

Book Chapter

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Handbook of mental retardation and development

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Maternal reactions to children with mental retardation

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STEVEN R. LOPEZ

Mental retardation has been described as "probably the most dreadful diagnosis a parent can receive" (Fewell, 1986). First-generation research on the impact of child disability and mental retardation on families (usually mothers) presented a bleak picture of stress, burden, depression, social isolation, and psychological dysfunction (Shapiro, 1983). As research became more refined, it was apparent that handicapping conditions and disability per se were not necessarily, in and of themselves, predictors of maternal dysfunction. Rather, a host of mediating and moderating variables, some fixed and some amenable to intervention, appeared to influence the relationship between disability and maladjustment. This line of investigation began to apply complex social, ecological, and stress-appraisal-coping models to the study of responses to disability in an effort to understand the interaction between the presence of disability and the development of dysfunction. In general, these models moved away from solely deficit interpretations of adjustment and recognized the possibility of positive maternal adaptation to child disability. Further, they emphasized the interaction and developmental nature of adaptation and attempted to locate the mother within the context of a host of intrapersonal and external factors.

First, in considering maternal reaction to child disability and retardation, we have adopted an essentially developmental approach, focusing on maternal reactions that appear to have some stability, often encompassing the entire life-span spectrum, rather than on initial responses, which may be transitory and not necessarily predictive of future adaptation. Second, we have defined "reaction" to include not only emotional responses but various components of psychological well-being, such as stress, burden, depression, marital satisfaction, family functioning, and physical health. These variables were chosen because they represent outcome measures used most often in the research literature and encompass individual emotional and physical well-being. Third, we have examined which facets either directly or indirectly related to disability have the strongest

association with maternal outcomes. Finally, we have attempted to identify mediating mechanisms between stressor and maternal adaptation.

In the broadest possible terms, we are exploring the question "Are mothers pathologically damaged physically and mentally by the presence of a child with disabilities?" To answer this question, we must then ask, "In comparison to whom?" We have identified relevant comparison groups and examined research on each "reaction" vis-à-vis each group. First, we shall discuss context, through literature comparing mothers of children with disabilities to mothers of children without disabilities, in an effort to identify differences among outcome measures that may be attributable to disability rather than to the experience of mothering in general. Second, we take a cursory look at literature comparing mothers to fathers, as generally being the two most significant caregivers of the child. (See Chapter 26 for a separate treatment of fathers.) Third, in a separate section, we consider mothers of children with disabilities who are functioning less well in comparison to mothers who are functioning more adequately. In these populations, we ask what factors in child, mother, social support, or family functioning are associated with increased maladaptation or adaptation? What appear to be the most important buffering processes? To set the stage for our review of the literature on maternal reactions to child disability or mental retardation, we first provide a brief review of key theories that have driven this literature.

Theoretical overview

For many years, maternal reactions to a child with mental retardation were portrayed in almost stereotypical fashion as invariant, stagelike, and presumed to culminate in acceptance or resolution (Allen & Affleck, 1985; Blacher, 1984b). Various stage-related models proposed a predictable progression from pathology-based responses of shock, denial, guilt, blame, anger, and depression to (potential) acceptance and resolution (Fortier & Wanlass, 1984; Jackson, 1985), considering presence of a child with mental retardation as a tragedy analogous to death (Davis, 1987; Nicholas & Lewin, 1986). Theoretical constructs such as chronic sorrow were popular (Copley & Bodensteiner, 1987; Olshansky, 1966; Phillips, 1991), which tended to imply a recurrent, inescapable state of grief and mourning.

However, stage theories, although conceptually satisfying, suffered from several deficits (Allen & Affleck, 1985). For example, one empirical attempt to validate stage theory indicated that certain stages simply did not appear to exist. Eden-Piercy, Blacher, and Eyman's (1986) factor analysis identified only three out of a theoretically hypothesized five stages. In addition, issues of unidirectionality versus recurrence were not always clar-

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ified in writings on stage theory (Blacher, 1984b). Further, empirical investigations noted that normative responses such as anger or depression predicted by stage theory were by no means inevitable. Researchers wondered whether stage theory might be more an example of consensual thinking than a reality-based paradigm (Wortman & Silver, 1989). A theory so deficit-based and invariable was criticized for restricting the range of normal responses and producing interpretations of maternal and family coping with mental retardation that were unnecessarily pathologizing. Despite these theoretical and methodological concerns, the notion that some parents move through distinct stages and phases is still propagated in literature with practical or clinical applications. There is recognition, however, that other parents exhibit no particular emotional pattern (Hardman et al., 1993).

Other theories offer more broad-ranging interpretations of maternal perceptions. For example, in his classic work *The Ecology of Human Development*, Bronfenbrenner (1979) discusses how parenting behavior is affected by ecological influences emanating both from within and outside the family system. In fact, he asserts that individual behavior can only be understood in the context of the larger community in which it is operating. He postulates four levels of concentric structures whose interaction has a profound effect on the parent/child relationship: microsystems (family, peer group, school); mesosystems (systems created by the interaction of microsystems, such as family and school); exosystems (environments that may exercise an indirect effect, such as social support networks); and macrosystems (legal systems, social environments, public policy-making institutions). In terms of maternal adaptation to disability, Bronfenbrenner's model stresses the contextual contributions of systems such as family, schools, support networks, and society at large.

Other more specific formulations of family stress and coping are derived from Hill's (1958) classic ABCX model, and McCubbin's modifications resulting in the Double ABCX model (McCubbin & McCubbin, 1987). These theories assert that the effects of a stressor on family members are dependent on mediating variables such as family resources (including personal resources of individual family members), internal or systemic characteristics of the family unit, social support, cognitive appraisals of the stressor by individual family members, and the family's general worldview (McCubbin, Thompson, Thompson, & McCubbin, 1993; Patterson, 1993). Like some of these previous models, Folkman, Schaefer, and Lazarus (1979) promulgated a comprehensive theory of stress and coping that also emphasized cognitive appraisal as a key mediator of stress. They conjectured that appraisal results from the intrapsychic, interpersonal, and utilitarian resources available to the individual and identified five resource categories: (1) health/energy/morale; (2)

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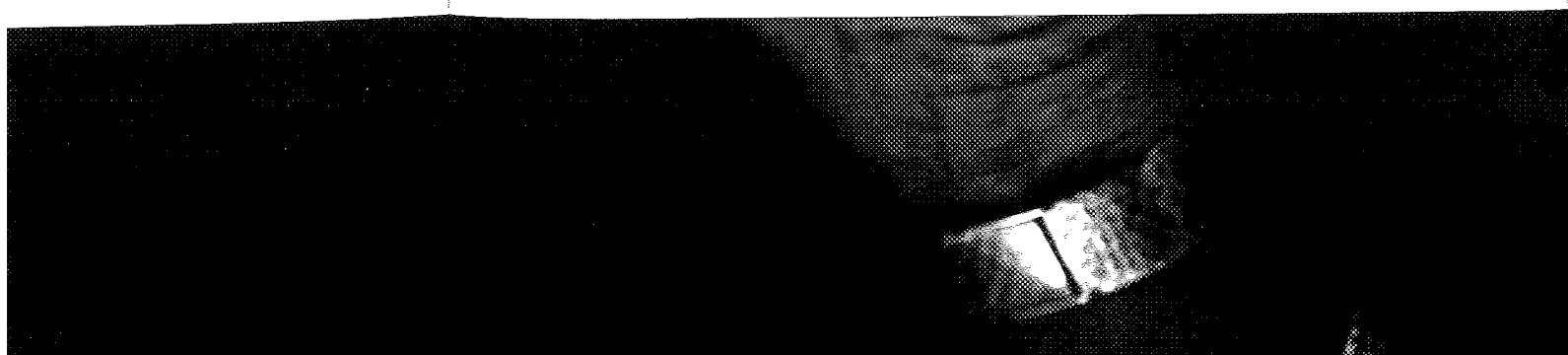
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problem-solving skills, ability to process information and generate pro-
 active behavior; (3) social networks; (4) utilitarian resources, such as so-
 cioeconomic status (SES) and marital status; (5) general and specific
 beliefs about control, self-efficacy, and religiosity. Their model predicts
 that problem-solving coping (i.e., information-seeking, planful action) will
 be positively related to successful adaptation, whereas emotion-focused
 coping (i.e., avoidance, wishful thinking) will be related to dysfunctional
 outcomes.

