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# Stress and coping in mothers of children with developmental disabilities across the lifespan.

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STRESS AND COPING IN MOTHERS OF CHILDREN  
WITH DEVELOPMENTAL DISABILITIES ACROSS THE LIFESPAN

by  
Nicole Stacey Li

A Thesis

Submitted to the Faculty of Graduate Studies and Research  
through the Department of Psychology in Partial  
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1997



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## ABSTRACT

Maternal stress associated with providing care at home for a son/daughter with a developmental disability was investigated using a cross-sectional design. Respondents included 186 mothers whose offspring ranged in age from 5 to 53 years. New measures were created to assess the contribution of stressors, resources, and the perception of stressors to the prediction of stress. Resources and perception were evaluated to determine if they had a moderating effect on stress. A negative relationship was found between maternal stress and age of the son/daughter with the developmental disability and between maternal stress and age of the mother. The statistical significance of the stressors, resources, and perceptions in predicting stress varied across the son/daughter's age and the mother's age. When collapsing across age, stressors and perceptions were found to be the best predictors of maternal stress. Perception of the stressor was found to have a moderating effect on stress only if there was a high number of stressors present in the family environment. Implications of these findings and suggestions for future research are discussed.

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CHAPTER I

INTRODUCTION

The addition of a child to the family unit represents a period of major transition in which the family learns to adjust to its newest member (Harris, Boyle, Fong, Gill, & Stanger, 1987; Kazak & Marvin, 1984). This transition period is made more difficult if the child is diagnosed with a developmental disorder (Harris et al., 1987; Schilling & Schinke, 1984; Trute & Hauch, 1988).

Parents of children who are developmentally delayed<sup>1</sup> are reported to go through a period of sorrow in which they mourn the loss of "the idealized perfect child" who will fulfill all their dreams. This is followed by a period of family reorganization in which parents attempt to cope with their child and with the normative family stresses that are independent of the child (Damrosch & Perry, 1989; Harris et al., 1987; Seideman & Kleine, 1995). Then, as the child matures, the family is faced with long-term uncertainty regarding the child's present and future functioning (Kazak & Marvin, 1984), and with disappointment if the child fails to achieve motor, language, and/or cognitive milestones (Schilling & Schinke, 1984). Moreover, individuals with developmental disabilities tend to require more care and supervision than those without such disabilities (Beckman-Bell, 1981).

Thus, parents of children/adults with developmental disabilities are seen as being at higher risk for a multitude of family life problems, such as marital difficulties (Floyd & Zmich,

1991) and psychological problems such as emotional instability (Ali et al., 1994; Ryde-Brandt, 1990). However, some families still manage to function adaptively (Chetwynd, 1985; Seltzer & Krauss, 1989).

The purpose of the present study was to determine how mothers adapt to their children's developmental disabilities at different points throughout the lifespan. In addition, this study attempts to determine how psychosocial factors, such as the availability of resources and mothers' perceptions influence this adaptation.

This issue is particularly relevant since government policies and legislation over the last several decades have emphasized deinstitutionalization and continue to do so today. Consequently, the number of families in North America caring for offspring with developmental disabilities at home has increased (Cameron, Armstrong-Stassen, Orr, & Loukas, 1991). In fact, Stanfield (1973) found that three years after graduating from public school, 94% of moderately developmentally delayed adults were still living at home. Furthermore, current improvements in health care have increased the longevity of individuals with developmental disabilities (DiGiovanni, 1978; Seltzer & Krauss, 1989), thereby extending the period of parental responsibility (Goodman, 1978).

With these changes in the family environment has come the realization that the impact of a developmental disability is never restricted to the individual with the disability, and that members of the immediate and sometimes extended families are affected to differing degrees (Crnic, Friedrich, & Greenberg, 1983). In general, researchers (e.g., Ali et al., 1994; Chetwynd, 1985;



Kazak & Marvin, 1984) have found that families with members who have developmental delays are at greater risk of experiencing higher stress than are families without members who are developmentally delayed. However, it is still unclear whether the stress of caring for a child with a developmental delay will have long-term deleterious effects on the family. Thus, there is a substantial gap in our understanding of how caring for a child who is developmentally disabled impacts the family across the lifespan (Seltzer, Krauss, & Tsunematsu, 1993).

Moreover, findings regarding how stress changes with time vary widely from researcher to researcher. For instance, Gallagher et al. (1983) suggest that parental stress will increase as children get older. Gallagher and colleagues believe that while parents may in time adapt to some stressors, this mitigating effect is eventually overridden by the new challenges and problems that parents face as their children get older. Some of the new challenges faced by these families include uncertainty regarding their child's future, financial burdens, a reduction of available social services, and so on.

Others such as Byrne and Cunningham (1985) and Cherry (1989) believe that stress varies as a function of key developmental milestones in the child's life (e.g., age of normal walking, age of normal entry into school), which suggests a more variable or fluctuating pattern of stress. In fact, Wikler (1986b) found that mothers of children with developmental delays who ranged in age from 2 to 21 years of age had higher stress levels during transition periods in the child's life cycle (e.g., adolescence

and young adulthood) than mothers of children not going through transition periods. Similarly, in a study of children with developmental disabilities who ranged in age from 2 to 18 years, Orr, Cameron, Dobson, and Day (1993) demonstrated an inverted U-shaped relationship between age of the disabled child and maternal stress, such that the most stress was experienced during middle childhood years. Orr et al. (1993) hypothesized that one possible explanation for this inverted U-shape may be that over time mothers learn to adapt so that only major events, such as first entry into the school system, produce noticeable changes in stress levels.

Findings from other researchers tend to suggest that maternal stress decreases as the individual with the developmental disability ages. For instance, Whittick (1988) found that mothers of children with developmental delays ( $M_{age} = 9.1$ ,  $SD = 2.6$ ) report higher levels of stress than mothers of adults with developmental delays ( $M_{age} = 25$ ,  $SD = 7.1$ ). Similarly, Cameron, Orr, and Loukas (1991) found that when compared with normative data on mothers of children with mental delays, their group of mothers of adults with mental delays aged 21 to 53 years demonstrated lower levels of stress. Thus, it would seem that mothers of adults with developmental delays tend to report more moderate levels of stress. These findings support the findings of others, such as Seltzer and Krauss (1989) and Kaufman et al. (1990), that older mothers of adults with mental delays report rather moderate levels of stress in comparison to younger mothers.

Contrary to all of these findings, however, Dyson (1993) found that over a period of 4 years from early childhood to school years (i.e., 5-11 years), there was no significant change in overall parenting stress and family functioning. Parents of children who are developmentally delayed reported experiencing substantially greater amounts of stress than parents of children who are not developmentally delayed, regardless of the child's age. This lack of difference may be due to the limited age range employed in this study. Flynt and Wood (1989) also reported no significant differences in perceived maternal stress levels for school age children (ages 6-9), adolescents (ages 12-15), and young adults (ages 18-21) who were moderately disabled. Instead, these authors found comparably high stress levels across these three normative transition periods, which suggests chronic stress throughout the family life cycle. However, these researchers did not include children with mental delays who were currently not in a transition period (i.e., 10-11 years and 16-17 years). Thus, it is possible that mothers of children not going through transition periods would report lower levels of stress than mothers of children in transition periods, which in turn suggests a fluctuating pattern of stress.

In general, mothers of younger children with developmental disabilities reported that stress levels fluctuated. The only exceptions to this were Dyson (1993) who utilized a limited age range and Flynt and Wood (1989) who failed to include nontransition comparison groups. Moreover, mothers of children

with developmental delays generally reported higher stress than mothers of adults with developmental delays.

Not only is there a need for more data on how the stress of having a disabled child affects the family over an extended period of time, there is also a need for more precise measures of family stress. According to Glidden (1993), current measures of family stress, such as the Questionnaire on Resources and Stress, fail to delineate among stressors and stresses when considering family adjustment to a child/adult who is disabled. Instead, these scales lump these constructs together under the heading "stress."

