Abstract

Title of Dissertation: PARENTS OF CHILDREN WITH MENTAL RETARDATION:

COPING MECHANISMS AND SUPPORT NEEDS

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and Personnel Services

The purpose of this research was to explore the subjective experiences of families of children with mental retardation, specifically the sources of stress and coping for these families. Interviews were conducted with families to shed light on their subjective experiences of coping and stress. In an effort to increase understanding of the worldview of these families, issues in theory, practice, and future research are briefly discussed. Social support and empowerment oriented professional practice were found to have a mediating effect on family stress.

PARENTS OF CHILDREN WITH MENTAL RETARDATION:

COPING MECHANISMS AND SUPPORT NEEDS

by

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Dissertation submitted to the Faculty of the Graduate School of the
University of Maryland, College Park in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
2004

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Chapter 1 Introduction

The American Association of Mental Retardation (aamr.org, 2002) defines an

individual with mental retardation as someone having substantial, sub-average

intellectual and adaptive behavioral functioning with onset before 18 years of age and

limitations in at least two of the following areas: (a) communication, (b) home living, (c)

social skills, (d) community use, (e) self-direction, (f) safety, (g) functional academics,

(h) leisure, or (i) work activities. Previous research has revealed that, given appropriate

support and resources, parents of children with mental retardation can cope with the

challenges presented by their children and, in turn, provide a nurturing home environment

(Crnic, Friedrich, & Greenberg, 1983). A nurturing home environment is a consistent

predictor of success in school and subsequently in habilitation programs aimed at job

training and increased independence (Mott, Fewell, Lewis, Meisels, Shonkoff, &

Simeonsson., 1986). Most previous research has been oriented toward pathologizing

families of children with disabilities (Guess, 1996). This research will take a more

strengths-based focus and add to the current body of literature on family coping and

implications for theory and practice. A grounded theory approach (Strauss & Corbin,

1998) will be used to give families a strong voice in building a theory of coping. This

qualitative approach promotes research that moves from what is seen and heard to an

unexplored abstract understanding. There has been only relatively modest attention to the

family voice in guiding theory and practice regarding family stress and resilience in

families of children with mental retardation. Because of this lack of a strong family voice,

there may be critical data missing in current theory, research, and practice. The major

thrust of this study is to achieve a more thorough understanding of these families as a fundamental building block for future research. A grounded theory approach is ideal for achieving this more thorough understanding. Grounded theory means theory that is derived from data gathered in the research process. A grounded theory research project does not begin with a preconceived theory in mind. The grounded theory project begins with an area of study and allows the theory to emerge from the data. Theory derived from data is more likely to represent the research subject's reality rather than concepts based on speculation. Research derived from grounded theory is more likely to offer insight, enhance understanding, and provide meaningful guidance to professional practice. For this study, direct quotations from interviews and journal entries will be documented and analyzed. Dewey (1934) noted that, "if the artist does not perfect a new vision in his process of doing, he acts mechanically and repeats some old model fixed like a blueprint in his mind." The grounded theory approach, which can assist the researcher in perfecting a new vision, will be discussed further in Chapter 3, Methodology.

This research is based on three precepts. First, because mental retardation is a frequently occurring condition, affecting approximately seven million individuals in the United States, quality research and services are needed. Second, early intervention aimed at strengthening family resources appears to have the most significant effect on increased level of functioning of the child with mental retardation and family satisfaction (Ziolko, 1991). Finally, the research is based on a humane philosophy that individuals with mental retardation can be contributing members of society.

The coping abilities of families are a key feature of this research. Zeidner and Endler (1996) define coping as a stabilizing factor that can help individuals maintain psychosocial adaptation during stressful periods. It encompasses cognitive and behavioral efforts to reduce or eliminate stressful conditions associated with emotional distress.

The Importance of Humane Treatment

Historically, there are precedents for intolerance of individuals with disabilities. The Spartans were known to drown obviously defective infants in the river. The laws of Lycurgus required the deliberate abandonment of idiots. Luther and Calvin regarded mental incompetents as filled with Satan (Davies, 1923). Sir Francis Galton advocated for eugenics in the nineteenth century (Hollander, 1986). In 1998, some parents of typically developing public school children expressed dismay over the costs of special education (Charles County Public School Budget Hearing, 1998).

Despite these historical prejudices, there are four arguments for humane treatment of individuals with mental retardation. First, a society is judged by how its less fortunate are treated. The great scholar, Hillel said, "Be of the disciples of Aaron, give peace and love to thy fellow creatures" (Hertz, 1945). A central ethical teaching of Jesus based on the Sermon on the Mount was, "All things whatsoever ye would that men should do to you, do ye even so to them," known as the Golden Rule (Hirsch, 1993). In 1770, Samuel Johnson said, "A decent provision for the less fortunate is the true test of civilization." The teachings of Jesus, Bishop Myra (Saint Nicholas), and later other

religious and social leaders recognized the social responsibility and compassion towards the mentally deficient.

Second, while in earlier times, individuals with mental retardation contributed little to society (Davies, 1923), current habilitation practices allow for increased independence, satisfaction, and vocational success. These effective outcomes for individuals with mental retardation are directly related to family adjustment and available support (Ziolko, 1991).

Third, although Wilson (1995) would argue that organisms need to do what is best for the species, for humans it becomes difficult to know where to draw the line. If a human society were to decide to euthanize any individual with an I.Q. less than 70, that society would eventually have to address euthanizing individuals with an I.Q. of less than 80 (Muhammed Ali), individuals with club foot (Lord Byron), and individuals with known learning disabilities (Albert Einstein). Macklin and Gaylin (1979) reviewed the issue of sterilization for individuals with mental retardation and concluded that restricting the civil liberties of these individuals presented a plethora of ethical concerns.

Finally, the issue of humane treatment affects not only the individual with a disability but also the rest of society. Individuals, groups, families, and society observe carefully to see how vulnerable members of a society are treated as a model for their own behavior. Mainstream inclusion projects of the public school, in which special education students are involved in the same classroom with their more typical peers, are designed so that the special education students may observe other students for appropriately modeled learning behavior and so that they might teach tolerance and compassion to the more typical students.

Statement of the Problem

Prior research on families of children with mental retardation have yielded mixed results: Whereas some studies have noted increased stress among these families, other studies have indicated that families have tremendous resiliency and can mobilize resources to cope with their particular challenges (Abbott & Meredith, 1986; Bebko, Konstantareas, & Springer, 1987; Trivette, Dunst, Deal, Hamer, & Propst, 1990).

Parents of children with mental retardation face a multitude of challenges (Cherry, 1989; Minnes, 1988). The literature suggests that one challenge faced by these parents is social isolation. Friends and family members may not understand the special needs of a child with mental retardation (Friedrich, Greenberg, & Crnic, 1983) and thus, may not be able to provide the child-care support often available to families with more typical young children. It is often more challenging for families with a special needs child to go out into the community for shopping, meals, or other typical family outings (Kazak & Wilcox, 1984).

A second challenge frequently reported in the literature is that parents of children with mental retardation are subject to stigma. Most community or neighborhood members are not exposed to or educated about individuals with mental retardation (Kazak & Wilcox, 1984). Further, the general public has low tolerance for behavior outside of the norm. Families of children with mental retardation are often sensitive to drawing negative attention to their families in public places.

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Third, parents of children with mental retardation often express concern regarding balancing the needs of the child with special needs with those of other siblings (Harris, 1994). It is natural for parents to try to invest a great deal of time and energy into the child with the most significant needs. However, siblings of children with mental retardation often express feeling neglected or jealous due to perceived extra attention paid to their special sibling (Crnic, 1983). Parents often struggle intra-personally with the competing needs for the more typically developing son or daughter. One challenge is the conflict between the need to instill a sense of responsibility and caring in their other children for their disabled sibling and the need to allow the more typically developing children to experience a true childhood, one that does not require acting as deputy parents.

Parents of children with mental retardation experience chronic disorientation regarding expectations for raising the child with special needs (Blacher et al., 1987). There are few, and no readily available, models for expectations around raising a child with mental retardation. The mastery of developmental milestones does not match those of the typical child. Discipline techniques need to be tailored for the child with mental retardation. Parent need to modify their expectations regarding following verbal directions. Involvement with educational and other institutional systems needs to be enhanced (Costigan, Floyd, Harter, & McClintock, 1997).

The early research on families of children with mental retardation suggested that families went through a period of grieving when they learned that their expectations for a normal, healthy child would not be met. This research further suggested that families then gradually come to accept their child.

It appears from more recent research that this earlier literature may have oversimplified the experience of the exceptional family (Beckman, 1983). These special families do seem to go through an initial course of grieving followed by some degree of acceptance. However, there seem to be other periods of stress and grief fluctuations especially around times of traditional developmental milestones such as walking, talking, school entry, and school graduation (Beckman, 1983; Cherry, 1989; Rimmerman & Duvdevani, 1996; Winkler, 1981).

Family Stress Theory

The family stress literature for this population has yielded inconsistent findings. Although some studies previously reviewed indicated heightened levels of stress specific to child characteristics (Kazak & Marvin, 1984), not all studies have reported that family stress was consistently different than control groups (Cameron, Dobson, & Day, 1991; Dyson & Fewell, 1986). In addition, although depression and pathology have frequently been reported for parents of children with disabilities (Crnic, Friedrick, & Greenberg, 1983; Stoneman & Brody, 1990), other studies have not consistently supported this finding. Several studies indicated that parents of children with disabilities were not significantly different than control groups on measures of depression (Bristol, Gallagher, & Schopler, 1988; Goldberg, Marcovitch, Macgregor, & Lojkasek, 1986). Longo and Bond's (1984) review of literature on family dysfunction also supported the idea of variability in family response in terms of level of stress, self-esteem, and personality variables.

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Pahl and Quine (1987) conducted a large-scale study to investigate the impact of a child with a disability on maternal stress that was assessed through administration of the Malaise Inventory. Although the average score for the sample of mothers of children with disabilities ($n = 200$) was significantly higher than average scores in a control group, variability in scores was demonstrated with some high scorers and some low scorers. Factors that contributed to high scores included child characteristics such as level of disability and family characteristics such as social isolation, adversity in the family, and financial difficulties. Maternal perceptions and coping were not assessed and thus not included as factors that possibly mediated stress. With the exception of the studies by Pahl and Quine (1987), few investigations provided normative information when comparing target samples of parents and controls.

Within the family context, data regarding parent reactions to a child with a disability seem to vary. Similarities and differences between mothers and fathers, marital distress versus enhanced marital quality, child-related stress contrasted with stress from the environment, and maladaptive emotional responses as opposed to adjustment were all represented in the literature (Abbott & Meredith, 1986; Bebko, Konstantateas, & Springer, 1987; Beckman, 1991; Costigan et al., 1997; Dyson, 1997, Lavee, Sharlin, & Katz, 1996). As with child characteristics, a continuum of responses was reported.

Methodologically, several limitations may have contributed to differences. First, only a limited number of studies compared target samples' responses with normative data (Breslau & Barklay, 1988; Innocenti, Huh, & Boyce, 1992; Pahl & Quine, 1987); determining statistical differences between a target and control group was more predominant (e.g., Friedrich & Friedrich, 1981; Gold, 1993; Goldberg et al., 1986).

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However, families of children without disabilities were assumed to represent the norm without a comparison to a statistical measure.

This methodological approach perpetuated the pathology-based model that predicted problems because of the presence of a disability. Families of children without disabilities were assumed to be "normal."

Another limitation related to methodology was a failure to report the full range of responses that may be best represented on a continuum or other qualitative method. The presentation of group scores and not individual variations may have eliminated important data available from highly adjusted family units. A third restriction on accuracy concerns how differences were reported. Frequently, following identification of statistically significant differences, authors stated facts such as 50% of the siblings fell within the depressed range (Gold, 1993) or 28% of the families reported some stress (Palfrey, Walker, Butler, & Singer, 1989). These results do not focus on the 50% who were not depressed or the 72% who did not report stress. Further, differences that did result were not analyzed with attention given to other variables. For example, samples consisted of children with various disabilities of different severity levels; given that results have been unclear regarding the impact of these variables, controlling for possible confounding variables would be important.

As described by Beckman (1991), the role of individual perceptions has been infrequently explored. Results from Gold (1993) and Palfrey and colleagues (1989) suggested individual perceptions about the child with a disability were associated with varying responses. The assumption that "disability equals distress" has been prevalent, and investigations of possible mediators of stress have been limited. Professionals

reported perceptions of greater levels of family distress than the family members themselves reported (e.g., Bebko et al., 1987; Nelson, Ruch, Jackson, Bloom, & Part, 1992); the bias that the presence of disability causes distress in families operates in professional assessments as suggested by these results. Results indicate a need for investigation of these perceptions. Related to intervention, it is imperative that literature that may influence professionals' perceptions be accurately portrayed. A more accurate and balanced portrayal of family perception of sources of support and stress can be more clearly explored in a qualitative method.

Within the family stress literature, several stereotypes have been suggested even when conflicting and/or inconclusive information has existed. First, the overall view that all families of children with disabilities have experienced distress has overlooked data that suggest that some families have not been distressed (e.g., Beckman, 1991; Byrne & Cunningham, 1985; Hauenstein, 1990; Longo & Bond, 1984). Although families frequently reported increased stress when dealing with behavior problems, financial strain, and concerns about the futures of their children (Beckman, 1983; Holroyed & McArthur, 1976; Singer & Irvin, 1989), not all families reported maladjustment. As Beckman (1991) stated, "Over the years, it has become clear that increased stress does not necessarily lead to distress or dysfunction in families" (p. 585). A continuum of responses to possible stress associated with parenting a child with a disability has been indicated.

A second stereotype concerns various effects on the parents. Although mothers have typically been the primary caretakers, fathers have not consistently been neglectful as has generally been presumed (Kazak, 1986). Thus, results of indicators of satisfaction

in the parent–child and marital relationships have not consistently suggested dysfunction. Not only has significant marital distress been reported, but some couples have indicated increased marital quality (Kazak & Marvin, 1984; Palfrey et al., 1989; Waisbren, 1980). In contrast to general beliefs that divorce rates are higher, Winkler (1981) noted that the divorce rate for families of children with disabilities has not been significantly different than that for families of children without disabilities. Specific to mothers, increased psychological maladjustment and depression have been hypothesized although not consistently indicated (Breslau & Davis, 1986; Crnic et al., 1983).

A specific focus on child variables such as age, sex, and severity and type of handicap has yielded inconclusive results. The assumption that solely having a child with a disability causes distress was not unequivocally supported. In contrast, data suggest a continuum of responses to having a child with a disability. Summers, Behr, and Turnbull (1989) stated,

Families who have a member with a disability have long been objects of pity. Society as a whole tends to view the presence of a child with a disability as an unutterable tragedy from which the family may never recover. (p. 27).

Thus, according to Goffman (1961), these stereotypes reflect societal attitudes about the negative and valueless aspects of individuals with disabilities. Therefore, stereotypes from the literature that have impacted intervention strategies have likely reflected societal values (Summers et al., 1989).

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Information provided by Bebko and colleagues (1987) and Nelson and colleagues (1992) regarding perceptions of inordinate family stress underscores the need for professionals to refine their views beyond general stereotypes. The assumption of inevitable psychological distress from the "pathological approach" has led professionals to the erroneous generalization of homogeneity in families rather than considering a continuum of responses (Byrne & Cunningham, 1985). An underlying assumption among professionals that "children without disabilities are easy to raise and children with disabilities are a burden" (Turnbull & Turnbull, 1986, p. 111) further reflects this perception. Professionals have evinced biases toward identifying problems when none exist and operating from a pathology-based approach. These professionals have learned how to deal with crises but not how to deal with coping in families of children with disabilities (Longo & Bond, 1984; Summers et al., 1989; Trute & Hauch, 1988). These biases have inherently caused stress to families due to interactions shaped by these negative attitudes (Summers et al., 1989). Therefore, distress is not always produced by the child with a disability but may emanate from societal perceptions (Bronfenbrenner, 1979).

Research has been structured toward pathologizing families of children with disabilities (Nelson et al., 1992). Focusing on problems and distress, pathologizing has subtly been communicated through predicting differences from the outset and focusing on deficits rather than strengths. In addition to negative generalizations, Turnbull and Turnbull (1986) indicated bias has been demonstrated by explanations of "unexpected positive findings through a negative interpretation" (p. 111). For example, the authors explained that positive responses from parents and siblings have been discounted by

researchers and reasoned to occur because of social desirability and methodological

flaws. As previously noted, bias in research has been demonstrated through a focus on the

percentage of families who reported problems, ignoring the remainder that did not.

Winkler (1981) discussed the bias of attributing results to methodological flaws

and provided an example of their own work in which this had occurred. Winkler (1981)

noted the majority of parents had described "chronic sorrow." However, the authors

omitted results from a second questionnaire that indicated that 75% of parents described

parenting a child with a disability as a strengthening experience. Only 9% of the

professionals surveyed believed parents' perceptions would be that of gaining strength.

Winkler (1981) asserted the need for alternative research approaches and professional

interactions that focus on family strengths.

Byrne and Cunningham (1985) provided a conceptual review of literature

specific to families of children with mental retardation. Outlining three approaches, the

essence of the review identified preconceptions within investigations about the impact of

children with disabilities. The first approach, the pathological orientation, has focused on

inevitability of stress as previously described. Although this approach has predominated

the literature, a modified approach that attempts to identify families more at-risk for

distress "caused" by the child has developed. Conclusions from a review of research from

this approach indicated that stress was not inevitable. Instead, factors such as number of

stressors present, life-cycle stage, and the families' cognitions about their situations

appeared to predict family response.

A second approach, the unmet service-needs orientation, has focused not on

families but on practical needs that may have contributed to distress. The third approach,

the coping orientation, has reversed the pathological perspective through a focus on family adaptation. Recognizing that stress has existed, this approach emphasizes the "normality" of families and the resources that assist with coping. Byrne and Cunningham (1985) described this approach as relatively undeveloped and cited investigations specific to social support and family perceptions as beginning steps in developing this approach. The authors described all three approaches as necessary to identifying families possibly at-risk and to obtaining knowledge about families who do well.

The modification of the pathological view and the normality view as described by Byrne and Cunningham (1985) has facilitated investigations that refute existing stereotypes and biases. Some families have indicated that they were being described in an overly negative and pessimistic way to justify the research or intervention grants of professionals (Turnbull & Behr, 1986). Nelson and colleagues (1992) indicated that families identified positive contributions and strengths in response to research questions developed with a normality assumption.

Summers and colleagues (1989) discussed the imbalance in the depiction of families of children with disabilities. Although asserting that families with coping difficulties do exist, Summers and colleagues described families who have made "positive adaptation." These families were described as well adjusted with or without intervention, accepting of their child's disability, and successful in other relationships. Summers and colleagues (1989) indicated that the majority of information regarding positive adaptation and the contributions of the children with disabilities has been represented in anecdotal reports.

In an attempt to document positive effects and coping, Hancock, Wilgosh, and McDonald (1990) interviewed six mothers of children with visual impairments. On the basis of qualitative analysis, three themes emerged: (a) emotional issues, including stress and positive effects; (b) coping resources, which included the mothers' "inner strength" and support networks; and (c) problems and concerns about interacting with professionals and the public, advocating for their child educationally, and allotting time for their child. Hancock and colleagues (1990) concluded, "Perhaps the most valuable results would be to help professionals develop empathy towards the families of children with disabilities" (p. 413).

Parents' reports delineating positive contributions by children with disabilities resulted from a content analysis completed by Turnbull, Guess, and Turnbull (1988). Letters sent by parents ($n = 174$) to the U.S. Department of Health and Human Services that comment on regulations for treatment of newborns with disabilities were coded by the authors. Several categories including positive attributes and positive contributions were identified. Subcategories included (a) source of joy (39%), (b) source of learning lessons (28%), (c) source of love (28%), and (d) source of family strength (5%).

Turnbull and Behr (1986) completed interviews with 18 parents of children with disabilities and 10 parents of children without disabilities. Questions focused on the impact children had made on their lives, how their lives would be different without their children, positive and negative experiences, and positive contributions. In addition to the categories noted above, parents in both groups reported contributions such as expanded social support, increased sensitivity and patience, personal growth, and strengthened

family relationships. The authors concluded parents of children with and without disabilities reported positive contributions and similar perceptions.

An empirical investigation by Trute and Hauch (1988) explored various factors in families of children with a variety of disabilities that appeared to be "satisfactorily adjusted" on the basis of professionals' ratings. The purpose of the study was to provide descriptive information about these families in comparison to standardized measures. Family functioning, marital quality, self-esteem, and depression were assessed via standardized instruments. Scores within the normal range were obtained for primary caretakers on measures of self-esteem with 82% reporting no significant signs of depression. Trute and Hauch (1988, p. 188) described marital quality as falling within the normal range with cohesion ("tightly bound as a marital pair") significantly higher ($p <$ .001) and conflict ("disagreed on issues which arose in the family") significantly lower than average ($p <$.001). On the measure of family functioning, the majority of parents were reported to have strengths in expression of emotion, involvement with one another, and adherence to family values. The relationship between the parents was highlighted as an important source of support. Clinical implications discussed by the authors included attending to the marital and social relationships as well as coping techniques used by parents.