In addition to changing theoretical research models, parents themselves
 expressed concern that the reality of their experience with a disabled
 child was inadequately reflected in the professional literature. For exam-
 ple, they were concerned that most research, including stage theory, posi-
 ted maternal responses to child disability in terms of pathologically based
 conditions and deviations from normalcy. These concerns challenged re-
 searchers to test hypotheses of well-being as well as dysfunction. Indeed,
 Turnbull et al. (1993) raised several questions about the accuracy and
 ethics of research on families of children with disabilities. Anecdotal re-
 ports from parents pointed to positive personal and familial effects re-
 sulting from the presence of a child with disabilities, including personal
 growth and development, greater compassion and tolerance (Summers,
 Behr, & Turnbull, 1989), and new relationships formed with other parents
 of similarly disabled children. These observations suggested that adapta-
 tion, rather than dysfunction, may be the rule in families of children with
 disabilities.

Mothers of children with retardation in context

The extant literature pertaining to parental reactions to children with
 retardation focuses almost exclusively on mothers. Here, we acknowledge
 the broader family context in which mothers may feel and display these
 emotional reactions. With the exception of some of Holroyd's work in the
 1970s (Holroyd & McArthur, 1976), it is only in the last decade or so that
 responses of both parents, as opposed to mothers exclusively, have been
 regularly studied. The picture that emerges is complex, both in terms of
 the similarities and of the differences that exist. Although the impact of
 a child with disabilities is significant for both parents, mothers tend to
 report stronger reactions. It is also a commonly held viewpoint that moth-
 ers of children with disabilities differ significantly from mothers of chil-
 dren who are developing normally. However, as a global generalization,
 this is not a highly accurate statement, although on several dimensions
 measurable differences do exist, and many of these do favor mothers of
 children who do not have disabilities. We consider maternal reactions
 along the following dimensions: perceived stress, perceived burden, psy-



chological health and well-being, depression, family relations and marital adjustment, parenting competence, physical health, and social support.

Perceived stress

Stress is one of the most commonly measured maternal outcomes, and can be assessed both through global scores and specific subscales of distress. Most measures of stress used in the literature on disability measure child characteristics and problems (e.g., dependency and management, cognitive impairment, adaptability, demandingness); parental attitudes (e.g., lack of personal reward, personal burden, depression, attachment to child, relationship with spouse); and family problems (e.g., limits on family opportunities, family disharmony). Stress measures may also include daily parenting hassles, and occasionally anxiety and depression measures. However, as Beckman (1991) observes, increased stress is not necessarily synonymous with increased psychological dysfunction, although some definitional overlap may exist. Thus, in evaluating findings in this area, caution must be exercised at the interpretive level. For example, it is possible that mothers of children with disabilities are able to adapt functionally to higher levels of stress.

When we compare mothers of children with disabilities to their non-disabled counterparts, we find much of the evidence contradictory and inconclusive. For example, it is almost a sacred tenet of the literature on disability and mental retardation that mothers of children with disabilities experience more stress than do mothers of children with no disabilities. Indeed, almost all of the early and much of the contemporary literature does support this contention (Beckman, 1991; Kazak, 1987; Kazak & Marvin, 1984; Scott, Sexton, & Wood, 1986; Solis & Abidin, 1991). However, some recent studies challenge the finding of differential stress in comparisons of families of children with and without retardation (Behr & Murphy, 1993; Krauss, 1993; Spaulding & Morgan, 1986). Other studies find no differences in overall stress levels, but do detect differences in the magnitude or perception of stressors that are disability-specific (Waisbren, 1980), such as increased feelings of uncertainty, helplessness, anger, and rejection. Walker, Van Slyke, and Newbrough (1992) conclude that the basic dimensions of family functioning are not necessarily impaired by the presence of a child with a chronic medical condition. Still other studies suggest that differential stress responses may occur, but emphasize the substantial variability in the nature and extent of this stress (Beckman & Pokorni, 1988). Also unclear is the clinical significance of stress scores, with some studies pointing out that mothers of children with disabilities score below a clinically significant range (Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986; Krauss, 1993).

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maternal outcomes, and specific subscales of disturbance on disability measurement (agency and management, competence); parental attitudes (anxiety, depression, attachment problems (e.g., limits on stress measures may also increase anxiety and depression levels, increased stress is not a psychological dysfunction, although, in evaluating findings at an interpretive level. For example, mothers with disabilities are able to

with disabilities to their non-vidence contradictory and tenet of the literature on children with disabilities and children with no disabilities. The contemporary literature (Kazak, 1987; Kazak & Mar- & Abidin, 1991). However, differential stress in com- hout retardation (Behr & gan, 1986). Other studies do detect differences in the disability-specific (Waisbren, y, helplessness, anger, and (1992) conclude that the necessarily impaired by the condition. Still other studies occur, but emphasize the of this stress (Beckman & gnificance of stress scores, of children with disabilities oldberg, Marcovitch, Mac-

With these caveats in mind, mothers of children with disabilities, in general, do not report greater stress than fathers of these same children (Goldberg, Marcovitch et al., 1986; Hagborg, 1989; Krauss, 1993; Rousey, Best, & Blacher, 1992; Scott, Sexton, & Wood, 1986; Spaulding & Morgan, 1986; for a contradictory finding, see Beckman, 1991). However, though their overall level of stress may be comparable, they often experience this stress in different arenas of their life. For example, mothers have been portrayed as having greater concern about personal impact and emotional strains associated with child disability (Price-Bonham & Addison, 1978), whereas fathers may report stress due to instrumental concerns such as financial strain. Other studies describe mothers as having more difficulty adjusting to personal aspects of parenting and as being more stressfully affected by child acting-out and aggressive behaviors. Fathers, on the other hand, appear to be more stressed by child temperament, such as social withdrawal and isolation (Beckman, 1991; Hagborg, 1989; Margalit, Shulman, & Stuchiner, 1989; Sloper, Knussen, Turner, & Cunningham, 1991).

Perceived burden

Mothers of a child with significant handicaps are generally faced with additional parenting burdens in multiple realms, including maintaining the physical health of the child and assisting the child in achieving certain developmental goals that normally occur without much parent effort (walking, talking, self-care, etc.). Other components of burden may relate to feelings of anxiety and uncertainty regarding issues of child survival, development, and long-term care. In addition, burden may be related to the impact of required care on the mother's personal life, in particular a sense of limitedness and restriction resulting from a prolonged and chronic care commitment.

We note, however, that when out-of-home placement of children occurs, mothers report dramatic changes in their sense of burden. In one study (Baker & Blacher, 1993), 62 mothers were interviewed up to two years after placing their child with severe retardation. All but one of them readily stated the advantages of placement to herself and other family members. Advantages included a reduction in day-to-day parenting stress, a sense of freedom to pursue hobbies and interests, and overall better family relationships. These findings are consistent with reports gathered from siblings and other samples of parents – that post-placement family life is less burdensome (Baker & Blacher, 1994; Blacher & Baker, 1994a, 1994b). However, one cross-sectional study of older sons and daughters with mental retardation found that residential placement status (home versus placed) did not relate to parents' perceived caregiving burden (Heller, Markwardt, Rowitz, & Farber, 1994).

When children with retardation do live at home, studies consistently report greater maternal burden when comparing mothers and fathers (Bristol, Gallagher, & Schopler, 1988; Damrosch & Perry, 1989; Holroyd, 1974; Krauss, 1993). Perhaps related to burden is the finding that mothers express more needs, in more areas, than do fathers, especially in terms of family and social support, explaining their child's condition to others, and child care (Bailey, Blasco, & Simeonsson, 1992). Mothers, even when employed, frequently still bear a disproportionate amount of childcare responsibilities, which may account in part for the sense of burden and restrictiveness in their personal lives.