For the purposes of the present study, a stressor is defined as any life event or situation that could potentially tax the resources and coping abilities of the family system, thereby producing a change in that system. Stressors can be either positive events such as getting married or graduating, or negative events such as having a child with a developmental delay or losing one's job (Cherry, 1989; Margalit, Shulman, & Stuchiner, 1989; McCubbin et al., 1980)<sup>2</sup>. Stress, on the other hand, refers to the pattern of physiological and psychological responses to the stressor, that is, to the residual tensions generated by the stressor when it remains unmanaged (Beckman-Bell, 1981; McCubbin et al., 1980). Some examples of stress responses include fatigue, decreased health, irritation, worry, and depression.

To illustrate, suppose we have a single working mother and a two-parent family where one parent stays at home. Both families have a child who is developmentally delayed and both children require a one hour daily physical therapy session (i.e., a

stressor). This situation may be perceived as being more stressful for the single working mother who has limited resources and major time constraints than for a two-parent family because, in the latter case, the stressor can be met by more individuals or spread out over a longer period of time. If, however, the stay-at-home parent resents this responsibility because it is preventing him/her from pursuing his/her goals, then this situation may also be stressful for that parent (Glidden, 1993).

Thus, a greater number of stressors is not necessarily indicative of higher stress. This idea is especially relevant given the moderating effect of resources (i.e., psychological, interpersonal, and/or social characteristics of a person(s) that help lessen the impact of a stressor) on stress, and the moderating effect of perception of the stressors (i.e., subjective appraisal of the stressors and efforts to manage or resolve) on stress (Hill, 1958; McCubbin & Patterson, 1983; Taylor & Aspinwall, 1996). Moreover, because the stressors facing these families are often greater than those of comparable families of children without disabilities, the use of scales that do not delineate between stressors and stresses may lead to the erroneous conclusion that these families are functioning more poorly than they actually are.

Resources and perceptions of the stressor have only recently begun to be explored as moderating variables<sup>3</sup> (Konstantareas & Homatidis, 1991). According to Wikler (1986a), most studies in this area have simply correlated the stressor of having a child with a mental delay with some definition of family stress. Others

have included either resources or perception in this correlation; but very few studies have included both moderator variables. Moreover, many of these studies fail to distinguish among the various types of resources or to determine which of the moderating variables has a greater impact on stress.

The first purpose of the present study was to cross-sectionally assess the impact of caring for a son/daughter who is developmentally delayed on maternal adaptation across the lifespan. In so doing, this study provided an opportunity for comparisons to be made between mothers who were at different stages of their life course but who share similar experiences. The study's second purpose was to delineate between stressors and stress so that a more precise and adequate measure of stress could be developed. Finally, the study was designed to determine whether resources or perception of stressors had a greater moderating effect on maternal stress.

Toward these ends, family stress theory will be described, particularly as it pertains to the ABCX and the Double ABCX model. Following this there will be examples of studies to substantiate the relevance of this model to the current area of study and an explanation of the rationale behind the hypotheses.

### Family Stress Theory

Family stress theorists have attempted to explain why some families appear to make positive adaptations to stressful events with relatively little difficulty, while other families seem to adjust maladaptively to similarly stressful events. Although there is a substantial body of theory and research to explain this

variability there is little consensus regarding how best to conceptualize family adaptation (Crnic & Acevedo, 1995).

In the present study, family adaptation is defined in terms of maternal stress. Maternal stress is defined as the state in which mothers are overextended by an event or situation such that their individual resources or the collective resources of their families are insufficient and they fail to function adaptively (Hobfoll & Spielberger, 1992). The level of stress mothers experience will depend on the nature of the stressor, the characteristics of their family units, and their psychological and physical health. In this way stress is seen as a continuous variable that can range from high stress to moderate stress to low stress.

#### The ABCX Model

Sociologist Reuben Hill was among one of the first family stress theorists to formulate a model explaining why some families respond more adaptively to stressful situations than others. Hill's classic ABCX model was originally developed to account for family stress resulting from war-induced separation and reunion (Hill, 1958). Since then his theoretical model has provided a foundation for understanding the functioning of families with children with developmental disabilities (Wikler, 1986a).

According to the ABCX model, the characteristics of the objective stressor event (A), the family's existing resources for dealing with the stressor (B), and the family's subjective perception of the stressor (C) all influence family adaptation by either preventing or precipitating a crisis (X) (Hobfoll &

Spielberger, 1992; McCubbin et al., 1980). Moreover, if a crisis occurs, this results in a demand for change in the family structure. On the other hand, if the family is able to make use of existing resources and to define the stressor such that family stability is maintained, then the stress may never reach crisis proportions (Cherry, 1989).

Consequently, the presence of a child who is developmentally challenged in the family unit does not invariably produce a crisis (Bristol, 1987; Hanson & Hanline, 1990). In fact, Koller, Richardson, and Katz (1992) found that more than a third of Scottish families with a child who is developmentally delayed functioned well, while less than a third of these families functioned poorly. Furthermore, Cameron and Orr (1989) reported that at least half of a sample of 84 parents of school age children with developmental delays had low to moderate levels of stress as measured by the Parenting Stress Index.

#### The Double ABCX Model

McCubbin and Patterson (1983) later advanced the Double ABCX model, an elaboration of Hill's original model, to explain family adaptation to the cumulative effects of a stressor subsequent to the influence of the original crisis. In their model "double" refers to the accumulation of additional stressors secondary to the original crisis stressor that may have an impact on family functioning, such as changes in the caregivers' functional ability (Smith, Tobin, & Fullmer, 1995). Since having a child who is mentally delayed is an ongoing stressor, this model is probably a



more accurate reflection of the family dynamics taking place in these families.

The Double ABCX model acknowledges that the impact of a stressor can accumulate over time as a result of other family stressors piling up (aA); that the family can strengthen existing resources or develop new ones in response to the stressors (bB); and that the family's perception of these stressors may change over time as a result of new learning and experience (cC). The interaction of aA, bB, and cC represents the family's level of adaptation to the stressor over time (Cherry, 1989) [see Figure 1].

Thus, an important feature of the Double ABCX model is the notion that stressors, family resources, and family perceptions all interact to directly and indirectly to influence family adaptation. Presumably, the availability of resources and the perception of the stressor can affect family adaptation both directly and indirectly, whereas the stressor affects adaptation indirectly through these two moderators (Smith et al., 1995).

aA: The pile-up of stressors. Lavee, McCubbin, and Patterson (1985) claim that stress is best conceptualized of as a process rather than a single short-term stimulus. Consequently, a single stressor, such as having a son/daughter who is developmentally delayed, can produce a sequence or pile-up of stressors. In addition, these families are often faced with a unique set of problems as they attempt to deal with having a child who is mentally disabled. Thus, stressors can be related directly to characteristics of the person with the disability, or they may

