put it in a developmental context. The first 4 or 5 years I saw this issue as the defining issue for Robbie. Then since we've gotten through latency and it's really gone away cause he's been able to do all of the things that I never thought, or that there were big question marks about his doing. Now it's come back again. In anticipation of adolescence he's very apprehensive about it. . . . I'm used to it [his odd reading style, etc.] and didn't think so much about it. I don't know what the next couple of years will be like. What I have said to him for the last few years is, "This is part of who you are." It's one of many things. You have developed many effective strategies for dealing with it and that's who you are. It's part of your package. I guess I hadn't really anticipated appropriately the pre-adolescence, of not wanting anything different [different from other teens].

We can hear her perception change as she recalls how her experiences

with Robbie and her own **personal growth** have provided new ways of thinking about his disability and have resulted in new behavioral responses.

I think the fundamental shift in Robbie and me is that Robbie has demonstrated to us all that he's very smart and very capable and he's just going to have to do the best with this thing that he's got and it shouldn't be an excuse. So in some ways I have come 180 degrees from where I started out. Maybe that's where families do get to at some point, even with a much more visible and challenging disability, is that's who you are and you should have the same aspiration and expectations for yourself as anybody else. You may have to spend four hours doing homework instead of three but hey, that's the way it is.

Sarah's astute insight and well-spoken thoughts offered me clarity on some of the early conceptual themes and provided a different developmental perspective on this process of coping with children with special needs.

The Donahue Family

Theresa and David Donahue are a talkative and vibrant couple who have two daughters, Shelley, age 8 who was born with Spina Bifida, a congenital malformation of the spine in which the vertebrae fail to fuse, and Melissa age 6. Both parents were brought up in Chicago in large working class families. Theresa's parents immigrated from Latin America when she was a young child so Shelley and Melissa are the first generation of American-born citizens. Both Theresa and David talk about family values, their beliefs in hard work, and a spiritual faith which has sustained them over the years. They attribute the foundation of these beliefs to their own parents' influence but were clear to add that their own personal experiences have had a large part in formulating these strong opinions and beliefs.

David is a developmental optometrist, practicing independently, and Theresa helps him at his office serving as part-time office manager. We met for our interviews at David's office which is under renovation in an old downtown building. They have worked hard for over 10 years to build a practice and make his business successful. David made a point to tell me

that as a young man he decided that he would find a career which was meaningful and associated with helping others. Today, he is enthusiastic about his career and both he and Theresa seem proud of their achievements. They have made the business a family affair which seemed congruent with the rest of their lives.

The most outstanding feature of both interviews with the Donahue's was their clarity of purpose and coordinated effort to surround their first born daughter with tender loving care. They are in agreement that Shelley's medical care will be the best and for them this means that she will have no unnecessary interventions or surgeries and the most opportunities for growth and natural development. David and Theresa are equally skeptical of doctors and medical personnel who tell them one thing one day and something else the next. They are both well-read on Shelley's condition and make all decisions with great care and informed minds. They both say that they have learned to rely on themselves and are confident that they as parents have the most to offer their daughter.

They see Shelley's Spina Bifida as one part of her that does not in any way determine her future. They are very vocal and persuasive advocates for

their daughter and although both were raised to believe in a fatalistic world view, where one is taught to "go along with life and make the most of it," they say that they have had to become realists and recognize that life requires hard work and "tough choices" to get what you need.

Our interviews seemed comfortable for David who was able to express a lot of opinions and clearly thought out beliefs regarding Shelley and how her condition has impacted the family. He was quick to note that her special challenges "galvanized" him and Theresa and clearly marked a difference between their extended family and themselves. Theresa was more emotional and less polished in her accounting of the impact and coping process that evolved since Shelley's birth but she is in complete agreement that the event "knitted" her and David together. She also told me more than once that she "takes her parenting very seriously" and makes a point to expose her daughters to people of all backgrounds and nationalities particularly women who have professional careers which are non-traditional. They have many family rituals and spend a lot of informal family time together going on trips, out for meals and socializing with friends. They are clearly united in their parenting and display a partnership of beliefs and styles.

Findings

Theresa and David Donahue's story exemplifies several of the core categories and family themes that have emerged in the data with other families. In addition, they have an overriding spiritual belief guiding their personal philosophy of living that incorporates spirituality, belief in their family of origin traditions, and beliefs in self that have resulted from their mutual experiences. Unlike the other families, the Donahue's **initiation to special needs** was the same day as Shelley's birth. As David said, "When Shelley was born it was obvious that she had something different."

The difference was clearly Spina Bifida and she was taken to a local hospital that specializes in children. Spina Bifida is a malformation of the spine where a sac containing the covers of the spinal cord, the fluid and the spinal cord itself protrudes between the split vertebrae. Surgery is required to repair this although it cannot undo damage to the spine and typically causes some impairment in walking and bowel and bladder functions.

Shelley had surgery on the third day, David spent hours in the medical library during the next few days, and Shelley came home on day eight against medical advice. Both Theresa and David are wary of physicians and were

immediately put off by the way they were **initiated to special needs** and the disability.

. . . They told us all the things that are supposed to happen. They told us Shelley would be in a wheelchair, that she was never going to walk, they asked us, "Would you like to put her up for adoption?"

They rallied however, and their "fighting spirits" led them to find out all they could about Spina Bifida in order to prepare themselves to make informed decisions. This fighting spirit was not a new trait but an old strategy for each of them. Both of them talked about making their own way as kids and being strong minded, self-reliant individuals. As they talked I had the impression that they consider themselves to be somewhat different from the majority of other people. There were several references to "other people do this and that but not us." Theresa used the following words to describe their **external systems management style of confrontive questioner**:

We are fighters in everything. We don't accept anything easily, if someone tells us one thing we investigate it ourselves and find out if it's accurate. We are not swayed by people easily.

Although there was a **high degree of ambiguity** in Shelley's prognosis, this did not seem to sway David and Theresa from their position of maintaining responsibility. Their determination to be in charge of Shelley's

care added to their **perception of control**.

David echoed Theresa's thoughts as he recalled several experiences they had with doctors and medical researchers who tried to persuade them to participate in extensive programs and was very clear about how he and Theresa demanded information and refused to go along:

There were lots of things that they tried to get us involved with. Where they wanted to run tests on her and we were to pay money for thousands of dollars to run tests for kidney, liver stuff like that. Basically I confronted the doctors and said what are you doing and why are you doing this study? What information will you get out of it? [They reply] oh, we're going to do this and all this mumbo jumbo. So I asked what if they did find reflux, what are you going to do about it? Why pay for it and put Shelley through this, laying still, she was 1 1/2 or 2 years old. The exposure to the radiation which she had been exposed to countless times for orthopaedic films. What are we getting out of this deal? And basically it is all for their information . . . They hold a carrot out as a promise and say, "Oh, it's research" or something like that. It's to enhance or rationalize their education. But it doesn't trickle down to the individual, to the people!

Sentiments similar to David's have been frequently cited in the literature written by parents of handicapped children (Featherstone, 1980; Duffy, 1985) and more recently in the professional literature as well (Turnbull, et al., 1993). Theresa agreed, adding that she thought, "some people need it in order to feel that they are doing something for the child."

But the Donahue's see themselves as different than other people. They already had an established pattern of making decisions for themselves. She went on to tell about witnessing an episode which convinced her that it was time to take things into their own hands.