Mothers of children with disabilities consistently report more perceived burden, more impact and restrictions on their personal life, than comparable populations of mothers without disabled children (Bailey et al. 1992; Beckman, 1991; Erickson & Upshur, 1989; Gowen, Johnson-Martin, Goldman, & Applebaum, 1989; Rodrigue, Morgan, & Geffken, 1990). Only one study concluded that there were no significant differences in burden between the two populations (Krauss, 1993).

Psychological health and well-being

Psychological health is generally measured in a variety of ways and includes measures of depression, anxiety, and global inventories of general psychological adjustment, well-being, distress, and demoralization. They may or may not include physical symptomatology, generally associated with psychological dysfunction. They may more rarely include measures of general life satisfaction and social functioning. Because of the importance of its clinical implications, depression will be considered separately below.

The preponderance of research suggests that the psychological adjustment of mothers of children with disabilities and retardation is lower than for fathers (Gath & Gumley, 1986; Goldberg, Marcovitch, et al., 1986; McConachie, 1986; Vadasy, Fewell, Meyer, Schell, & Greenberg, 1984) and for mothers whose children do not have these problems (Blacher, 1984a; Breslau, Staruch, & Mortimer, 1982; Byrne & Cunningham, 1985; Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Hirst, 1985; Krauss, 1993; Miller, Gordon, Daniele, & Diller, 1992; Singer & Irvin, 1989; Wallander, Varni, Babani, Banis, DeHaan, & Wilcox, 1989). However, it is important to note that, in most studies, mothers of children with disabilities do not fall within clinical ranges, indicating that although they may have more specific clinical symptoms, they are not clinically dysfunctional (Wallander, Varni, Babani, DeHaan, Wilcox, & Banis, 1989). Further, level of psychological adjustment may be influenced by developmental life cycle phase, as there are some reports of older mothers of mentally retarded

t home, studies consistently comparing mothers and fathers (Schuch & Perry, 1989; Holroyd, 1989) is the finding that mothers, not fathers, especially in terms of child's condition to others, (Miller et al., 1992). Mothers, even when they donate amount of childcare for the sense of burden and

tently report more perceived stress in their personal life, than comparable children (Bailey et al., 1989; Gowen, Johnson-Martin, Morgan, & Geffken, 1990). There are no significant differences in scores (Miller et al., 1993).

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that the psychological adjustment of children with retardation is lower than that of children without (Berg, Marcovitch, et al., 1986; Bell, & Greenberg, 1984) and these problems (Blacher, 1984a; Bell & Cunningham, 1985; Goldberg, 1990; Hirst, 1985; Krauss, 1993; Miller & Irvin, 1989; Wallander, 1989). However, it is important to note that children with disabilities do not differ from children without although they may have more emotional and socially dysfunctional (Wallander, 1989). Further, level of depression is related to level of disability by developmental life cycle stage (Miller et al., 1993) and mothers of mentally retarded

adults functioning at least as well, if not better, than appropriate comparison groups (Krauss & Seltzer, 1993). Finally, as in the case of stress, studies exist that indicate no difference between disabled and comparison groups (Barakat & Linney, 1992; Harris & McHale, 1989; Spaulding & Morgan, 1986).

Depression

Most studies tend to report significantly higher depression ratings for mothers of children with disabilities and/or mental retardation than for mothers of children without disabilities (Breslau & Davis, 1986; Breslau et al., 1982; Miller et al., 1992), although these generally do not exceed clinical cut-off criteria (Bristol et al., 1988; Gowen et al., 1989). However, in an elegant study, Miller et al., (1992) showed that not only did mothers of children with disabilities have significantly higher levels of depression, but that this difference persisted in the clinically significant range and when pre-birth diagnoses were controlled for. On the other hand, three studies report no differences in depression levels between mothers of children with and without disabilities (Erickson & Upshur, 1989; Gowen et al., 1989; McKinney & Peterson, 1987), and one study of adoptive versus birth parents showed significant differences in depression level at birth that disappeared over time (Glidden, Kiphart, Willoughby, & Bush, 1993). Other researchers have observed that, in longitudinal designs, depression is quite variable, with different mothers reporting high scores at different points in time (Gowen et al., 1989). This finding suggests potential limitations in cross-sectional studies that do not take such variability into consideration. Furthermore, there are gender-based differences in depression rates between men and women, where the reporting ratio is approximately 1:2 (Nolen-Hoeksema, 1990). It is not surprising, then, that studies considering mothers and fathers of children with disabilities tend to report more depression in mothers (Beckman, 1991; Bristol et al., 1988; for a contradictory finding, see Krauss, 1993).

Family relations and marital adjustment

On these dimensions as well, the majority of reported studies do find differences favoring mothers of children without disabilities (Bristol et al., 1988; Donovan, 1988; Friedrich & Friedrich, 1981; Goldberg, Morris, et al., 1990). An early study by Gath (1978) documented more marital discord and divorce in families with children who had Down syndrome than in a comparison group. However, Kazak's 1987 study found no differences in marital satisfaction between a sample of mothers of children without disabilities and three matched samples of mothers whose children did



have disabilities. Additionally, we note again that scores for parents of children with disabilities usually do not fall within a pathological range (Bristol et al., 1988), and that studies exist which find no differences in family functioning, family adaptability and cohesion, or marital satisfaction (Kazak, 1989; Kazak & Marvin, 1984; Spaulding & Morgan, 1986; Wikler, Haack, & Intagliata, 1984). Indeed, Martin (1975) concluded that the presence of a child with handicaps may actually improve marriage. At least one study found no differences in marital adjustment as reported by mothers and fathers of children with mental retardation (Bristol et al., 1988). However, a recent study of shared care and marital satisfaction of parents of children with disabilities showed that greater father participation in child care was associated with greater marital satisfaction. This was true for both mothers and fathers (Willoughby & Glidden, 1995).

Parenting competence

Parenting a child with mental retardation often requires special family adaptations that are not necessary when a child is developing normally. These include, but are not limited to, educational efforts to understand the child's behaviors, needs, and strengths; assistance with behavior management; long-term interactions with educational and medical professionals (Baker, Blacher, Kopp, & Kraemer, in press). The literature in this area focuses on comparative studies. (For a thorough review of the normative and nonnormative aspects of parenting adults with retardation, we refer the reader to Seltzer & Ryff [1994]). Though it is often assumed that mothers of children with mental retardation will experience less competence as parents than will mothers of children without retardation, the research does not tend to support this point. A few studies support this conclusion (Goldberg et al., 1990), but most show no difference (Erickson & Upshur, 1989; Gowen et al., 1989; Haldy & Hanzlik, 1990; Hanson & Hanline, 1990; McKinney & Peterson, 1987), and one reports that parents of infants with Down syndrome actually feel more competent than a normal control group (Haldy & Hanzlik, 1990; this difference, however, shifted in the direction of parents of children without disabilities as the infants grew older). In one study comparing mothers and fathers on self-perceived comfort and ability as a parent, surprisingly, mothers tended to report a poorer sense of parenting competence than did fathers (Beckman, 1991). However, another study comparing mothers and fathers found no difference (Krauss, 1993).