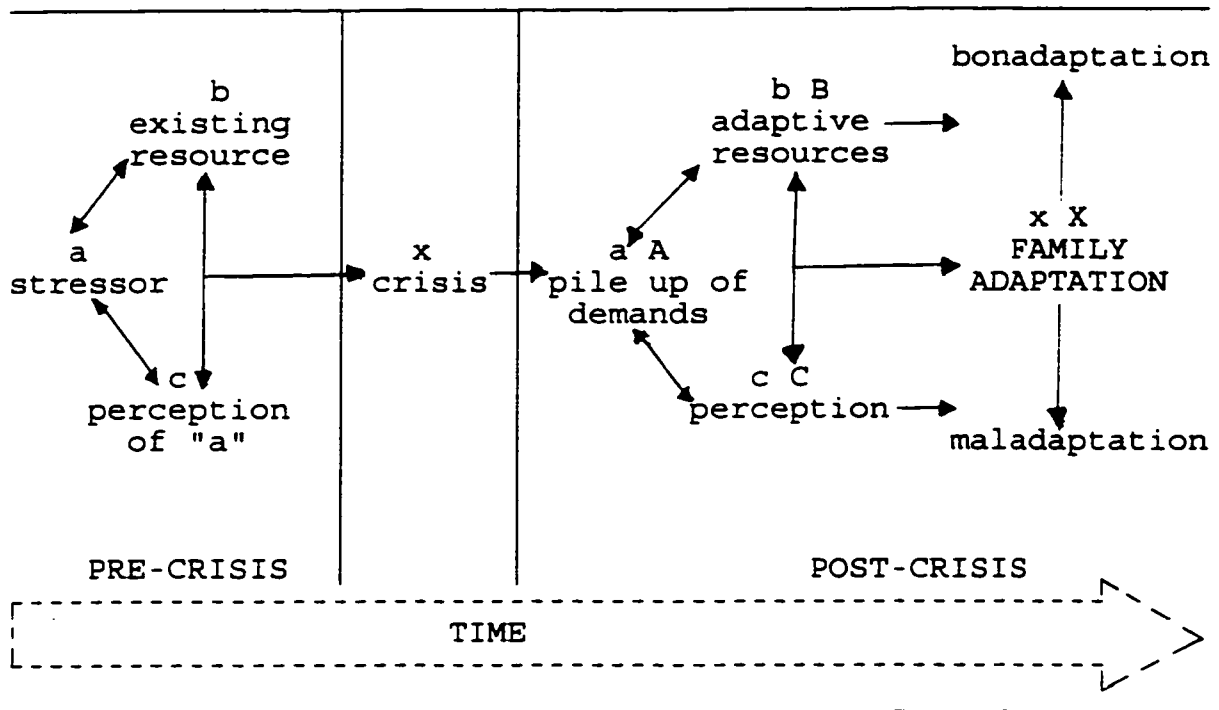


Figure 1. The double ABCX model (adapted from Lavee, McCubbin, & Patterson, 1985).

result from incidental events that have accrued because the family has not managed to regain "normal" functioning in the aftermath of the original stressor.

Lower levels of family adaptation (i.e., higher levels of stress) are correlated with characteristics directly related to the person with the disability, such as behavior problems (e.g., Cameron & Orr, 1989; Hanson & Hanline, 1990; Kaufman, Campbell, & Adams, 1990) and with pile-up stressors, such as extended and laborious care giving demands (e.g., Black, Cohn, Smull, & Crites, 1985; Jennings, 1987).

Behavioral problems such as self-stimulation, self-mutilation, bizarre use of the body, age-inappropriate behavior, and unusual rocking are rated as very stressful by parents (Konstantareas & Homatidis, 1991). Cameron and Orr (1989) found that when comparing high and low stress families, behavior problems accounted for 50% of the variance in parents' total stress scores on the Parenting Stress Index. Similarly, Baxter (1989) reported that both behavior management problems and noticeable speech deficits account for 57% of the variance in explaining parental stress, indicating a strong association between behavior problems and stress. Moreover, for mothers, behavior problems are predictive of an aversive parent-child relationship (Dumas, Wolf, Fisman, & Culligan, 1991; Floyd & Zmich, 1991).

Unusual and/or extensive care giving demands (e.g., feeding, personal hygiene, the provision of medical care) are another major source of stress. Beckman-Bell (1981) found that 66% of the

variance in the number of problems that parents of children with developmental delays report is accounted for by care giving demands. In accordance with this finding, Gallagher, Beckman, and Cross (1983) reported that additional care giving demands are associated with higher levels of parental stress.

Extensive care giving demands are especially problematic for parents of adults who are developmentally delayed since these parents face "perpetual parenthood." For these parents care giving demands extend beyond the time when such responsibilities are usually terminated or greatly reduced and well into old age. As these parents age, their continuing ability to provide for their children may be negatively affected by their own increasing health problems, their child's increasing health problems, and their growing concern regarding who will take care of their child when they are gone or can no longer do so (Jennings, 1987).

Thus, so far we have seen that a pile-up of stressors is positively correlated with stress. However, these stressors also interact in complex ways with family resources to influence family stress (Konstantareas, 1991). For instance, although it may not be possible to eliminate an individual's behavior problems or his/her need for extended care, resources such as day programs and in-home service providers may make it possible to reduce the impact of these stressors. Hence, resources can sometimes counteract the deleterious effects of stressors.

bB: Adaptive resources. A resource is defined as any psychological, social, interpersonal, or material characteristic of the individual, family, and/or community that may help lessen

the impact of a stressor and help the family adapt such that there is a reduced probability that the family will enter into crisis. This definition is consistent with those proposed by researchers such as Margalit, Shulman, and Stuchiner (1989) and Wikler (1986a). The term resource refers to both existing resources already available to the family that help minimize the impact of the initial stressor and prevent a crisis situation, and to new resources that have been developed or strengthened as a result of new or additional demands created by the crisis (Lavee et al., 1985).

In general, the availability of resources is inversely related to stress such that when there are sufficient and appropriate resources, the stressor is less likely to be perceived as being stressful (McCubbin et al., 1980). Moreover, according to Hobfoll and Spielberger (1992) there is a reciprocal relationship between resources and the stressor, such that resources do not simply buffer against stressors but also are themselves transformed by said stressors.

For the purpose of the current study, resources are conceptualized as primarily intrafamilial or extrafamilial resources. Intrafamilial resources are those resources that are characteristic of individual family members or of the immediate family as a whole. Intrafamilial resources can be further conceptualized as reflecting mainly intrafamilial interpersonal resources or intrafamilial financial resources. Intrafamilial interpersonal resources include characteristics of the interaction among immediate family members that help lessen the impact of the

stressor, such as family cohesion, flexibility, organization, and communication (Lavee et al., 1985; McCubbin et al., 1990; Taylor & Aspinwall, 1996). Intrafamilial financial resources include aspects of the nuclear family's financial status, such as available income and property owned. Extrafamilial resources are those resources outside the immediate family that have a moderating effect on family functioning, for instance, social support networks (Taylor & Aspinwall, 1996). Social support networks are networks within which information and services are exchanged among people so as to provide the emotional and psychological support, goods and services needed for daily functioning or in times of crisis (Dunst, Trivette, & Cross, 1986; Schilling & Schinke, 1984; Seltzer, 1985). Support networks are classified as either informal or formal sources of support. The former are defined as those supports that do not involve the exchange of money or any formal organization, such as members of the nuclear and extended family, friends, and neighbors. The latter includes paid support persons or services, such as baby-sitters, respite care programs, health care workers, and professional and community agencies in general (Bristol, 1987; Konstantareas & Homatidis, 1991).

The distinction between these two types of resources is not absolute. For example, although the intrafamilial resource, money, is an aspect of the family environment, it may have originated from outside support networks such as funding agencies or welfare (Taylor & Aspinwall, 1996). Thus, these categories are not mutually exclusive.

Generally, the effects of a stressor on family functioning have been found to be moderated by these two types of resources (Byrne & Cunningham, 1985; Taylor & Aspinwall, 1996). In fact, Petersen (1984) found that family organization, emotional and physical support, financial stability, and community support services were among some of the resources that acted as powerful moderator variables in buffering mothers from stress related problems.

With respect to intrafamilial interpersonal resources, Lavee et al. (1985) reported that family cohesion, flexibility, and communication among family members are related to family adaptation in families with offspring who are developmentally delayed. This finding suggests that family unity plays an important role in a family's ability to recover from a crisis situation.