Well I kind of knew that Shelley was going to be just fine when she was home. After she had surgery on her back and the nurse had to catheterize her, the nurse could not do it. . . . I watched her and I asked her, "are you having trouble?" And, she said no but I said, "I think you are because that is the third "cath" and I have to pay for this," And she said no I'm not but I said give me the gloves, I'll do it. She asked me if I knew how to do it and I said no but that I could see what she was trying to do. So I put on the gloves and got it right in and said, "I'm taking her home tomorrow." . . . They were concerned that we wouldn't know how to do a catheterization and I looked at David and said, "I'm taking her home, she needs to be at home, and I did."

She came home with sutures, . . . we had a wonderful room where the sunlight came in and we laid her on her tummy and let the sun dry off her scar and we would pull the little sutures as they popped out. We did it ourselves, we took responsibility for that and I think a lot of parents sometimes they are very, they are mourning and they are afraid they can't handle it.

In adding his perception of other people's dilemmas, David touches on the possible feelings of guilt that are frequently associated with parents of disabled children in the quote below.

They don't want to make another mistake, they don't want to be

responsible anymore because they feel its their actions that led them there to begin with. So they have completely discharged their responsibility.

He adds his own thoughts about God's punishment and the fact that they are not hampered by self-doubts. David also notes the shift in thinking and changed **world view** as a result of this **shared trauma**.

When this happened it didn't throw us back. . . we went into it with a clear conscience and knowing we didn't do anything physically that could have caused it. . . . people think it's a punishment from God for having done something ten years ago. We realize it is not a punishment and we have recognized that so throughout this process we haven't had the guilt that a lot of people have. . . . We are just passing through this life and it's been a maturing process and recognizing . . . it was sad to lose the innocence, . . . and we did everything physically and spiritually right which we did to come to the understanding that bad things happen, because the world isn't perfect we cannot isolate ourselves from the world.

David's conclusion that the world isn't perfect was shared by several other parents in this study. For David and Theresa their "loss of innocence" was associated with at least three factors. These were the **shared trauma** of Shelley's birth defect, the secondary trauma of being let down by their extended families, and experiencing a sense of betrayal by the societal sales pitch of the "American Dream." Although it sounded as if they were clear from the outset about their **confrontive questioner style** of dealing with

external systems I got the impression that this behavior emerged after a lot of bumping up against reality.

As David and Theresa adjusted to their new baby, they were faced with another unexpected stressor which in David's words was, "more damaging" than Shelley's disability. This was the realization that there would be little if any support from either of their extended families. Both of the Donahue's talked at great length about the disappointment during that period when they were so in need. This illustrates the process of event/perception/behavior. Shelley's birth was a **boundary defining event** for them. The years after were full of incidents which they perceived as unhelpful and counter to their understanding of Shelley's disability. They drew a clear **boundary** between themselves and their extended families. David noted the irony of how, at this point, he and Theresa are in a financial position to help her siblings and parents but that they have learned to "respond in kind," meaning they are not willing to put themselves at risk for anyone other than each other or their daughters. Theresa broke into tears as she told me her own feelings at the time:

At the time, when we weren't getting the support I think I was very

resentful. We heard a lot of pat answers, "She'll be OK." It was their way of not acknowledging that this was major. They were comforting themselves to not accept the full impact of it and avoidance is sometimes the best protector. Well we couldn't avoid it, we had to confront it as educated parents who had wanted to have children. . . . I don't know if I'm resentful now but I think I'm at the point where they missed out on a lot of things where they could say "Wow, she's come a long way." They missed out on that. But I guess I expected more.

Theresa demonstrated a quick turn around which I came to label as the **cognitive coping strategy of construed benefits**, when in the next breath she started to tell me about the positive impacts resulting from that difficult time. She also illustrates their high level of **family congruence**.

The positive thing about not having the support of our families is we're very close knit. We are very tight. We can be in different rooms and think the same things, it's kind of eerie sometimes. We think so much alike and we depend on each other it's almost like getting married. The less family involvement you have the better it is the first couple of years because you become very knitted together. . . so we got to depend on each other and look towards each other for everything that we do.

In an individual session David voiced a similar theme of a shared belief system and talked about how his family's lack of support prepared him to **define boundaries** between his young family and the people who they had once trusted.

As a couple it made us a lot stronger because we recognized that

without other support we were the only ones we could depend on. So it strengthened our relationship. And it fixed in our minds that when things happen and your back's against the wall you basically find out who your friends are. I was always raised with the impression that, "I'm here for you." You know people saying that. Well I had never had the opportunity to have my back against the wall to this degree. . . . We got verbal support but no emotional support or financial support, it was challenging financially. You learn to pray when your back's against the wall and you have no one else to turn to you find God. But we already knew God. We were studying the Bible prior to that, so again it strengthened that because we couldn't trust, quote MAN. We couldn't trust the ties and the friendships that we thought were there. They ended up being paper bridges.

The galvanization enhanced what was already a marriage **high in congruency**. Both of them talked about thinking very much alike and sharing identical values. Their spiritual lives reflected their own personal philosophies which were based on Christian spiritual beliefs. They have rejected the more formal Catholicism of their childhoods for a more personal home-study of biblical teachings. Theresa talked about the cultural influence of Hispanic tradition which she has rejected but finds that it continues to follow her into the greater world:

My culture, its like . . . if I do something wrong that's why I got this It's like you reap what you sow type of thing. When I meet Spanish people all the time and they say, "Oh, pobrecita" which means "oh poor little thing" and I constantly fight with them, "she's not a pobrecita,

she's a very intelligent little girl and she's very happy because she has two parents that love her. There is no pobrecita!"

Theresa was very demonstrative in her telling of this story and finished it with a long list of reasons why Shelley was so fortunate (**construing benefits**) and how it could have been much worse (**making favorable comparisons**). Theresa told me how she "sets people straight" who might draw the conclusion that Shelley is to be pitied. Throughout the interview both parents made many comparisons to other children where Shelley is just like other children (**normalizing**) or better off than many other special needs children (**favorable comparisons**). These cognitive coping strategies are common with families and were evident to some degree in each family interviewed. I came to understand these cognitive coping strategies as a useful mental perspective, one that builds on itself. The more these families perceive their child as "the same as" or "better off than" the more positively they appraise their own situation. Lazarus & Folkman (1984) note the importance of positive appraisal in family adjustment. This positive appraisal leads parents to an increased feeling of competence and **sense of control** which works as fuel for the energy required to face the **everyday reminders**

that special needs children present.

Theresa and David's non-traditional approach to religious study is congruent with their pattern of doing things their own way. Theresa talked at length about how they live the biblical teachings and in our interviews she frequently mentioned how she perceives God's presence. As an eight year old Shelley is at an age where she is beginning to see herself in comparison to others. Occasionally she will ask her mother about her disability and it's impact on their family and Theresa finds herself responding with words that "seem just right." She believes they are inspired by God who sends her what she needs when she can't think of quite the right way to deal with Shelley's difficult questions.

It seemed to me that a high level of **family congruence** and united **behavioral response to external systems** assisted in their getting on with life. It is important to note however, that this getting on with things did not occur instantly or without a fair degree of **personal growth** and **change in perception**. Both of them talked about the incongruence of life, where things did not turn out as expected. This break in the illusion of a perfect life went beyond the lack of family support and seemed to encompass Shelley's

disability and perhaps other trials in their life as well. It seemed to me that in a **search for meaning** this couple embraced a belief system that made sense of all the unknowns, and that was their faith in God. This was matched with their personal philosophies which in some ways appeared to be a paradoxical combination. The Donahue's believe that God's plan will prevail, and at the same time they as individuals have the power to effect changes. Theresa talked at great length about God's great wisdom and how everything that happens is part of a plan. This belief allowed her to relinquish control, with the faith that good would come and that "what would be would be." It also imbued her with a **sense of meaning** in her own role as Shelley's mother.