Physical health

Most studies show mothers of children with disabilities and retardation reporting more physical symptoms than mothers of children without these

that scores for parents of children within a pathological range which find no differences in cohesion, or marital satisfaction (Spaulding & Morgan, 1986; Martin (1975) concluded that actually improve marriage. At adjustment as reported by children with retardation (Bristol et al., 1989) and marital satisfaction of children with retardation that greater father participation in marital satisfaction. This was reported by Glidden, 1995).

often requires special family support if the child is developing normally. Additional efforts to understand the child's assistance with behavior management and medical professional (e.g., psychologist). The literature in this area has been reviewed in a thorough review of the needs of parents of children with retardation, we find that although it is often assumed that children with retardation will experience less marital satisfaction than children without retardation, the literature shows that a few studies support this finding. These studies show no difference (Erickson & Hanzlik, 1990; Hanson & Hanson, 1990) and one reports that parents of children with retardation are more competent than a normal child; this difference, however, is not significant when children without disabilities as the control group. The mothers and fathers on self-reporting surprisingly, mothers tended to report more marital satisfaction than did fathers (Beckman, 1991). Comparing mothers and fathers

of children with disabilities and retardation and children without these

difficulties (Goldberg, Morris, et al., 1990; Hirst, 1985; Miller et al., 1992; Wallander, Varni, Babani, Banis, et al., 1989). Several studies indicate reports of poorer physical health in mothers than in fathers as well (Beckman, 1991; Dunst, Trivette, & Cross, 1986; Krauss, 1993).

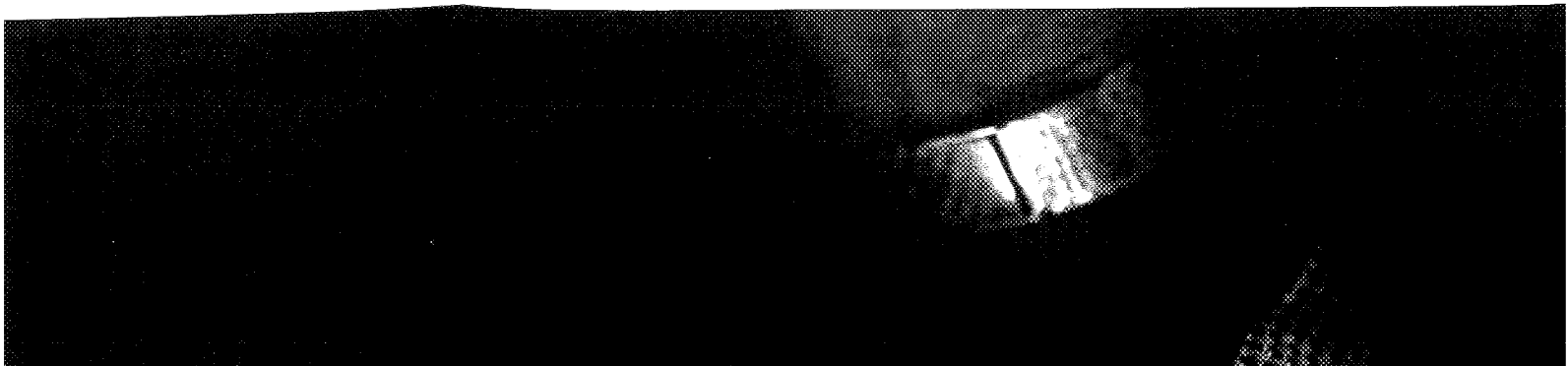
Social support

Finally, much has been written about the purported social isolation of families of children with disabilities (Darling, 1979; Gayton, 1975; Trute & Hauch, 1988), although recent studies report no differences between mothers and fathers in terms of their social isolation (Beckman, 1991).

Evidence exists that in some instances families of children without disabilities may have larger and less dense social networks than families of children who are disabled (Friedrich & Friedrich, 1981; Kazak & Wilcox, 1984), both attributes indicative of less adequate support. However, several studies show no differences in social support, either in terms of utilization of formal support services (McAlister, Butler, & Lei, 1973) or in terms of networks or satisfaction (Barakat & Linney, 1992; Beckman, 1991; Rodrigue et al., 1990; Ryde-Brandt, 1988). A few studies indicate that certain populations of families who have a child with retardation, such as Down syndrome, may have even better social support structures than their nondisabled counterparts (Erickson & Upshur, 1989), a finding that may be in part attributable to the presence of early intervention programs and strong parent advocacy groups.

Predictors and correlates of maternal adaptation to child disability

From the above discussion, we have seen that, although there is great individual variability and change over time, the existing evidence tends to suggest that, as a group, mothers of children with retardation often fare less well psychologically and physically than the fathers of these same children. Furthermore, they appear to have more stress, to perceive more burden, and to be more vulnerable to dysfunction than mothers of children who do not have mental retardation. We next examine influences that promote better adaptation for some mothers. A range of correlates, moderators, and predictive variables has been identified in an effort to explain these differences. Here, the overview of predictors proceeds according to Bronfenbrenner's model (1979) of ecological influences, mentioned earlier. The first level of predictors considered includes the element of microsystems, such as child characteristics that directly affect the parent-child relationship, and maternal characteristics. Family relations, part of Bronfenbrenner's mesosystem, are next considered. Environments or variables that may exercise a more indirect effect on maternal



perceptions include predictors of burden, social support, or cognitive appraisal. Finally, the influences of culture and ethnicity, characteristics of the macrosystem, are explored. General trends in each major area of investigation are summarized below.

Child characteristics: Age and sex

Earlier literature assumed that increasing child age would be associated with increased stress (Bristol, 1979; Bristol & Schopler, 1984; Friedrich, Wilturner, & Cohen, 1985; Gallagher, Beckman, & Cross, 1983). Now that seems to be an overly simplistic analysis. One study, for example, shows no overall differences in maternal stress associated with child age, but does report differences in areas of parenting that are stressful for mothers of children at different points of development (Heller, 1993). Younger parents are more likely to report stress related to obtaining information and supportive services, whereas older families report stress related to finding services for their child and to future residential placement. The majority of recent studies report no significant association between increasing age of child and anxiety (Ryde-Brandt, 1990), depression (Heller, 1993; Ryde-Brandt, 1990), and stress (Donovan, 1988; Flynt & Wood, 1989; Flynt, Wood, & Scott, 1992; Hanson & Hanline, 1990; McKinney & Peterson, 1987; Walker et al., 1992). (For contradictory studies on child age, see Behr & Murphy, 1993; Hagborg, 1989.) Indeed, Minnes (1988) reports that stress associated with child's level of cognitive impairment actually diminishes with age, and Beckman (1991) also reports decreasing stress with child age. Although preliminary findings suggested that developmental transition periods might also be associated with increased stress (Wikler, 1986), this has not been substantiated empirically for family stress scores (Flynt & Wood, 1989; Flynt et al., 1992). A recent study has documented a curvilinear relationship between age and burden, with the most maternal burden reported during adolescence (Heller, 1993).

Sex of the child is not consistently associated with maternal outcomes, although a few studies conclude that higher levels of family and maternal adjustment are associated with having girls with disabilities (Frey, Fewell, & Vadasy, 1989).

Diagnosis and severity of disability

It seems intuitively obvious that diagnosis would make a difference in maternal and parental adaptation. However, the data defy a simple yes-no resolution. Early studies, as well as some more recent ones, tend to suggest a relationship between diagnosis and maternal stress (Cummings, Bayley, & Rie, 1966; Holroyd & McArthur, 1976; Wallander, Pitt, & Mel-

social support, or cognitive and ethnicity, characteristics of ends in each major area of in-

child age would be associated & Schopler, 1984; Friedrich, man, & Cross, 1983). Now that one study, for example, shows associated with child age, but does not are stressful for mothers of (Heller, 1993). Younger parents to obtaining information and report stress related to finding placement. The majority of variation between increasing age and depression (Heller, 1993; Ryde-; Flynt & Wood, 1989; Flynt, 1990; McKinney & Peterson, 1990). Longitudinal studies on child age, see indeed, Minnes (1988) reports that cognitive impairment actually also reports decreasing stress levels suggested that development associated with increased stress (Wilk-1 empirically for family stress (1992). A recent study has documented age and burden, with the most evidence (Heller, 1993).

associated with maternal outcomes, or levels of family and maternal stress with disabilities (Frey, Fewell,