In addition, the nature of the marital relationship seems to be a key determinant of successful adaptation. Consistent with this hypothesis, McKinney and Peterson (1987) found, in a study of mothers of children with mental delays, that spousal support was associated with lower stress scores. Floyd and Zmich (1991) found that negative marital interactions were associated with the occurrence of more aversive parent-child interactions. Moreover, marital conflict is a major reason for parents requesting out-of-home placement for their child who is developmentally challenged (Sherman & Coccozza, 1984, as cited in McCallion & Toseland, 1993).

Intrafamilial financial resources have also been found to contribute to family adaptation. For example, Salisbury (1989)

found that family income was correlated with personal and family well-being. Furthermore, research has repeatedly supported the finding that money difficulties can have a negative influence on family functioning (Ali et al., 1994; Harris & McHale, 1989). This is especially relevant given that parents of children with delays often experience greater financial problems because of the extra expenditures incurred for care of the child with the delay, and because of disruption of parental wage earning activity due to frequent absences from work (Singhi et al., 1990). For these families the burden of financial responsibility continues well into retirement since the majority of individuals with mental delays are unemployed, and of those who are employed many receive low pay and limited benefits (Frank, Sitlington, & Carson, 1992; Schalock, Holl, Elliott, & Ross, 1992)

Research on the moderating influence of extrafamilial resources has emphasized the role of social support in contributing to a family's invulnerability (Dunst et al., 1986). Research has additionally emphasized the importance of social support in promoting recovery from crisis situations, thereby influencing the family's regenerative power (McCubbin et al., 1980). The dimensions of social support include instrumental help, the provision of information, feedback, guidance, emotional empathy and understanding, and adult contact (Byrne & Cunningham, 1985; Schilling & Schinke, 1984).

Many investigators have found informal and/or formal support networks influence family adaptation (e.g., Friedrich, Cohen, & Wiltturner, 1987). Dunst and colleagues (1986) report that more



supportive social networks are associated with better personal well-being and more positive attitudes. Moreover, families with strong informal support networks cope more effectively with stress than those who do not have these resources (Wikler, 1986a).

According to Heller and Factor (1993), as the number of formal support services needed by families of adults with mental delays increases, the burden of caregiving and a preference for out-of-home placement is also increased. Furthermore, Vincent (1983) found that more formal resources, such as professional help, were usually requested only after all other attempts to gain informal support were unsuccessful (as cited in Wikler, 1986a).

Moreover, social isolation often characterizes a family with a child who is developmentally delayed (Wikler, 1986a). According to Jennings (1987) this impoverished social life begins at the point of diagnosis and continues as the child ages. Social and friendship networks of these families are smaller and more dense (Cherry, 1989). These families have a diminished circle of acquaintances and contacts, belong to fewer organizations, and share fewer leisure-time activities (Wikler, 1986a). Furthermore, according to Kazak and Marvin (1984), since these families generally ask more than they can give in return, the extended family is perceived to be more accepting of this inequality than friends. Also, the development and maintenance of friendships is often based on common interests and activities. The specialization required of these families often reduces the chances of developing the outside interests through which friendships are often developed. Moreover, Suelzle and Keenan

(1981) claim that social isolation may be cumulative because older parents report more isolation than younger parents.

Although the availability of resources clearly influences family stress, it is not the only moderating factor. Parental perceptions regarding having a child who is developmentally disabled have also been found to play a role in moderating stress.

cC: Perception of the stressors. Perception of the stressors refers to a family's subjective definition of stressors and their cognitive appraisal of the seriousness of these stressors. A family's perception is influenced by their expectations and values, their perception of change, and their past experiences with stressors (Cherry, 1989).

Parental expectations regarding their offspring may indirectly influence stress by directly affecting perceptions. For instance, if one's expectations are high, then the birth of a less than perfect child will be seen as more catastrophic than if one's expectations are lower (Konstantareas & Homatidis, 1991). In addition, the mother's ability to function effectively as a caretaker has been shown to be adversely affected by the inability of some children with developmental delays to be as affectionate and demonstrative as hoped (Beckman, 1983). Disappointments are especially prevalent during key developmental milestones, when parents' expectations for their child go unmet. For example, Wikler (1986b) found that families whose offspring with developmental disabilities were entering adolescence and young adulthood had increased levels of stress as compared to families whose offspring were not going through transition periods.

Moreover, the family's perception of the stressor will most likely affect the coping strategies (i.e., the behaviors and cognitions employed in an effort to manage or resolve potentially stressful situations) employed, and this can ultimately affect how the family adapts to the stressor. For example, Seltzer et al. (1995) found that mothers of adults with mental delays who believe that they have influence and authority over the daily life of their adult child are more likely to use positive and proactive coping strategies for managing stressful events. In addition, Bristol (1987) found that mothers of children with autism or communication disorders who assigned unwarranted blame to themselves for their child's condition and who perceived their child's condition as a family catastrophe adapted more poorly than mothers who did not blame themselves or define the situation quite so negatively.

Coping behaviors may take the form of seeking out or making use of already available individuals, groups, or institutions that provide assistance. Cognitive sets (i.e., how one appraises a situation) and self-talk (i.e., self-directed thoughts used to reduce stress) are examples of how one can use cognitions to cope with a potentially stressful event (Schilling & Schinke, 1984). Similarly, changing one's perception is another coping strategy that may prove useful in mitigating a stressor. For instance, researchers (e.g., Cameron et al., 1991; Cherry, 1989) have found that families can function successfully if they learn how to reappraise the crisis situation and their world view by clarifying

issues, by reducing the intensity of the emotional burden, and by encouraging each other to move on.

The use of effective coping strategies is one well established way of resolving or mitigating the potentially maladaptive effects of a stressor (e.g., Cameron et al., 1991; Cullen, MacLeod, Williams, & Williams, 1991; Seltzer, Greenberg, & Krauss, 1995).

For the purpose of the present study, perception of stressors refers to both the mother's subjective appraisal of stressors present in the family environment and her appraisal of how her family attempts to manage or resolve the potentially negative effects of these stressors. Consequently, in the remainder of the present paper, the term perception is used to refer to both perception of the stressor and coping.

xX: Family adaptation. Family adaptation is the outcome of the interactions of aA, bB, and cC in which the family has managed through coping strategies to maintain a balance in family functioning (Cherry, 1989). It is important to note that current adaptation does not mean that disorganization or change did not occur in the family unit prior to this. On the contrary, adaptation merely suggests that the family system has reached a routine level of functioning after having to cope with change (Lavee et al., 1985).

According to Lavee and colleagues (1985) adaptation is a continuous dynamic process that ranges from maladaptation to bonadaptation [see Figure 1]. Maladaptation is the ongoing imbalance between the pile-up of demands and the family's ability

to cope with those demands. Maladaptation is characterized by a loss in family cohesiveness, a decreased sense of well-being, and/or a deterioration in physical and psychological health. In contrast, bonadaptation is an ongoing balance in family functioning resulting from a minimal discrepancy between the pile-up of demands and the family's capabilities. Bonadaptation is characterized by a strengthening in family cohesiveness and by an increased sense of well-being.

As mentioned previously, for the purpose of this study adaptation is conceptualized in terms of maternal stress. Stress refers to an individual's response to stressors which in many cases involves indices of one's emotional and physical state. As a result, the measurement of stress is subjective, and it lends itself well to being studied using individual self-report questionnaires.

#### Summary, Conclusions, and Hypotheses

To summarize, research in this area has generally found that mothers of children with developmental disabilities are at risk for experiencing high levels of stress; this stress may be moderated by resources and by the mother's perception of the stressor. However, it is still unclear how this stress changes across the lifespan of the individual with the disability, whether or not this stress is simply an artifact of the types of scales used to measure family stress, and which moderator variable has a greater impact on family stress.