I look at it as God has thought highly of me to put me in this situation. My philosophy is that God would never allow you to be put in a situation you couldn't handle. So that means in any situation you have already won the war. It's just a matter of getting through it. And as you're getting through it try to have as much fun as you can rather than, "Oh, woe is me." I don't buy that from anybody so I look at it that way and say God has found me worthy. He thinks I'm going to be a conqueror in this so I've just got to go with the program here. You know but have fun doing it and bless people.

This viewpoint does not prevent Theresa from having great faith in the belief that an individual has some **control over outcomes** if they think in a positive way:

The way you feel about things and the way you believe or perceive things is your outcome. If you feel that things are going to happen negatively and you're not going to move from that idea, then there's not going to be a result for that.

The power of Theresa and David's positive thinking is evidenced in the energy they direct toward their parenting and their conviction to do things in their own way. Their spiritual beliefs have not hampered their sense of personal control over most aspects of their daily lives. It is clear that they do not use their religious beliefs to avoid thinking for themselves but take those beliefs into account as they go through the **mastery process** of perceptual and behavioral responses to make sense of the events in their life and achieve **personal growth and a shift in world view**. Somehow as they talked about this rather complex connection between the trials they have been through, their faith in God's wisdom and their own personal power to effect changes I was able to see how this complex process of learning from one's beliefs, perceptions and real life experiences has played out in this family.

The Edwards Family

John and Patty Edwards were the second family contacted and the last set of interviews that I completed. The Edwards have three children, Kelly (10), Sean (8), and Brian, (6). Sean has a spinal cord injury which occurred during delivery and has left him with significant nerve damage and muscular weakness in his arms, abdomen and legs. Patty Edwards was pleasant on the phone when I first called and told her about the research project but she was very ambivalent about participating. Several weeks went by before she got back in touch with me to say they would participate and then another month before a convenient date for Patty and her husband, John could be set up.

We finally did meet in their home on a weekday evening when the boys were already in bed and the live-in baby sitter was in charge of keeping Kelly occupied elsewhere. Both parents seemed somewhat anxious and expressed discomfort at the idea of talking about Sean's birth, the subsequent events (which had legal and medical involvement) and their impact on the family as a whole. Before we started I asked them if they would like to reconsider participating but they both agreed that they would like to continue.

The story of Sean's birth was the dominant theme of the first interview. During delivery a sequence of events (including what came to be found as medical error) resulted in Sean's spinal cord injury. The Edwards knowledge of the diagnosis and extent of the injury was a long, frustrating, and frightening experience. Although Sean's physical impairment became evident within the first two days of his life, his condition was mis-diagnosed several times before a firm diagnosis of spinal cord injury was made when he was almost a year old. The Edwards travelled out of town on many occasions to see specialists and get second opinions. After the diagnosis it was several more years before the extent of Sean's disability could be estimated and there remain many areas of unknown prognosis today.

It is those unknowns which loom large for both John and Patty. They are quick to point out all of Sean's progress and they are thrilled that he has the range of motion and independence that allow him to walk on his own at this age, but they are reluctant to celebrate too much or breathe too great a sigh of relief because this type of injury leaves many questions about future physical development unanswered. My second interview with Patty was held at her office which allowed us more time and privacy to discuss the process

of their adjustment and how she sees the changes over time for her family.

Patty is a Research Librarian by training and spent many years working for a large company in a high pressure fast paced career. Recently she stopped work there and decided to work for a local school which puts her in sync with the children's schedules and allows for more family time. She sees her decision to slow down and enjoy life more as a direct result of Sean's disability and her personal growth. Like Sarah Conway she sees real shifts in her thinking and approach to Sean's disability over the last few years. She credits that shift to Sean's progress and her own emotional maturity that she believes came from facing this hardship head on and learning to deal with other difficulties in that same fashion. She is no longer willing to stay quiet or take a back seat to her husband, her father, or a doctor. She sees her marriage and family as having survived some rough times but ultimately believes this has strengthened her marriage and her family as a whole.

John works in the Real Estate business and runs a small but lucrative firm. The joint interview was dominated by Patty's enthusiastic and articulate responses. I found myself making a conscious effort to get John involved and to expand on his few brief comments. In the individual session, in the

privacy of a conference room at his office, he was able to talk more freely and echoed Patty's sentiments about the hard work of marriage in the face of an event like Sean's. He repeatedly pointed how important it is to prepare parents for the inevitable stress and resulting fall-out that challenges a families home-life. John credits his basic values as bringing him through those periods where it would have been easy to bail out.

John's perception of his own personal growth was in the realm of the marriage. He was quite clear about his role as a father and the "head of the house" which included the financial management of stupendous medical bills and looking out for "the overall good of the family." But the fact that he and Patty approached Sean's early years in such different ways lead to conflict and lots of opportunities for negotiating between partners. He wanted to be sure I understood just how hard that was and implied that both of them had come to terms with the others "mistakes" and "stupidity."

As he talked it became clearer to me why this couple hesitated before agreeing to participate. I was left with the impression that their son's injury shook the foundation of their family in a way that has taken years of deliberate effort to settle down. Both he and Patty shared with me that their

primary motivation for participating was to be of help to other parents. As both a couple and individuals they repeatedly shook their heads saying "Nobody told us what to expect or what might happen." They still seem surprised by that lack of preparation and betrayed by the medical community and their own family members. It is the experience of that self-taught lesson that they were willing to share.

Findings

John and Patty made no secret of Sean's difficult beginning and the impact of the **initiation to special needs** on their family life. Patty told me over the phone that their experience was like "walking through Hell." But, I had not appreciated the extent to which John and Patty's differing coping styles and lack of **family congruence** had disrupted their marriage. They both talked at length about how surprising and painful it was to be separate from their partner in this job of parenting. As Patty put it in our first meeting:

I don't think either of us was prepared, or at least I wasn't, that we would go through it and deal with stress in our own individual ways. You just kind of assume that everyone is going to do it your way, or I assumed that.

When I asked Patty to talk a little bit about what her way was she

responded :

Probably talking, and John's not a talker. I was the one when Sean was tiny, . . . that knew every single bit of information. I thought if I knew every bit of everything that's going to help make it work. That will bring it all together and you so identify with this child that it got out of whack, there's no question. And John just channeled it in different ways. [He thought] if I'm disciplined and I really work hard then I'll be able to protect him and provide for him. . . .but you don't see that you are working towards the same goals and you didn't see that you were ships passing in the night.

Sean's birth was indeed traumatic and the extended period of **ambiguity** with no diagnosis or prognostic information added to the trauma. Sean's spinal cord was injured during delivery. It was found to be the fault of the delivery room physician and an event which is so rare and unspeakable that other medical personnel tend to discount it as an impossibility. The Edwards spent over two years going up and down the east coast meeting with specialists and trying to find out if this was a tumor, congenital abnormality, or a birth trauma. Even after the diagnosis the doctors were unable to make any assessment of what to expect.