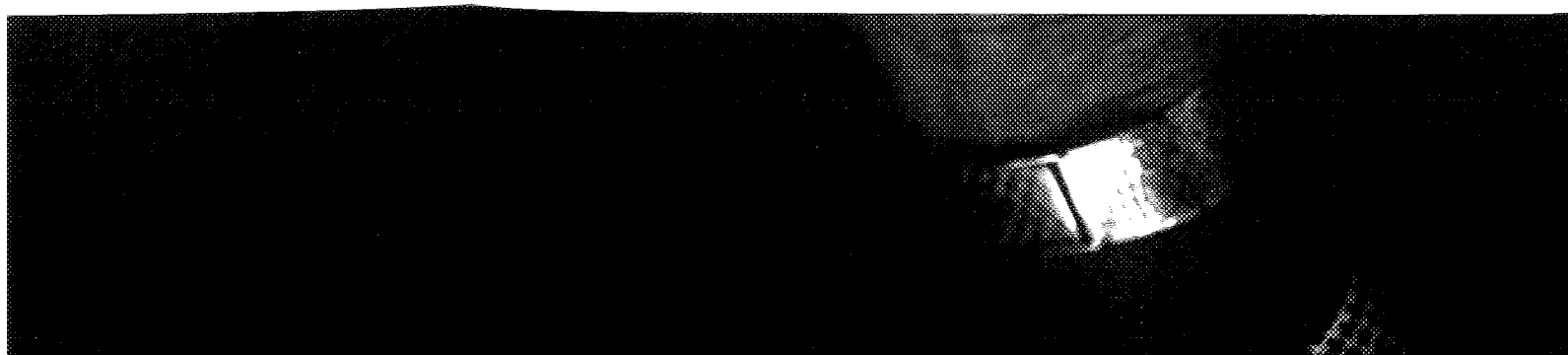
would make a difference in stress, the data defy a simple yes-no answer. More recent ones, tend to find increased maternal stress (Cummings, 1976; Wallander, Pitt, & Mel-

lins, 1990). In many more recent studies, disability diagnoses were unrelated to levels of maternal stress (Beckman, 1991; Donovan, 1988; Kazak, 1987; McKinney & Peterson, 1987), burden, depression, well-being (Hanson & Hanline, 1990; Hirst, 1985), family functioning (Krauss, 1993), marital satisfaction (Donovan, 1988), and parenting competency (Hanson & Hanline, 1990).

Certain diagnoses, however, are likely to place the mother at increased risk for maladaptive stress, burden, depression, and poorer family functioning – notably, autism (Bouma & Schweitzer, 1990; Donovan, 1988; Rodrigue et al., 1990), psychosis (Ryde-Brandt, 1990), and significant mental retardation (Kazak, 1988; Walker et al., 1992). Walker, Van Slyke, and Newbrough (1992) found that parents of children with mental retardation, compared to parents of children with diabetes and cystic fibrosis, scored higher on certain stress scales (such as dependency and management), but showed no significant differences on scales of limits on opportunities, family disharmony, personal burden, or lack of reward. Goldberg, Marcovitch, et al. (1986) confirmed an early finding of Holroyd and McArthur (1976) that parents of children with Down syndrome, when compared to parents of neurologically impaired children and children with developmental delays of unknown etiology, performed better on measures of positive experience with child, support, and family relations. Indeed, consistent with a fairly substantial body of research in attesting to the superior well-being of mothers who have children with Down syndrome (e.g., Erickson & Upshur, 1989; Mink, Nihira, & Meyers, 1983; Minnes, 1988; Noh, Dumas, Wolf, & Fisman, 1989), Seltzer, Krauss, and Tsunematsu (1993) found that aging mothers of adults with Down syndrome reported less conflicted family environments, more satisfaction with social support, and less caregiving stress and burden than mothers of adults with retardation due to other causes.

Other researchers have concluded that it is probably not diagnosis per se so much as severity of disability that is problematic for mothers. The weight of the literature supports the association of increasing severity of disability with increased maternal stress and burden (Donovan, 1988; McKinney & Peterson, 1987; Seltzer & Krauss, 1989). Frey, Fewell, and Vadasy (1989) concluded that children at higher ability levels had mothers with better adjustment to child and family, and who also exhibited better personal adjustment. In a study comparing three populations of disabled children and their families, Hanson and Hanline (1990) found that mothers of less developmentally advanced children reported more stress in certain areas. Tew and Laurence (1975) also found that severe disability predicted greater stress.

However, with the exception of Blacher, Nihira, and Meyers (1987), a study that considered severity of handicap or retardation and impact on



families, severity of disability is not necessarily a strong predictor of overall maternal well-being or family functioning. In studies of children with physical handicaps, Wallander, Varni, Babani, DeHaan, et al. (1989) and Wallander, Pitt, and Mellins (1990) found no relationship between child disability status and maternal adaptation, a finding confirmed in another study of physical handicap (Barakat & Linney, 1992). Similarly, Haldy and Hanzlik (1990) found no relationship between maternal parenting competence and child level of retardation. Bristol, Gallagher, and Schopler (1988) also found disability status to be unrelated to maternal depression. Paradoxically, Kazak and Clark (1986) concluded that marital satisfaction was *higher* in families of children with more severely disabling spina bifida than in families whose children had less involvement.

Child attributes and temperament

Most studies suggest that problematic child characteristics, such as slower rate of development, lack of social responsiveness, aggressiveness, or unusual caregiving demands, are associated with increased stress (Beckman, 1991; Beckman-Bell, 1981; Frey, Greenberg, & Fewell, 1989; Gallagher et al., 1983; McKinney & Peterson, 1987; Margalit et al., 1989; Minnes, 1988; Noh et al., 1989), increased depression (Gowen et al., 1989; McKinney & Peterson, 1987; Walker et al., 1992), increased marital discord (Korn, Chess, & Fernandez, 1980), poorer maternal adjustment (Sloper et al., 1991), and psychological adjustment (Frey, Fewell, & Vadasy, 1989; Frey, Greenberg, & Fewell, 1989; Noh et al., 1989), as well as decreased parenting competency (McKinney & Peterson, 1987) and marital satisfaction (Kazak, 1986). In a longitudinal study, Hanson and Hanline (1990) concluded that the child attributes of demandingness and lack of social acceptability were associated with increased maternal stress.

Maternal characteristics: Socioeconomic stress, age, and maternal employment

The evidence regarding the buffering effect of socioeconomic status (SES) is equivocal. Although early studies suggested that SES influences the level of perceived parental stress (Rabkin & Streuning, 1976; Wikler, 1981), most studies report either a weak or nonsignificant effect (Beckman, 1991; Donovan, 1988; Flynt & Wood, 1989; Haldy & Hanzlik, 1990). The strongest support for SES as a predictor of maternal stress, burden, and overall functioning is found in developing countries (Singhi, Goyal, Pershad, Singhi, & Walia, 1990), which still lack an adequate infrastructure of formal support for all but well-to-do families with a disabled child.

In general, maternal age does not reliably predict stress, adjustment,

ly a strong predictor of overall studies of children with physical disabilities (e.g., Haan, et al. (1989) and Waldo (1992)). Similarly, Haldy and colleagues (1992) found a positive relationship between child disability and maternal depression. Similarly, Haldy and colleagues (1992) found a positive relationship between maternal parenting competence and maternal depression. Similarly, Haldy and colleagues (1992) found that marital satisfaction was a significant predictor of maternal depression in severely disabling spina bifida children.

characteristics, such as slower cognitive development, increased aggression, or increased stress (Beckman, et al., 1989; Gallagher et al., 1989; Minnes, 1988; Owen et al., 1989; McKinney & Peterson, 1987). Similarly, Haldy and colleagues (1992) found that marital satisfaction was a significant predictor of maternal depression in severely disabling spina bifida children.

stress, age, and

of socioeconomic status (SES) has been found that SES influences the level of maternal stress (e.g., Beckman, 1991; & Hanzlik, 1990). The strongest predictor of maternal stress, burden, and overall adjustment is the child's disability (Singhi, Goyal, Pershad, & Sinha, 1990). Similarly, Haldy and colleagues (1992) found that marital satisfaction was a significant predictor of maternal depression in severely disabling spina bifida children.

family functioning, or maternal mental health (Beckman, 1984, 1991; Donovan, 1988; Ryde-Brandt, 1990; for a contradictory finding, see Sloper et al., 1991). One study found that older mothers of disabled children used similar coping strategies to those of younger mothers but appeared to derive more benefit from them and reported less stress than their younger counterparts (Flynt & Wood, 1989). In another study associating positive adaptation and coping in older mothers, the investigators indicated that their sample showed at least as high a level of well-being as several comparison groups (Krauss & Seltzer, 1993). Furthermore, in this same sample, demographic characteristics of older mothers of adults with mental retardation were associated with mothers' physical health and life satisfaction (Seltzer & Krauss, 1989).