The majority of information reviewed regarding child characteristics and parent characteristics offered inconclusive information. Inconsistencies in literature about factors that affected family responses were noted. The overall conclusion from the review has been that a continuum of responses has existed, with some families reporting significant distress whereas others have reported no significant problems. Many families

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have indicated they have been strengthened from the experience of living with a child with a disability (Dunlap & Hollinsworth, 1977; Hancock et al., 1990; Turnbull et al., 1986; Trute & Hauch, 1988).

According to Crnic and colleagues (1983), a coping-based framework for investigating family responses would be useful in investigating variables and should be considered as an alternative to seeking pathology. One aspect of coping that has been implied from research involves the family's perceptions, expectations, and attitudes regarding the experience of having a child with a disability (Dyson, Edger, & Crnic, 1989; Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981; Winkler, 1981). Abbott and Meredith (1986) directly questioned parents about coping; they identified "positive outlook" and "acceptance" of the child as positive contributors. In other qualitative analyses, parents also discussed cognitive factors such as realistic appraisal of the disability, "inner strength," and identifying positive contributions made by their children (Hancock et al., 1990; Mullins, 1987; Turnbull et al., 1988). All of these could be considered cognitive coping strategies.

Summers and colleagues (1989) discussed the role of family perceptions as "powerful predictors of successful family coping" (p. 31). These authors related perceptions to cognitive coping strategies, which are the means used to adapt subjective perceptions during stressful experiences. To emphasize family strengths as opposed to a problem-centered approach, Trivette and colleagues (1990) discussed assessment of "family functioning style," the family's unique style in dealing with life experiences. Similar to Turnbull's description of family resources, Trivette and colleagues described

coping behaviors as one means families use as part of their functioning style to adapt to life events.

Theoretical Foundation

In general, theories in stress research have historically followed the input–output model. A primary assertion of the research from this approach has been that the presence of a stressor inevitably results in distress and dysfunction (Breslau & Barkley, 1988; Lazarus, 1993). The basic premise has been that of a stimulus–response relationship. Another approach has defined stress as physiological responses to "noxious agents" or stressors (Lazarus, 1993).

Interventions therefore have focused solely on controlling physical responses as a means of modifying stress. However, the weakness of these approaches has been that the presence of what would commonly be viewed as a stressor has not consistently resulted in a stress reaction such as physiological disturbances or anxiety in all individuals who have been exposed to the stressor (Folkman et al., 1991; Rutter, 1991).

More specifically, as established by this research review, distress has not always been an inevitable response to living with a child with a disability. Conceptually, the cognitive–phenomenological theory proposed by Lazarus and Folkman (1984) can assist in interpreting this result. Specifically, in summarizing research within the theory

framework, Lazarus (1993) stated, "Stressful conditions did not produce dependable effects; for some persons the stress aroused by a given condition was great, while for others it was small" (p. 3). Individual differences have been emphasized in theoretical constructs, particularly in terms of the role of cognitive variables. Further, Lazarus (1966) indicated, "the important role of personality factors in producing stress reactions requires that we define stress in terms of transactions between individuals and situations rather than either one in isolation" (p. 5). It is worth noting that McCubbin, Joy, Cauble, Comeau, Patterson, and Needle (1980) discussed the need to better understand the phenomena of social support, esteem support, and networking as mediating factors in family stress.

The Need for Additional Research

The research on family stress phenomena is well represented throughout the literature. There is, however, insufficient literature on successful coping efforts by these special families. At the same time, there is a significant body of literature regarding positive family adaptation. Research by Byrne and Cunningham (1985) refuted prior stereotypes by discounting negative family bias. In their research, families indicated that they felt that they were being described in a pessimistic manner in order to justify further intervention grants (Turnbull & Behr, 1986). Research by Nelson and colleagues (1992) indicated that families identified many strengths in response to research questions developed with a normality assumption. Summers, Behr, and Turnbull (1989) asserted that although coping difficulties do exist, many families have adapted positively.

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Summers and colleagues described these families as well adjusted, with or without intervention, accepting of their child's disability, and successful in their relationships. Mullins (1987) used a qualitative approach and analyzed 60 books written by parents to identify themes relevant to raising children with disabilities. Four themes emerged: (a) realistic appraisal of disability; (b) inordinate treatment coordination demands on the family; (c) stress due to uncertainties; and (d) resolution. Mullins indicated that the majority of parents discussed the positive contributions and additional meaning that these children had given to their lives. Dunlap and Hollingsworth (1977) conducted interviews with 404 families who reported few negative effects on the family, including the marital relationship. The self-report of relatively few negative effects is especially significant because the purpose of the research was to identify and conceptualize problems. Turnbull, Guess, and Turnbull (1988) conducted a content analysis of letters, mentioned above, regarding regulations for newborns with disabilities sent to the U.S. Department of Health and Human Services. Turnbull and Behr (1986) conducted interviews about the impact of children on their lives with parents of children with disabilities and parents of children without disabilities. Parents in both groups reported contributions such as expanded social support, increased sensitivity and patience, personal growth, and strengthened family relationships.

There are anecdotal and some empirical references to coping strategies employed by these families. Social support, family hardiness, and a sense of empowerment all appear to have a significant positive effect on the ability of families to cope (Beckman, Newcomb, Frank, Brown & Filer, 1993; Gill & Harris, 1991; Kazak &Wilcox, 1984; Trivette, Dunst, Deal, Hamer, & Propst, 1990; Trivette, Dunst, Hamby, & LaPointe,

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1996). Many of these strategies appear to make sense intuitively. However, the mixed

indications in the research are mirrored in mixed practice applications: both pathology-

based and strengths-based approaches in treatment are common. A major focus of this

study was to give a strong voice to families by using a grounded theory approach (Strauss

& Corbin, 1998) that will help guide theory, practice, and future research. The

importance of uncovering successful coping mechanisms should be evident to theorists,

counselors and researchers.

Research Questions

This study attempts to answer the following three questions:

1. What are the subjective experiences in families of children with mental retardation?

2. What coping mechanisms, if any, appear to have a mediating effect on stress for these families?

3. What family, community, and other factors appear to be most closely associated with coping or stress for families of children with mental retardation?

Chapter 2 Literature Review

The following literature is reviewed under four categories: family stress, needs specific to families of children with mental retardation, description of families of children with disabilities and policy implications, and family resilience and coping. The findings in these areas will then be synthesized in a summary that emphasizes explored and unexplored research in this area.

Family Stress

Lavee, Sharlin, and Katz (1996) studied the effects of having typically developing children on the marital relationship and the general psychological well-being of parents. The authors interviewed 287 families of typically developing school-age children regarding marital stress, economic factors, work, and home roles and number of children. From the interview data, the authors cited sources of normative and nonnormative stress. The following sources of normative stress were reported: birth of a child, child entering school, empty nest period, and retirement. For nonnormative stress, the following items were reported: layoff from work, natural disaster, and disability within the family.

The authors noted on the basis of their interview and previous research that married adults living with children report more worries, distress, anxiety, and less satisfaction than married adults who do not have children. The article states that few

findings in social science research are as robust and consistent as the ones that find that children living at home lowers marital satisfaction and psychological well-being.

Lavee and colleagues offer two explanations for their findings. One possibility is that bad marriages may stay intact for the sake of the children and thus skew results. Another possibility is that having children increases stress due to the enormous role adjustments. Of all the stress factors noted by the authors, parenting role stress had the strongest negative effect on marital satisfaction; however, economic stress adds substantially to marital stress. Women's employment was the strongest factor having a positive effect on the marriage.

The strengths of this article are that it suggests a systemic approach for treatment and suggests prevention services. The weakness of the article is that it does not specify the nature of the interviews, who conducted the interviews, or how the families were chosen. There is no discussion of methodology.

McCubbin and colleagues (1980) provided a meta-analysis based on ten years research on family stress. The authors noted that the ABC-X model of family stress has served as a major building block for additional research in this area. In the ABC-X model, A is the activating event, B is the stress meeting resources available to the family, C is the family perception, and X is the amount of stress experienced by the family. The authors particularly note the contributions of three authors to the field of family stress research. Burr (1973) made modifications to existing research to measure stress, available resources, and other variables. This type of modification has led to a stronger basis for quantitative research. Lippman and Blumen (1977) distinguished eight criteria for assessment of the family experience of stress:

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1. Internality versus externality: Where is the family locus of control?

2. Pervasiveness versus boundedness: Can the family section off stress or does it affect other areas?

3. Precipitive versus gradual onset: Do families have some chance to plan for coping?

4. Intensity versus mildness: How intense is the stress?

5. Transitory versus chronic: Will it be short or long term?

6. Randomness versus expectability: Can the family make sense of the experience?

7. Natural generation versus artificial generation: Is it normative or nonnormative stress?

8. Perceived insolvability versus solvability: Can the issues be resolved?

The authors further noted the research of Alduous (1978) who discussed how stress affects and is affected by normative life cycle phases. This focus on life cycle allowed researchers to note dynamic as well as static effects of stress.

In the discussion section the authors note that the implications of the research in the 1970's decade have significant effects on subsequent research; stress is more quantifiable and other variables are better categorized and defined. The authors note two additional research areas of focus during this decade. First, there appears to be a beginning of interest in the experience and effects of fathers in the family. Second, there has been some beginning focus on the concept of types of support that mediate the family's experience of stress: social support, emotional support, esteem support, and network support. The authors note two areas for future research: develop a better system

for measuring family stress during different life cycles and further develop the current understanding of family coping and sources of support.

The strengths of this article are that the authors lend their considerable experience in analyzing a decade of research. The authors are able to point out pertinent factors affecting a developing research area and suggest future research areas. The weakness of the article is its age. It is interesting to note that McCubbin and colleagues (1980) predicted accurately the subsequent two decades of research in family stress.

Sabbeth and Leventhal (1984) conducted a meta analysis of 34 articles to review marital adjustment to chronic childhood illness. The authors were most interested in the effects of chronic childhood illness on marital adjustment, divorce figures, communication, decision making, and role flexibility. The authors theorized that there would be a transactional effect in which chronic childhood illness would affect the marriage that, in turn, affects the psychological adaptation of the child. Sabbeth and Leventhal noted the relatively weak methodology in many of the articles they reviewed. Many of the studies were characterized by poor sampling, a lack of control groups, no information on changes over time, the absence of a distinction among types of childhood illness, and no substantiation of survey or assessment instrument reliability.

From this meta-analysis, the authors concluded that there appears to be no significant difference in divorce rates between parents who have a chronically ill child and parents who have relatively healthy children. The authors further concluded that parental (self-report) stress is higher for families of children with chronic illness compared with families without chronic health issues. The authors noted that this higher stress level is consistent with anecdotal reports from the field.

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The weakness of this article is that the authors criticized almost all of the reviewed articles, yet use the findings to draw their own conclusions. The strengths of the article include clear definitions of marital satisfaction, role flexibility, and communication, and the authors' suggestions for future research. The authors suggested studying the possible adaptive role of conflict: Does chronic childhood illness somehow pull families together? Does an overly harmonious family point to dysfunction? The authors strongly suggested that future research be tied to an existing theory of family stress or adaptation.

Summary of Family Stress Research

There seems to be some agreement among these articles that family stress is multidetermined and multidimensional. There is research pointing to normative and nonnormative stress among families in general. Major normative factors contributing to stress are economic issues, having children, unclear parent roles, and a lack of marital satisfaction. Nonnormative factors affecting stress are natural disasters and unexpected disabilities or chronic illness. There are several models available for assessing family stress: the Lippman-Blumen (1977) criteria, the ABC-X model (Hill, 1949), systems theory (Bronfenbrenner, 1979), marital stage theories (McCubbin et al., 1983), and transactional models (Lazarus, 1993). All of these models offer different ways to understand family stress. A unified theory that incorporates criteria such as locus of control, role-flexibility, solvability, family resources, and dynamic issues such as how the parents and children mutually affect one another and family development issues has yet

to be proposed. It appears that research in the area of family stress, although readily available, has remained bound to existing family stress theories without adequate attention to a well-understood representation of families' own subjective experience.

Needs Specific to Families of Children with Mental Retardation

Dyson (1997) studied fathers and mothers of school-age children with developmental disabilities and compared them with parents of typically developing school-age children regarding stress, family functioning, and social support. This article is one of the few to explicitly make an effort to include fathers in the study. The author noted that the "school years" can be a particularly stressful time for parents of children with a developmental disability. Dyson was interested in seeing if fathers experienced this family stage differently than mothers. It is commonly understood that mothers experience greater stress than fathers due to a childhood illness because it is more often the mother who takes care of an ill child.

Thirty parents of children with a developmental disability were compared with 32 parents of typically developing children by interview and survey instruments. The two groups of parents were matched on socioeconomic status, family structure, and children's age. Instruments included the Questionnaire on Resources and Stress—Short Form (family perception of stress and resources), the Family Environment Scale (environmental characteristics of a family—cohesion, growth), and the Family Support Scale (evaluates different sources of support).

In this study, Dyson found that there appears to be no difference in levels of stress between fathers and mothers in either group. The author suggested that the discrepancy between these findings and those of previous studies was because previous studies were conducted during a time when fathers spent considerably less time with their children. However, perceived stress regarding child rearing was significantly higher for the families of children with a disability, which is consistent with previous studies. These families expressed more pessimism regarding the future. Families that reported a satisfactory amount of social support also reported less stress and better family functioning, also consistent with previous studies. The author noted that the implication for policy makers is to focus more attention on family-centered practice. When children with disabilities are infants and toddlers, an Individual Family Service Plan is the common practice; but when a child enters school, it then becomes an Individual Education Plan. The family can be somewhat excluded from the service component and feel disempowered.

The strength of this study is that it included fathers in the sample and subsequent discussion of fathers and mothers. Further, there was some discussion of the limits: the sample size was relatively small and only middle-class families were surveyed. The article did not define some of its key terms such as family support. Some of the survey results were not discussed such as access to extended family, child-care, strength of marriage, or length of marriage. The author does suggest further longitudinal research to explore how families change over time.

Dunst, Trivette, Hamby, and Pollock (1990) studied the relationship between social support, personal well-being, family well-being, and child behavior characteristics

in families of children with disabilities. The authors discussed the concept of *embeddedness* that refers to a child being enveloped within his or her family, and the family unit being embedded in larger social units such as school, community, and faith community. The authors note that parents' performance in the parenting role is influenced by role demands, stresses, and support from other settings. These factors appear to play an especially significant role in families of children with disabilities. Social support, which is described as informational, psychological, material, and physical resources, appears to buffer families from negative stress reactions.

Forty-seven mothers of children with disabilities were surveyed and interviewed regarding stress and support. These mothers were described as ranging from lower- to middle-class socioeconomic status. Their children had a physical disability, developmental disability, or both. As part of the study, mothers completed the Family Support Scale (measures resources and social support), the Maternal Social Support Index (measures resources and support) and the Health/Mood, Time Demands, and Family Integration subscales of the Questionnaire on Resources and Stress. In addition to these self-report measures, the Carolina Record of Individual Behavior was administered for each child by a trained interventionist.

The authors were particularly interested in reviewing the validity of a model for depicting the direct and indirect influences of social support on parent, family, and child functioning. In this study, parent well-being, family well-being, and social support appeared to be the most important correlates of child behavior characteristics. Along with prior research by the authors, this study helps to establish the mutual interdependence between family systems variables and child functioning.

The strengths of this study include extensive prior research on portions of this study, discussion of the proposed model of interactional effects, and an overt call for family-centered interventions. The authors note the weakness of a relatively small sample size. Further, there was no discussion of children who have severe behavioral disorders despite a healthy functioning family. There is always the risk of "shame and blame" (vilifying parents) when it comes to tying parent characteristics with child characteristics. The authors conclude with the suggestion for broader-based intervention with families.

Beckman, Pokorni, Maza, and Balzer-Martin (1986) investigated the experience of family stress over a period of time for parents of pre- and full-term infants. The authors were particularly interested in understanding how the experience of stress may be related to environmental factors. They hypothesized that parents of pre-term infants would report higher levels of stress than would parents of full-term infants. Subjects were parents of 17 pre-term and 17 full-term infants; parents were matched with respect to sex, race, and socioeconomic status. These parents were visited at 3 months, 6 months, and 12 months. The Questionnaire on Resources and Stress and the Carolina Parent Support Scale were administered to the parents. The Bayley Scales of Infant Development were administered to the children.

The authors found that parents of pre-term infants reported more problems and significantly more stress than did parents of full-term infants. The number of child problems with pre-term infants appeared to decrease over time. Parents of pre-term infants received more formal and informal support. Formal support was associated with stress. The authors noted that differences in experienced stress persist over time. It appears that if support is needed, families mobilize resources. More support received in

one reporting period was related to less experienced stress in the next period. Stress appears to be a dynamic and not a static function. One limitation in their study that the authors noted is that adjusting for a gestational correction may yield different results. One strength in the article is that it is relatively longitudinal and begins to review the effects of formal and informal support in mediating the experience of stress.

Baker, Landen, and Kashima (1991) studied a home-based parent training program that provided support, behavior management training, and teaching material to families of children with mental retardation. The authors were interested in discovering whether the families involved viewed the parent training program as supportive or as just another burden. The authors were interested in analyzing the broad impact of parent training and any family characteristics predictive of successful outcomes. Forty-nine families completed the UCLA Parents as Teachers curriculum, a program that is self-help oriented and includes behavior management techniques. For assessment, the researchers gave parents the Behavioral Vignette Test, the Teaching Proficiency Test, the Questionnaire on Resources and Stress, and a Parent Evaluation Questionnaire.

Parents did appear to learn to be teachers and behavioral managers; however, the focus of the research was on families' subjective experience. Parents consistently rated their experience as appropriate or very appropriate. Parents felt that the program was helpful, and they felt confident in their ability to teach their children. No family reported that the program was too stressful. The negative scores Questionnaire on Resources and Stress declined over time except in the pessimism subscale. Families with higher reported pessimism going into the program reported doing less well at the outcome. Perhaps these families were so stressed that they were not able to make use of the services. The authors

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noted that some attention needs to be given to these more stressed families in the field and in research; perhaps earlier intervention could yield better results.

The strength of this article is the variety of instruments and its suggestions for future research on early intervention and marital satisfaction. The weakness is the dropout rate of 27% that may have skewed the results (only motivated parents participated in the study). Further, there is no control group against which to measure.

Minnes (1988) explored the area of family resources, stress, and other factors associated with parental adjustment in families of children with mental retardation. Minnes reviewed the ABC-X model of family response to stress; when a stressful life event introduces itself to a family, the family is thrown into a state of disequilibrium. The family's long-term functioning may depend on the family's stress-meeting resources and the family's perception of the stressful event. Minnes hypothesized that family support and positive family perception will have a mediating effect on experienced stress. Minnes stressed the importance of external informal support due to the family's risk of feeling isolated.

The Questionnaire on Resources and Stress, the Family Environment Scale, and the Family Relations Index were administered to 60 mothers of children with mild, moderate, and severe mental retardation. Although some of the results of this research were contradictory, other areas appeared clear. Better family relations were associated with less stress. Behavioral and management concerns on behalf of the older child were associated with increased stress and concerns about limited opportunities for work and leisure for the rest of the family. Social support from extended family, friends, and faith

community was associated with less stress. Level of retardation was not a significant factor in this study.

This research discussed findings different than what Hill or McCubbin would predict without offering an alternative theoretical explanation. There are significant strengths in this article including a 93% participation of requested subjects. Further, the author noted an area of future research that few authors have mentioned: describing the level of stress experienced by families associated with receiving professional support.

Summary of Literature Regarding Needs Specific to Families of Children With Mental Retardation

Although these articles all took a different angle on families, there was some agreement that parents of children with mental retardation experience more stress than do parents of more typically developing children. These differences in levels of stress appear to continue over a long period of time. The time when a child begins attending school has emerged as particularly stressful. Families of children with mental retardation appear to rely more on support from extended family and friends. Further, social support not only mediates the negative effects of stress, it also has a positive effect on children's behaviors. Families of children with mental retardation report a higher than average level of isolation. These families want to be involved in their child's education and accompanying treatment. Families of children with mental retardation express a strong need for leisure and other meaningful outlets. Although most of the research on families relied on the perceptions of mothers, some of the newer research has involved fathers. In

earlier research, it was reported that fathers were less stressed, perhaps due to less involvement in the role of child rearing. This phenomenon has changed in more recent studies, as fathers appear now to be more involved in child rearing. A significant portion of the research in this area used the Questionnaire on Resources and Stress or the Parenting Stress Index. Both of these instruments are pathology-oriented with little focus on family strengths. Further, both of these instruments are static in nature. Thus the dynamic issues such as changes in work status, changes in medical status for any family member, and mediating effects from parent education programs cannot be adequately explored unless follow-up interviews were conducted. In the studies that incorporated interviews there is consistency in reporting that there are some factors that mediate stress: being part of a strong parenting team, having basic support needs met, receiving support from their faith communities, and having received some behavioral management training. In general, these families have similar needs to more typical families, but their needs and stresses are at a deeper level.