In order to address these issues, data obtained in a 1991 study by Orr et al. and a 1991 study by Cameron et al. were

combined. Consequently, it was possible to assess the maternal stress associated with having a developmentally challenged son/daughter ranging from elementary school age to middle adulthood. The measures used in these studies were reformulated so that the items reflected separate measures of stressors, intrafamilial and extrafamilial resources, family perception, and parental stress. Individual responses were then reanalyzed to examine the following hypotheses:

1. Based on the aforementioned findings of lower stress in mothers of older individuals with developmental disabilities (e.g., Cameron et al., 1991; Whittick, 1988) and lower stress in older mothers (e.g., Kaufman et al., 1990; Seltzer & Krauss, 1989), the level of maternal stress was expected to decrease as a function of both the increasing age of the individual with the disability and the increasing age of the mother. Moreover, based on the findings of Wikler (1986b) and Orr et al. (1993), greater fluctuations in maternal stress were expected during major developmental milestones, especially for younger offspring.
2. According to McCubbin and Patterson's (1983) Double ABCX model, stressors, resources, and perceptions were all expected to make a significant contribution to the prediction of maternal stress across the lifespan. Furthermore, the relative importance of these variables was expected to vary across the lifespan. However, because little is known about the changing needs of these families over time, exactly how

the significance of these variables will vary over time remains unclear.

3. The overall relationship among the factors (aA, bB, cC, and xX) was not expected to differ from McCubbin and Patterson's model even after confounds within the measure have been controlled. Consequently, stressors were expected to have a direct effect on stress, and both resources and perceptions of the stressors were expected to have a moderating effect on stress.

## CHAPTER II

## METHOD

Participants

The participants consisted of 185 mothers ranging in age from 24 to 91 years ( $M = 50.51$ ,  $SD = 13.52$ ) who were caring for their developmentally disabled son/daughter at home. Seventy-seven of these participants were originally part of a study by Orr et al. (1991) on stress and coping in mothers of developmentally delayed children aged 5 to 20 years; the remaining participants were part of a similar study by Cameron et al. (1991) on stress and coping in mothers of developmentally delayed adults aged 21 to 53 years. Mothers were recruited through the Public and Separate Boards of Education and through Associations for the Mentally Retarded in Windsor and Essex County.

Table 1 illustrates the demographic characteristics of the two samples. This table includes information regarding marital status, level of education, employment status, number of persons in the home, and socioeconomic status as calculated by Hollinghead's Four Factor Index of Social Status (1975).

The offspring, 54.3% of whom were male, ranged in age from 5 to 53 years ( $N = 186$ ,  $M = 22.95$ ,  $SD = 10.94$ ). School-aged children/adolescents were all classified as trainable mentally retarded (i.e. their IQ scores fell in the 30 to 70 range). These children were being educated in a variety of educational settings ranging from full segregation (schools in which all the students are trainable mentally retarded) to full integration (schools in which students with and students without a mental disability share



Table 1

Demographic characteristics of the mothers in the two samples

Characteristic	Orr et al. (n=77)	Cameron et al. (n=109)
Marital status		
Married	86%	71%
Single/widowed/divorced	14%	29%
Education		
Lower than grade 12	40%	54%
Grade 12 and higher	60%	46%
Employment status		
Unemployed	57%	65%
Employed	43%	35%
Socioeconomic status		
Major business, professional	18%	6%
Medium business, minor professional	17%	20%
Skilled craft, clerical, sales	21%	23%
Semi-skilled, machine operator	26%	28%
Unskilled	18%	23%
Number of persons in the home		
Two	4%	17%
Three	19%	49%
Four	39%	17%
Five or more	38%	17%

the same class). Adult sons/daughters were classified as having moderate to severe developmental disabilities. Approximately 90% of these adults were employed at sheltered workshops or elsewhere, and approximately 10% stayed at home or attended school.

#### Original Measures

The measures in this study were administered as part of a larger battery of tests focused on family stress and coping associated with caring for a son/daughter who is developmentally delayed. The measures used included a demographic questionnaire, the Social Support Inventory (Cooke, Rossmann, McCubbin, & Patterson, 1987), the Family Inventory of Resources and Management (McCubbin & Comeau, 1987), the Family Crisis Oriented Personal Evaluation Scales (McCubbin, Olson, & Larsen, 1987), the Parenting Stress Index (Abidin, 1986), and the Short-Form Questionnaire on Resources and Stress (Holroyd, 1987).

Demographic questionnaire. The demographic questionnaires (DEMO) were used in both these studies to obtain general information regarding the respondent's family. Of interest to the present researcher were those questions regarding stressors present in the family, child characteristics and behavior problems, and available resources. The two studies used slightly different versions of the DEMO, however, only those items that were common to both versions were included.

Social Support Inventory. The Social Support Inventory (SSI) is a measure of the social support individuals perceive themselves as receiving. The inventory consists of 60 items to which the participant can respond "no," "yes," or "yes a lot." The items

measure five kinds of social support (e.g., "I have a feeling of being loved or cared about"). Under each of the five statements of kinds of support there are 11 identified potential sources of social support, including "other" (e.g., spouse, children, relatives, close friends, and professional or service providers). This scale has an internal reliability ranging between .79 and .81 depending on the sample used.

Family Inventory of Resources and Management. The Family Inventory of Resources and Management (FIRM) is a 98 item self-report questionnaire measuring the social-psychological resources available to the family. Items are measured on a four point Likert scale ranging from zero (not at all) to three (very well). The FIRM was originally developed to encompass personal resources, family system internal resources, and social support. Factor analytic procedures resulted in four scales representing perceived family resources: Family strengths I - Esteem and communication, Family Strengths II - Mastery and Health, Extended Family Social Support, and Financial Well-Being (McCubbin & Comeau, 1987). The internal reliability for the entire scale is .89.

Family Crisis Oriented Personal Evaluation Scales. The Family Crisis Oriented Personal Evaluation Scales (F-COPES) is a 49 item self-report measure identifying the problem-solving and behavioral strategies that families use in problematic situations. Items are measured on a five point Likert scale ranging from one (strongly disagree) to five (strongly agree). The F-COPES was designed to measure the integration of family resources and family perception into coping strategies. This instrument focuses on two

levels of coping: internal family coping patterns and external family coping patterns. Internal family coping patterns consist of three subscales: confidence in problem solving, reframing family problems, and family passivity. Five subscales comprise the external family coping patterns: church/religious resources, extended family, friends, neighbors, and community resources (McCubbin et al., 1987). The overall internal reliability is .77.

In order to assess maternal stress, one of two measures was used depending on the age of the son/daughter who manifests the developmental delay. In the Orr et al. study, the Parenting Stress Index (PSI) was used as it is suitable for assessing the stress experienced by mothers of developmentally delayed sons/daughters younger than 21 years of age. In the Cameron et al. study, the Short-Form Questionnaire on Resources and Stress (QRS-SF) was used as it is suitable for assessing the stress experienced by mothers of developmentally delayed sons/daughters older than 21 years of age.

Parenting Stress Index. The PSI is a 121 item self-report questionnaire that measures the level of stress in the parent-child relationship. Items are measured on a five point Likert scale ranging from one (strongly disagree) to five (strongly agree). The questionnaire is divided into two domains of stressors - child characteristics and parent characteristics. The child domain has subscales on: adaptability, acceptability, demandingness, mood, distractibility/hyperactivity, and reinforces parent. The parent domain includes the following subscales: depression, attachment, restriction of role, sense of competence,

social isolation, relationship with spouse, and parent health. The sum of these two domains yields a total stress score which represents maternal adaptation.

Short-Form Questionnaire on Resources and Stress. The QRS-SF is a 66 item self-administered "true" or "false" questionnaire designed to assess the degree of stress and coping associated with caring for a physically or mentally challenged member of the family. The items are comprised of 11 subscales which cover three domains, namely, patient problems, respondent attitudes, and family problems. The patient problem domain is composed of three subscales: dependency and management, cognitive impairment, and physical limitations. The respondent attitudes domain is composed of five subscales: life span care, lack of personal reward, terminal illness, preference for institutional care, and personal burden for respondent. The family problem domain is composed of three subscales: limits on family opportunities, family disharmony, and financial stress. Overall internal reliability for the test is .85. Scores on each domain are summed to yield a total stress score which represents maternal adaptation.