The impact of maternal employment has not often been investigated. However, one study reporting on maternal employment indicated that it was unrelated to stress (McKinney & Peterson, 1987), whereas another investigation suggests it may even exert a buffering effect on depression (Walker et al., 1989).

Marital status

It is widely assumed that because the marital relationship appears to have a mitigating influence on negative maternal outcome, single parents will be at significantly greater risk for dysfunction and maladaptation (Jones, 1987). However, studies considering marital status per se are mixed. Some report a negative relationship between marital status and maternal stress (Salisbury, 1987), indicating that single mothers have more stress than mothers from two-parent families (Beckman, 1984). Several others find no relationship between marital status, maternal stress, psychological adjustment, and family functioning in families with children who have disabilities (McCubbin & Huang, 1989; Romans-Clarkson et al., 1993; Schilling, Kirkham, Snow, & Schinke, 1986). These studies, though showing no overall differences, do tend to find item differences related to family life in general rather than to the rearing of a child who has a disability. One innovative study distinguished between marital status and adult companionship, concluding that it is the presence of the latter that best predicts maternal satisfaction (Fagan & Schor, 1993).

Family relations

This concept refers to the internal functioning of the family on dimensions such as cohesion, adaptability, and conflict. Positive family relations are consistent predictors of decreased maternal (and paternal) stress and burden (Krauss, 1993; Minnes, 1988; Sloper et al., 1991), decreased levels



of depression (Friedrich, Cohen, & Wilturner, 1987; Harris & McHale, 1989; Rousey et al., 1992), maternal well-being and psychological adjustment (Blacher et al., 1987; Fagan & Schor, 1993; Minnes, 1988; Seltzer & Krauss, 1989; Wallander, Varni, Babani, Banis, et al., 1989), and parenting competence (Fagan & Schor, 1993; Gowen et al., 1989). Psychosocial family resources, including family support, marital satisfaction, and the social support network, have been shown to predict maternal psychological and social adaptation (Wallander, Varni, Babani, Banis, & Wilcox, 1989).

Social support

The presence of and satisfaction with social support systems are consistently associated with reduced maternal stress (Beckman, 1984, 1991; Beckman & Pokorni, 1988; Brandt, 1984) and depression (Gowen et al., 1989; Hanson & Hanline, 1990). Social support also has been associated with improved physical health (Dunst et al., 1986; Wallander, Varni, Babani, et al., 1989), better family adjustment (Frey et al., 1989), more positive adaptation and well-being (Barakat & Linney, 1992; Capuzzi, 1989; Dunst et al., 1987; Frey et al., 1989; Minnes, 1988; Peterson, 1984) and higher parenting competency and satisfaction (Fagan & Schor, 1993; Gallagher et al., 1983; Haldy & Hanzlik, 1990; Hanson & Hanline, 1990; Seybold, Fritz, & MacPhee, 1991). There are a few studies, however, that report no relation between social support and maternal mental health (Romans-Clarkson et al., 1993) and stress (McKinney & Peterson, 1987).

We are even able to distinguish inert from active social support components for mothers of children with mental retardation. For example, satisfaction with support seems more crucial than size of one's social support network (Frey et al., 1989; Peterson, 1984). Another study identified a key component of support mediating maternal attachment to an infant with handicaps to be affirmation, in contrast to instrumental or affective support (Capuzzi, 1989). A similar study emphasized instrumental help as being more significant than acceptance or understanding of feelings (Haldy & Hanzlit, 1990). A third study noted that mothers of children with disabilities rely more heavily on social support from family members than from nonrelatives (Marcenko & Meyers, 1991). It is also possible that severity of disability may be related to decreased satisfaction with social support (Seybold et al., 1991).

Spousal support appears to be an especially critical mediating variable and is consistently predictive of decreased maternal stress (Bristol, 1987; Bristol et al., 1988; Friedrich et al., 1985; Krauss, 1993; McKinney & Peterson, 1987), depression (Gowen et al., 1989; McKinney & Peterson, 1987), adjustment (Dunst et al., 1986; Fewell, 1986; Friedrich et al., 1985) and parenting competency and satisfaction (Gowen et al., 1989). Expres-

ner, 1987; Harris & McHale, 1988; Minnes, 1988; Seltzer & Minnes, et al., 1989), and parenting (Fagan & Schor, 1993; Galambos & Hanline, 1990; Seydel et al., 1989). Psychosocial family factors, such as marital satisfaction, and the social support systems are consistently associated with maternal psychological and physical health (Beckman, 1984, 1991; Gowen et al., 1989). Support also has been associated with maternal depression (Beckman, 1984, 1991; Wallander, Varni, Battaglia, & Frey et al., 1989), more positive coping (Linney, 1992; Capuzzi, 1989; Linney, 1992; Peterson, 1984) and maternal mental health (Fagan & Schor, 1993; Galambos & Hanline, 1990; Seydel et al., 1989). In a few studies, however, that have examined the relationship between social support and maternal mental health (McKinney & Peterson, 1987), the relationship between social support and maternal mental health is not as strong as in the case of children with mental retardation. For example, a study by Linney (1992) found that the size of one's social support system was not related to maternal mental health (Linney, 1992). Another study identified that maternal attachment to an infant was related to instrumental or affective support (Fagan & Schor, 1993). It was noted that mothers of children with mental retardation who received social support from family members reported decreased satisfaction with social support (Gowen et al., 1989). Express-

sive support from the spouse has been shown to be the best predictor of quality of parenting for both mothers and fathers (Bristol et al., 1988). And for mothers, marital satisfaction is the best predictor of positive coping (Kazak, 1986). Fewell has documented the importance of fathers in providing social support to mothers of retarded children (1986). One study concluded that the single best predictor of negative adaptation in mothers (and fathers) was the discrepancy between actual and ideal "appropriate" spousal support (Bristol et al., 1988). The evidence regarding actual father participation in caretaking is ambiguous, with some studies (Parke, 1986) reporting low participation in caregiving and mothers sustaining the primary burden of care (Carr, 1988; Hirst, 1985; McConachie, 1986), and others concluding that fathers actively participate in child care in families with a child with retardation, according to both self and maternal report (Van der Giessen, 1991).