Description of Families of Children With Mental Retardation and Policy Issues

Trivette, Dunst, Hamby, and LaPointe (1996) reviewed research regarding empowerment as a philosophy, practice, and perception. The authors then interviewed mothers of children with a developmental disability to better understand key elements of empowerment and their implications for family centered practice. The authors note that empowerment has become a major concept over the past several years. For the purpose of

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this study, the authors defined the empowerment philosophy as one that believes in the families' competency to acquire additional competencies.

The subjects were 74 mothers of children with developmental disabilities. These families were involved in a strengths-based infant and toddlers early intervention program. Seventy-seven percent of these children had mental retardation; the rest had other developmental disabilities. The authors reviewed empowerment as a practice, philosophy, and perception and how these domains related to one another. They were specifically interested in identifying the characteristics of help-giving practice that gave families a sense of control. Mothers completed two self-reports: The Help Giving Practice Scale, which identifies help-giving style, and the Parent Empowerment Survey, which reviews parent self-perception of efficacy and knowledge.

The authors found that parents who were involved in planning and treatment for their children felt a sense of control, efficacy, competence, and satisfaction. They note that Individuals with Disabilities Education Act (IDEA) emphasizes family choice, a key element in family empowerment. The families in this study were given choices for services. The authors hypothesized and were correct in that assumption in that an empowerment philosophy by the provider was strongly related to family-centered practice and subsequently parent perception.

The strengths of this article are its replication of other elements of previous work and its practical guidelines for family-centered practice. The authors emphasize meaningful involvement of families in the treatment of their children while being realistic about how this may be viewed as threatening or uncomfortable for some providers.

Further, the authors do a fine job of noting implications for policy. The authors do not specify any areas for future research.

Gill and Harris studied the effects of hardiness and social support on stress in mothers of children with autism. The authors were interested in understanding why some families appear to cope better with the stress of raising a child with a developmental disability. Previous research has shown that internal factors such as hardiness and external factors such as social support have been helpful in buffering the effects of stress on families. For the purpose of this study, hardiness was defined as the ability to remain healthy after experiencing a high degree of stress due the personality characteristics of self-control, commitment, and the ability to cope with challenges. The authors selected families of children with autism because the research on autism shows it to be a particularly challenging developmental disability.

The authors of this study surveyed 60 mothers regarding psychological factors, stress, and support. Four instruments were used: the Interpersonal Support Evaluation List (which measures perceived availability of support), a modified version of the Inventory of Socially Supportive Behavior (which measures the receipt of functional support), the Hardiness Test (a measure of hardiness), and the Beck Depression Inventory (a depression assessment instrument). The authors found social support and hardiness to have a significant effect on reducing stress and depressive symptoms. Hardiness (as measured by the Hardiness Test), by itself, was a significant predictor for positive outcomes. Commitment to a belief system (meaning attribution) was another significant factor in reducing the effects of stress. The authors note that these findings are consistent with previous research on families' ability to cope with stress, particularly the ABC-X

model (McCubbin et al., 1980). Hardiness could be considered an available resource in the model and commitment to a belief system relates to the family perception portion of the model. The authors conclude by noting that if parents of children with disabilities can be helped to find philosophical views (meaning attribution), to view life events as opportunities for growth (hardiness), and to obtain formal and informal support (social support), the effects of stressful events may be lessened.

The article calls for future longitudinal research to see the long-term effects of social support and hardiness on families. There is no discussion of the interactive effects of hardiness and social support. In other words, the article does not answer the question: Does a hardy attitude assist one in obtaining support or is the fact that one is receiving social support make one feel hardy? There is the potential for a parent to feel self-blaming if the level of family stress was the fault of a parent who did not happen to feel very hardy in facing the situation of having a child with a disability.

Rimmerman and Duvdevani (1996) examined out-of-home placement applications for 88 Israeli families for their children and adolescents with mental retardation. The authors were interested in reviewing marital status, family stress, family environment, and other factors that related to the decision to seek out-of-home placement for their child. Over the past several years, there has been a shift in many countries to home- and community-based services for families of children with mental retardation. Although this change represents more humane treatment for the child with a disability, having a child with a disability at home can reduce family members' freedom and increase stress. Timing is noted as a possible factor when considering placement: A

family may not wish to place a young child out of home because of concerns about breaking up the family,

The authors surveyed 88 families who had applied for out-of-home placement in the Tel Aviv area. Parents responded to formal and informal instruments: the Family Environment Scale (the social climate subscales), the Interpersonal Support Evaluation List (perception of availability of support), the Questionnaire on Resources and Stress, a demographic questionnaire designed by the researchers, and a six-question survey on attitudes of normalization designed by the researchers.

This study found that parents who reported higher stress and perceived less social support were more likely to apply for out-of-home placement for their child with mental retardation. The child's age and family environment were related to the decision for placement but not strongly enough to count as predictive factors. The authors note that parents of children with disabilities appear to need a lot more support than they are getting. The authors call for research on the effects of social support on reducing stress and ultimately reducing requests for out-of-home placements. The strength of the article is the high response rate to the surveys and the responses from families who appeared to be at a high level of stress. It was interesting to contrast available services in Israel with services in the United States.

Baird and Peterson (1997) identified issues relating to the match between family-centered practice and infant–parent interaction in early intervention. A model is proposed in this article that brings these two ideas together. The authors note that with the passage of P.L. 99-457 (IDEA), the concept of family involvement has been redefined and strengthened to include families and not just individual children as service recipients.

Previous research has identified several guidelines for best practice in working with families of children with disabilities:

1. The family is the expert on the child.

2. The family is the ultimate decision maker for the family and child.

3. The family is a constant in the child's life; providers are temporary.

4. The family sets the priorities for goals and services.

5. The family chooses their level of participation.

6. There is a need for a collaborative, trusting relationship between parents and providers.

7. Providers need to respect cultural differences and a variety of coping styles.

These guidelines are summarized by the advice that practitioners do things *with,* not *to* families. The strong interest in being mindful of best practice appears to come from the robust empirical evidence that infant–parent interactions have a profound, long-term effect on the child and family relations.

The authors discuss a model early intervention program at Auburn University. This model program has developed four strategies for assisting families:

1. Identifying the family's vision for the future.

2. Discussing with the family implications of infant–parent interaction.

3. Prioritizing family decisions regarding intervention choices.

4. Families are the primary evaluator of outcome.

The authors learned several lessons from their involvement with this program. The nature of the relationship between the professional and the family is a critical variable for success. Several factors appear to determine the families' level of involvement in treatment including the nature of the parents' concerns about their child, the family's level of stress, the availability of social support to the family, the family's preferences for participation, prior experience with other children, and the family's education level. The authors call for a variety of future research including single-subject design and long-term outcome evaluation. They conclude by reiterating the need for families to take a leadership role. The strength of the article is its practical outline of a model program. There is no real discussion of methodology, instruments, or outcome measures for the model program. Further, the article serves as a debate on current practice in early intervention that is not totally family centered; it does call for a paradigm shift, but at the cost of putting off many providers.

Costigan, Floyd, Harter, and McClintock (1997) explored problem-solving abilities in typical families and families of children with mental retardation. Because previous research has indicated that having a child with mental retardation has pervasive effects on a family, it is important for families to learn ways to adapt and thus solve problems. The authors were particularly interested in family collaboration in problem solving and understanding how having a child with mental retardation influences that process. A resilient–disruption hypothesis was proposed in which families are both disrupted by and resilient to the stress associated with raising a child with a disability.

Participants were 165 families of children with mental retardation and 52 families in which all children were typically developing. There was a diverse ethnic mix in both groups. 72% were two-parent families. Each family was interviewed, surveyed, and videotaped for a 10-minute problem-solving task. Coding of the video interaction was based on well-validated observational systems. Typically developing siblings in both groups engaged in a similar level of problem. Parents of both groups were active participants in problem solving, but parents of children with mental retardation spent considerably more time in behavior management activities. In single parent families of children with mental retardation, significantly less time was spent on problem solving due to the need to play multiple roles by the single parent. The strength of this article is its focus on the one specific area of family adaptation. The reader gets a strong sense of problem-solving dynamics for these families. The authors do not suggest any further research.

Mink, Blacher, and Nihira (1988) proposed a taxonomy for families of children with special needs. The authors argued that scientific study requires some type of classification system as a baseline for understanding. The authors looked at the home environment, family behaviors, and stage of family life to assist in defining their proposed taxonomy. To examine this proposal, Mink and colleagues studied the home environment and behavior of 97 families who had children with mental retardation. Sixteen measures of proximal home environment were used.

The authors found five types of families:

1. *Cohesive Oriented:* characterized by a degree of closeness, lack of conflict, organized at home, but with some cost to other family members.

2. *Control Oriented:* characterized by rules, disharmony, conflict, focus on safety, but emotionally deficient.

3. *Responsive to Child Oriented:* characterized by closeness between the primary caregiver and the child.

4. *Moral–Religious Oriented:* characterized by low achievement orientation, moral or religious values, and high community involvement.

5. *Achievement Oriented:* characterized by a focus on competition and success, lack of religious focus, little expression of affect, and good level of stimulation.

The strength of this article is the fine attempt the authors make in beginning to classify family characteristics. The authors argue that by understanding types of families, interventions can be tailored to family type and need. The weakness is that the authors never address any philosophical concern that comes with typing. The authors appear to categorize families into one type, not even addressing the possibility that a family may share significant characteristics of two or more types in their taxonomy. Moreover, like ethnic typing, family taxonomy typing cannot be used by itself to type families or else professionals will run into the same stereotyping that characterizes ethnic typing.

Hodap and Zigler (1993) explored the phenomenon of how parents of children with mental retardation appear to be punished by the "system" for providing appropriate home care for their special needs child. Children with multiple needs (medical, mental

health, and developmental) may require some residential care that frees the parents of these children to be able to work outside of the home, to care for other children, and to pursue other leisure activities. On the other hand, parents who are providing appropriate home-based services to their children with mental retardation may be limiting their ability to engage in other activities. This article appears to support the cynical adage, "no good deed goes unpunished." The authors based their discussion on their extensive field experience. Hodap and Zigler did not interview any new families for this article. The authors discuss further practical details about these families providing care at home for their children. Experiences that many families take for granted can become sources of significant stress for these families, such as planning a vacation, scheduling a myriad of psychiatric or medical appointments, having a social life, or even having some financial flexibility.

The authors make specific macrosystem and exosystem suggestions on the basis of their field experience:

1. Encourage insurance companies to look at health care more broadly.
2. Promote the family as the unit of service, rather than the individual child.
3. Advocate for Medicaid to cover more home-based services for these families.

The strengths of this article are the authors' extensive experience and familiarity with these families and their specific systemic suggestions. The weakness is that they do not identify how recent their experience is or under what conditions they interacted with these families. Further, there was little direction for future research.

Freedman, Litchfield, and Warfield (1995) conducted a qualitative exploratory study to begin to understand the perspectives of parents of children with developmental disabilities regarding work outside of the home. The authors were interested in understanding how families balance work and home responsibilities and whether there are any adverse caregiver effects on work performance. The authors note that previous literature states that mothers of children with developmental disabilities are more likely than mothers with more typical children to work part time, earn less money, or reduce work hours to care for children at home. Previous literature noted that parents of children with a disability usually took a longer maternity leave period than did parents of more typical children.

For the purpose of this research, the authors conducted four focus groups with 26 total parents (about 6 or 7 per group). The age of the children in these families ranged from 4 to 32 years old. The parents in these groups viewed work as a welcomed distraction from the stresses at home; there was a sense that at work some of these parents felt a sense of control, predictability, or competence. At home, often things were not as predictable. Many of the parents in this study went back to school or work in the human services or education fields, stating that they had been influenced by their family needs or by a human services professional. Some parents noted that having a child with a disability had influenced them not to take a new job (in a new area) if the current service system was working for their child. Parents noted that after-school programs were helpful (but sporadic) in supporting work efforts. Respite care was seen as a nice, but not existent, theoretical service. Parents stated that their greatest source of support was other

families of children with disabilities. Parents noted that, in most cases, employers were understanding and supportive.

Although the authors note the weakness of poor generalizability of this study, there are great strengths in a study of this nature. It points to many areas for future research: studies on employer family-friendly policies, longitudinal studies on ability to continue to work, descriptive studies on how parents negotiate their home–work schedule, and phenomenological studies of sense of fulfillment.

Friedrich and Friedrich (1981) explored the psychosocial assets associated with parents of children with and without disabilities. The authors were interested in comparing these families in several domains: marital satisfaction, social support, religiosity, psychological well-being, and measures of resources and stress. The researchers interviewed 34 parents of handicapped children and 34 parents of nonhandicapped children using the Questionnaire on Resources and Stress. All 68 families were "intact"—that is, each had both parents present. The researchers used the Lock Wallace Marital Adjustment Inventory, the Psychological Well-being Index, and the Social Support Index as measures for the study. The authors found that families of children with disabilities reported more stress, less marital satisfaction, less psychological well-being, less social support, and less religiosity than did families of nonhandicapped children. In general, the study revealed more stress and fewer assets for parents of children with disabilities.

The article offers good baseline (given its age) on comparison between exceptional and more typical families. It offers several areas for future research: longitudinal studies, defining social supports, and reviewing other stress mitigating

variables. Further, the article uses a variety of family stress and asset measuring instruments. Finally, the authors note that social support appears to offer hope to these families, and they suggest exploring ways to increase this support.

Blacher, Nihira, and Meyers (1987) studied the differences in families of children with mild, moderate, and severe retardation. The hypothesis is that a higher level of retardation (lower IQ) in a child will have a more significant effect on the family in terms of stress levels. The authors surveyed and interviewed 53 families of children with severe retardation, 54 families of children with mild retardation, and 50 families of children with moderate retardation. Intelligence of the children was determined by the Weschler Intelligence Scale for Children Revised scores. Each family was interviewed and surveyed over a 6-hour period using the Family Environment Scale (Moos, 1976) and the Home Quality Rating Scale to understand the home environment and the child-rearing values operating in each home. The authors were most interested in the impact of having a child with retardation on marital adjustment, the impact on family atmosphere, and the impact on family life and routine. Most of the children in these families were of similar age.

Family adjustment scores and family coping scores were significantly lower for families with severely retarded children than either of the other groups of families. Similarly, scores for negative impact to family routine were most significant in families with severely retarded children. The impact on daily life appeared to diminish over time as children grew older. There appeared to be no significant differences across family groups regarding marital adjustment. From interview material, the authors noted some additional information. The ambiguity of having a child with mild retardation may lead to

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other types of stresses due to unclear expectations. A child with severe medical involvement has far more home and case management consequences for the family. Parents often listed their spouse as their most important source of support. The authors make specific suggestions for future research: defining types of families and exploring the differences in support need for families and the complex decision process among parents. The weakness of this article is that it ends with an emphasis on how families make decisions regarding out-of-home placement. There is no earlier reference or attached explanation for discussing out-of-home placement. This non-referenced note on out-of-home placement is reminiscent of research on this field forty years earlier.

Summary of Literature Regarding Description of Families With Mental Retardation and

Policy Issues

In trying to describe families of children with mental retardation, researchers have proposed a variety of methods: family typing, self-descriptions, or descriptions of certain aspects of family life. Family typing begins to describe how families operate; however, typing may have the effect of further stigmatizing. In general, the literature appears consistent in stating that families who have more needy children experience more stress. Hardiness and social support appear to have a mediating effect on this stress, and the lack of these attributes may result in demands for deeper end services, such as out-of-home placement. Families appear to be saying that employment is a break from the stress at home and gives parents some sense of accomplishment. Parents of children with mental retardation have more challenges in finding employment that blends in with their

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atypical family needs. Some of the parents reported being influenced by their situation in choosing a career in human services. The qualitative research in this area enables the reader to have a glimpse into the life of families of children with disabilities. A great amount of time is spent in behavior management, and even basic family problem solving is a challenge. In general, these families report less available social support and more family stress. Practitioner-researcher teams have developed family-centered best practice guidelines; these guidelines have not yet been adopted widely in the field. These types of family-driven guidelines (Baird & Peterson, 1997; Trivette, Dunst, Hamby, & Lapoint, 1996) suggest not only a theory shift in treatment practice but also a paradigm shift in regards to policy. These significant shifts in theory, practice, and future research do not come easily or quickly. Freedman, Litchfield, and Warfield (1994) begin to explore the phenomenological experiences of these families, but only from the angle of the effects that work has on increasing or decreasing family stress. Further definition and specification of family needs and strengths has yet to be explored from a more holistic, qualitative view.

<div align="center">Family Resilience and Coping Literature</div>

Trivette, Dunst, Deal, Hamer, and Propst (1990) described the qualities of strong families and demonstrated the reliability and validity of the Family Functioning Style Scale, a strengths-based measure for families. The authors made several specific suggestions for community-based family practitioners regarding strengths-based assessment and treatment. These researchers noted that strengths-based work has a short

but rich history and has been best put to use in early intervention programs. Up until recently, strengths-based family work has been limited because field practice has been primarily deficit oriented. The authors described family strengths as relationship patterns, interpersonal skills, and social and psychological characteristics that create a sense of positive family identity, promote satisfying interaction among members, and contribute to the family's ability to deal effectively with stress.

These authors reviewed substantial literature regarding family strengths. There appears to be agreement on 12 qualities of strong families.

1. Commitment to the well-being and growth of each family member.

2. Appreciation for the small things that each family member does well.

3. Time commitments made for formal and informal activities together.

4. A sense of purpose for understanding good times and bad times.

5. A sense of congruence regarding goals and needs.

6. The ability to communicate with one another that emphasizes positive interactions.

7. Clear rules, values, and beliefs.

8. A varied repertoire of coping strategies.

9. Problem-solving strategies that result in meeting needs.

10. The ability to see some positive in all aspects of life, even going so far as to consider stressful events as "opportunities for growth."

11. Flexible and adaptable roles.

12. Balance between internal and external family resources.

The authors take a strong stand for strengths-based work. They note that successful intervention rests as much with the resources of the family as with the skill of the interventionist. To access these strengths, clinicians need to be able to build on positive aspects of a family, not just fix what is broken. The authors noted that moving to a strengths-based model is a paradigmatic shift and may take some time.

The authors reviewed the relative strengths and weaknesses of previous family strengths assessment scales: the Family Strengths Inventory, the Family Strengths Scale, the Family Hardiness Index, and the more recently developed Family Functioning Style Scale. This last scale was developed by three of the authors and includes a comprehensive assessment of family qualities. The remainder of the article is focused on the use of this instrument. The authors used this instrument to survey105 parents, half of whom had a child with a disability. The instrument appeared to be internally consistent and predictive in terms of family functioning. The authors conclude by noting that for the field of family intervention to shift toward a strengths-based approach, valid assessment tools are needed as well as additional training for treatment. The strengths of this article include specific advice on assessment and interviewing techniques and its inclusion of families in the development of the instrument. They practiced what they preached. The article was limited in scope, yet that appeared to be intentional.

Beckman, Newcomb, Frank, Brown, and Filer (1993) explored family support and described a systemic approach to families of infants and toddlers with disabilities. Social support appears to buffer the stress associated with raising a child with a disability. The purpose of this article is to describe the need for social support for families, and to describe a model for developing and implementing a flexible program. The authors noted

that there is considerable discrepancy between current and ideal practice. There appears

to be some barriers to moving toward more family-centered practice. Existing service

systems are more oriented to individual children rather than families. Further, there has

been a lack of clearly identified family-centered protocols for treatment.

In describing this model program for families, the authors first noted five guiding

principles:

1. The family is viewed as a system in which members exert mutual influence.

2. Families are the primary decision makers for their children and themselves.

3. Families are self-defining regarding who participates in treatment.

4. Families concerns may change over time.

5. Families vary on multiple dimensions and practitioners need to be respectful of
   diversity.

The authors go on to describe Project Assist, a family–centered, university-sponsored

program in which parents of children with disabilities received individual and group

support and instrumental support. Instrumental support is described as concrete

consultation, assistance, and advocacy with Individual Education Plan meetings, child

welfare systems, medication, and health-related issues. Parents determined how much

support they needed in this project. Individual support was tailored for families. Specific

themes were discussed for family exploration and staff training. The authors noted some

patterns or phases in the group support: the beginning phase, in which expectations were

shared; the second phase, in which families choose how much they will share; the third

phase, in which collaborating with the group facilitator and other group members is common; and the fourth or termination phase, in which members begin to deal with closure. These group phases are consistent with other models of describing group dynamics.