The confusion and **ambiguous** nature of the resulting disability added to the families stress which was compounded by the couples differing personal coping styles and **external systems management styles**. The low

level of **family congruency** resulting from a lack of a **shared definition** added to the existing stress and delayed adaptation. According to Lazarus and Folkman (1984), ambiguity is one of the factors that influences appraisal and it is also understood that the greater the ambiguity, the more influence personal factors have in determining the meaning of an environmental stressor (Lazarus & Folkman, 1984). Patty's perception of the ambiguity relating to her son's survival was one of great threat and was interpreted as a call for her to respond with the full force of her coping styles. This was a combination of external systems management styles influenced by her own childhood experiences and family of origin traditions.

Patty was brought up in a southern city, the eldest child of four with three younger brothers, under the paternalistic values of a highly successful and domineering father. She was brought up to listen to doctors and all other authority figures and not to question or stand up for her point of view. She talked about how her beliefs about motherhood and marriage were formed out of that family context and how some of these values and perceptions were working against her by keeping her stuck. Patty's **external system management** approach to the medical crisis was a high-gear blend of the

confrontive questioner and the compliant consumer. On the one hand, she faithfully followed up on each and every recommendation and did exactly as she was instructed by the specialists which is typical of the **compliant consumer** who casts her faith in the doctors' expertise. At times this called for round the clock medicine and catheterization every four hours for which Patty assumed the management and most of the actual care. On the other hand, her skills as a competent researcher had served her well in her professional life so she launched into an urgent personal quest to learn all that she could. This kept her anxiously searching for information about spinal cord injuries and hoping for an answer to Sean's multiple symptoms. This approach is more like the **confrontive questioner** who seeks answers on their own and places their faith in their own abilities to control the situation. Unfortunately neither of these approaches brought Patty the answers or solutions she hoped for and left her with no **sense of control** and little faith in the doctors or herself. Today she recognizes how in her words, "my emotional reactivity of that period fueled the panic" that urged her to try and get a **sense of control.** Now she works more from a **managing partner** stance, where she develops a cooperative relationship with physicians with

whom she shares a mutual respect. But at the time she was invested in her perception of her role as mother and by her standards she was not being successful. As she said,

"Initially I was struggling a lot where, as a good mom if you can just keep the kids well [you were doing your job]. Well I wasn't keeping the kids well! What was I to do about it?"

John early on could let it go and roll with it, whereas I was still working with each of the doctors and I thought if I could get a handle on this it will be better. [Now I know] this is not a possibility, but you can help, you have to be involved. I did go to the hospital every week and learn how to do all the exercises and moves to keep his hands from freezing up.

Her perception of herself as a mother who was not performing her role well was continually reinforced by Sean's increasing medical problems over the first four years (e.g., respiratory problems and multiple kidney infections). His poor health encouraged her to work even harder at her job (as she perceived it) and she did. It also kept her exhausted and at one end of a polarized situation with John at the other.

John's first response to the period of **initiation to special needs** and **ambiguity** of the diagnosis, was to shut down and go into shock. This is John's description:

The thing about Sean's [birth] was that it was a blur. It happened so fast I didn't, I was stunned for probably three or four months and didn't recognize the significance of what was happening. If I had I might have panicked.

As he recalls it, Sean was five months old when he recovered from the shock and "made his peace" with the trauma. At that time he came to the conclusion that his job was quite different from Patty's.

My job is to maintain the family, that's my job. I deal with the macro and Patty runs the micro. From a macro standpoint it was here's where we are let's just keep going. It really did become very clinical for me. Maybe it's the training, in business you get to a point where you say, hey (hand gesture of cutting-off) . . . and cut your losses and go from there.

In contrast to Patty's emotional and frenzied efforts to get control of this trauma by rigorously following all medical leads and keeping a vigilant watch on Sean's development for any changes, John sought out a **sense of control** and competence by relying on his own strengths and experiences which trained him to be cold and calculating. He had been the captain of a college basketball team and was trained with the mental discipline to "shoot the ball and not think about it again." As John said, "you don't think about it, you don't do what ifs. Never, it's over and you become disciplined enough to do that and never look back, never look back." This style had been

successful for him in high school and college and in the business world as well. There would be no second guessing himself or getting distracted by the "what ifs" of all the unknowns. He told me that he was able to see Sean's situation very "clinically". He defined that as "being able to get rid of the emotional aspects and the anger and just get on with the facts." It is not surprising then, that a man who is accustomed to a high level of competence when faced with a crisis would revert to form. He saw his role as calling for decisive action managed in a calm and unemotional fashion.

Well all of a sudden our medical expenses went up to \$100,000 a year out of pocket. Somebody had to worry, how are we going to fund this stuff? And then the question long term. . . you can't take the whole family down for a single unit. That was something Patty couldn't understand and you have to make some very tough decisions and we try to make them in the best interest of everyone but it might seem harsh at times and I was prepared to make some of those decisions. I don't think emotionally she could. Again my job was looking out 25 or 30 years down the road, that's my job.

This "clinical" approach was incomprehensible to Patty who was focused intensely on the immediate needs of Sean and working frantically to put those in place. Each in their own way was striving for some **sense of control** and a way to **attribute some meaning or cause** to the situation.

They righteously stuck with their individual styles accusing the other of being

"a control freak" and "in denial." This led to much less commonality, little team work and hampered the family's ability to create a common definition of their **shared trauma**. Without this mutual understanding the **family congruence** was low resulting in coping behaviors that were isolated efforts rather than a coordinated partnership. The event-perception-behavior figure eight was in play but on two different fields.

As mentioned in earlier cases the concept of experiencing a **shared trauma** has been a familiar theme for many of these families. When I asked Patty and John what their thoughts were on this phenomenon they were both quite clear about the powerful negative effects of the **extended initiation to special needs** period on their marriage. We talked about one of the possible consequences of shared trauma, that of creating a wedge in the marital partnership and pushing people apart. There is also the flip side of that effect which is the creation of a close bond serving as an adhesive for people. John clearly saw the trauma as a wedge for Jane and him:

I think the for the great majority it is the wedge. Oh, yeah, we don't explain to people what is going to happen to you, it's very traumatic, you have to understand what that wedge . . . that's a tremendous area that needs to be worked on because nobody understands the impact of that trauma.

When I asked John how he accounted for their strength and apparent resilience in spite of their different views, he let me know that it took hard work and a commitment to the values that he grew up with.

I don't think it was quite as easy as you think it was. . . You know, it takes a lot of work. . . there were a lot of bumps in the road, there were a lot of times when you could have easily just said, "I got other things to do and other places to go." . . . I think both of us would have been justified in doing it, but again I come from a very traditional conservative background where this concept of going steady and divorce is not in my vocabulary. I got married to stay married.

Patty also saw the fall-out from **shared trauma**. She agreed with John's assessment and noted that there was also a spill-over effect onto her relationship with her own parents. She talked at length about how the interaction between the trauma of Sean's injury and the perception and reaction of her parents created what I call a **boundary defining event**.

Although her parents had not been actively opposed to Patty's efforts on her sons behalf, they let her know that she should "leave the diagnosis and analysis to the professionals." They didn't understand why she felt that she needed to "know all this stuff." An even more powerful boundary defining even occurred when the Edwards decided to bring a malpractice suit against

the doctor. Patty's father, who is in the health field, was overtly opposed to this:

. . . Well, clearly my father who is part of the medical community and an authoritarian, and a wonderful kind man, but his word was the last word in our family. When we said we were doing to sue, it was like saying you're going to assassinate the Pope. I mean it was that big of an extreme to the point where he said on the telephone, "Good people don't sue." and being a doctor of course you don't sue another doctor. And I'm not one to stand up to my father much but that night I finally said, "Well I'm really sorry you feel that way and we will keep you out of it because that's what you've asked, but I do find it hard to believe that you'd side with a professional you don't know against your own grandchild." At which point he hung up the phone, and that's not sort of the way we normally tend to deal with stuff. . . And I'd never stood up to him before but it was like, you gotta stand up, you gotta stand up for your kids.