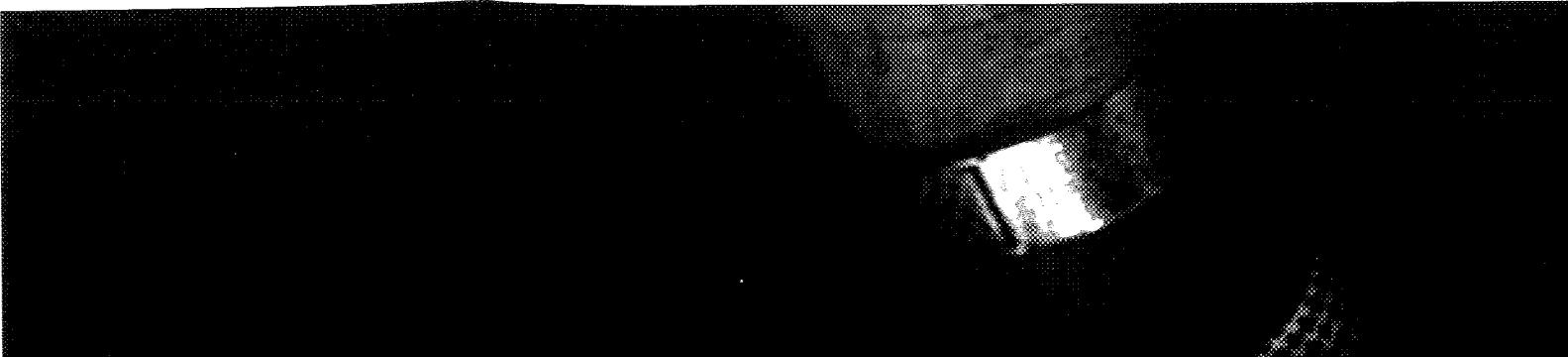
Cognitive coping and appraisal

Various intrapsychic qualities and cognitive processes, such as religiosity, internal locus of control, problem-focused coping, hardiness, and positive appraisal of the situation, have all been associated with reduced maternal stress and increased well-being (Affleck, Tennen, & Rowe, 1988; Frey, Greenberg, & Fewell, 1989; Glidden, 1989; Glidden, Kiphart, Willoughby, & Bush, 1993). Emotion-focused coping has been associated with increased psychological distress, whereas problem-focused coping has been associated with decreased distress (Affleck & Tennen, 1991; Frey, Fewell, & Vadasy, 1989; Friedrich, Wiltturner, & Cohen, 1985; Miller et al., 1992; Patterson, 1993). The extent to which mothers believed they could psychologically adjust to the stressor was also associated with lower levels of stress (Miller et al., 1992). Religious beliefs have also been shown to have a positive relationship to maternal depression and well-being (Dulan & Blacher, 1995; Friedrich, Cohen, & Wiltturner, 1988; Rogers-Dulan & Blacher, 1995), although one study (Frey, Fewell, & Vadasy, 1989) found that religious beliefs were not predictive of parental adjustment.

Internal locus of control has been correlated with decreased maternal depression (Affleck, Tennen, & Gershman, 1985; Friedrich et al., 1988; Heller, 1993; Rimmerman, 1991), increased well-being (Affleck & Tennen, 1991; Friedrich et al., 1988), and parenting competency (Heller, 1993; McKinney & Peterson, 1987), and appears to predict decreased maternal stress (Affleck et al., 1985; McKinney & Peterson, 1987). In one study (Rimmerman, 1991), the interaction of high internal locus of control with high social support predicted the lowest degree of pessimism in mothers. A similar interaction with high spousal support was found by McKinney and Peterson (1987).

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Cognitive appraisals linked to positive maternal adaptation include the following: (1) finding meaning, (2) regaining a sense of mastery and control, and (3) optimistic outlook and trust in benevolent others (Affleck & Tennen, 1993). Affleck and Tennen (1993) also showed that both primary control (exercising personal mastery over a situation) and secondary control (positive emotional appraisal) were associated with adaptational outcomes. To this list, Behr and Murphy (1993) add construing positive benefits from the event and favorable downward comparisons. Other positive coping strategies include acceptance, positive reinterpretation and growth, turning to religion, and planning (Krauss & Seltzer, 1993). Empirical validation for many of these adaptive cognitive coping strategies (e.g., downward comparisons, endowing illness with meaning, and living in the present) is not yet robust.

Burden

A series of studies relate perceived burden to additional maternal stress (Beckman, 1983, 1991; Erickson & Upshur, 1989; Gowen et al., 1989; Harris & McHale, 1989; Krauss, 1993), depression (Walker et al., 1992), poorer parent and family functioning (Crnic, Friedrich, & Greenberg, 1983), and maternal mental health problems (Wallander et al., 1990), although Wallander, Varni, Babani, Bani, Dehaan, and Wilcox (1989) failed to find a significant relationship between chronic strain and maternal adaptation. At least two studies conclude that the burden of caregiving successfully predicts maternal depression (Erickson & Upshur, 1989; Gowen et al., 1989). Stress and burden uniquely related to the child's handicapping condition may put mothers at particular risk for maladjustment (Wallander, Pitt, & Mellins, 1990).

Culture and ethnicity

It is probably safe to say that culture and ethnicity exert important influences on the reactions of mothers to disability and mental retardation (Quirk, Ciottone, Minami, & Wagner, 1986; Seligman & Darling, 1989; Tanaka & Niwa, 1991). However, it is difficult to be specific about these effects because this aspect of maternal and family adaptation has rarely been investigated. Studies reported in the literature on families with children who are developmentally delayed and mentally retarded rarely consider race or ethnicity as a variable of analysis.

The few studies that have examined culture and ethnicity suggest some intriguing insights. For example, a study of Scandinavian mothers of Down syndrome children (Ryde-Brandt, 1988) found little evidence of depression or anxiety, revealed normal social and emotional contacts, and ob-

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served the negative feelings experienced at the birth of the child almost invariably changing in a positive direction. In contrast, a study from India showed significantly greater burden, disruption, poorer social interaction, and ill effects on the physical and mental health of mothers of children with physical and mental disabilities when compared to control families of nondisabled children (Singhi et al., 1990). An ethnographic study examining Belizean mothers of mentally retarded children concluded that they relied almost entirely on themselves and religion for coping, rather than turning to social support networks (Killion, 1990). Mothers from non-American backgrounds may rely more on attributions of blame or magic (Singhi et al., 1990; Stahl, 1991) and see disability as punishment for wrongdoing. In one study, African American mothers reported less stress than Caucasian mothers (Flynt & Wood, 1989), a finding associated with more extensive usage of their kinship network. On the other hand, there is preliminary evidence that both African American and Latino mothers may be less satisfied with their maternal role in parenting a child with mental retardation than Anglo mothers, perhaps as a consequence of their greater tendency to lack another adult with whom to share child-rearing responsibilities (Fagan & Schor, 1993).

In comparison to other ethnic groups, Latino mothers may evidence less anger and negative affect in response to disability while exhibiting greater tendencies toward self-sacrifice, resignation, and acceptance (Mary, 1990). On the other hand, a recent study found depressive symptomatology to be quite elevated in a sample of Latino mothers who have children with mental retardation (Blacher, Shapiro, Lopez, Diaz, & Fusco, in press). Almost half of these 148 mothers (49%) reported negative experiences in excess of a commonly used cut-off for depression. Their depression scores related to variables pertaining to the child, to the mother's health and level of acculturation, and to aspects of stress and coping. These mothers in the recent Latino immigrant community in Los Angeles appear highly vulnerable to psychological challenges related to their child with retardation, and they do not seem to have the resources or supports to buffer depression.

In another study, Latino mothers reported a greater impact of child disability on the family unit than did non-Latino mothers, although this was attenuated by paternal involvement in child care (Wasilewski, Clark, & Evans, 1988). Latino mothers of children with disabilities report higher levels of parenting stress than do Latino mothers of children with normal development (Solis & Abidin, 1991). There is some evidence that there may be higher stress in more acculturated, English-speaking Latino families (Chavez & Buriel, 1988). Perhaps acculturation and being embedded in one's traditional culture may create both buffers and additional stressors, but in different domains (Mardiros, 1989). One pervasive problem

with current research on ethnicity is the persistent confounding of culture and SES. In one study that controlled for class and educational levels, differences between Latino and Caucasian mothers were reduced to non-significance (Stein & Jessop, 1989).

Models of prediction

Intriguing work has been done that points to both validation and limitations in the predictive value of current theoretical models. For example, Wallander, Varni, Babani, Dehaan, Wilcox, and Banis (1989) have developed a comprehensive conceptual model based on stress and coping paradigms that identifies major risk-factor parameters, buffering resistance factors, and outcome variables of mental and physical health and social functioning. In testing this model, they discovered that severity of child handicap and intellectual functioning were unrelated to maternal adaptation, but that social environment was significantly associated with maternal mental health and adaptive functioning, although not to physical health. These findings suggest the specificity of interaction among variables identified by theoretical modeling. In another example, Dunst, Trivette, Hamby, and Pollock (1990) examined child rather than maternal outcome. They were able to specify degrees of influence for the variables of social support, maternal health and well-being, family functioning, and styles of parent-child interactions.