The authors surveyed families regarding their satisfaction with the program and with the Parenting Stress Index. Parents reported a high level of satisfaction with the support they received. The mean level of stress experienced did not decrease as measured by the Parenting Stress Index; this was possibly due to extenuating circumstances in this small sample of parents. Parents did indicate that they felt less isolated, an increased sense of empowerment, and more knowledge of resources. The strengths of this article are the practical guide given to family practitioners in the field and its discussion of current federal policy regarding infant and toddler services. The article is based on evaluating a theory-based model that relies on social support, a consistent factor in mediating family stress. Further, the article gives some ideas for fiscal support and even evaluation. The Parenting Stress Index did not appear to capture similar results of the satisfaction survey, but perhaps that was due to the relatively small sample size.

Trivette, Dunst, and Hamby (1996) explored factors contributing to parent decision making, choice, and self-determination as part of best practice efforts in early intervention. Decision making, choice, and self-determination are key elements of self-efficacy and empowerment. Previous research indicates that families only feel that they are true partners in the treatment of their child if they truly have the power to make important decisions regarding their children. The authors noted that five decades of

research have established perceived control as a robust predictor of people's motivation and performance.

This article was based on surveys of parents of children with developmental disabilities. The authors conducted two series of surveys, one involving 128 parents and the other involving 81 parents. All participants were involved in a family support program for children at risk of developmental disabilities. The background characteristics of the families were diverse on all demographic measures except ethnicity (93% White). Participants completed the Helpgiving Practices Scale (measures help-giving attitudes and behavior), the Early Intervention Control Scale (measures perceived control over interventions) and the Personal Control Appraisal Scale (measures perceived control in obtaining resources). The help givers in this study had varied backgrounds: special education, social work, nursing, speech and physical therapy, psychology, or general education. In previous studies, it was found that nurses and social workers received more preservice training in family centered practice than did other disciplines.

Staff discipline and help-giving practice accounted for a significant amount of variance in perceived control. Families being served by a social worker indicated the highest amount of perceived control. A help-giving style of encouraging parents to play an active role in the treatment of their child was strongly related to perceived control. Active participation was more important to parents than traditional treatment skills such as empathy and good listening. Thus, good clinical skills are necessary but not sufficient factors in empowerment-oriented family practice. Parents' control appraisals were notably higher if staff has had family related training.

The authors acknowledge weaknesses of this article as being a review of only one program and the one dimension, perceived control. Strengths include the study of real-life situations and its call for future research in the area of other variables: intensity of intervention, length of involvement, and across different programs.

Lucyshyn, Albin, and Nixon (1997) evaluated a comprehensive behavioral approach with one family of a child with multiple disabilities. The purpose of this research was to examine both the outcome of the interventions and to evaluate the value of having the family participate as part of the research team. The authors were particularly interested in reviewing interventions in the natural environment in which the behaviors of concern occurred. It was noted that for some individuals with multiple disabilities, it is a nearly impossible challenge to learn from a behavioral intervention in one setting and then transfer that learning into other settings.

The lead author was a major part of the treatment team. The team assessed the family psychological and physical environment as part of the preliminary work. The goal of the treatment was behavioral improvement in valued family routines such as eating dinner together in the family home, eating dinner out at a restaurant, participating together in a leisure activity, and going out to the grocery store. The researchers collected baseline and outcome data on rate of problem behaviors, frequency of maladaptive behavior, child involvement in community activities, and occurrences of appropriate behavior. All of these variables were measured by observation except the involvement in community activity that was measured by the Resident Lifestyle Inventory. The treatment team provided training and support to the family so that the family could follow through when support staff were absent. Training occurred 2 or 3 times each week from 20 to 75

minutes over a 6 months period of time. The rate and frequency of problem behaviors decreased significantly at the end of treatment and remained lower at a 9-month follow-up. Participation in community activities had doubled from 6 to 12 per month. Appropriate behavior increased. Parents expressed satisfaction not only with the treatment but also with being included on the research team.

The strength of the article is that it gives the reader a strong sense of how this family is coping and the steps it took to improve its situation. The authors included the family as part of the treatment team and research team, yet empowerment is not addressed in this article. Having the lead researcher be a part of the intervention and observation team gives the reader concern for potential conflict of interest, yet it certainly appears as if this family was helped. The authors called for future research in the areas of replicating comprehensive behavioral intervention with other families and reviewing the durability of behavioral changes in such studies.

Beckman and Bristol (1991) reviewed earlier studies of family support and discussed, in general, the system of support for families of children with a disability in the United States. The authors were interested in understanding how systems that were designed to be supportive to families often do not feel supportive to those families. Instead, informal support is often noted by these families as being of much more help. The authors noted that most of the time, service providers have focused on individual families that have the obvious multisystemic issues.

The authors examined the subsystems noted by Bronfenbrenner (1979) as macrosystem (social, political, and cultural factors), exosystem (agencies involved with a family), and mesosystem (relationship between family members and professional service

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provider). In regards to macrosystem issues, the author noted the impact of poverty, access to services, and the cultural values that define available services. The authors noted that services typically are designed for middle-class, nonminority families. The authors noted exosystem issues that affect the way families receive services. In several service systems, there are gaping holes in available services to families. Most notably, specialized child care is not available, which is a barrier to parents' finding employment. Families may be confused by the advice they receive from a myriad of professionals. Lastly, some services are available to families at certain times of the year, rather than year round. The authors noted the mesosystem issues that affect the relationship between parents and practitioners. Parents often feel as if practitioners are not listening to them, are disrespectful to them, have a poor attitude, and are insensitive. The authors concluded with several specific suggestions for systemic improvement based on previous research and feedback from parents. The suggestions call for an honest look at the nested systems as suggested by Bronfenbrenner (1979). The strengths of the article are the specific systemic suggestions and some directions for future research. The authors suggested exploring formal and informal supports for families and for studies that demonstrate the effectiveness of support for families.

  Eiserman, Weber, and McCoun (1995) reviewed two models of parents as teachers programs, one home based, the other clinic based. The authors noted the dearth of research in parent involvement programs or alternative roles of parents. Anecdotal reports from the field note that high parent involvement in the treatment of their disabled child yields better treatment results. Although the literature does not support that conclusion, the literature in this area has been thin and poorly managed. The authors

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conducted this research over a period of 42 months and used the Battelle Developmental Scale to obtain before and after scores on speech and language functioning of the child in these families. How many families, what the family configuration is, or what child diagnosis is used are not discussed anywhere in this brief article.

The authors noted that both the clinic-trained and home-trained parents reported high satisfaction with the program. Initially the children of home-trained parents had higher gains in language functioning. There were no significant differences in children's scores between the two groups over a longer period. Over the long term, parents appeared to express higher satisfaction with home-based services.

The strengths of this article are the field and research suggestions. The authors suggested flexibility in services in the field. For future research, the authors suggested a descriptive approach to understand family needs and to look at other family variables and their interactive effects. The weaknesses of this article are methodological: there is no information regarding the research participants. If the reader assumes that those parents who could financially afford to stay at home during the day chose the home services, the sampling would certainly be skewed. The details for this article were limited.

Abbott and Meredith (1986) reported that limited studies have been conducted on coping strategies within families of children with disabilities. They directed an empirical study to investigate the influence of crisis event interpretations, the "crisis" being having a child with a disability. The parent's personal resources related to personality were also examined. Sixty parents (30 married couples) of children with mental retardation were compared in terms of marital and family strengths with 60 parents of children without disabilities. Matching on child's sex, race, age, and number of siblings was completed.

Researchers administered the Family Strengths Scale to measure family characteristics in solving problems, the Dyadic Adjustment Scale to assess marital characteristics, the Edwards Personal Preference Schedule to describe psychological characteristics, and an open-ended survey about family adjustment. No significant differences were indicated on the Dyadic Adjustment Scale, the Edwards Personal Preference Schedule, or the Family Strengths Scale. On the last instrument, however, parents of children with mental retardation reported they were less critical of other families ($p < .04$) and reported fewer family problems ($p < .05$).

On the Family Adjustment Survey administered only to parents of children with mental retardation, 94% of the families perceived themselves as doing as well as their peers. These parents did report more difficult parenting, financial concerns, concern about their child's future, and restriction on family activities. Seventy-one percent of the families reported positive coping because of a "positive outlook" and "acceptance" of their child. Other coping strategies were as follows: (a) taking one day at a time, 39%; (b) commitment to facilitating the child's potential, 20%; and (c) willingness to complete extra responsibilities for their child, 20%. The majority of the families also reported greater family strength and closer family relationships as a result of their experience. Abbott and Meredith (1986) concluded that their results supported the idea that some families have been able to adapt to having a child with a disability, a conclusion that contrasts with the problem-centered focus prevalent in prior literature. Positive parental perceptions and spousal support were identified as particularly important coping strategies. The role of spousal support was consistent with information from Trute and Hauch (1988).

Summary of Resilience and Coping Literature

In this area of research, there was less available literature. Researchers appear to be just beginning to explore and understand what helps in mediating stress for families of children with mental retardation. This shift from pathology-oriented theory, practice, and research can be seen in a shift of measurement instruments: more recent research appears to make use of the Family Strengths Survey and the Family Strengths Index rather then the formerly popular Questionnaire on Resources and Stress or the Parenting Stress Index. In regard to theory, respected authors acknowledge empowering the family as full partners as a key to success in resiliency and in long-term outcomes for their children. The Center for Effective Collaboration and Practice has proposed and begun implementing programs and research on families as full partners with the treatment team, the evaluation team, and university faculty in preparing new practitioners, a promising but, as of yet, not widespread practice.

Factors associated with successful coping can be categorized into two areas: formal support and informal support. Informal support appears to be more promising, according to self-report from families. Informal support comes from extended families, friends, and other families with similar issues. In terms of formal support, there are suggestions that appear helpful: family-centered practice as opposed to child-centered intervention; empowering families; keeping an eye on meso-, exo-, and macrosystem issues; and involving parents in teaching or treatment. Guidelines for strengths-based family assessment and treatment are now available and used in some communities. Parent

decision making and choice are key elements in empowerment and family satisfaction. Families want to be part of treatment and evaluation. All of these strategies that work with families will require extensive field training for community-based practitioners. To better understand and clarify the specific needs of these families, additional qualitative research is indicated. This research must have a family-driven perspective that will have implications for theory building, practice, and future research.

<center>Prior Research Findings and Justification for Additional Research</center>

There are areas of prior research that inform and guide the proposed study. Previous studies have been consistent in determining certain areas of stress and sources of support. Having the responsibility of caring for children increases family stress, and having the responsibility of caring for children with disabilities has been noted as even more stressful than caring for more "typical" children. It has been noted that normative (socioeconomic and environmental issues) and nonnormative (disaster or unexpected disability) factors have an effect on family stress. Classification schemes of families of children with disabilities have been discussed in the literature, and have been found to be clumsy, too narrow in defining families, and possibly stigmatizing. In regard to factors associated with decreased stress, prior studies have noted that social support has a mediating effect on stress. Families of children with disabilities tend to have social support networks with friends and family members having multiple roles (e.g., friend, babysitter, or alternative soccer practice driver). Family members have reported feeling support from their faith communities and from understanding some reason for their

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situation. Both of these factors appear to be related to meaning attribution as noted in the ABC-X model (McCubbin et al., 1980) of family crisis response. Work appears to be a mediating factor in that it serves as a respite from the challenges of family management. Family involvement in the treatment and education process leads to a greater sense of empowerment and family satisfaction. Family-centered services are consistently more highly rated than child-centered services. Hardiness is associated with less stress, yet there is little research on what encourages or strengthens hardiness. The body of knowledge generated from prior research has guided theory development, practice, and additional research in this area, yet much remains unknown.

Although previous studies have been informative, relatively few have defined the view from the family perspective, and none have proposed a grounded theory approach in which to better understand families. A grounded theory approach in research will promote additional theory development, practice guidelines, and further research from the family perspective. This grounded theory approach explores relatively unmapped areas related to the family experience of raising a child with a developmental disability. Whereas previous research has explored school-related services and its effects on families, relatively little has been written about the family perspective of these services. Previous research has described factors associated with family stress, but relatively little has been reported about the family perspective of their experience of stress, and their ability to cope with stress. Whereas previous research has reported that factors such as social support, hardiness, extended family, and faith community appear to mediate stress, little has been written about the family perspective on how the family created, supported, or struggled with maintaining these supportive variables as part of their lives. Although

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previous research has contributed significantly to establishing baseline data on variables associated with coping and stress, there needs to be additional research oriented toward deepening existing knowledge about the family perspective in raising a child with a developmental disability. The study reported in this paper adds to existing knowledge by focusing exclusively on the family perspective by initiating a research process that incorporates the family experience into data collection, theory development, suggestions for practice, and suggestions for future research.

Chapter 3 Methodology

The objective of this qualitative study was to examine relative stress, resources, and successful coping strategies using a grounded theory approach in families who have an elementary school-age child (5 years old to 11 years old) with mental retardation. In this type of study, research was directed toward how participants make sense of their experiences and how that may influence their behaviors and cognitions (Strauss & Corbin, 1998).

A grounded approach is characterized by classifying events, action and outcomes as the foundation for developing a theory about research.   Research does not begin with a preconceived theory in mind; theory is to emerge from the data. To develop a theory based on the data gathered from grounded approach, the researcher must:

1. Step back and critically analyze data

2. Recognize one's tendency toward bias

3. Think abstractly

4. Be flexible and open to criticism

5. Be sensitive to words and actions of others

6. Have absorption with the research process

It has been established that families who have a child with mental retardation experience stress because having a special needs child is a phenomenon of significant

magnitude that necessitates a change in the family system (Cherry, 1989; Winkler, 1981). It was the intent of this study to examine the resources and coping strategies a family uses and the effect of these mechanisms on the relative level of reported stress.

The two variables of family resources (i.e., extended family, faith community, socioeconomic status, and others) and successful coping strategies (i.e., meaningful family rituals, feedback, respite, and others) have been reviewed for their relationship to the level of relative stress. A grounded theory approach, in this study, strongly supported the notion that themes and a subsequent theory can emerge from analyzing the raw qualitative data (rather than the traditional research project which begins with a hypothesis).

The specific factors of family support, community variables, and interactions with professionals have been discussed with participants and analyzed for their significance. The nature of this study is a grounded theory approach. In grounded theory, the researcher is sensitive to the words and actions of the respondents, is able to think abstractly and has a sense of absorption to the issues being studied. Description in grounded theory is based on conceptual ordering or organizing the data into discrete categories. The theorizing phase is a process of formulating the conceptual ordering into a logical, systematic, and explanatory scheme (Strauss & Corbin, 1998). To understand parents of children with mental retardation, it is necessary to understand the interconnected systems in which they live. Parents of children with mental retardation have had little opportunity to tell their stories as part of research. Ten parents of children with mental retardation were interviewed for this study; they were encouraged express themselves through the interview and an informal logbook. All of the parent responses to

the semi-structured interview questions were included in the results section of this research. Names that identify the participant, partner, children, and other family members have been left out to protect participant's privacy. All of the participants signed an informed consent form that advises them of their right to privacy. An open-ended logbook was given to the parent participants in this study in order for them to record, at their own discretion, what occurred during their waking hours and what their perceptions were of those occurrences. Direct quotes from the log books are included in the results section. At least one follow-up interview was conducted with each family to ensure the interviewers' understanding of the parents' logbook entries and to ask specific and open-ended questions about sources of support and stress in their lives. Grounded theory openly acknowledges a tendency toward researcher bias and encourages openness toward helpful criticism. For the purpose of clarifying and analyzing researcher bias, a second licensed clinician reviewed the initial analyses made by the researcher. A descriptive analysis noted which factors appear to be most closely associated with stress and which factors appear to have a mediating effect on stress.

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Three research questions were used to guide the interviews and data analysis:

1. What are the subjective experiences in families of children with mental retardation?

2. What coping mechanisms, if any, appear to have a mediating effect on stress for these families?

3. What family, community, and other factors appear to be most closely associated with coping or stress for families of children with mental retardation?

Participants

The participants of this study were 10 parents of school age children with mental retardation who attend public school in Charles County, Maryland. The families selected for this study have at least one other typically developing child. The reason for this purposeful sampling is to ensure that these families have had some normative experience with typical developmental milestones.

The principal investigator met with the Charles County Special Education Coalition (a group of educators and family members planning for the special education needs of Charles County students) and a parent support group in early November, 2003, in order to recruit family members interested in participating in the research. There was strong interest from both of these groups, and interviews with 10 families were conducted in November and December 2003.

Although the 10 families met the criteria suggested, the family configurations did vary among subjects. Two of the households were multigenerational, with one home having a grandmother living with the family that also required care. Another home had both grandparents in the home who were often the primary caretakers of the child with a disability. Seven of the families were Caucasian, two were African American, and one household was biracial (Caucasian and African American). It is also worth noting that

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although all of the households contained at least one child with an intellectual disability (mental retardation), most of these children also had co-occurring impairments (asthma, partial blindness, pervasive developmental delay, obsessive compulsive disorder, seizure disorders). Thus, some of the caretaking responsibilities varied depending on needs attributed to factors unrelated to an intellectual disability. Health concerns can impact caregiver demands, and thus, have an impact on stress experienced by the parents (Beckman, 1983; Singer & Irvin, 1989). The following table illustrates demographic characteristics of the participants.

Participant Demographic Variables

Family #	Race	# of children	Mother employed	Multi-generational	Other Med Concern	Primary Diagnosis of Child	Marital Status
1	Cauc.	3	Part time	no	clubfoot	MR	Married
2	Cauc.	2	Part time	no	Kidney replaced	MR	Married
3	Cauc.	2	Part time	no	no	MR/ Autism	Married
4	A.A.	2	Full time	no	no	PDD/ MR	Married
5	Cauc.	4	no	no	allergies	PDD/ MR	Married
6	Cauc.	2	no	no	no	PDD/ MR	Married
7	Bi-racial	2	no	Yes, as care-giver	seizures	PDD/ MR	Married
8	Cauc.	2	Part time	no	Pronated gait	MR	Separated
9	A.A.	2	no	no	no	MR	Married
10	Cauc.	2	Full time	Yes, as care-recipient	Blind in one eye	PDD/ MR/ ADHD	Separated

Interviews

Each of the interviews lasted between 60 and 90 minutes. All but one of the interviews was conducted in the family home. One interview was conducted in the individual's place of work, after hours. In all but two of the interviews, the father was not present. In the two interviews in which the father was present, the mother was the primary respondent. The interview responses were analyzed and coded into naturally occurring themes of empowerment and disempowerment under the following domains: microsystem (within the family), mesosystem (relationship with professional caregivers), exosystem (the available service system in a given community), and macrosystem (economic, political, and cultural factors affecting a community

Charles County is 19 miles southeast of Washington, DC. There are few major industries or business in the county, and nearly 65% of county residents commute outside of the county for employment. At the 2000 census, the average household income for the county was calculated at more than $51,000 per year, the second highest per household income in Maryland. The county is made up of a geographically small but densely populated suburban area near the nation's capital and a substantial rural farming area that is home to 300 Amish families. Of the more than 100,000 county residents, 80% are Caucasian, 18% African American, and 2% consist of other races. The racial makeup of the research participants are representative of Charles County.

Because of the rural nature of Charles County, it is inevitable that many of the research participants knew each other from support groups, advocacy efforts or parent outreach efforts. Some of the participants who were involved in a parent support group have knowledge of each others frustrations and successes; this knowledge may have

skewed some responses to interview questions. The principle investigator had been a director of a family counseling practice in Charles County for more than a decade, but has no previous personal or professional contact with any of the participants.

The general environment of Charles County provides both opportunities and challenges for families in need of support. In the northeast corridor of the county, resources for counseling and other family support services are plentiful and easy to access via public transportation. In other, more rural areas of the county; however, service availability is often negligible and public transportation is almost nonexistent. Economic factors have an impact on the quality of life and availability of public services in Charles County. Because of its close proximity to Washington, DC, and its comparatively low county tax rate, Charles County is an economically attractive bedroom community. The relatively low tax rate, however, accounts for the comparatively modest availability of family support and special education services. This has had a negative impact on families needing special education, mental health, or child welfare services. Although basic, legally mandated services are available; the myriad of services needed by families of children with mental retardation is often unavailable and can leave these families feeling frustrated. The impact of community factors will be analyzed further in the discussion section.

Available Services

The following services are available in Charles County and were discussed in the structured interviews with the parents.