This phone conversation and Patty's **boundary defining behavior** marked a new phase in Patty's relationship with her father, her husband, and her own way of looking at the world and where she fits in (change in world view). The many months of pre-trial legalities, the trial itself, and it's aftermath came to represent a **boundary defining event** for Patty. She says that the experience of taking a stand was one of great **personal growth** for her and has resulted in many changes both for her as an individual and for her family.

Although Patty and John were in agreement that legal action was an appropriate course of action they had two very different reactions to conclusion of the trial where it was determined that Sean receive a large financial settlement. For John it was a nightmare and the beginning of a period of what he suspected was a 3-4 month depression.

You have to understand the traumatic experience it was. The damage of the trial was more damage to us emotionally, . . . It was tougher to take than anything I'd been through. I've told Patty somebody should have prepared me for those settlement negotiations, it is not a normal human thing.

John noted that a few months prior to this time a business associate had died and left him in charge of a floundering company. John's perception at the time was that he needed to earn as much money as possible in order to care for his family. This kept him leaving for work early and returning home very late. The Edwards' health insurance benefits were linked to Patty's full-time job and she was "locked into" her career by choice but also in order to continue to receive insurance coverage for Sean's expensive medical care. The job-related stresses for both Patty and John, the financial burdens, and concerns about Sean's sister Kelly who was experiencing some emotional problems related to her parent's constant anxious attention on Sean, all

combined to create a tremendous pile-up of stressors.

McCubbin and Patterson's (1983) Double ABCX model identified this very process with families who experience an unusual stress and as a result of efforts to cope, experience secondary stressor which confound the problem. John seemed to have hit "rock bottom" at this point right after the trial. He shook his head as he talked about how shocked he was by his own reaction. He looks back on that period as the most difficult time but has not arrived at any explanation or analysis of it. I wondered if he was having a delayed reaction to the trauma of the **initiation to special needs** period that seems to have ended so early and abruptly for him. It is also possible that the large financial settlement for Sean did not bring him the sense of satisfaction or control that he had expected. He talked about the "tremendous sense of let down" and "feeling numb." He remarked on how even though they had won this "unwinable case" they didn't celebrate. John's years of focus on the financial responsibility may have kept him distracted from the larger issue of Sean's life long disability that no amount of money will fix. As he talked about the tremendous impact of the trial on his own functioning I wondered if the trial brought that reality into a larger focus for him. Unlike Patty who had

been busy using **cognitive coping strategies** and making changes in her behavioral responses through **boundary definition** and a more **managing partner** approach to outside systems, John had relied on **faith** and due to his efforts to be a "good provider" a **perception of control**. The months of legal battles and the "charade of justice" of the trial may have symbolized his ultimate lack of control. This left him with faith.

I think I have a strong sense of faith. I grew up in a Irish Catholic family and if it happened it happened. . . . faith is crutch. Absolutely it is. But it works, it works for me and in those moments when you don't know, you say, I give up. I guess somebody else is running this deal. That happened, sure.

John told me several times that he is not a "deep thinker" and is not inclined to try and unravel all of the turmoil from three years ago. But he clearly has a great respect for the powerful emotional upheaval that he experienced a **boundary defining event**. It seems to have allowed him to move closer to Patty and perhaps be more empathetic with her earlier state.

It was interesting then that for Patty the trial was vindication providing public proof that she had not been responsible for Sean's disability.

For me I had harbored this intense fear of, "oh my God did I sit in front of the computer at work and shouldn't have." Did this create some problem I was not aware of. For me the trial was such a relief because

they (the defense attorneys) couldn't find anything and they would have if they could have. . . It was a huge, huge relief.

Patty talked about how that relief allowed her to let go of her need for control and to think more clearly about what she could and couldn't do for her son. She **redefined** her role as Sean's mother, allowing herself, for the first time, some margin for error. The post-trial period became her opportunity to think about her own **perceptions** and **behavioral responses** of the first few years and to consciously make some changes in her approach to Sean's medical needs, her career, and her relationship with her husband and extended family. She attributes each of those changes to the tremendous **personal growth** that she experienced and continues to promote.

I looked inwardly and said what are you all about? I was brought up, as a pretty southern female, you go along to get along, . . . You don't stand up for yourself you don't, I had three brothers and it was low man on the totem pole. For me it wasn't so much idealism it was this is just the way it is. It's just the way it is where as now I feel so much more solid. And I do my own evaluation and I have my own input and if I don't agree I do have a right to say, "hold it." So I see a grounding there . . . Where I see control as being very reactive and emotionally charged . . . and now although I still care deeply, I am able to separate that emotion from the fact and sort of evaluate, "What is this, and what is the most constructive way to move forward to solve it." So there's that difference for me and I wouldn't want to go back. . . . I see it [growth] as a different developmental stage almost, I feel much more complete as a person where I am now than I saw myself then. And

that's sort of a silver lining.

Patty's self-description sounds like a move towards increased differentiation (Bowen, 1978). Her change in self-perception instigated changes in the way she was able to see her family. She talked about her own childhood and how she was taught to never bring up uncomfortable issues. She has learned that the best thing to do is "face things head-on" and "put them out on the table" so you can discuss them. She gave several examples where her new approach was much more successful than the old. She used to panic if other kids commented on Sean's funny way of walking. Walking into summer camp with Sean this happened:

Walking into camp one day he didn't have his braces on and there were two children behind him who were talking to each other and one turned to the other and said, "Why is he walking funny?" . . . my heart stopped, and Sean's heart stopped but we kept on walking and didn't say anything cause I didn't know what to do. I was like, oh God it's coming. My worst fear, I had said from the day of his birth was the day that peers rejected him. My worst fear and I was like "I'm not ready for this, I don't know what to do, maybe he didn't hear it." So I'd ignore it and hope he didn't hear it. But I knew he did.

Now Patty makes a point to address the issue when they are home or at a appropriate time. She has found that even ugly or distasteful topics are not so scary if, as a family, you can talk about them. Patty has gone for

counseling over the course of the last six years and she credits her therapists with helping her to develop new parenting skills. Her decision to seek out counseling was an indication of a **shift in world view** for Patty who had been raised with the idea that "people like us" don't go to therapists.

John was less articulate about **personal changes** for himself but when I asked him to consider from a man's point of view what personal growth there might have been he replied, "As a human being I finally understood what marriage really meant." I found this a poignant statement and very symbolic of the profound impact that Sean's injury and resulting disability have had.

Patty mentioned how giving up her notion of being the "perfect family" has opened up new and healthier ways of coping. Again a change in perception has carried her along the spiral to new ways of doing things, and back again to a different way of thinking about things.

We were the "perfect" family. I grew up in the perfect family, but we clearly weren't cause everybody has faults but of course we [went along] as "everyone is happy and everything is fine." Then you get that reality check. But you want that reality. It's not a bad thing. We don't want to be the perfect family,. . . We're connected to human kind and that's good and bad. You can make mistakes and you do make mistakes but you learn making those mistakes rather than fearing making a mistake means that something's wrong. That's the acceptance, not only of yourself but the greater world and God's part in

that and just letting go in that regard of that control and realizing that good can come from that.