We have already cited the 1992 study of Miller et al., which tested a cognitive behavioral model of stress and coping, generated theoretically derived hypotheses, and was able to validate them empirically, thus lending confirmation to the model under investigation. Further support for this model is found in a study by Bristol (1987), which demonstrated that family adaptation (including marital adjustment, few maternal depressive symptoms, and positive family functioning) was related to social support and active coping patterns. Self-blame, the presence of additional stressors, and negative appraisal were related to poorer adaptation. On the other hand, Behr and Murphy (1993) found only a modest relationship between appraisal and stress and family well-being, although appraisal had a stronger relationship than such variables as child age, severity of disability, marital status of parents, and socioeconomic variables.

In an interesting study testing Hill's ABCX model, Minnes (1988) found the model useful but not completely predictive; the relationship between stressors and resources did not always operate in tandem, as described by the model, but rather each alone predicted a particular kind of stress. Similarly, although many models predict that social support plays a key role in adaptation, Gowen et al. (1989) indicated that social support overall was less important in predicting feelings of depression and parenting

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competence than was maternal perception of quality of relationships with husbands and parents. A similar conclusion was reached by Fagan and Schor (1993), who stated that family functioning played a far more important role than the number of social supports in predicting maternal competence and well-being. Seltzer and Krauss (1989) also found that family environment was a predictor of maternal well-being superior to informal or formal support structures. In another study, mothers who had either a positive belief system or a nonjudgmental family network scored lowest in terms of psychological distress (Frey, Greenberg, & Fewell, 1989).

Summary and future directions

A careful review of the literature suggests that, although we need to correct a pathological view of mothers of children with disabilities, significant differences do exist, at least on some dimensions, between mothers of children with and without retardation, as well as between mothers and fathers of children with mental retardation. The evidence suggests that mothers continue to be more strongly affected than fathers by the caregiving requirements associated with a child with disabilities, although there is little reason to believe that their greater sense of stress and burden is reflected in clinically significant maladaptation. Further, it is not completely clear whether higher levels of physical and emotional symptomatology are related to the presence of a child with mental retardation, to a host of mediating variables, or to differences between men and women in the larger population unrelated to child disability. Similarly, though a growing body of information finds few differences on many adaptive outcome measures between mothers of children with and without disabilities, usually differences that are found favor mothers of children with normal development. This is not to say that families of children with disabilities and retardation are dysfunctional or poorly adaptive, but simply that they are required to respond to more challenges in the process of raising their child with disabilities (Baker et al., in press).

What we are beginning to realize is that maternal and family reaction to disability, and to mental retardation in particular, is highly variable, so that it is difficult and inaccurate to talk about "families of children with retardation" in a general sense. Within the universe of families of children with retardation, there is a great range in the nature and extent to which individual mothers report maladaptation (Beckman & Pokorni, 1988). A variety of factors influence maternal and family response in a highly complicated (and to date, not completely predictable) fashion, of which we are able to ascertain only bits and pieces. What we do know suggests that, although mothers are stressed and burdened by the presence of a child

with retardation and do experience some psychological distress, they usually do not meet criteria of emotional and psychological maladjustment for a clinical population. Though they may find their children with disabilities more difficult or more time-consuming to care for than children without disabilities, in general they perceive little caretaking difficulty in their role as parents (Erickson & Upshur, 1989), are equally attached to these children, and generally feel equally competent as parents. Mothers of children with retardation do not necessarily have more dysfunctional home lives than mothers of children without disabilities, nor do they always have worse marriages or less adequate systems of support. Further, as Kazak (1986) notes, it is possible that what is considered to be normal functioning in families of children with disabilities may look different, but not necessarily be less adaptive, than "normal" functioning in families of children who do not have any known disability. It is even possible that apparent dysfunction may be adaptive when considered in the broader context of the family's social environment. Thus, it may be important to develop norms of coping specific to families of children with retardation and other disabilities, and not simply to assume that the form of coping in families without disabled children is the standard that should be applied cross-situationally.

Model testing

We have reached the stage in research on families of children with mental retardation where greater specificity in refining various components of existing models is required. For example, many models have paid insufficient attention to outcome variables. Which are the most significant outcome measures? Is depression a more salient measure than burden? Are both of equal significance? Interestingly, despite the multitude of studies using some variant of a stress measure, the literature is largely silent on whether the presence of stress is predictive of maladaptive mental or physical health outcomes (see Friedrich, Greenberg, & Crnic, 1983; Walker et al., 1992, for correlational data between stress scores and depression).

Similarly, we may be able to sort out which are the most significant predictive and buffering factors. Early research emphasized inert variables: age and sex of child, diagnosis, severity of disability. It is clear that all these bear some relationship to maternal outcome; but it is also becoming apparent that their impact on maternal well-being may be significantly modified by factors more susceptible to intervention, such as the presence of social support, spousal support, maternal appraisal, and family environment. Here again, we need to ask which of these, and in what combinations, are most powerful? Can positive attitude outweigh poor social support? Are the combined effects of internal locus of control and high

psychological distress, they usually find their children with disabilities to care for than children with little caretaking difficulty (Walker, 1989), are equally attached to their children as competent as parents. Mothers of children with disabilities usually have more dysfunctional coping systems of support. Further, mothers of children with disabilities are considered to be normal mothers. Their coping strategies may look different, but they are usually functioning in families of normal ability. It is even possible that mothers of children with disabilities are not considered in the broader context of family. Thus, it may be important to consider the form of coping strategies of children with retardation and to determine that the form of coping strategies is a standard that should be applied.

families of children with mental disabilities. In examining various components of adjustment, many models have paid insufficient attention to the most significant outcome: the child's adjustment. Is it a measure of burden? Are there other measures? In spite of the multitude of studies, the literature is largely silent on the issue of maladaptive mental or physical health (Walker, Crnic, 1983; Walker et al., 1988; Walker et al., 1989). What are the most significant outcomes? Which emphasized inert variables? What are the most significant outcomes? It is clear that all outcomes; but it is also becoming apparent that well-being may be significantly affected by the presence of adjustment, such as the presence of appraisal, and family environment, and in what combination. The combination of these, and in what combination, outweigh poor social support. The combination of appraisal, locus of control and high

spousal support more effective than cohesive family environment and strong religious conviction? Is the potency of these variables cumulative? And which maternal outcomes are affected by their presence or absence? Furthermore, attention needs to be paid to the role of culture in analyzing adaptive parental responses. We know very little about cognitive coping, utilization of social support, and parent-child interaction as they are mediated by cultural values and beliefs. Finally, it is reasonable at this point to contemplate a comparison of theoretical models to determine which, or which components, have more predictive validity.

Beyond current models

It is possible that, just as with earlier models of chronic sorrow and stage theory, our current models will prove inadequate to capture the totality of experience of mothers of children with disabilities and retardation. For example, social ecological models identify as an area of theoretical importance the interaction of the family with the larger society in predicting maternal outcome. Yet few studies have examined the effect of perceived stigma and bias on maternal adjustment (Baxter, 1989). Similarly, we have little information on whether a family's ability to enter into the subculture of disability is relevant to maternal outcome.

In order to examine such issues, we must be receptive to new ideas and innovative research methodologies. For example, much of the research on families with disabilities has been self-reported and retrospective (although some longitudinal studies exist). Observational studies, and studies involving direct family interaction and problem-solving tasks, though time-consuming and difficult to implement (Hampson, Hulgus, Beavers, & Beavers, 1988) may yield more accurate information about adaptation. Anthropological studies (Gallimore, Weisner, Kaufman, & Bernheimer, 1989), which pay attention to qualitative data and actual daily routines of families, may also lend important insights. Refinements of both models and methods are critical to furthering our understanding of how mothers of children with mental retardation adapt successfully to parenting challenges and what kinds of support are needed to facilitate this task.

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