Charles County Public School's Special Education

Charles County Public School's Special Education Division makes a variety of services available for students with mental retardation including support within an inclusive setting, modified curriculum, speech and occupational therapy, smaller classroom settings with trained staff, and placement at private settings. The focus of these services is on the student, with little attention to the family environment.

Charles County Health Department

The local health department is the fiscal manager for services sponsored by the Maryland Developmental Disabilities Administration (DDA). DDA sponsors residential, behavioral management, respite, and other services for individuals with mental retardation and their families. Because of limited funding, there are limited resources for residential placement. There are some resources available for respite care and home-based behavioral management services.

Family Counseling Services

There are several family counseling organizations within the county, but only a few of these agencies have the expertise to support families of children with mental retardation.

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In the past 10 years, only three organizations have sponsored parent support groups for children with mental retardation (Tri-County Youth Services, Arc of Southern Maryland, and Charles County Association for Handicapped and Retarded Citizens). These parent support efforts have been well received, but time limited. These public and private services may or may not be working collaboratively on behalf of the families they serve. The impact of these and other services will be analyzed in the discussion section.

Instruments

The two methods for gathering data for this study were an open logbook for families to self-report, at their discretion, on activities during waking hours for a 1-week period and a semistructured interview with both specific questions and open-ended questions. The logbook gave families the opportunity to express themselves in their own words and communicate their experiences and their perceptions of those experiences.

A semistructured interview was conducted to understand more clearly the needs and strengths of families of children with mental retardation. The interview gave families additional time to express themselves. Hearing from the family directly allowed the interviewer time to follow up on significant points. Currently, there are few adequate qualitative instruments that measure family resources and coping strategies for families with special needs children. To review family resources and coping strategies, a semistructured interview instrument was designed that uses items derived from empirical research as well as anecdotal reports. The first part of the interview contained items that are potential strategies or resources aimed at mediating the specific stress associated with

raising a child with mental retardation. Each interview was audio taped and extensive

noted were taken by the interviewer. The responses were later transcribed verbatim and

are included in the appendix. Responses from the interview were coded by a naturally

occurring classification theme of empowerment and disempowerment. This them will be

discussed further in chapter four. Many of these potential coping strategies, although

seeming to make intuitive sense, have not been effectively analyzed in any methodical

manner. Helpful resources appear to be available extended family, attachment to a faith

community, adequate financial stability, peer support, and adequate health care coverage.

These and other resource factors will be studied. Helpful coping strategies appear to be

meaningful family rituals, sharing success stories about the special needs child, providing

positive feedback between partners, and committing to the respite concept (e.g., alone

time). These and other coping strategies will be explored. As noted earlier, it is expected

that theory building for successful coping will emerge from the raw data reported by the

families in this study. The second part of the interview contained items that have been

most often associated with family stress in previous research.

Structured Interview Questions

The interview questions were split between two groups: Sources of support and sources

of stress. Dividing the questions in this way helped to clarify the full range of stress and

coping sources in the subjects' experience, and it helped parents to evaluate their

experiences in detail

Sources of Support

1. Are extended family and friends available to you when you need them?

2. How is the public school able to support you with your child?

3. Do you receive any professional support? Does it help?

4. Do you receive any formal or informal respite services? Is it helpful? What is your system?

5. Do you belong to a faith community? Does it support you?

6. How do you view your volunteer or paid work outside of your home?

7. Do you have any rituals that you find helpful? Singing with your child, discussing achievements, integrating siblings, sharing dreams, prayers?

8. How do you as, a couple support, one another?

9. What do you find to be the most important source of support?

Spouse or partner_____

Extended family____

Friends_____

Faith Community____

Professional Counseling____

Support Services or respite____

Other (please specify)_____

Sources of Stress

In what ways does having a child with special needs affect your family life?

What kind of health-related concerns do you have for your child? Can she or he

    communicate discomfort?

In what ways does having a child with special needs affect his or her siblings?

What are your thoughts on the future care of your child?

What kinds of things raise your stress level (e.g., school, family, neighbors)?

Procedure

      Parents of children with mental retardation were identified with the assistance of

the Charles County Public School's Special Education Division. An informed consent

form along with a cover letter explaining the nature of the research project, expectations

for parent participation, and how confidentiality would be maintained was mailed out to

identified parents. Follow-up telephone calls were necessary to obtain 10 participants.

After parents were identified for the study, the interviewer visited with families at their

convenience, usually at their home. As part of that visit, families were asked to sign an

informed consent form. Families had a chance to ask any question of the interviewer or

discuss any concerns. No parents were coerced into participating. Protocols for

maintaining the logbook were discussed with each of the families.

Data Analysis

The goal of data analysis for this study was to describe sources of stress and support for families of children with mental retardation. Analysis of the data is based on an approach that allows key themes to emerge (Strauss & Corbin, 1998). There were no comparison groups and no treatments that are associated with this study. Data gathered from the logbooks and the structured interviews were analyzed using a grounded theory approach to better understand the types and levels of stress experienced by families of children with mental retardation. The data were further analyzed to understand what factors are associated with the mediation of their stress. The general focus of this analysis was to uncover patterns of stress and support in the lives of these families.

Credibility

To ensure credibility, the strategies of cross checking data between the logbooks and the interviews and peer debriefing were used. A peer debriefer reviewed the transcripts of the interviews and the coding of the interview responses. Second interviews were conducted by the principle investigator to ensure that statements from the interviews were interpreted accurately

Chapter 4 Results

This chapter will address the three research questions and the themes of empowerment and disempowerment that emerged from the analysis of the data. Quotes from the interviews are used within this analysis. All of the responses from the interviews are included in the appendix.

Empowerment and Disempowerment by Ecological System Domain

Interview and journal responses from participants support and clarify previous qualitative research, but also have created a theme of its own based on empowerment. A grounded theory approach to research strongly supported the notion that themes and a subsequent theory can emerge from analyzing the raw qualitative data. In this study, the participants comments mostly centered around the theme of empowerment among the ecological systems noted by Bronfenbrenner (1979) microsystem, mesosystem, exosystem, and macrosystem. The following chart notes some of the most significant comments from participants, and is categorized by ecological system domain and whether the participant was expressing empowerment or disempowerment.

Empowerment and Disempowerment by Ecological Domain

Ecological System	Empowering	Disempowering
Microsystem (within family)	"…(husband) is a great source of support"	"…just dropped his present at the floor and left"
	"A lot of aunts are involved in care"	"My brother just gets agitated"
	"I've gotten better at asking for help"	"We don't have much family around"
	"My husband goes to all doctor appointments"	"We were separated and blamed each other for … problems"
	"I do advocacy work, and it's very rewarding"	"We are not a normal family; sometimes my daughter gets left out of things"
Microsystem (within the family)	"we, as a couple, make time to discuss our children and their successes"	
	"We (husband and I) give each other breaks"	"We can't be spontaneous"
	"My husband and kids are a great source of joy"	"Any family decision takes a lot of thinking"
	".. has made the other children more sensitive and accepting"	"He gets hurt and doesn't tell us"
	"I am hoping he can learn to be independent and happy"	"The other two kids are jealous of extra attention"
		"My husband calls him luggage"
Mesosystem (relationship with professional caregivers)	"Our dentist is really good with kids"	"I'm trying to get him a different teacher"
	"… a professional counselor… was	"They (school personnel) treat us like trash"

	outstanding"	
Exosystem (available service system)	"We are thankful for speech, OT and vision services" "we've been lucky with the school system" "We received respite services and it was helpful"	"We have to fight for everything" "We had to hire a lawyer to get basic services" "teachers need training"
Macrosystem (political, and cultural factors)	"Respite is covered by Medicaid" "Our church has been tolerant and supportive" "My job has been flexible and supportive" "The support group is a lifeline"	"One of the most stressful things is having to explain his behavior to other adults" "… we get people staring"

Question 1

What are the subjective experiences in families of children with mental retardation?

The subjective experiences of these families as expressed through the interviews and the logbooks emerged in the themes of empowerment and disempowerment related to ecological systems (Bronfenbrenner, 1979). Comments from the interviews and the logbooks indicated feelings of empowerment and disempowerment within the ecological systems: microsystem (family system), mesosystem (relationship with professional

providers), exosystem (system of service providers), and macrosystem (political and cultural factors).

Microsystem

There were several comments related to the subjective experience of families within the microsystem which emerged into a theme of empowerment. These comments included "My family has always been there for me, especially my sister and my father" and "We are a very blessed family." Interviewed families were committed to their children even as they grew older (we may build an addition to our house so --- can stay near us All 10 families noted that the support from family and friends was very important to them. Family unity was the sub theme of empowerment within the microsystem.

There were also several comments related to the subjective experience of families within the microsystem which emerged into a theme of disempowerment. Two parents noted that certain extended family members had low tolerance the behavior of the child with a disability, and thus visited infrequently or not at all. An example of a comment regarding extended families not being involved would be "they dropped off ---'s birthday present at the door and left." It was of particular concern to these families that their children have had limited ability to express discomfort or pain. Eight of the ten families interviewed noted that their child either seemed immune to discomfort or was unable to communicated discomfort. Some of the mothers reported that much of the responsibility for child rearing falls to them, and this perceived inequity also contributed to stress. In two instances, the interviewed parent noted that they were at a different stage of grief

than their partner. Four families in this study spoke of issues related to grief. In two instances, the interviewed parent noted that the grieving process had been at least partially responsible for marital distress and even separation. In this study, all 10 families who were interviewed noted that having a child with a disability affects every facet of their lives including recreational activities, shopping, dining out, and family vacations. This pervasive effect of having a child with a disability has been noted in other research (Cherry, 1989). Grief in the immediate and extended families and the burden of family management were the sub themes of disempowerment within the microsystem.

There were several comments related to the subjective experience of families within the mesosystem which emerged into a theme of empowerment. The specific resources (occupational therapy, speech therapy) were appreciated. 3 of the 10 parents made comments about the public school system staff that could be perceived as indicating a trusting relationship (We've been lucky with the school system."). . Parents that commented on the concrete support they received were very appreciative of these resources. For the families that did receive professional counseling services in this study they noted a high level of involvement and satisfaction with the results (marital counseling saved our marriage). The three families that had received professional counseling services spoke with praise of those services. Appreciation for the relationships with instrumental support providers was the sub theme of empowerment within the mesosystem.

There were several comments related to the subjective experience of families within the mesosystem which emerged into a theme of disempowerment. Of the 10 families interviewed, 8 perceived the public school system as a source of stress even though specific services were appreciated. School is expected by families to be a stress meeting resource and yet it appears to be a major source of stress, if not *the* major source with comments such as, "Don't get me started" and "Most of them {teachers} don't know what they are doing." Families in this study did report satisfaction with the Individual Family Service Plan (IFSP), but were a lot less satisfied when the planning process became the Individual Education Plan (IEP). It is protocol in Charles County that when a student moves from early intervention to grade school, their education plan changes from an IFSP to an IEP; the focus, from the family perspective is on the student alone and much less inclusive of the role of the family. Six of the parents interviewed for this study noted that they felt disempowered in their relationship with the public school system. A typical comment was "They are condescending to us parents." Most of the comments were about not feeling understood, and not having individualized support services. Feeling personally disrespected by public school personnel was the sub theme of disempowerment within the mesosystem.

There were several comments related to the subjective experience of families within the exosystem which emerged into a theme of empowerment. In this study, 4 families were using respite services on a regular basis. One participant noted the encouragement she had received from her child's teacher by recalling that her child was student of the

month. Appreciation for ancillary services was the sub theme of empowerment within the exosystem.

There were several comments related to the subjective experience of families within the exosystem which emerged into a theme of disempowerment. Most of the parents interviewed noted that the teachers they had been working with were very nice, but they seamed to need more training and more resources to be able to work successfully with children with disabilities. The stress-oriented comments in the journals were similar to comments from the interviews and were centered on school. Examples included "IEP is today, it's just a big joke" and "We have to fight for everything." The majority of responses to the question about support from the school system note significant disappointment. Examples of this disappointment include "Most of the IEP team appears to be working against us" and "We had to hire a lawyer to get basic services."   Non-cooperation was the sub theme of disempowerment within the exosystem.

There were several comments related to the subjective experience of families within the macrosystem which emerged into a theme of empowerment. One of the ten parents interviewed for this study discussed spiritual meaning in response to this question. That individual reported that the family clergy told a story about a child who was considered disruptive by the community, but served as a great inspiration in the end. The interviewee acknowledged feeling comfort from this story.   Most of the individuals noted that they did expect some kind of comfort or solace from their faith community and that certain members and their clergy had been supportive on occasion. Some participants noted that friends, neighbors, family members, and coworkers were

understanding of their situation and were able to support them emotionally with sympathetic listening or instrumental support such as a flexible work schedule or child care. It is worth noting that the families in this study have been particularly creative in developing their support network. Creativity and spiritual meaning were the sub themes of empowerment within the macrosystem.

There were several comments related to the subjective experience of families within the macrosystem which emerged into a theme of disempowerment. Six parents noted that they had received inappropriate comments from strangers while out in the community with their children (i.e., "that kid just needs to be whipped"), and thus felt reluctant, at times, to be out in the community with their children. The theme of stigma or intolerance for atypical behavior was the sub them of disempowerment within the macrosystem.

Question 2

What coping mechanisms, if any, appear to have a mediating effect on stress for these families?

There were several comments related to the mediating effects of coping mechanisms within the microsystem which emerged into a theme of empowerment. Many of these comments were related to a personal resource or skill that the family had developed. Examples from the interviews regarding skill development include "I've gotten better at asking for help" and "I do advocacy work, and it's very rewarding." Another coping mechanism within the microsystem includes purposeful adaptations. Examples from the interviews of these adaptations include "we, as a couple, make time to discuss our

children and their successes" and "We (husband and I) give each other breaks." Two of the interviewed families mentioned contacting an estate planner to assist them in their future planning. Some of the participants mentioned both feeling strengthened by their experiences as a couple and being weakened by their experiences. Despite the many challenges that these families are facing there was a lot of optimism expressed for example, "we will figure this out; we always find some place for a mini-vacation." Some participants reflected on how they make time to rejuvenate for example "I turned on music and baked for several hours which I really enjoyed." It is worth noting that three of the four who wrote in the journals noted that it an enlightening experience to discuss the strengths in their family and support system, rather than focusing solely on stress. Personal skill development, cognitive skill development and adaptation were the sub themes of empowerment within the microsystem.

There were several comments related to the mediating effects of coping mechanisms within the microsystem which emerged into a theme of disempowerment. Most of these comments were related to the immense challenges facing these families and the sense of feeling chronically overwhelmed. Comments such as "We can't be spontaneous", "Any family decision takes a lot of thinking" and "He gets hurt and doesn't tell us" are descriptive of the ongoing burden of responsibility. Only 4 of the families were able to make time to use the journals. The other 6 families noted that they were too overwhelmed at the end of the day to write anything in a journal. Feeling chronically overwhelmed was the sub theme of disempowerment within the microsystem.

There were several comments related to the mediating effects of coping mechanisms within the mesosystem which emerged into a theme of empowerment. Three of the parents indicated that they had expended a lot of energy in communicating with all of the school personnel, including the bus drivers. The result of this commitment to communication, according to these parents, was a satisfactory relationship with the public school personnel. Some of the families indicated that they had made some efforts in identifying and working closely with other professional providers. Three professional counselors and two dentists were identified as being especially helpful for these families. The coping mechanisms of assertiveness, commitment and clear direct communication were sub themes of empowerment.

There were several comments related to the mediating effects of coping mechanisms within the mesosystem which emerged into a theme of disempowerment. Many of the parents indicated dissatisfaction with professionals with whom they interacted on a regular basis. Most of those professionals were school personnel. A typical comment was "They (school personnel) treat us like trash." Although many of the families had been involved in effective service advocacy over a period of many years, some of the parents had been frustrated and overwhelmed for such an extended period that they appeared to hold little hope of resolving concerns regarding their child's education. Hopelessness, frustration and learned helplessness were sub themes of disempowerment within the mesosystem.

There were several comments related to the mediating effects of coping mechanisms within the exosystem which emerged into a theme of empowerment. Most of the parents were involved in some form of systems advocacy or support group. The support group had several functions. It served as a personal support entity for its members. It kept the participants from feeling isolated. One parent noted that she was looking forward to the annual holiday party. The support group also served as a resource for services. Several of the research participants mentioned the support in a favorable light. Other comments related to coping mechanisms within the exosystem were "We have to fight for everything" and "We had to hire a lawyer to get basic services." Both of these comments note the extent and commitment to advocacy in which these families were involved. Assertiveness and passion were sub themes of empowerment within the exosystem.

There were few comments related to the mediating effects of coping mechanisms within the exosystem which emerged into a theme of disempowerment. These comments were about managing the day to day challenges of their children. Although it is true that families with typically developing children consider the children when they make decisions about short- and long-term planning, the decision making in the families interviewed for this study was characterized by fewer assets (hard to find a child care provider who has the skills to manage their children), and more creative problem solving (designing a shopping mall routine to be tolerable for all involved). Frustration and feeling overwhelmed were sub themes of disempowerment within the exosystem.

There were no comments related to the mediating effects of coping mechanisms within the macrosystem which emerged into a theme of empowerment. However on participant had created a small information card about her son and developmental disabilities which she handed out to people in public places who were staring at her child. This effort can have the effect of educating the public and reducing stigma. Further, although it was not discussed directly in the interviews, it was evident that some of the research participants had created the parent support group which can have some effect on the culture of the local community. Creativity was the sub theme of empowerment within the macrosystem.

There were few comments related to the mediating effects of coping mechanisms within the macrosystem which emerged into a theme of disempowerment. These comments were related to feeling embarrassed or stressed while being out in public paces with their child. Examples from the interviews would be "One of the most stressful things is having to explain his behavior to other adults" and "… we get people staring." Stigma was the sub theme of disempowerment within the macrosystem

Question 3

What family, community, and other factors appear to be most closely associated with coping or stress for families of children with mental retardation?

There were several comments related to family, community and other factors within the microsystem related to empowerment. Some of these comments relate to how family members have adapted to their situation and learned to manage their lives. Examples of this adaptation include "I've gotten better at asking for help", "I do advocacy work, and it's very rewarding" and "we, as a couple, make time to discuss our children and their successes." A few of the comments in this area related to how research participants conceptualized their situation. An example of this conceptualization is "My husband and kids are a great source of joy." Adaptation and appreciation were sub themes of empowerment within the microsystem.

There were several comments related to family, community and other factors within the microsystem related to disempowerment. Some of these comments were related to the additional burdens associated with raising a child with a disability. Examples would be "We can't be spontaneous", "Any family decision takes a lot of thinking" and "He gets hurt and doesn't tell us." Some of the other comments were related to how the other children in the family were experiencing their lives. An example would be "The other two kids are jealous of extra attention." The additional burden of family management due to their special circumstances was a sub theme within disempowerment in the microsystem.

There were several comments related to family, community and other factors within the mesosystem related to empowerment. The comments in this section were all related to how the parents had worked to form a good relationship with a professional provider.

Examples would be "Our dentist is really good with kids" and "… a professional counselor… was outstanding."   The ability to establish good rapport with a professional was a sub theme within empowerment in the mesosystem.

There were several comments related to family, community and other factors within the mesosystem related to disempowerment. Nearly all of the comments in this section related to the inability to establish or maintain a mutually respective relationship with public school personnel. Some of the details regarding these strained relationships have been left out of this paper in order to protect the confidentiality of those involved. A typical comment in this section was "They (school personnel) treat us like trash." Disrespect was the sub theme within disempowerment in the mesosystem.

There were several comments related to family, community and other factors within the exosystem related to empowerment. All of the comments in this section were related to the appreciation of available services and the ability to obtain those services. Examples would include "We are thankful for speech, OT and vision services" and "We received respite services and it was helpful." Appreciation for instrumental (direct help) support was the sub theme within empowerment in the exosystem.

There were several comments related to family, community and other factors within the exosystem related to disempowerment.   All of the comments in this section were related to the availability of resources for special education and ancillary services. An

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example would be "They (teachers) need more training." In the current study, the families seemed pretty confident in their abilities to manage their child in the family home, but a question regarding respite did generate a great deal of interest. Inadequate professional service resources was the sub theme within disempowerment in the exosystem.

There were several comments related to family, community and other factors within the macrosystem related to empowerment. This section addresses the political and cultural factors associated within a community. In this research the participants commented indirectly on how their community has chosen to utilize its resources (taxes). An example of resource utilization was "Respite is covered by Medicaid." Participants commented on the support from their faith community. An example of this support was "Our church has been tolerant and supportive." Further, one participant noted the culture of her place of employment by stating, "My job has been flexible and supportive." Societal compassion was the sub theme of empowerment within the macrosystem.