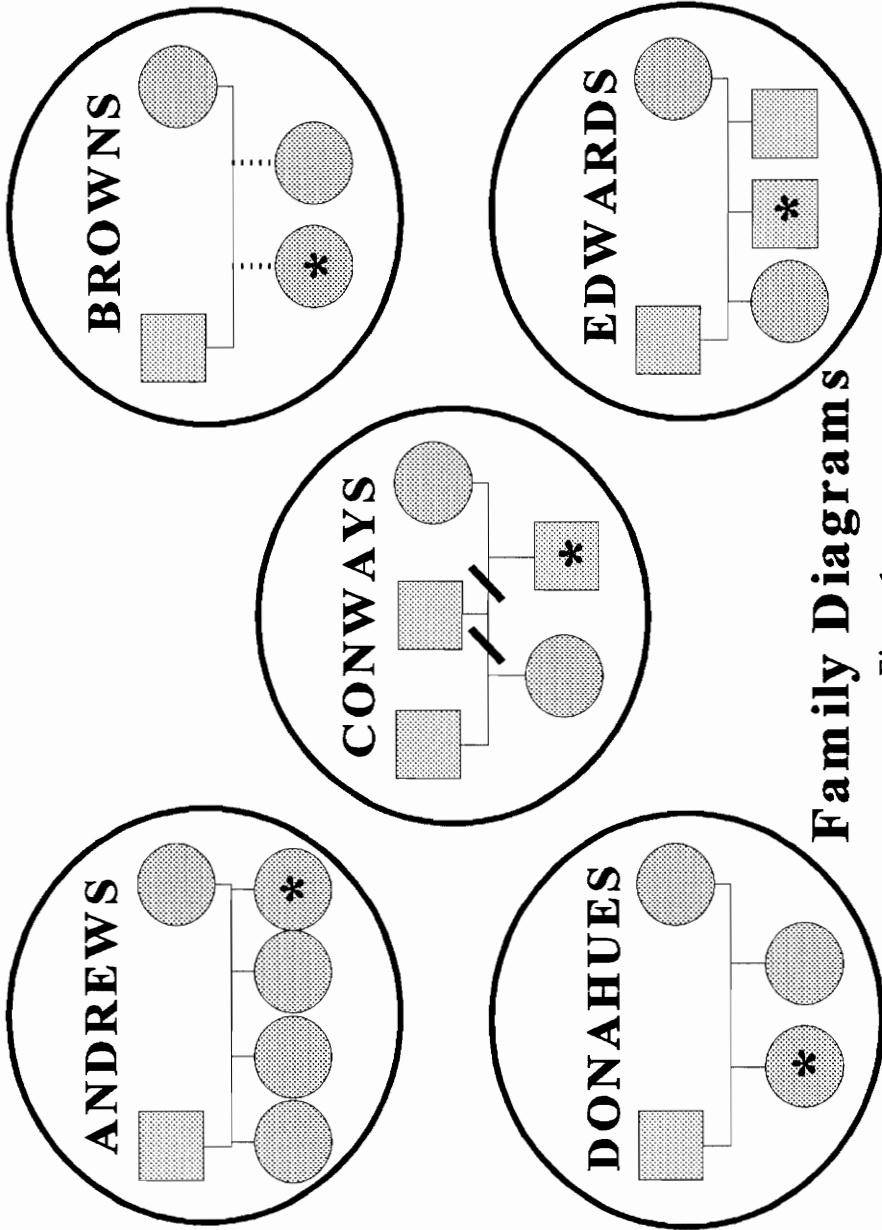
Patty's ability and interest in expressing her thoughts was very compelling. Our second interview ran long as we talked about the events of the past eight years and how her thinking has changed. She was able to summarize their experience with the process of change in perception and how it interacts with changes in behavior and experience over time.

For a while it was like treading water and "Oh my God I'll go under if I don't keep this up" and the pace of all of it. And then at some point you get to a point, I mean as Sean got stronger it was easier to fall back . . . to be able to enjoy things again and to laugh again. Brian was a big one in that regard. . . . He's got a wonderful gut belly laugh and when he laughs we all laugh with him in ways that are healing. Initially, when you called, . . . Threatening is probably the wrong word, but I thought back to that first acceptance and said, "Oh my God do we have to go back there?" And yet going back to it now it's not as scary. I mean you knew you'd make it, you knew you'd survive but sometimes you didn't know how. . . . The growth for me and our family is a very positive thing, I would not want to go back to where I was. I wish I could have learned it differently, but I probably wouldn't have had it not been so colossal.

John and Patty's courage to prevail as parents and ability to talk so candidly about their struggles impressed me as an essential piece of the mastery process. Their willingness to share their story has enriched my understanding of the larger story for all parents who face challenges.

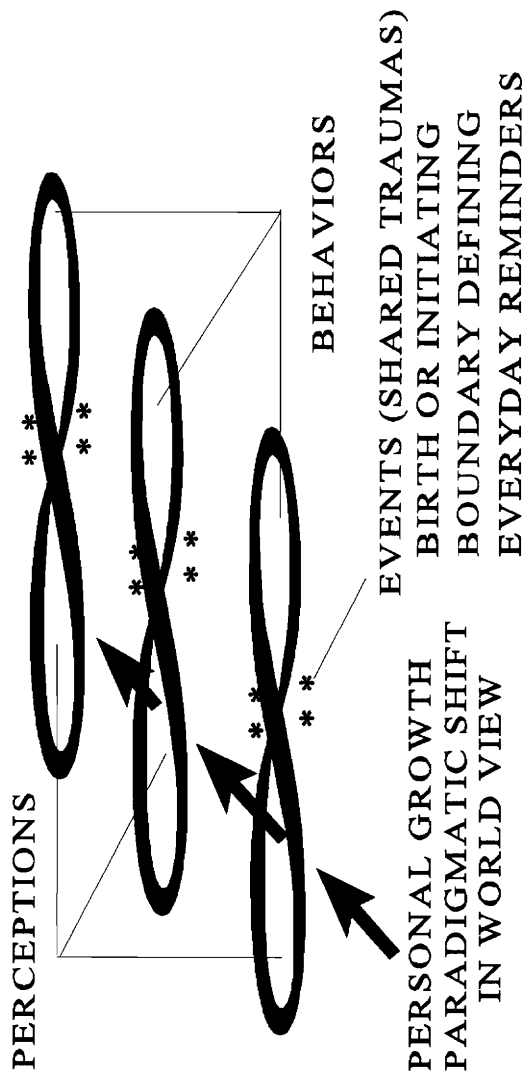
Summary

Each one of these stories illustrates the iterative **Mastery Process** of parenting a child with special needs. Within each family's unique story the continuous process of learning from experience and the resulting development of adaptive responses is evident. The back and forth cycle of perception and behavior is evidenced in these parents' narratives of change over time and highlighted by their stories of personal growth. The child's progressive growth, paired with the parents' ability to recognize and respond to the child's development seems to be a key factor in healthy family adaptation.