#### Reformulated Measures

The first stage of analysis involved generating more suitable measures of stressors, resources, family perception, and stress using items on the various scales employed in the original studies (i.e., DEMO, SSI, PSI, QRS-SF, FIRM, and F-COPES). Items were only included if they met the following criteria: (a) the item applied to all age groups, (b) the item fit primarily into one of the above categories, and (c) items were not redundant. It should

be noted that items taken from the PSI were matched with items of similar content for the QRS-SF, and vice versa. Given the aforementioned criteria, the following four scales were created.

Reformulated Stressor Scale. A 36 item Reformulated Stressor Scale was developed to measure any life events or situations that could be potentially stressful to the mother and her family. There were two versions of this scale: one that applied to children with developmental delays who ranged in age from 5 to 20 years (STRESSOR-R-C), and one that applied to adults with developmental delays who ranged in age from 21 to 53 years (STRESSOR-R-A). The STRESSOR-R-C scale included 19 DEMO items<sup>4</sup>, two FIRM items, and 15 PSI items, and the STRESSOR-R-A scale included the same 19 DEMO items, the same two FIRM items, and 15 QRS-SF items. For the purpose of analyzing the data, these two versions of the stressor scale were treated as though they were equivalent (see Appendix A).

Reformulated Total Resource Scale. A 77 item Reformulated Total Resource Scale (TRESOURCE-R) was developed to measure the psychological, interpersonal, and/or social characteristics of the mother, her family, and/or her community that help lessen the impact of a stressor on the family. This scale applied to all ages and was subdivided into three subscales: a 23 item Intrafamilial Interpersonal Subscale (IIS) with four items from the SSI and 19 items from the FIRM, measuring characteristics of the immediate family such as family cohesion, flexibility, organization, and communication; a 21 item Intrafamilial Financial Subscale (IFS) all from the FIRM, measuring aspects of the

immediate family's financial status, such as available income and property owned; and a 33 item Extrafamilial Social Support Subscale (ESSS) with eight DEMO item, seven FIRM items, and 18 F-COPES items, measuring social support networks outside the immediate family (see Appendix A).

Reformulated Perception Scale. A 24 item Reformulated Perception Scale (PERCEPTION-R) was developed for all ages. This scale consisted of 13 FIRM items and 11 F-COPES items measuring the family's perceptual orientation toward stressors and their means of managing or resolving a potentially stressful situation as reported by the mother (see Appendix A).

Reformulated Stress Scale. An 11 item Reformulated Stress Scale was developed to measure the mother's psychological and/or physical responses to stressors. There were two versions of this scale: one that applied to children with development delays who ranged in age from 5 to 20 years (STRESS-R-C), and one that applied to adults with developmental delay who ranged in age from 21 to 53 years (STRESS-R-A). The STRESS-R-C scale included five FIRM items and six PSI items, and the STRESS-R-A scale included the same five FIRM items and six QRS-SF items. For the purpose of analyzing the data, these two versions of the stress scale were treated as though they were equivalent (see Appendix A).

### Reliability

In order to determine the content reliability (Miller, 1987) of these scales two independent raters were utilized (both female). The first rater categorized a randomized version of the items based on the definitions of a stressor, resource, family

perception, and stress outlined in the Appendix. The categorization scheme of the first rater was then compared to that of the investigator and all discrepancies were resolved. Those items for which a consensus could not be reached were excluded from further analysis, and category definitions were made clearer.

Another rater (blind to the categorization scheme agreed upon by the investigator and first rater) then categorized an updated randomized version of the items. Inter-rater reliability between the author and the second rater was calculated. Cohen's kappa of agreement (Cohen, 1960), which reflects the percentage of agreement after correcting for chance agreement, was found to be 0.79. Although there are no significance tests for kappa, values of 0.40 to 0.60 represent fair reliability, values of 0.60 to 0.75 represent good reliability, and values over 0.75 reflect excellent reliability (Fleiss, 1981).

### Scoring

Once a reliable set of measures was established, all the items from the various scales used in the original study were converted to a nominal three point scale ranging from zero to two. A response coded "zero" indicated that the item was not applicable to the mother or her family. A response coded "one" indicated that the mother disagreed with a negative statement or agreed with a positive statement. A response coded "two" indicated that the mother agreed with a negative statement or disagreed with a positive statement. In other words, a score of zero represented a neutral event, a score of one represented a positive event, and a score of two represented a negative event. Thus, higher scores



represented negative outcomes, and lower scores represented positive outcomes.

Specifically, for the DEMO, an item was recoded zero if the condition/event was not applicable to the mother, recoded one if a positive condition/event was applicable to the mother, and recoded two if a negative condition/event was applicable to the mother.

For the SSI, an item was recoded zero if it did not apply to the mother, recoded one if the mother gave a "yes" or "yes a lot" response on the original scale, and recoded two if the mother responded "no" on the original scale.

For the FIRM, an item stated in the negative was recoded one if the original response was a "zero" or a "one", and recoded two if the original response was a "two" or a "three." This coding scheme was reversed for items stated in the positive. Hence, an item stated in the positive was recoded one if the original response was a "two" or a "three", and recoded two if the original response was a "zero" or a "one." an item was only recoded zero if the mother did not originally respond to that item.

For the F-COPES, an item stated in the negative was recoded zero if the original response was a "three", recoded one if the original response was a "one" or a "two", and recoded two if the original response was a "four" or a "five." As with the FIRM, this coding scheme was reversed for items stated in the positive.

For the PSI, an item stated in the negative was recoded zero if the original response was a "three", recoded one if the original response was a "four" or a "five", and recoded two if the

original response was a "one" or a "two." This coding scheme was reversed for items stated in the positive.

Lastly, for the QRS-SF, an item was recoded one if the original response was "false," and recoded two if the original response was "true." This coding scheme was reversed for items stated in the positive.

### Data Analysis

Subsequent to this initial coding, a single score for each of the four scales was generated by taking the ratio of twos to the total number of applicable items. Using ratio scores made it possible to convert the three point scale to a continuous scale ranging between zero and one. Using ratio scores also helped control for differences in the number of applicable items per measure among the participants.

The participants were then grouped according to the age of their son/daughter. The following six age groups were developed on the basis of normative developmental milestones across the lifespan, and on the number of participants in each group: 5-9 (n = 21), 10-13 (n = 28), 14-19 (n = 28), 20-29 (n = 59), 30-39 (n = 35), and 40-53 (n = 15) years of age. Comparisons were then made within and among the six groups.

Mothers were also grouped according to their own ages. Based on a cutoff age of 50 years, a group of younger mothers aged 24 to 50 years (n = 94), and a group of older mothers aged 51 to 91 years (n = 91)<sup>5</sup> were created. Comparisons were then made within and among the two groups.

## CHAPTER III

### RESULTS

Before combining the 1991 Orr et al. sample and the 1991 Cameron et al. sample, t-tests for independent samples were carried out to determine whether the two samples differed significantly on any of the demographic variables (see Table 2). Mothers differed significantly on marital status and number of persons in the home, in that mothers of younger offspring were more likely to be married and to have more persons living at home, than mothers of older offspring. On the other hand, mothers in the two samples did not differ significantly from each other with respect to the proportion of male and female offspring, marital status, level of education, employment status, and socioeconomic status. Thus, the demographic characteristics of the two samples were relatively comparable.

#### Descriptive Statistics for the Pooled Data

The means, standard deviations, and ranges for the measures were calculated for the pooled data and are presented in Table 3. All of the mean ratio scores were less than 0.5, indicating that the number of negative events was less than the number of positive events for all the measures. In other words, on average mothers reported fewer negative outcomes than positive outcomes for all the measures. Of all the measures, mothers reported the most negative outcomes on the stressor scale, and the least number of negative outcomes on the interpersonal resource subscale.