There were several comments related to family, community and other factors within the macrosystem related to disempowerment. Some of the comments in this section pertained to a generic misunderstanding of childhood disabilities and some community intolerance for atypical behavior. An example would be "One of the most stressful things is having to explain his behavior to other adults." Another cultural factor within the macrosystem is that due to the father being more likely to be the breadwinner, mothers still have the majority of child rearing duties. Although only one research participant

commented directly on this burden, the mothers handled all of the interviews in this

research and fathers were only present in two of the interviews. Stigma and child rearing

duties were the sub themes of disempowerment within the macrosystem.

Chapter 5 Discussion

" …how a man rallies to life's challenges and weathers its storms tells everything of
who he is and all that he is likely to become."

- St. Augustine

Introduction

This chapter will define coping, discuss theories associated with family stress and
coping, discuss the current study and its relationship to theory, implications for
practitioners, and suggestions for future research. The discussion of the current findings
will note how prior research failed to uncover significant factors associated with family
coping. Coping, which encompasses a wide variety of behavior, cognitive strategies, and
other self-management techniques, is a stabilizing variable that can help individuals and
families maintain a sense of well-being and adaptation during periods of stress (Zeidner
& Endler, 1996).

Models of Stress

A. Positivistic Models

Hill (1949) developed the ABC-X model of family stress and adaptation based on the
stress experienced by families who had a veteran returning to the family after World War
II. In this positivistic model, A represents the activating event, B represents the family's
stress meeting resources, C represents the family's perception (meaning attribution), and
X is the amount of stress experienced by the family. The model proved to be useful in

identifying specific variables associated with stress and adaptation. The ABC-X model

is a positivistic because its purpose is to identify causal relationships that specify patterns,

and it assumes a cause and effect relationship. More recent researchers (McCubbin et al.,

1980) attempted to repair the rigidity in this model by introducing the concept of the

feedback loop among the variables, and thus make the model more systems oriented.

Field researchers and practitioners had complained that the ABC-X model was not

systemic or heuristic and offered little in the way of practical application for the field.

The McCubbin update of the ABC-X model still contained many problems, although it

allowed for more flexibility and it inspired a great deal of research in the area of family

stress. The McCubbin model noted that these factors had an interactional effect on each

of the components: external resources, internal resources, social support, and caregiver

satisfaction. For example, if a family had good internal resources such as adequate health

insurance, hardiness, and a strong sense of faith, that may affect the social support

available to them, thus an interaction between these two variables. If the family has the

good external resource of the workplace being flexible with the work schedule and a

family friendly environment, that may have an effect on the family's perception of the

stress ("one meaning I can derive form this difficult situation is that I found out how

many people are really there for us…").

In 1946, Koos developed the roller coaster model of family adaptation to stress, which

includes a line denoting the original level of family functioning, a point noting the crisis,

a steep decline noting the period of instability, an incline noting the angle of recovery and

then a new line noting the level of recovery (most recent level of family functioning).

Koos Roller Coaster Model

Original level of functioning   *Level of recovery*

--X \   /--------------------------------------

                                        Crisis Point \   /

   Period of   \   /   *Angle of*

   Disorganization   \ /   *Recovery*
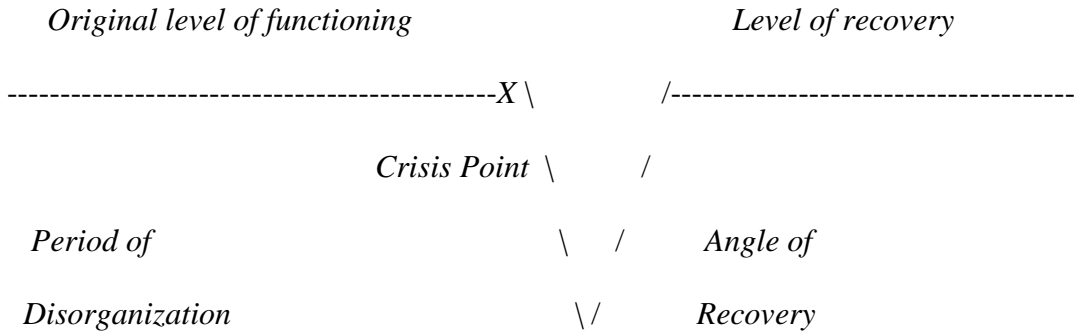
In the Koos model, the period and angle of disorganization depends on the level of crisis

experienced by the family. The angle of recovery depends on the family's stress meeting

resources. The level of recovery may be the same level of functioning prior to the crisis,

but it could be higher or lower than the previous level of functioning depending on the

family's ability to mobilize internal and external resources.

The Koos model is also positivistic; it is linear and supposes a cause and effect

relationship. Further, it does not specify what factors are associated with a deeper level

of disorganization, a less stressful angle of recovery or a higher (or lower) level of

recovery.

B. Nonlinear Models

Dispositional Approaches: In dispositional approaches to stress, family members use

cognitive mechanisms (that may involve behavioral components) whose main function is

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to distort reality or emotional focused mechanisms whose main function is to reduce tension (Zeidner & Endler, 1996). Common to this model and associated research are assessments of coping traits. Dispositional approaches in research and clinical practice have some use in noting pathological thinking and behaving; however these approaches do not consider family strengths, healthy coping mechanisms, or the family perspective. Further, it assumes that coping traits are fixed and do not change for different family stressors.
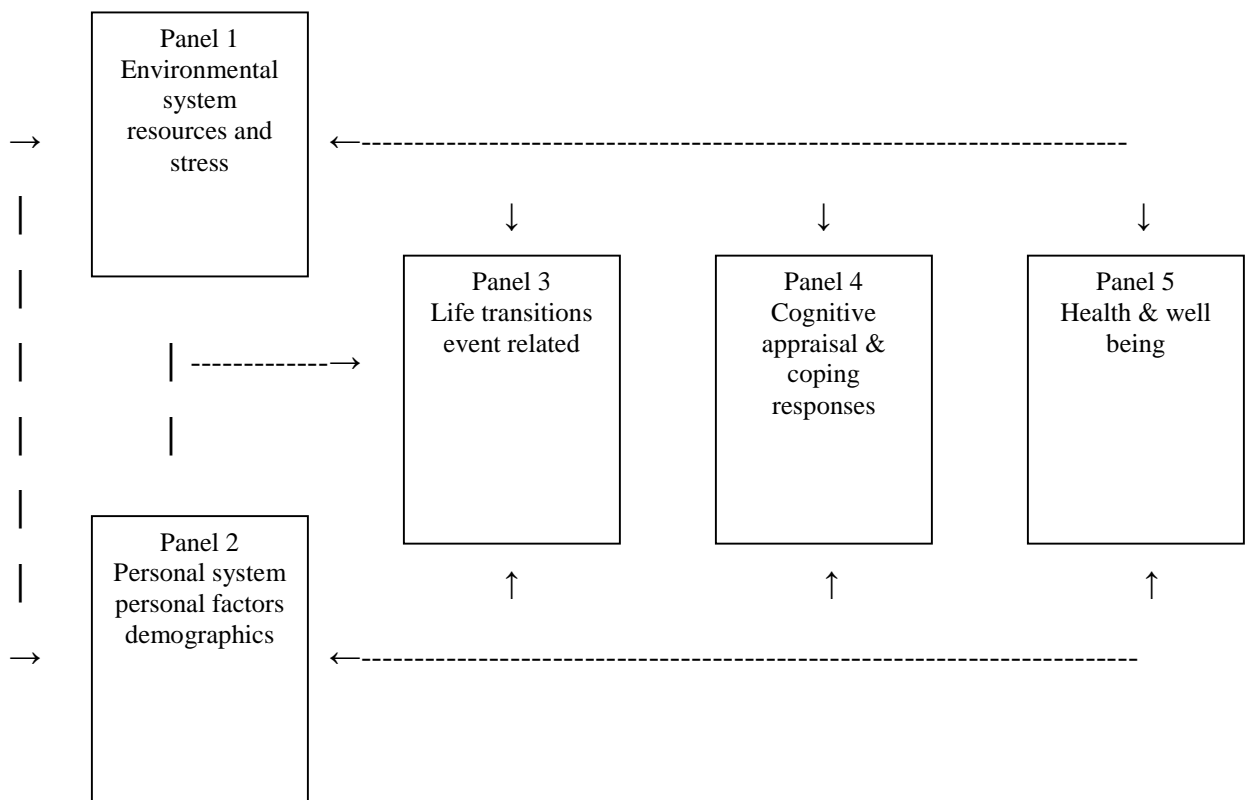
Contextual Approaches: Contextual approaches view coping as a response to a specific stressor rather than as a permanent personality or family function (Zeidner & Endler, 1996). Coping is seen as a dynamic process that may change over time as a family develops and adapts. Common to the contextual approach in research and clinical practice is the measurement of specific cognitions and actions that individuals and families use to cope in specific situations. In this model, clinicians and researchers may explore decision making processes, frustration tolerance, authority conflict, and peer disagreements. This model does consider some strength-based aspects of individual and family processes; however, it remains predominantly pathology oriented. The model allows for more flexibility in coping style than dispositional models, but still attends only nominally to the worldview of the family.

C. Integrative Model and Grounded Approach Findings

Integrative Approaches: Integrative approaches recognize the strengths and limits of dispositional and contextual models; however, this type of approach is strengthened by

incorporating the environmental system and by noting interactions among variables such as personal system, environmental factors, cognitive appraisal, personal well-being, and event-related factors (Zeidner & Endler, 1996).

Integrative Model

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┌─────────────────┐
│     Panel 1     │
│  Environmental  │
│     system      │
│  resources and  │←----------------------------------------------------------------
│     stress      │
└─────────────────┘        ↓             ↓             ↓
  |                  ┌──────────────┐┌──────────────┐┌──────────────┐
  |                  │   Panel 3    ││   Panel 4    ││   Panel 5    │
  |        |--------→│Life transitions││ Cognitive  ││Health & well │
  |        |         │ event related ││ appraisal & ││    being     │
  |        |         │              ││   coping    ││              │
  |        |         │              ││  responses  ││              │
  |                  └──────────────┘└──────────────┘└──────────────┘
┌─────────────────┐        ↑             ↑             ↑
│     Panel 2     │
│ Personal system │
│ personal factors│←----------------------------------------------------------------
→│  demographics   │
└─────────────────┘
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In this model, the relatively stable environmental and personal factors influence the life crises that the family must face. The combined influences affect well-being. This model emphasizes the mediating effects of cognitive appraisal and coping responses

during the life crisis. Bidirectional feedback note the reciprocal influences at each stage.

The integrative model of family stress is a useful tool when using a grounded theory

approach to research. The grounded approach is dynamic, similar to the integrative

model. Both approaches validate family perception as a key ingredient to the coping

process. The integrative model refers to family perception with the phrase cognitive

appraisal, and grounded theory refers to perception as the voice of the research subject.

Further, both models note the interactions among the individual–family; the environment

in which she, he, or they exist; and the other assets and liabilities operating within the

system. A grounded approach is characterized by classifying events, action and

outcomes as the foundation for developing a theory about research. Research does not

begin with a preconceived theory in mind; theory is to emerge from the data.

Incorporating Findings into the Integrative Approach

The themes of empowerment and disempowerment from the grounded approach in

this study can best be explored and discussed within the context of the integrative model.

The personal (panel 2) and environmental systems (panel 1) were two of the main sub-

themes that emerged from the analysis of the data. The sub-themes of life transitions

(panel 3), cognitive appraisal or meaning attribution (panel 4) and well being (panel 5)

also emerged.

Panel 1 of the integrative model includes the environmental system, resources, and

stress. The participant responses in the semistructured interviews and the journal entries

refer to the components of panel 1. The environmental system includes the community

awareness and understanding of childhood disabilities and tolerance for atypical behavior. The interviews and journal entries noted evidence both for understanding and misunderstanding of childhood disabilities. Some participants noted that neighbors had been very friendly and supportive to their child and family despite atypical behavior. There were, however, a few more comments regarding community members either not understanding or being intolerant of atypical behavior. Empowering comments included "We have been fortunate to have a lot of family around" and "the neighbor kids are nice to …." Disempowering comments include "Most of my friends don't understand what it's like" and "Sometimes our friends don't want our child at their house." The interviews and journal entries noted available resources including the family support group, available services, and access to professional support. Several participants noted the importance of the support group as a coping mechanism. Further, most of the participants appreciated school-related services such as speech therapy, occupational therapy and physical therapy. In addition to these services, the two most discussed services were professional counseling and respite care. The individuals who had considered professional counseling and sought that service reported being satisfied with the service and pleased with the outcomes. Empowering statements included "We did see a professional counselor; she was outstanding" and "Our dentist is really good with kids." Disempowering statements included "We had to hire a lawyer to get basic services (from school)" and "They (school personnel) treat us like trash." The public school system is a pervasive component of these families life at this stage and can have a profound effect, positive or negative, for families (Baird and Peterson, 1997). There were only a few individuals who had been able to access respite services, yet respite was

highly demanded within the community.   Almost all of the reported stress was related to not having available services or the perception of inadequately trained school staff.

Panel 2 of the integrative model includes the personal system, personal factors, and demographic factors. The interviews and journal entries noted factors associated with panel 2 including hardiness, the ability to obtain social support, and socioeconomic variables. All of the individuals interviewed noted that they had found a source of strength or hardiness. Hardiness is a key ingredient for coping and is often associated with the ability to obtain social support (Gill & Harris, 1991). There were examples of individuals feeling both empowered and disempowered in their quest to feel rejuvenate. Empowering comments included "My job is really flexible with me" and "We make time to talk about our children's successes." Disempowering comments included "I couldn't work initially because of all that needed to be done for the kids" and "Our church has been a disappointment." Some of the individuals interviewed noted that they felt strong because of the support around them from a spouse, friend, or extended family. Some of the individuals interviewed were part of the founding members of the parent support group, a creative way for these families to empower themselves. These individuals created a resource where there was a need. The establishment and maintenance of this support group speaks to the creativity and hardiness of the individuals involved. Although there were no specific questions regarding socioeconomic factors in the interviews, there were comments that shed light on this variable. Nine of the ten women interviewed worked either part time or only as a volunteer. Each of these women noted that they felt being a parent took up too much of their time to consider full time employment. For these women, their spouses earned enough to support the family and

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had health insurance as part of a benefits package. One-earner families, of course, bring

in less revenue to the family, and are at risk should the one earner lose his job (Freedman

and colleagues, 1994). Although these families are not at risk at this point in time, there

are at a higher risk than families with two earner household incomes.

Panel 3 of the integrative model includes life transitions and event-related factors.

The interviews and journal entries noted some event-related factors, mostly associated

with developmental milestones. Some of the individuals discussed the period of time

when they became aware that their child had a disability, and noted how that knowledge

affected them and their family. Individuals noted that some of these milestones had been

particularly stressful, especially the child's entry into the public school system.

Empowering comments related to development or event related transitions included

"…he has been getting help from Infants and Toddlers (service) since he was two" and

"Marital counseling saved our marriage." Disempowering comments related to Panel 3

included "They (Sunday School staff) wanted to promote him even though the couldn't

read" and "We (husband and I) are at a different stage of grieving." The process of

grieving (the loss of the fantasized child) was discussed by only two of the participants.

Two of the individuals noted that their spouse was in a very different stage of grieving

and that had been an additional source of stress. Every individual interviewed noted a

sense of joy that there had been some developmental achievements. Only one family has

initiated estate planning to ensure that there is a smooth transition when the parents can

no longer take care of their child. Prior research notes that attending to grieving and

milestones is important for family adaptation (Abbot & Meredith, 1986).

Panel 4 of the integrative model includes cognitive appraisal and coping responses. This portion of the integration model refers to the cognitive and behavioral components associated with adaptation. Prior research identifies these components but may refer to them as meaning attribution (cognitive appraisal) and coping mechanisms (coping responses). This panel in the model represents a major component in the family's ability to respond to stress because it is strongly linked to perception. An individual's perception of coping resources, social support, and ability to tolerate stress is closely linked with wellness or, conversely, illness (King et al., 1999). There were both empowering and disempowering comments related to coping responses from participants. Disempowering comments included "That situation (with school) is very stressful and has never been good" and "It (child's disability) is something my husband can't fix." Empowering comments related to panel 4 included "He (clergy) once gave a sermon about a child with weird behavior being the hero, very comforting" and Work is an escape; it's a release to be productive." Only two of the participants noted that their faith community had offered a satisfactory level of support to their family. Other individuals did acknowledge that the faith community was a potential source of support, but it was not a source of support at this time. Prior research has noted the importance of support from faith communities (Applequist & Bailey, 1999; Gill & Harris, 1991; Minnes, 1988); however, it was not a significant factor for the majority of the participants in this study. The coping responses noted in the interviews and journal entries reveal creativity and motivation. Half of the individuals interviewed had been through an extensive, 10 weekend training provided by the Maryland Coalition for Inclusive Education (MCIE).

This training included sections on family support, family and community advocacy, modified curriculum development, the Individual Education Plan (IEP) process, implications from the Federal Individuals with Disabilities Education Act (IDEA), and the inclusion programs within the State of Maryland. This training provided many of the individuals with a sense of hope and the tools necessary to advocate appropriately for the needs of their child. Some of these individuals were instrumental in establishing the local family support group which has evolved into an advocacy entity. All of the individuals interviewed noted that they are active in requesting support from formal and informal sources. Most of the individuals interviewed noted that they trade "designated parent" time with their spouse to give each other breaks. However, only one individual noted the importance of establishing and maintaining time for the couple to be alone. Prior research notes the importance of continuing to strengthen the relationship of couples raising a child with a disability (Ammerman & Campo, 1998; Trivette et al., 1990).

Panel 5 of the integrative model refers to the health and well being experienced by families as they negotiate a stress related experience. Prior linear family stress models would view panel five as an endpoint, however, the integrative model indicates that all of the panels are bi-directional and that reciprocal feedback can occur at any stage. Items that are related to health and well being are emotion or problem focused coping in managing stressful periods (Zeidner & Endler, 1996). Examples from this research of problem focused coping or feeling empowered would include the following statements made by interview participants: "When I am down, ---- (husband) pulls me up, and when he is down, I pull him up", "Mutual back massages, and a lot of telephone calling when we are not in the same place is helpful", "We are supportive to each other's individual

pursuits: work, leisure, exercise, music, adult education" and "After caring for ... (my child), I can handle anything." These comments from the participants indicate some effort at appreciating themselves and/or strengthening their relationship, a factor associated with positive family adaptation (Ammerman & Campo, 1998; Trivette et al., 1990). Examples from this research of emotion focused coping, again related to feeling empowered would include the following statements made by participants: "---- had a good day at school and that always makes my day. --- had his EEG today, he did really good; it's usually hard for him to be still", "--- was student of the month this month", "We are a very blessed family" and "I've been trying to think positively and not stress over the small stuff." These comments from the participants indicate a hardy perception of their family, a factor associated with positive emotional coping (Gill & Harris, 1991). Examples of feeling disempowered or struggling with emotional coping are "I feel like I get stuck with doing all of the tasks" and "So we're (husband and I) not closer from this experience but further apart."

Using a grounded theory approach to the research allowed several factors to emerge that may have been ignored if a standard hypothesis approach had been used. These factors have had little attention in previous research, yet figured prominently in the current study and answer question three of the research questions: What family, community and other factors are most closely related with coping or stress for families of children with mental retardation?

A. The unmitigated pain of being a parent who sees their own child in distress and can do little to ameliorate their child's condition. Several of the parents in this study discussed this concern with a great deal of emotion; some become tearful.

B. That in reviewing day to day life with families, parents are so focused on struggles of daily living that most (9 of 10) have been unable to focus on how to carve out alone time for the two parents together. However, strengthening the parent team is a key ingredient in stress reduction (Ammerman & Campo, 1998; Trivette et al., 1990; Ziolko, 1991).

C. The strong negative visceral response to the lack of support from professional educators. Prior research indicates that the school years can be particularly stressful for these families (Dyson 1997; Lloyd, 1993) Further, prior research indicates that families strongly prefer to be equal partners with educators and others involved in the development of their children (Baird & Peterson, 1997; Lucyschyn & Albin, 1997). The literature is thin regarding the strong negative response when families feel disempowered. The long-term effects of disempowerment in the family have not been reviewed in the literature.

D. Community organizing is not discussed in the literature even though it is a natural outcome of support groups for families of children with

disabilities. Many of these support groups develop into advocacy groups as part of their support efforts. In the Charles County parent support group, members serve as IEP support to other families going through this process. Further, several families had gone through an intensive 10 weekend training sponsored by the Maryland Coalition for Inclusive Education (MCIE). This type of training gave many of the families a sense of confidence, empowerment, and hope. This type of natural support system can be a key mediating variable (Ziolko, 1991). Strengthening the community has only been sporadically discussed (Hutliner, 1988).