Family Diagrams

Figure 1



MASTERY PROCESS

Figure 2

Table 1

MASTERY PROCESS CORE CATEGORIES

Shared Traumas

- Initiation to special needs
- Ambiguity
- Boundary defining periods and events
- Everyday reminders

Coping Processes

Perceptual

- Family Congruence
- Cognitive Coping Strategies
 - Attribution of cause and meaning
 - Assigning a special purpose
 - Construing benefits
 - Making favorable comparisons
 - Redefinition
 - Normalizing

Faith

Behavioral

- Boundary Definition
- External Systems Management Styles
 - Confrontive Questioner
 - Compliant Consumer
 - Managing Partner

Personal Growth

- Paradigmatic shift in world view

CHAPTER V

DISCUSSION

In this study I examined the coping processes of families who seem to be coping well with children with physical disabilities. I found these families to be using both cognitive and behavioral coping processes that work together to create a dynamic process that evolves over time. The results support earlier research indicating that parents' coping is enhanced by positive appraisal and active coping responses (Lazarus & Folkman, 1984). The participants' positive appraisal may come in the form of cognitive coping strategies, an understanding of the disability which is congruent with individual family members' larger world view as well as between family members, and some form of spiritual faith. Parents' behavioral coping responses include the definition of boundaries at critical times and the use of external systems management styles. Participants in the study identify the areas of personal growth and a change in world view as by-products of the coping process. This, in turn, feeds back into the ongoing coping process providing an increased sense of mastery and congruence.

Limitations

It is important to note the limitations of this study prior to identifying clinical implications and avenues for possible future research. The limitations include aspects of the research design and the participants' homogeneous makeup.

Due to practical constraints of time the research proposal called for a theoretical sampling of four to six families. The five families interviewed were very generous with their time and thoughts but the small sample size did not allow for theoretical saturation. A larger sample size would have allowed for a more in-depth investigation and theoretical tightening that exhausted the data (Gilgun et al., 1992). In addition, the participants were not selected at random, but through a preselection process to gather a pool of families who were coping relatively well with their physically disabled child. While not generalizable in the traditional sense the findings generalize to theory and provide a rich description and theoretical notion about the process of coping.

The participants are not a diverse group in terms of socioeconomics and education. They are a very clearly defined population of highly educated parents who have the where-with-all to get services and to make the most of

an unfortunate situation by taking advantage of their resources. Besides their own resources of education and financial security, external resources may include hired babysitters, private schooling, tutoring, private physical therapy and counseling support.

Atkinson, Heath, and Chenail (1991) state, “Establishing the trustworthiness of the insights generated through exploratory research is the job of those who are consumers of the research, not the job of social science researchers (p. 163).” Finally, it is up to the reader to make up their own mind about the usefulness of these findings. As each reader brings their own lens to the interpretation of research results, they may identify limitations and implications for clinical work that were not evident to the primary researcher.

Clinical Implications

In the final stages of coding and during ongoing analysis, implications for therapy, hospital-based parent support systems, and clinical training were noted. The implications for therapy are rooted in the larger societal changes regarding individuals with disabilities. These sociohistorical changes, which represent the societal influences on the family system (Turnbull, Summers &

Brotherson, 1986), became more evident as participants spoke about changes in self perception and changes in world view.

Most of the parents in this study were brought up in the 1950's when individuals with handicapping conditions were considered second class citizens. There were few public schools for children with disabilities available, and families' expectations and preparations for their children with disabilities were a private matter. The image of the "American family" of the 1950's did not include a child with special needs. Some parents in this study talked about growing up with little exposure to disabled children. In fact, families with their financial resources were more likely to send "handicapped" children to a residential care facility or special school that removed the special child from the daily affairs of the rest of the family (Shenkoff & Meisels, 1990). Parents today are living in another time, where acceptance of differences is legislated and socially promoted as an American value. The parents that participated in this study welcome and demand equal opportunities for their children. They have high expectations for their children's futures. However, this change in perception and world view has not come without some cost. Several parents talked about the pain and effort

associated with the loss of the image of the “perfect family” that they associated with the American dream. They felt torn between loyalty to their own parents’ ideals and their more realistic assessment of a family imposed by the realities of daily living. This struggle between the “belief in what was supposed to be” and the recognition of “what is” was a long and self-searching one for some participants. No two parents were alike, but each of them talked about the need to reconcile their childhood understanding of the “American dream,” which included health and well-being, with their circumstances today.

Mental health professionals working with families with children with special needs are advised not to underestimate the personal struggle and growth required for parents who present themselves as highly competent, resourceful individuals. It would be easy to assume that these upper-middle class, educated families make a relatively easy transition due to their resources and traditional family backgrounds. As I heard participants talk about the struggle to reconstruct an image of their “perfect family,” to include a child in a wheelchair or with disfigured legs, I wondered if that experience of having lived the “All American family life” was a help or a hindrance.

Several families talked about how difficult it was to let go of their narrow focus on fixing their child's problem so they could get back to the way things used to be. Family therapists working with this population will do well to respect a family's orientation toward "solutions" and "answers" and gently to prepare families for the inevitable changes that will occur.

Additionally, the findings encourage therapists to set aside the theories that rely on regimented pathways to acceptance and family adaptation. Recognizing each family's unique style allows clinicians to build on personal and family strengths. One parent's stubborn resistance to intervention may serve a similar function as another parent's ready compliance. Examining these responses within the family context is critical to the assessment of family coping. A key to healthy adaptation seems to be the "goodness of fit" between a parent's individual style, their experiences and their coping strategies. A clinician's ability to recognize and enhance a variety of active coping responses will be most helpful to families as they work toward that "goodness of fit."

Clinicians who can normalize certain aspects of parenting children with special needs and help parents to understand their own efforts as meaningful

coping responses rather than “denial,” “enmeshment” or “avoidance,” can help families make the most of their own resources. The value of positive illusion (Baumeister, 1989) and the variety of cognitive coping strategies that lend a moderating influence to the challenges of everyday life may be the family’s version of the therapeutic reframe. Although there is not a standard pathway to family adaptation there are many common aspects of parenting a child with special needs. A therapist’s familiarity with the stressful initiation to special needs period and a sensitivity to the impact of an ambiguous diagnosis will help parents to prepare for some potential rough times. The therapist who can forewarn parents about possible boundary defining events and support clients in their decisions about how to deal with unsupportive family members may help to avoid long term cut-offs (Bowen, 1978). Therapists may also help parents to identify aspects of daily life that are interfering with their adjustment and establish new boundaries whether it is with extended family relationships or professional support services. A therapist’s confidence in the clients’ abilities to learn from their own experiences is invaluable to the therapeutic relationship.

Hospital-based counseling is another area for increased sensitivity to

parents' dealing with children with disabilities. One father made it clear that he would have benefitted from counseling prior to his son's discharge. He regretted that none of the doctors or medical personnel even hinted at the impact that the disability might have on family relationships. He recommended that all parents receive information about the potential for marital stress and for secondary problems with siblings. Again, these parents are accustomed to a high level of competence and self-control and will hang-on to those attributes in times of crises. Hospital-based social workers and physicians will encounter parents who appear well-educated and financially secure. They may make the false assumption that these families do not need the same degree of counseling support and basic information about the broader impacts of disabilities as families with fewer resources.

Finally, the use of videotapes in training mental health workers and medical personnel would be helpful in sensitizing the professionals to the larger family issues associated with children with special needs. The impacts of families' spoken words are minimized when they are reduced to written print. I learned this from my own experience in transcribing interviews. Converting the spoken words of the participants to a typed page helped me to

get some distance from the emotional nature of the interviews and this was useful for the coding and analysis. But, as I reviewed the transcripts I was keenly aware of the difference in impact between reading a story about a family's reaction to a child's birth and hearing it in person. Note that not only is the intensity of emotion about crises lost, but the individual's strength of character and personality as well. A therapist's job is certainly more difficult if they are provided with only a two-dimensional view of parents with children with special needs. The essence of the human potential is lost in the translation. A good portion of this can be replaced by the use of videotaped interviews. Families who are willing to share their stories do so in hopes that they can smooth the parenting process for families in the future.