The zero-order correlation matrix for these measures is

Table 2

Means, standard deviations, and t-tests comparing the demographic variables for the two samples

Sample	<u>M</u>	<u>SD</u>	<u>t</u>	<u>p</u>
Sex of son/daughter				
Orr et al.	1.49	0.50	-1.14	.257
Cameron et al.	1.58	0.50		
Marital status				
Orr et al.	2.14	0.45	-3.13	.002
Cameron et al.	2.48	0.86		
Mother's education				
Orr et al.	1.60	0.49	1.56	.121
Cameron et al.	1.48	0.50		
Employment status				
Orr et al.	1.43	0.50	1.10	.271
Cameron et al.	1.35	0.48		
Socioeconomic status				
Orr et al.	3.09	1.38	-1.59	.113
Cameron et al.	3.40	1.23		
Number of persons in home				
Orr et al.	4.23	1.06	4.13	.000
Cameron et al.	3.50	1.29		

Table 3

Means and standard deviations of the ABCX measures for the combined sample

Measure	Range	<u>M</u>	<u>SD</u>
STRESSOR-R-C/A	0.00 - 1.00	0.48	0.22
TRESOURCE-R	0.00 - 0.69	0.29	0.17
IIS	0.00 - 0.84	0.20	0.19
IFS	0.00 - 0.86	0.33	0.21
ESSS	0.00 - 0.91	0.36	0.21
PERCEPTION-R	0.00 - 0.91	0.25	0.17
STRESS-R-C/A	0.00 - 1.00	0.32	0.23

Note. STRESSOR-R-C/A = Reformulated Stressor Scale for children/adults, TRESOURCE-R = Reformulated Total Resource Scale, IIS = Intrafamilial Interpersonal Subscale, IFS = Intrafamilial Financial Subscale, ESSS = Extrafamilial Social Support Subscale, PERCEPTION-R = Reformulated Perception Scale, and STRESS-R-C/A = Reformulated Stress Scale for children/adults.

illustrated in Table 4. All of the measures correlated with each other at the .005 level of significance or better. The interpersonal, financial, and social support subscales were all highly correlated (i.e., they had correlations of .72 or higher) with the reformulated total resource measure. This is not surprising given that the reformulated total resource measure is comprised of these three subscales. The next strongest correlations occurred between the stressor measure and the stress measure and between the perception measure and the stress measure, and the weakest correlations occurred between the resource measure(s) and the stress measure.

#### Demographic Variables and Maternal Stress

Separate t-tests and one-way analyses of variance (ANOVAs) were conducted in order to evaluate the relationship between maternal stress (i.e., the dependent variable) and the following demographic variables: age of son/daughter (5-9/10-13/14-19/20-29/30-39/40-53 years), sex of son/daughter, age of mother (24-50/51-91 years), marital status (single/married/divorced/widowed), level of education (lower than grade 12/grade 12 and higher), employment status (unemployed/employed), socioeconomic status (major business, professional/medium business, minor professional/skilled craft, clerical, sales/semi-skilled, machine operator/unskilled), and number of persons in the home (two/three/four/five or more persons). As shown in Table 5, maternal stress differed significantly only as a function of the age of the individual with the developmental disability and the age of the mother.

Table 4

Zero-order correlations between the ABCX measures for the combined sample

Measure	1	2	3	4	5	6	7
1. STRESSOR-R-C/A	--	.32**	.22*	.30**	.24**	.33**	.66**
2. TRESOURCE-R		--	.78**	.72**	.77**	.64**	.39**
3. IIS			--	.43**	.47**	.65**	.37**
4. IFS				--	.32**	.39**	.35**
5. ESSS					--	.44**	.21*
6. PERCEPTION-R						--	.52**
7. STRESS-R-C/A							--

\*  $p < .005$ , \*\*  $p < .001$

Note. STRESSOR-R-C/A = Reformulated Stressor Scale for children/adults, TRESOURCE-R = Reformulated Total Resource Scale, IIS = Intrafamilial Interpersonal Subscale, IFS = Intrafamilial Financial Subscale, ESSS = Extrafamilial Social Support Subscale, PERCEPTION-R = Reformulated Perception Scale, and STRESS-R-C/A = Reformulated Stress Scale for children/adults.

Table 5

Means, standard deviations, t-tests, and analyses of variance on maternal stress as a function of the demographic variables

Characteristic	Range	<u>M</u>	<u>SD</u>	<u>F</u>	<u>p</u>
Age of son/daughter					
5-9 years	0.00-0.91	0.46	0.29	3.01	.012
10-13 years	0.00-0.91	0.38	0.22		
14-19 years	0.00-1.00	0.31	0.24		
20-29 years	0.00-0.70	0.28	0.21		
30-39 years	0.00-0.64	0.26	0.19		
40-53 years	0.00-0.64	0.30	0.18		
Sex of son/daughter					
Male	0.00-0.91	0.33	0.21	0.20	.656
Female	0.00-1.00	0.31	0.24		
Age of mother					
24-50 years	0.00-1.00	0.37	0.24	11.661	.001
51-91 years	0.00-0.73	0.26	0.20		
Marital status					
Single	0.00-0.55	0.27	0.39	2.43	.067
Married	0.00-1.00	0.33	0.23		
Divorced	0.00-0.82	0.39	0.27		
Widowed	0.00-0.64	0.22	0.19		



Mother's education					
Less than grade 12	0.00-0.91	0.32	0.21	0.16	.688
Grade 12 and higher	0.00-1.00	0.33	0.24		
<hr/>					
Employment Status					
Unemployed	0.00-0.91	0.31	0.23	0.61	.435
Employed	0.00-1.00	0.34	0.22		
<hr/>					
Socioeconomic status					
Major business prof	0.00-1.00	0.34	0.23	0.43	.788
Medium business prof	0.00-0.91	0.35	0.25		
Skilled	0.00-0.90	0.33	0.22		
Semi-skilled	0.00-0.90	0.29	0.19		
Unskilled	0.00-0.60	0.33	0.24		
<hr/>					
Number of persons in the home					
Two	0.00-0.70	0.29	0.22	1.15	.335
Three	0.00-0.82	0.28	0.21		
Four	0.00-0.91	0.35	0.22		
Five or more	0.00-1.00	0.35	0.25		
<hr/>					

Age of son/daughter. Figure 2 illustrates the mean stress reported by mothers as a function of their son/daughter's age. Inspection of this figure revealed fluctuating stress levels, especially for mothers of individuals age 30 and older. Moreover, mean stress levels were higher for school age children and mature adults than for young adults. Figure 3 shows the mean stress reported by mothers as a function of their son/daughter's age for the six groups. Overall, a negative relationship was found between mothers' mean stress level and their offspring's age, such that maternal stress decreased systematically as a function of the mentally disabled individual's increasing age, for those individuals aged 5 to 39 years. For those individuals aged 40 to 53 years, there was a slight nonsignificant increase in mean stress levels.

Maternal stress differed significantly across the six age groups, with the highest mean stress score reported for the 5 to 9 year olds and the lowest mean stress score reported for the 30 to 39 year olds. A Student-Newman-Keuls test was done to determine which groups differed significantly from the other groups on mean stress. It was found that mothers of 5 to 9 year olds ( $\bar{M} = 0.46$ ) differed significantly from mothers of 20 to 29 year olds ( $\bar{M} = 0.28$ ) and from mothers of 30 to 39 year olds ( $\bar{M} = 0.26$ ).