E.   The creative adaptation that many families in this current study used is rarely discussed in the literature. The subjects in this current study developed their own support group without any institutional aid. Several members have created an informal mutual respite support system. Further, several members volunteer as IEP support persons for families facing an IEP meeting and needing assistance in negotiating that process. Applequist and Bailey (2000) noted that encouraging or building a support system based on the community's unique culture results in high satisfaction expressed by service recipients.

Limitations of study

Several limitations to this study can be identified. First, the participant pool developed was based on specific criteria, the sample size was small, and generalizability may be limited. The participants were not equivalent on all demographic variables such as education level, family income, education level, or number of children in the home, making generalizability even more of a challenge. Although an attempt to obtain information from fathers was made, the number of fathers who participated was small. Even when fathers were present during the interviews, mothers were the primary participant. This role for mothers as the primary caregiver and psychological center of the family is consistent with prior research (Singer & Irvin, 1989). Conclusions from a future study with more participation from fathers may yield different results.

Future Research

Future research should include both qualitative and quantitative methods. Both qualitative and quantitative research should include fathers and siblings in their studies. Because fathers and typically developing siblings are not usually the primary caregiver, they are likely to have a different perspective on coping and stress. Qualitative research should include observations of parent–child and family interactions to cross validate self-report data. A case study analysis could yield even more specific variables related to coping and stress. Several factors noted in this current study need further exploration: the perception of social support, creative community-wide support systems, the unique grief

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experience of parenting an atypical child, and how some families have been successful

in creating periods of respite and rejuvenation. Quantitative research should focus on

many of the same areas; a regression analysis could be especially enlightening in

revealing which factors have the most notable mediating effects among social support,

couple support, respite, community organizing, partnership with public education, and

demographic variables. The development of a model program (with all of the known

mediating resources available) and comparing it with standard resources on the domains

of family satisfaction and long-term outcomes for the child should yield data significant

to researchers, practitioners, and policymakers.

Implications for Practice

   Professional counseling for families for typically and atypically developing children

has been pathology focused for several decades. Only recently have researchers and

practitioners been considering a strengths-based approach (Abbott & Meredith, 1986;

Applequist & Bailey, 2000; Bebko, Konstantareas, & Springer, 1987; Trivette, Dunst,

Deal, Hamer, & Propst, 1990). Families need to be seen as the experts with their child

and recognized as full partners in educational and any treatment efforts (Stroul, 1996).

During the assessment phase of any professional service, the practitioner needs to assess

what is working for families and not just what are the existing problems. In all phases of

professional services it is important to consider cultural aspects of the family and the

community (Applequist & Bailey, 2000; Sue & Sue, 1990). Practitioners need to be

familiar with the most recent best practice field research regarding families of children

with mental retardation and other disabilities. In the treatment phase of professional practice, clinicians need to make use of a broad range of available resources, and link their clients with those resources. If resources do not exist in a given community, professionals need to take an active role in developing those resources. The research clearly indicates that social support, natural support systems, case management that results in instrumental support to families and finding the leverage to access family hardiness are significant positive mediating variables for these families. Family resources have been defined as the means available to the family within and outside the family system. These variables include family aspects (cohesion, expressiveness, conflict management), resources (social support, recreation, access to health care) and organizational features. High levels of cohesion and expressiveness have generally been associated with lower levels of reported stress (Moos, 1976). Thus helping families learn how to express themselves and negotiate conflict and joy is supported by research associated with family resources.

Social support appears to include several components (Ammermen & Campo, 1988). These components include instrumental aid (money; access to health care, respite, and other services) informational advice, and emotional support. It has been well established that it is the individual's perception of the availability of support rather than the frequency of contact with friends or the size of the social network (Quitner et al., 1990; Trivette et al., 1996). In other words, a large network of friends may increase the availability of resources but it may bring with it additional social demands. Thus providing more social support may be clinically appealing but ineffective. Researchers

and practitioners need to know how, under what conditions, and in whom social support

will be perceived as beneficial.

Empowering families is a frequently cited mediating variable (Hutliner, 1988; Lloyd,

1993; Quittner et al., 1990). Components for empowerment include valuing the family as

an equal partner in the education and treatment of the child, acknowledging the family

strain inherent in raising a child with a disability, respecting the cultural differences

unique to each family, and focusing on family strengths.

To practice professional counseling without offering, exploring or encouraging this

support could be considered ethically negligent. Not to consider these sources of support

would clearly indicate that a professional counselor is practicing outside his or her area of

competence.

Appendix

The following questions and responses are directly from the interviews and logbooks. Responses are indented and are in random order to protect the privacy of the subjects. A summary and analysis is provided for each set of responses.

Sources of Support
2Sources of Support

1.   Are extended family and friends available to you when you need them?

My family has always been there for me, especially my sister and my father. My husband's family is not very supportive. They rarely visit, not even for birthdays. Last year, they dropped ----s' birthday present at the front door and left.

My family lives too far away to be a source of support. My brother was mildly retarded, and he was given everything by my parents, mostly because he was a boy. ---- [another parent of a disabled child] is a great source of support. Most of my friends don't understand what it's like.

My family isn't able to help very much. My Mom can be supportive on the phone and even sends me articles, but she can't do much when she's here in person. One time a man at the mall told me that --- just needs to be whipped.

My brother lives close by, but he gets agitated too easily to be much support. We had some trusted friends that were really helpful, but they moved to Florida.

We have been a military family, but our families were there to take care of ---- [brother] when we had to Medvac --- to Bethesda Navy Medical Center.

It's been real hard on our extended family. I know my father in law was real upset, especially because it was a boy; it might not have been as hard on him if it was a girl.

We are very fortunate to have a lot of family around. His aunts have been very involved in his care; they read reports and meet with the Doctor. A lot of my friends have children with disabilities. The neighbors are also good to the kids.

We don't have much family around; they are mostly in Junction, PA. Friends sometimes help. I don't ask friends who have disabled children to help because they always seem too overwhelmed.

All of our family is in Wisconsin. Our family rotated weekly care while we were in the hospital with ----; they were very supportive during this medical crisis. Sometimes I act strong, when I really need help.

Sometimes our friends don't want--- at their house because they don't understand. Both of us are lousy at asking at asking for help, but that is an upgrade from horrible at asking for help. The neighbor kids are nice to ----.

Summary and Analysis: Kazak and Wilcox (1984) noted that families of children with disabilities have fewer social contacts and the existing social network has thicker strands of connection. For example, a friend may also be one's respite provider and a peer in the local parent support group, thus serving multiple roles in that person's life. Several of the family members that were interviewed noted that other parents from the support group had multiple roles in their lives: friend, respite provider, and co-support group member.

Cherry (1989) and Minnes (1988) both noted that families of children with mental retardation run a high risk of feeling isolated socially ("they dropped off ---'s birthday present at the door and left."). Family members and friends may only desire limited contact with them because of their own difficulty in understanding the family situation, dealing with their own feelings regarding the child with a disability or just their low tolerance for deviant behavior. Two parents noted that certain extended family members had low tolerance the behavior of the child with a disability, and thus visited infrequently or not at all. Six parents noted that they had received inappropriate comments from strangers while out in the community with their children (i.e., "that kid just needs to be whipped"), and thus felt reluctant, at times, to be out in the community with their children

Quittner, Glueckauf, & Jackson (1990) and King, King, Rosenbaum, & Goffin (1999) note that social support has been reported in many studies as having a significant mediating effect on family stress, and thus it is important to continue to explore this

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factor, and how it can be mobilized by professionals working with families. In these interviews, parents perceptions of social support meant that friends, neighbors, family members, and coworkers were understanding of their situation and were able to support them emotionally with sympathetic listening or instrumental support such as a flexible work schedule or child care ("My family has always been there for me, especially my sister and my father").

Beckman and colleagues (1993), Gill & Harris (1991), and Trivette and colleagues (1996) all note that relationship between social support and family hardiness. In these interviews, parents expressed feeling hardy or in good spirits after they had perceived a positive social interaction associated with their child or family such as the child doing well on a shopping trip or at a party. Parents expressed feeling let down or in low spirits after experiencing a negative social interaction associated with their child such as a comment from a neighbor (or even a stranger) about the atypical behavior of their child. Hardiness can have a mediating effect on stress (Gill & Harris, 1991), and thus another critical ingredient needing further exploration.

2.   How is the public school able to support you with your child?

        Don't get me started. That situation is very stressful and has never been good.
        We had to hire a lawyer to get basic services.

Eva Turner [Elementary School] is not trained and it doesn't look like Stoddert [Middle School] is either.

A teacher at School restrained and beat and bruised ----; I have some pictures. We reported it to the State Police and they said there wasn't criminal intent. I'm trying to get him a different teacher.

We have received pretty minimal services even from "Child Find." We've had to fight for everything. We do get a bus service now for ----.

Some of the teachers have been nice, but most of them really don't know what they are doing with these kids. Early intervention and Child Find was great in Florida, and I have really liked 90% of his teachers here, but it does seem as if they really don't know what they are doing with disabled kids. They need more training.

We've been lucky with the school system; we don't want to move to St Mary's county, because they have even less resources than Charles county for kids.

We are upfront with the school system and share all information, including the bus drivers. ---- has been getting help since he was two with infants and toddlers.

I wish they would understand that these kids see school as school and home is a place of respite from the demands; no homework. We get speech, OT, Vision and transportation services; ---- is in the STAY program at the Gwynn Center.

The school does what it is supposed to do only if you force them; it's a shame. The school folks are useless and condescending to us parents. They would not take a recommendation from a nationally recognized behavioral institute.

They wait until there is a crisis to do anything. Most of the IEP team appears to be working against us. They have not been very flexible; they treat us like trash.

Summary and Analysis: Cherry (1989), in a review of the ABC-X model, stress-meeting resources are important to families in getting back to stasis. School is expected by families to be a stress meeting resource and yet it appears to be a major source of stress, if not *the* major source ("Don't get me started" "Most of them {teachers} don't know what they are doing."). The specific resources (occupational therapy, speech therapy) were appreciated. Of the 10 families interviewed, 8 perceived the public school system as a source of stress even though specific services were appreciated.

Bronfenbrenner (1979) notes that the macrosystem (politics and cultural factors) and exosystem (programs and service organizations) affect the mesosystem (parent–professional relationships). Most of the parents interviewed noted that the teachers they had been working with were very nice, but they seamed to need more training and more resources to be able to work successfully with children with disabilities.

Beckman and colleagues (1993) note that parents express satisfaction with early

intervention efforts and an educational plan that involves the family. Families in this

study did report satisfaction with the Individual Family Service Plan (IFSP), but were a

lot less satisfied when the planning process became the Individual Education Plan (IEP).

It is protocol in Charles County that when a student moves from early intervention to

grade school, their education plan changes from an IFSP to an IEP; the focus, from the

family perspective is on the student alone and much less inclusive of the role of the

family.

Baird and Peterson (1997) note that in their review of best educational practices that

the family is the expert with their child and a constant in their lives. They further note

that a trusting relationship between educators and families is a necessary ingredient for a

successful outcome. Only 3 of the 10 parents made comments about the public school

system staff that could be perceived as indicating a trusting relationship (We've been

lucky with the school system.").

Dyson (1997) and Lloyd (1993) note that the school years are particularly stressful for

parents of children with disabilities because the child's performance and abilities are a

focus during this time. Dyson further notes that family-centered practice and ensuring

that families are equal partners in decision making has an empowering effect on families

and is a predictor for better educational outcomes for students. Six of the parents

interviewed for this study noted that they felt disempowered in their relationship with the

public school system ("They are condescending to us parents.").

Lloyd (1993) noted that educators need to remember that having a child with a

disability puts a tremendous strain on families, and parents need to be treated in an

individual respectful manner. She further noted that individualized resources need to be considered in individualized treatment plans. The majority of responses to the question about support from the school system note significant disappointment (We've had to fight for everything" "Most of the IEP team appears to be working against us"). Most of the comments were about not feeling understood, and not having individualized support services. Hutliner (1988) noted that building on family strengths and providing concrete resources result in high satisfaction for the family and measurably educational outcomes for the student. Parents that commented on the concrete support they received were very appreciative of these resources.

3.   Do you receive any professional support? Does it help?

Our dentist is really good with kids like ----, and Children's Hospital has been great.

My husband and I have not considered counseling – he doesn't talk about his feelings. We really didn't see the need for counseling.

I don't think ---- would sit still for a dentist; maybe with sedation.

We did go to a pastoral counselor a few years ago, and our primary physician has been a good advocate for services. We could probably make good use of counseling at this point.

We were never advised to get any counseling; we may have tried to get some counseling if someone had offered it. We didn't get family therapy; just the support group and a workshop.

We did see a professional counselor for individual work with ----; she was outstanding.

My husband has hard a hard time with ----, at times, it's something that he can't fix. He is involved and goes to all appointments.

---- has his own Psychologist at school and (individual) therapy has been helpful for me. Support from a Developmental Psychiatrist, occupational therapist, physical therapist, and speech were helpful.

We haven't wanted to over-therapize our lives. Home-based school services were helpful.

Marital counseling saved out marriage.

Summary and Analysis: Applequist and Bailey (2000) noted that individually tailored early intervention is appreciated. Services that are easily accessible (home based, if possible) and in consideration of the family culture result in high family satisfaction. The three families that had received professional counseling services spoke with praise of those services. The rest of the families had never been apprised of the availability of those services or did not see how professional counseling could be of any help in their situation.

Lucyshin and Albin (1997) noted that a practical, easily accessible service in which the family establishes the treatment goals results in successful treatment goal attainment and high family satisfaction. For the families that did receive professional counseling services in this study they noted a high level of involvement and satisfaction with the results

Ziolko (1991) noted that at some point families of children with disabilities grieve the loss of the fantasized (nondisabled) child. Four families in this study spoke of issues related to grief. In two instances, the interviewed parent noted that they were at a different stage of grief than their partner. In the other two instances, the interviewed parent noted that the grieving process had been at least partially responsible for marital distress and even separation.

4.   Do you receive any formal or informal respite services? Is it helpful? What is your system?

---- [another parent of a child with a disability] and I have decided to provide respite for each other. I will watch her kids and she will alternatively watch mine. I want to go through respite care provider training.

---- is covered by Medicaid Waiver so he is qualified for respite, but we haven't received any yet.

I used to work in a group home, and I 'm not all that confident about the services. If the parent is around and advocating and bringing things, it seems to work out, but not if you just leave your child alone.

DDA [Developmental Disabilities Administration] has provided some respite support to us.

We have traded child care with friends; so we gave each other respite. We don't go out too much.

Family provides any respite that we need.

The Arc said it will pay for respite, but we haven't used it yet. ---- has DDA waiver and receives a UCP [United Cerebral Palsy] Aid 5 days per week, 2 hours each day. He has multiple disabilities: PDD [Pervasive Developmental Disorder], ADHD [Attention Deficit Hyperactivity Disorder], Blind in one eye, and

Intermittent Explosive Disorder [characterized by unpredictable aggressive outbursts] so this support is helpful.

We received respite services and it was helpful; our Church provides respite as well.

We traded respite with another family who has a disabled child; that worked great.

 I don't want to segregate my social contacts; I want my children to have contact with other typically developing peers as well.

Summary and Analysis: Beckman (1983) noted that caregiver demands are directly related to stress perceived by families; respite has a direct positive impact in terms of reducing caregiver burden. In this study, only 4 families were using respite services on a regular basis.

Freedman, Litchfield, and Warfield (1995) noted that mothers of children with disabilities chose to work on a part-time basis because of the difficulty in finding acceptable child care or professional respite services. Six of the ten mothers in this study worked (outside of the home) on a part time basis, two did not work outside of the home at all. These women all noted their commitment to their family and the need for them to be available to their children rather than being overcommitted.

Rimmerman and Duvdevani (1996) noted that if intermediate support is less available in a community, than the demand for more costly residential services rises significantly. In the current study, the families seemed pretty confident in their abilities to manage their child in the family home, but this question regarding respite did generate a great deal of interest.

5.   Do you belong to a faith community? Does it support you?

        We have not been involved in any Church – my husband was raised Catholic, but we got married in Vegas.

        Our Church is tolerant and supportive. We belong to United Methodist and the former Pastor there was really supportive; we haven't had the chance to know the new pastor yet.

        We don't belong to any church.

        We belong to Grace Brethren; they have been pretty good but there was some confusion with Sunday school. They wanted to promote him even though he couldn't read.

We don't belong; I haven't found much solace in Church – my Mom and I disagree on this point.

Our Church has been a disappointment; if we don't donate money, we don't get offered much support.

We volunteer with other kids, but our needs don't seem to be appreciated. ---'s behavior makes it a challenge to attend church activities.

Our church has been a great source of emotional support.

Our clergy visited us at the behavior training institute and hospital. He once gave a sermon about a child with weird behavior being the hero, very comforting.

It would be nice if we were asked how we can be helped.

Summary and Analysis: Gill and Harris (1991) noted that families that can find a meaning through their spirituality can find the inner strength to cope with stressful situations. Only one of the ten parents interviewed for this study discussed spiritual meaning in response to this question. That individual reported that the family clergy told a story about a child who was considered disruptive by the community, but served as a great inspiration in the end. The interviewee acknowledged feeling comfort from this story. Most of the individuals noted that they did expect some kind of comfort or solace

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from their faith community and that certain members and their clergy had been supportive on occasion.

Applequist and Baily (2000) noted that families are more responsive to culturally appropriate services and other research, and Minnes (1988) noted that faith community could certainly be a significant part of that support system. Although meaning attribution is frequently cited in the literature (McCubbin et al., 1983), there are rather few references regarding linking the faith community with professional counseling or other institutions as a support system for families of children with disabilities.

How do you view your volunteer or paid work outside of your home?

My job is really flexible with my schedule, and I really like it.

When I leave it can be stressful on my family, especially ----. He doesn't like it when I leave the house. Sometimes I don't' even tell him I'm leaving.

I'm a teacher Aid at a pre-Kindergarten class, and I like that, but taking off work for meetings and IEP's [Individualized Education Plan] is a challenge.

My job is my kids and I do a lot of volunteer advocacy work; it's very rewarding.

I couldn't work initially, because of all that needed to be done with the kids, but I did enjoy my part time position with the video store. I did enjoy it when I could work, but things get a little too crazy here for me to work. I still enjoy some occasional volunteer work.

I have a full time job that I am very good at; I review medical billing and insurance (nurse by training); they are very flexible with me. I did have a part time job as well, but the juggling was getting to be too much so I quit.

Work outside of the home has been good. It's a life-saver.

Work is an escape. It's a release to be productive.

I like the social interactions with other adults.

Nothing is ever life-threatening at work. After learning to care for ---, I can handle anything.

Summary and Analysis: Freedman and colleagues (1995) noted that work is a place of respite and esteem. Six of the mothers involved in this study worked part time due to child-raising responsibilities and the challenges in finding child care. The individuals noted that family friendly environment at the workplace was important. Singhi, Goyal, Pershad, and Singhi (1990) noted that because specialized child care is often not

available, many parents are limited in their options for employment. Being under-employed or working on a part time basis could put the family at risk of economic disadvantage, another risk factor for family stress.

7. Do you have any rituals that you find helpful? – singing with child, discussing achievements, integrating siblings, sharing dreams, prayers?

> We heard a lot of stuff about how kids like ---- can get stuck in a routine. So we decided to keep our routine with him varied, baths at different times, shopping at different places. We didn't want him stuck in a rut.

> We have a bath and bed time ritual every night (9pm) that helps get him settled.

> We have established a lot of routines to help the kids cope; we have a family meal time, and we do a lot of prep for anything that's going to be different (different than the usual schedule).

> We have had a lot of structure at home: snack time, homework, then play, and a pretty structured bed time routine; I'm working on letting him be more independent rather than prompting for every thing at night (teeth brushing).

We have had a lot of structure at home: we are big on routine here so that ---- can predict his life, and he likes that. He has a calendar of events so that he can keep track. Meds, bath and bed time are the same.

Taking a bubble bath, paying the bills, having a break, and my own therapy were helpful rituals.

We read stories every night.

We, as a couple, make time to talk about our children and their successes.

Bed time is a good time to snuggle.

The other kids sing to ---- for successful potty behavior.

Summary and Analysis: Summers and colleagues (1989) and Knox and colleagues (Knox, Parmenter, Atkinson, & Yazbeck, 2000) noted that the perception of control in the home environment was a mediating factor for stress. Family rituals can be a healthy method for families to have predictability and some sense of control.

Blacher and colleagues (1987) noted that homes of families of children with developmental disabilities appear to be less organized than more typical families. Having meaningful rituals may be an attempt to reorganize and provide some structure for the sake of the entire family.

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Ziolko (1991) noted seven factors in assessing family stress particular to these families. One of these is "unpredictability," and thus having some regularized rituals may reduce this factor and have an ameliorating effect on stress.