Implications for Future Research

Upon completion, qualitative studies with small sample sizes may leave the researcher with as many questions as answers. This was the case in this study. Future research with a larger sample size and greater diversity among participants would add depth to the current findings. It would be interesting to interview families who do not consider themselves as having grown up with the "American dream" or "perfect family" model. This could reveal

what manifestations of personal growth and changes in world view transpired, if any.

Families dealing with a broader range of disabilities would also be an area of interest as well as families who do not see themselves as coping well. A Solution-Oriented approach to an interview with families who identified themselves as non-copers would be enlightening.

Participants in this study believed the quality of their marital relationship to be of primary significance to their own healthy adaptation. Some parents in this study talked at length about the “bond” that developed between the two of them. Others talked about the “wedge” that appeared, highlighting their fundamental differences. It would be helpful to understand more clearly how couples with special needs children are affected by the child with special needs and vice versa. Young children with disabilities are no different from other youngsters who are quite sensitive to their parents’ moods. It would be interesting to see future qualitative research on the marital relationship and how it may have changed over time, specifically how the quality of that relationship has affected the family’s overall coping at critical times.

The area of spiritual faith is an area that deserves further study. Even

within this small group of five families, the use of the term "faith" represented a variety of processes. Some parents put their faith into play in defining an answer to their questions about their child's disability. Other parents regarded their faith as a cornerstone in helping to construct the larger questions of the meaning of life that effect us all. Clinicians who work in settings with a spiritual orientation may shed some light on the varieties of faith experience and find avenues to enhance this attribute of coping, particularly for families who do not participate in organized religion.

Collectively these families share common attributes and life experiences. As individuals they offer us a window into the complexity of the process of coping and the unique nature of that task.

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APPENDICES

APPENDIX A

Participant Informed Consent

Title of the Study: Families with Special Needs Children: A Qualitative Study of the Process of Coping

Investigator: This study is being conducted by Susan A. Snell, candidate for the master's degree in Marriage and Family Therapy at the Virginia Polytechnic Institute and State University. Her advisor is Dr. Karen Rosen. Susan can be reached at (703) 893-8324.

I. Study Purpose

The purpose of this study is to examine how families with special needs children cope. The study will focus on the development and significance of coping strategies as a process over time and will attempt to build a detailed description of the experience of families with handicapped children.

II. Procedures

Participation in this study will consist of two one and one half hour interviews with parent(s) of special needs children. The interviews will be audiotaped and transcribed for coding and analysis. A potential risk of participating may be a feeling of dredging up memories of difficult times. If you should become uncomfortable during this process and wish to withdraw, you need only inform the researcher.

III. Benefits of the project

A potential benefit of participating in this study may be the opportunity to reflect on and enhance your coping skills which have already served you well. Your participation in the project will provide other families and professionals information about coping processes in families with special needs children.

No guarantee of benefits has been made to encourage you to

participate.

If requested, you may receive a summary of this research when completed.

IV. Confidentiality

All information you provide will be treated as completely confidential. However, if there is suspicion of child abuse mental health professionals have the responsibility to report information to appropriate persons with or without your permission. Our conversations will be audiotaped. These tapes will be reviewed by the researcher and transcriptionist only. The transcriptionist will be required to sign a statement pledging confidentiality and to withdraw from further involvement should it be discovered that he or she knows you. Any oral or written presentations associated with this study will not include your real name and every effort will be made to eliminate any identifying features from information you provide. A pseudonym will be used to label your audiotape and any identifying material will be disguised or eliminated from the transcripts of your words. Tapes will be stored under lock and key and erased after August 1995.

V. Freedom to Withdraw

If at any time you change your mind about participating in the study, you are encouraged to withdraw your consent and to cancel your participation.

VI. Approval of Research

This research project has been approved, as required, by the Institutional Review Board for projects involving human subjects at Virginia Polytechnic Institute and State University and by the Department of Family and Child Development.

VII. Subject's Responsibilities

I know of no reason I cannot participate in this study. I have had all my questions answered and hereby give my consent for participation in this project.

Participant's signature

Date

Participant's signature

VIII. Subject's Permission

I have read and understand the informed consent and conditions of this project. I hereby acknowledge the above and give my voluntary consent for participation in this project. If I participate, I may withdraw at any time.

Should I have any questions about this research or its conduct, I will contact:

Susan A. Snell (703) 893-8324
Researcher

Karen Rosen (703) 698-6027
Faculty Advisor

Ernest R. Stout (703) 231-9359
Chair, IRB
Research Division

APPENDIX B

Guiding Interview Questions and Topics

(These questions will not necessarily be asked as they are written. They are a guide and will be phrased according to what seems appropriate during the actual interview.)

First interview

1. Tell me about when you learned that your child had a disability?
2. Tell me about a typical weekday.
3. Tell me about a typical weekend.
4. Describe how you manage work, home life and your child's/children's needs.
5. Is there time left for leisure activities?
6. Have either of you had any prior experience with handicapped individuals?
7. What kinds of external resources did you tap into right away? Extended family / community resources / religious organizations?
What resources did you develop over time?
Are there resources which you felt were missing?
Are there resources which were indispensable?
8. How did you learn to utilize those resources? Prior experiences?
9. How are decisions about who is responsible for what made? How have

these changed over time?

10. Do you and your husband/wife share a definition or understanding of the handicap? Which perspectives are similar and which are different? How have those differences and similarities enhanced or hindered your ability to cope?
11. Tell me about a time that you dealt with your child and did a good job.
Tell me about a time when you thought you did not do a good job.
12. How would you as parents define a well-functioning family?

Second interview

Share the summary of the first interview and ask for thoughts and impressions about the researchers interpretations as well as the parents' own thoughts about first interview.

1. Were there inner strengths that you utilized?
Are these inner strengths which you believe are critical?
How did you come by these? Learned, natural tendency or personality?
2. What societal values or expectations, perceptions, judgments and assumptions do you see and how do they impact you? How do you respond to them and how has this response changed over time?
3. How has your perception of your family changed since the first year of your handicapped child's life?
4. What would you identify as coping strategies that have been helpful? How and any ideas on why?
5. How have you seen your handicapped child cope? How have you seen your other children coping and adapting? What changes over time have you seen from each family member?

6. Some people say that the characteristics of flexibility and consistency play a role in coping processes? How do you see that?
7. What questions haven't I asked that you think are important?
8. How was this experience for you?

APPENDIX C

Transcriptionist's Confidentiality Statement

Title of Study: Families of Handicapped Children: A Qualitative Study of the Process of Coping

Primary researcher: Susan A. Snell

Confidentiality Pledge:

I understand that the information being collected in this study is sensitive, personal and is strictly confidential. I hereby pledge that I will keep all such information confidential. I also pledge to withdraw immediately from further involvement with a particular interview if I discover that the participant whose interview I am transcribing is an acquaintance of mine or known by me in any way.

Signature

Date

5. How have you seen your handicapped child cope? How have you seen your other children coping and adapting? What changes over time have you seen from each family member?

6. Some people say that the characteristics of flexibility and consistency play a role in coping processes? How do you see that?

7. What questions haven't I asked that you think are important?

8. How was this experience for you?

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