8. How do you as, a couple support, one another?

We give each other breaks. When my husband gets him during the day, I go somewhere with the kids so he can get some sleep, and he'll give me breaks too.

We have had a rough time; we were separated and had blamed each other for ----'s problems, and my husband travels on long trips for work. It seems like I get stuck with doing all of the tasks, but we do try to give each other breaks; today ---- is on a trip with my husband.

We give each other breaks. I sent him home this week. And he tells me to go out too sometimes. But ---- [husband] is still at a "why me" stage, and I've already done a lot of my grieving. So we're not closer from this experience but further apart.

I don't know why our marriage works. But it does. When I am down, ---- [husband] pulls me up, and when he is down, I pull him up.

He's away a lot, but when he is home, he will watch the boys so we can go

shopping. He takes off work to go to all Doctor Appointments.

We are recently separated, and the pain associated with having a child with a

disability was a factor in the separation.

Mutual back massages, and a lot of telephone calling when we are not in the same

place is helpful. We make sure to carve out time for just the two of us.

We are supportive to each other's individual pursuits: work, leisure, exercise,

music, adult education.

We try to give solace to one another and make time to be together.

Sometimes ---- [spouse] appears not to need support, so I might not give him

support. We have to be better at asking.

Summary and Analysis: To frame this discussion regarding couple's mutual support,

it is worth noting that Lavee, Sharlin, and Katz (1986) found that couples with children

report lower "marital satisfaction" than couples who do not have children. Their research

was based on families who have typically developing children. In their research, the

authors note that it is the commitment of time for the children that is often cited by those

with children that present a challenge to pursuing couple oriented activities.

Sabbeth and Leventhal (1984) noted in a meta-analysis that some families reported high marital discord when there was a child with a disability in the family, and some reported being more mobilized as a family; it actually strengthened their relationship. Families in this current study mentioned both feeling strengthened by their experiences as a couple and being weakened by their experiences.

Trivette and colleagues (1990) noted that a key component to family satisfaction was the commitment to the growth of each individual in the family. All of the families involved in this current study noted that they had tried to give each other breaks to pursue their own activities. Trivette and colleagues further noted that it was important for couples to find time to be alone together as the key leaders in the family system need to nurture their own relationship.

Ammerman and Campo (1998) noted that adults who have a child with a disability often find it difficult to carve out time to engage in social or recreational activities. Only 1 of the 10 individuals interviewed in this study mentioned making a commitment to doing things together as a couple.

9. What do you find to be the most important source of support? There are more than ten responses to this question because some individuals had multiple responses.

Spouse/partner: "My husband comes to IEP meetings if our lawyer is present. We try to support each other.

My husband and kids are a great source of joy for me and support.

The stress contributed to our separation.

My husband is the single most important source of support."

Extended family: "My sister and I are very close even though she lives in Florida,

I know if I called her she would come.

Not much help. Family is very important to us."

Friends: "All of my local friends have a child with a disability – they don't judge

me.

--- [another parent of a child with a disability]- is a great source of support.

That's the best support.

The support group is a lifeline.

Work friends have been supportive.

 Other parents of children with disabilities have been great."

Professional Counseling: "A Professional Counselor was great help."

Support Services and respite: "Staff from the developmental Disabilities

Administration has provided some life-saving resources including the UCP

[United Cerebral Palsy] respite provider."

Other: "Networking with other parents has been a great help; I always learn

something about adaptation or some resource."

Summary and Analysis: Turnbull and Turnbull (1986), Quittner and colleagues (1990) and King and colleagues (1999) noted that social support was well documented as a mediating factor for family stress. All 10 families noted that the support from family and friends was very important to them. Only three individuals mentioned professional counseling as a source of support. The risk for isolation is high for these families (Minnes, 1988), and the individuals involved in this current study appear to be actively working to ensure that they do not become isolated.

Sources of Stress

1. In what ways does having a child with special needs affect your family life?

> We can't do a lot of things, like go out to dinner or out to a movie. Shopping trips are very short, even our mall routine is short; I could spend all day at the mall. We only do mini-family vacations.

> We are not a normal family. We have to gear everything to fit ----'s needs. Sometimes my daughter, ----, gets left out of things because of our situation.

> ---- gets overly emotional at movies (loud crying and calling out) and he wears videos and DVD's out from watching them over and over.

We can't be spontaneous; we need lots of planning for a vacation. Disneyland
was fun, but the kids got over-stimulated at the Kingdoms and just wanted to go
swimming at the hotel pool. We always find a place for a mini-vacation.

Shopping is out, and only a few restaurants work for us (Old Country Buffet).

We did a lot of adaptive stuff; ---- kept sliding out of his chair as a baby, because
of low muscle tone, so we put a piece of carpet with a lot of friction on his high
chair so he wouldn't slip out. For a while, we couldn't find a sitter who would
stay with ----.

He is picky about some foods. We go out to dinner only rarely, mostly buffet or
McDonalds. ---- ran away at the mall.

Every aspect, social life, going out, I have a one day at a time or even one hour at
a time mentality; just getting through it. When --- wants something, it's hard to
get anything done.

Dinner is not usually much fun, and all these things put stress on our marriage.

Any family decision takes a lot of thinking: how long can an outing last, who can
be invited over to the house. I try to be optimistic.

Summary and Analysis: Covey (1989) noted that individuals and families need to have a way to rejuvenate in order to thrive. Individuals can rejuvenate in many ways according to Covey: planning for fun events, spiritual pursuits, recreation, and vacations are just a few examples. However, when families feel as if they are constantly responding to crises, or just surviving moment to moment, there is little or no time available for rejuvenating activities. In this study, all 10 families who were interviewed noted that having a child with a disability affects every facet of their lives including recreational activities, shopping, dining out, and family vacations. This pervasive effect of having a child with a disability has been noted in other research (Cherry, 1989).

Power and Dell Orto (1988) noted that families who have a member with a significant disability often organize their family system around that one individual. Although it is true that families with typically developing children consider the children when they make decisions about short- and long-term planning, the decision making in the families interviewed for this study was characterized by fewer assets (hard to find a child care provider who has the skills to manage their children), and more creative problem solving (designing a shopping mall routine to be tolerable for all involved). Despite the many challenges that these families are facing there was a lot of optimism expressed ("we will figure this out; we always find some place for a mini-vacation"). Gill and Harris (1991) note that hardiness and optimism is a key element in reducing stress for families of children with a disability.

2. What kind of health related concerns do you have for your child? - Can she or he communicate discomfort?

---- has eczema, but does not communicate pain – that is a real issue.

He gets hurt and doesn't tell us. ---- has asthma and has had a few seizures; he doesn't communicate pain. We only know he is not feeling well if he wants to sleep.

---- has Asthma and a very high tolerance for pain, ---- too [sister]. When she broke her foot, and the Doctor pressed on it, she just said a very mild "ouch".

The encephalitis episode was really scary, but since then, we haven't had too many health concerns. He seems to have a really high pain tolerance. He has a seizure disorder, but he rarely gets sick.

He can tell us he has a headache. He used to seem immune to heat, cold and other discomfort. Now he can tell us he has a headache.

He has multiple disabilities: mental retardation, PDD [Pervasive Developmental Delay], ADHD, seizure disorder, and possibly bipolar. He can communicate discomfort, but has only done so recently; like he didn't think of it. He can't eat regular food.

Whining increases when ---- is sick.

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Sometimes I worry about additional surgery and the accompanying emotional

trauma.

I worry about poor nutritional habits and safety concerns like crossing the street.

---- is not able to communicate physical pain or discomfort.

Summary and Analysis: Waisbren (1980) noted that the expectations for parenting a

child with a disability have never been clearly defined and there are fewer models for

comparison. In other words, there was no "Spock" book to refer to for families of

children with disabilities. It is of particular concern to these families that their children

have had limited ability to express discomfort or pain. Eight of the ten families

interviewed noted that their child either seemed immune to discomfort or was unable to

communicated discomfort. Beckman (1983) noted that the responsibilities associated

with caregiving is a factor which affects family stress; the greater the responsibility, the

greater the stress. Having the burden of health care concerns and children with limited

ability to communicate their discomfort in addition to general concerns about their child's

development can add up to a sense of feeling overwhelming with parenting

responsibilities.

3. In what ways does having a child with special needs affect their siblings?

The other two kids are jealous of the extra attention.

---- got a computer from the Health Department, and my daughter said she wanted to be disabled too so she could have a computer.

---- [daughter] is protective of him and sensitive to kids with challenges; sometimes she gets embarrassed by his behavior. When she was younger she used to get jealous.

It's good and bad, there is less time for ---- [sister], and ---- gets away with things that ---- [sister] did not, and she had to grow up fast. But she is very compassionate and great with disabled kids; knows how to work with them.

We missed ----'s [brother] 4th birthday because Dad and I were in the hospital with----. Both of our families gave ---- [brother] a lot of attention, but still as a 4 year old, he felt abandoned, and still remembers that episode. He, a lot of times, will root for the "underdog".

Sometimes ---- [brother] is jealous. He is getting to a place where he needs his own things like now he is into soccer, and he tried t-ball too. He could probably use his own room. He is having his own friends now, and he is a compassionate kid.

---- [sister] is compassionate with other kids who have disabilities, but she felt abandoned when I had to spend so much time away from home to be with ---- [hospital].

Having ---- has made my other children more sensitive and accepting of others, but sometimes it's hard on the other kids to be helpers.

We expect the other kids to know that the rules are different for ----.

We try to be fair with chores.

Summary and Analysis: Harris (1994) noted that siblings of children with disabilities have unique potential for personal assets and liabilities. These siblings are often more compassionate and empathic than average, but they are also are at risk of feeling jealous and becoming parentified. The risk of jealousy is due to their special sibling getting more attention. The risk of parentification comes from two sources: the unspoken expectation that the typically developing child be a high achiever to make up for their nontypical sibling, and the unspoken expectation that the typically developing child be a "helper" with their nontypically developing sibling. All 10 families in this study noted these assets and concerns for their typically developing children.

4. What are your thoughts on the future care of your child?

My husband calls him "luggage" because he says ---- will always be with us; he wants to build an apartment attached to the house so ---- can live there when he gets older.

I am hoping that ---- can learn to have a job, any job and be a little more independent, and be happy.

I worked with Melwood [a local residential services provider] to check out their group home services. I felt like it was all about the money. If the parent works with them it's ok.

My sister would raise our kids if my husband and I died (prematurely). I'm pretty sure they will achieve some level of independence, even if they need help.

Partners in Policymaking helped a lot with me having hope and seeing that possibility. I've learned a lot of adaptive techniques.

I am worried about his intellectual capacity; he is probably not college material. I want him to be more than the sweeper at McDonalds.

Other family members are involved just in case they have to step in and take care of ----. We have some disagreements about the use of a group home as he matures. I've heard people in the support group talk about how that would eventually be a good thing, but we disagree on that for now.

I hope he can live on his own; I heard that DDA has to offer a group home by the time a parent is fifty years old. I want to know where he is going before I die.

I feel overwhelmed thinking about future care. I would like to see ---- in a group home as an adult. We have talked about trusts and wills, and we have a meeting planned with an estate planner.

Summary and Analysis: Beckman (1991) noted that the typical pattern of family development is different for families of children with a disability. Instead of birth being a time of celebration, it becomes a time for grieving the loss of the fantasized healthy child. Instead of that first day of school being a time for pride and anticipation of achievement, it becomes a time for worry. Instead of anticipating a young adult who is preparing for college and perhaps marriage, it becomes a time for concerns regarding residential placement and day support services. With each of these developmental milestones, families can experience grief for their child with a disability. All of the families interviewed expressed concern for their child's future, and what planning may be needed to ensure their safety and well-being. Interviewed families were committed to their children even as they grew older (we may build an addition to our house so --- can stay

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near us), but there was also some sense of the ongoing burden of responsibility (my husband refers to him as "luggage"). Two of the interviewed families mentioned contacting an estate planner to assist them in their future planning.

5. What kinds of things raise your stress level?

He never wants to sleep at night.

One of the most stressful things is explaining his behavior to other adults who don't understand, and just think ---- needs to be spanked. ---- [the parent being interviewed] then showed me a card she carries around that explains her child's disability.

School IEP meetings and dealing with the teacher who restrained ---- are the greatest sources of stress.

Out in public, when our kids act weird and we have to help them along, we get people staring and saying mean things about abusing our kids or not beating them enough. One man told my daughter that he would report her for child abuse; she felt humiliated.

"Not knowing" – the uncertainty of the future is a big worry.

The Partnerships folks told us our kids could be whatever they wanted to be. ----

doesn't know what he wants to be yet. I just want him to be happy and

successful.

Lack of sleep, we can't be spontaneous, and simple plans are complicated.

 ---- [my other child] raises my stress level; I feel like I have to do it all. No one

cleans up, and I hate coming home to a mess.

Tantrums and the constant whining are stressful, and so is the transition from

work to home.

Feeling like I don't have enough hands is stressful.

Nothing is an easy decision: going out, swimming, even playing outside.

Summary and Analysis: Blacher and colleagues (1987), Ziolko (1991) Knox and

colleagues (2000) note that families of children with a disability are often disorganized

because a majority of the parenting time goes into insuring the moment to moment safety

and well-being of the entire family. Thus, there is less time for planning activities, timely

food preparation, house cleaning or other organizing activities. All 10 families

interviewed noted that their lives felt chaotic to them, and that this chaos contributes to

their stress level. Although Dyson (1997) noted that fathers are more involved in child-

rearing activities now than they were just one generation ago, mothers still appear to be

the primary caregivers for families of children with a disability. Although it is not cited

in the literature, this phenomenon may be due to the choice families make regarding

earning potential and the availability of child care for children with disabilities. If there

can only be one wage earner in a family and the potential for higher wages is for the male

partner, families may choose to organize themselves in this manner so as to minimize

risks for economic disadvantage on top of their other challenges. In 9 of the 10 families

interviewed for this study, the male partner was the primary wage earner for the family.

The mothers reported that much of the responsibility for child rearing falls to them, and

this perceived inequity also contributed to stress.

Journal (logbook)

In addition to the semistructured interviews, each of the 10 families was asked to keep

a journal for one week. The instructions for using the journal were kept at a minimum to

give the families maximum control over the amount and depth of content the structured

interviews. Only 4 of the families were able to make time to use the journals. The other

6 families noted that they were too overwhelmed at the end of the day to write anything

in a journal. Although families of children with disabilities can have tremendous

resiliency (Abbott & Meredith, 1986; Bebko, Konstantareas, & Springer, 1987; Trivette,

Dunst, Deal, Hamer, & Propst, 1990), many families can feel overwhelmed by the

enormous parenting responsibilities (Cherry, 1989; Minnes, 1988).

The journal comments, included verbatim below, are organized into five categories: general family, children's successes, stress oriented, social support, and self-reflective.

General Family Comments

We are a very blessed family.

I'm looking forward to the (extended) family coming over tonight.

The boys went out with their cousins; that should go well.

General Family Comments Summary and Analysis: These general family comments reveal that despite the many challenges faced, families of children with mental retardation can be resilient "We are a very blessed family"). Hardiness and resilience have been key mediatingfactors in prior research (Abbott & Meredith, 1986; Bebko, Konstantareas, & Springer, 1987; Gill & Harris, 1993; Trivette, Dunst, Deal, Hamer, & Propst, 1990). The importance of social support (including family support) has been well documented (Beckman et al., 1993; King et al., 1999; Quitner et al., 1990; Trivette et al. 1996).

Children's Successes

---- is doing well in school now.

Both boys were excited to be part of putting up the [Christmas] tree last night.

---- had a good day at school and that always makes my day.

--- had his EEG today, he did really good; it's usually hard for him to be still.

--- was student of the month this month.

Children's Successes Comments Summary and Analysis: The experience of families of children with mental retardation experiencing grief and stress during times when their child has not reached the typical developmental milestone has been discussed in prior research (Beckman, 1983; Cherry, 1989; Rimmerman & Duvdevani, 1996; Winkler, 1981); however, encouraging the family to celebrate children's successes has rarely been discussed. The participants in this study did express encouragement ("… was student of the month"). Prior research does note that a strengths-based approach has been effective for families (Beckman, 1991; Byrne & Cunningham, 1985; Hancock et al., 1990; Nelson et al., 1992; Trute & Hauch, 1988; Summers, 1989; Turnbull, Guess, & Turnbull, 1988).

Stress Oriented

I had to email all of the teachers the IEP plan, it's frustrating when they are not in compliance. --- didn't want to go to school today. IEP is today, it's just a big joke; they don't want to hear anything we have to say.

We always stop by McDonalds on the way home, but I was tired so we got food to go; he had a meltdown and cried hard all the way home.

He is up and down a lot (at night) and keeps his brother up too. ---- and shopping don't mix, so we have to do it in shifts.

Stress Oriented Comments Summary and Analysis: The stress-oriented comments were similar to comments from the interviews and were centered around school, social outings, and siblings ("IEP is today, it's just a big joke"). Costigan, Floyd, Harter, and McClintock (1997) noted that effective education efforts can only be realized with a true partnership between families and the public school personnel. Baird and Peterson (1997) noted that trust was a key ingredient for an effective partnership between families and the public school system. It appears from these journal comments that these families feel a lack of trust and respect from school personnel.   As noted by Kazak and Wilcox (1984) social outings can be a challenge for families which can put them at risk of feeling isolated. Harris (1994) noted that concerns about siblings of children with a developmental disability can add stress to an already challenging situation.

Social Support

My new job is going really well.

We are excited about the [support group] party tonight. ----- baked cookies today; all is well. I did some baking for ---'s teachers; I want to let them know they are appreciated.

In the afternoon, I went on a walk with my friends, I try to do this every day –

this is my time.

Social Support Comments Summary and Analysis: These comments again stress

the importance of social support as a critical mediating factor (Beckman et al., 1993;

King et al., 1999; Quitner et al., 1990; Trivette et al., 1996). It is worth noting that

the families in this study have been particularly creative in developing their support

network ("We are excited about the support group party tonight"). Finding a way to

encourage and support these natural resources can be very effective for families

(Zioloko, 1991).

Self Reflective

I turned on music and baked for several hours which I really enjoyed.

I've been trying to think positively and not stress over the small stuff.

Self-Reflective Comments Summary and Analysis: Covey (1989) noted the

importance for individuals and families to have time to rejuvenate in order to handle

stress ("I turned on music and baked for several hours which I really enjoyed").

Summers and colleagues (1989) and Turnbull, Guess, and Turnbull (1988) noted that

when researchers asked subjects strengths-based questions, they received answers with

strengths-based responses. It is worth noting that three of the four who wrote in the

journals noted that it an enlightening experience to discuss the strengths in their family

and support system, rather than focusing solely on stress.

October 15, 2003

Dear Parent:

   I am a doctoral candidate at the University of Maryland, Department of

Counseling and Personnel Services, and a parent of a child with a developmental

disability. I am working on a dissertation research project regarding sources of stress

and support in raising a child with a developmental disability. As part of this project,

I am interested in interviewing families who are willing to discuss their experiences

with me.

   Please let me know by October 31, 2003 if you would like to be a part of this

research. I am estimating that it will take no more than a few hours of your time to be

a part of this project. For those of you who participate, it should be noted that the

University of Maryland and my professional license require that strict attention is

paid to your privacy and human rights.

   Should you wish to be involved in this project, or wish additional information

about this study, please contact me during the day at 703.838.4455, ext.235, during

the evening at 301.843.7410 or via email at suess2000@aol.com.   Thank you in

advance.

Sincerely,

Sam Bauman, LCPC

Research Consent Form

Project Title: Parents of Children with Mental Retardation:
          Coping Mechanisms and Support Needs

I state that I am over 18 years of age, in good physical health, and wish to participate in a
      program of research conducted by Sam Bauman at the Graduate School, University of
      Maryland, College Park, Department of Counseling and Personnel Services.

The Purpose of this research is to explore the subjective experiences of parents who are raising a
      child with mental retardation.

The Procedures involve keeping an informal log book for one week to be used at the family's
      discretion, and to participate in one semi-structured interview. The informal log book is to be
      used at any time a family member wants to enter thoughts about the parenting experience,
      thus capturing some spontaneous perceptions that may be missed in a structured interview. It
      is estimated that the interview may take from 1.5 to 3 hours and the optional log book entries
      may take from 0 to 2 hours.

All information collected in this study is confidential, and names will not be identified at any
      time.

I understand that as a result of my participation, I may experience emotions associated with my
      experiences in parenting. I understand that there are very minor risks associated with being
      involved in this project.

I understand that the research project is not designed to help me personally, but that the
      researcher hopes to learn more about the subjective experience of parents. I understand that I
      am free to ask questions or to withdraw from participation at any time without penalty.

Name, Address, and Phone # of Faculty Advisor:
David Hershenson, Ph. D., Counseling and Personnel Services
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suess2000@aol.com

_____   _____
Signature of Subject   Date

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