Age of mother. Similarly, Figure 4 illustrates the mean stress levels reported by mothers as a function of maternal age. Inspection of this figure revealed fluctuations in stress levels across all ages. Furthermore, there was an overall decrease in mean stress levels for mothers over 50 years of age. Figure 5

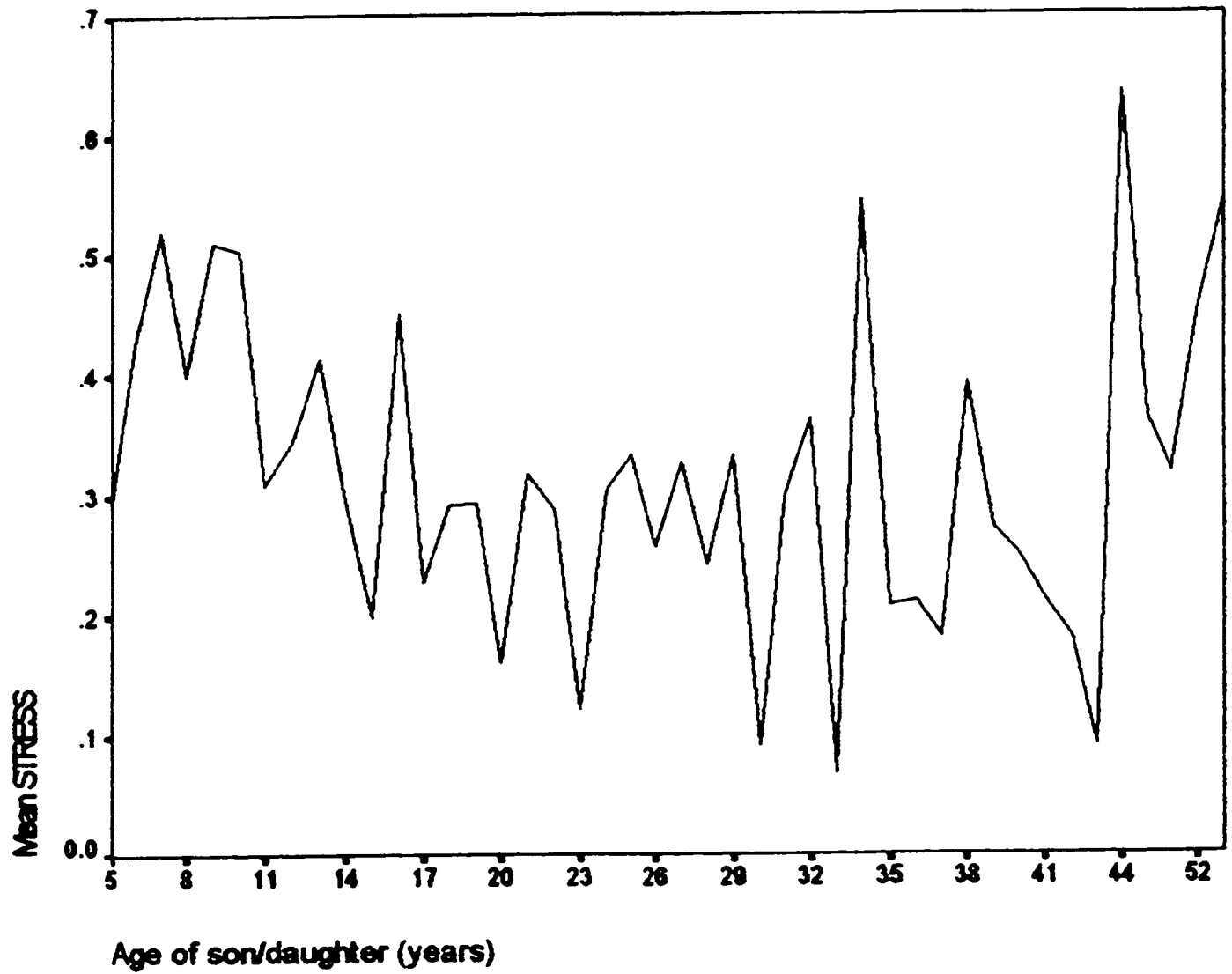


Figure 2

Mean stress level as a function of son/daughter's age

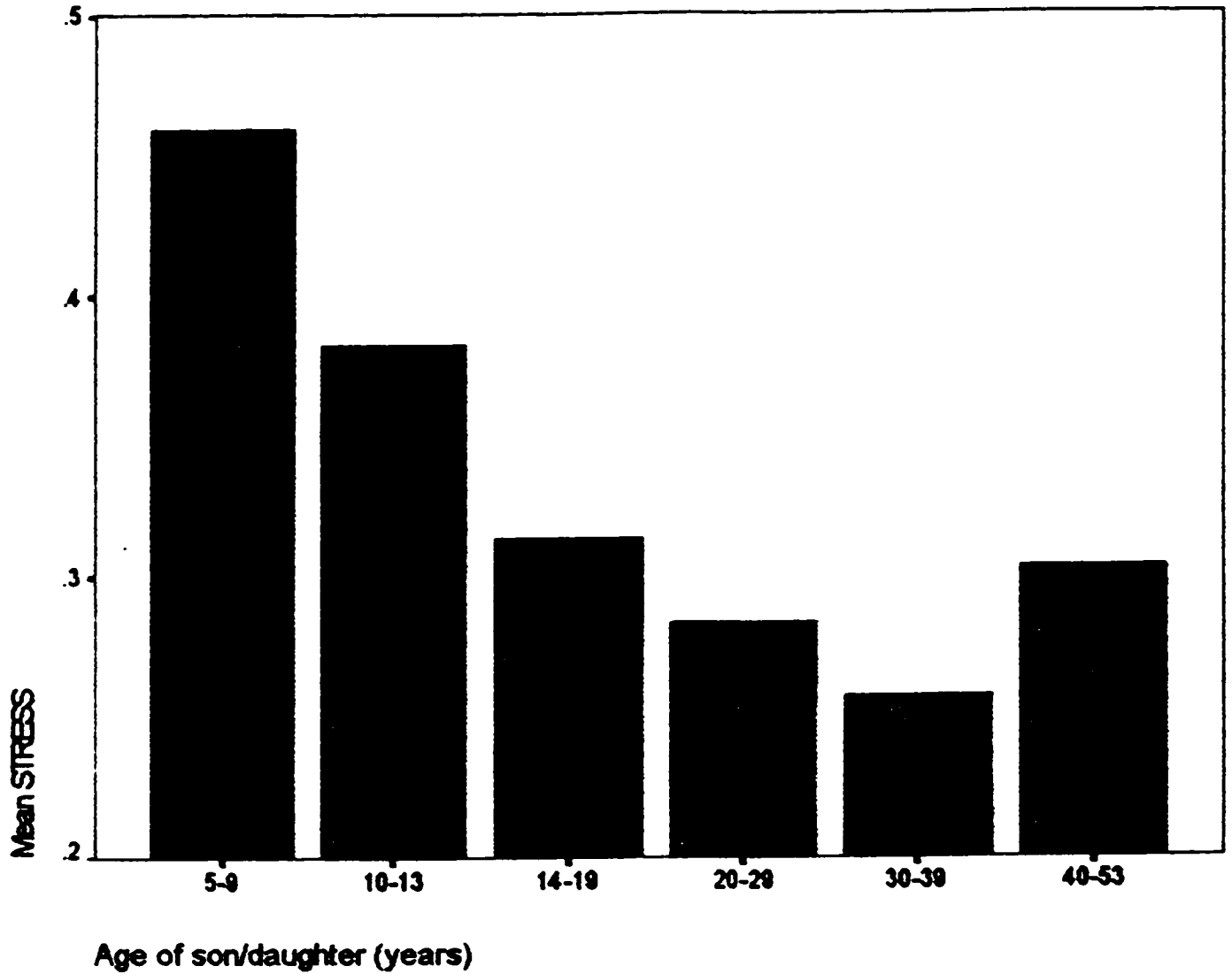


Figure 3

Mean stress level as a function of son/daughter's age group

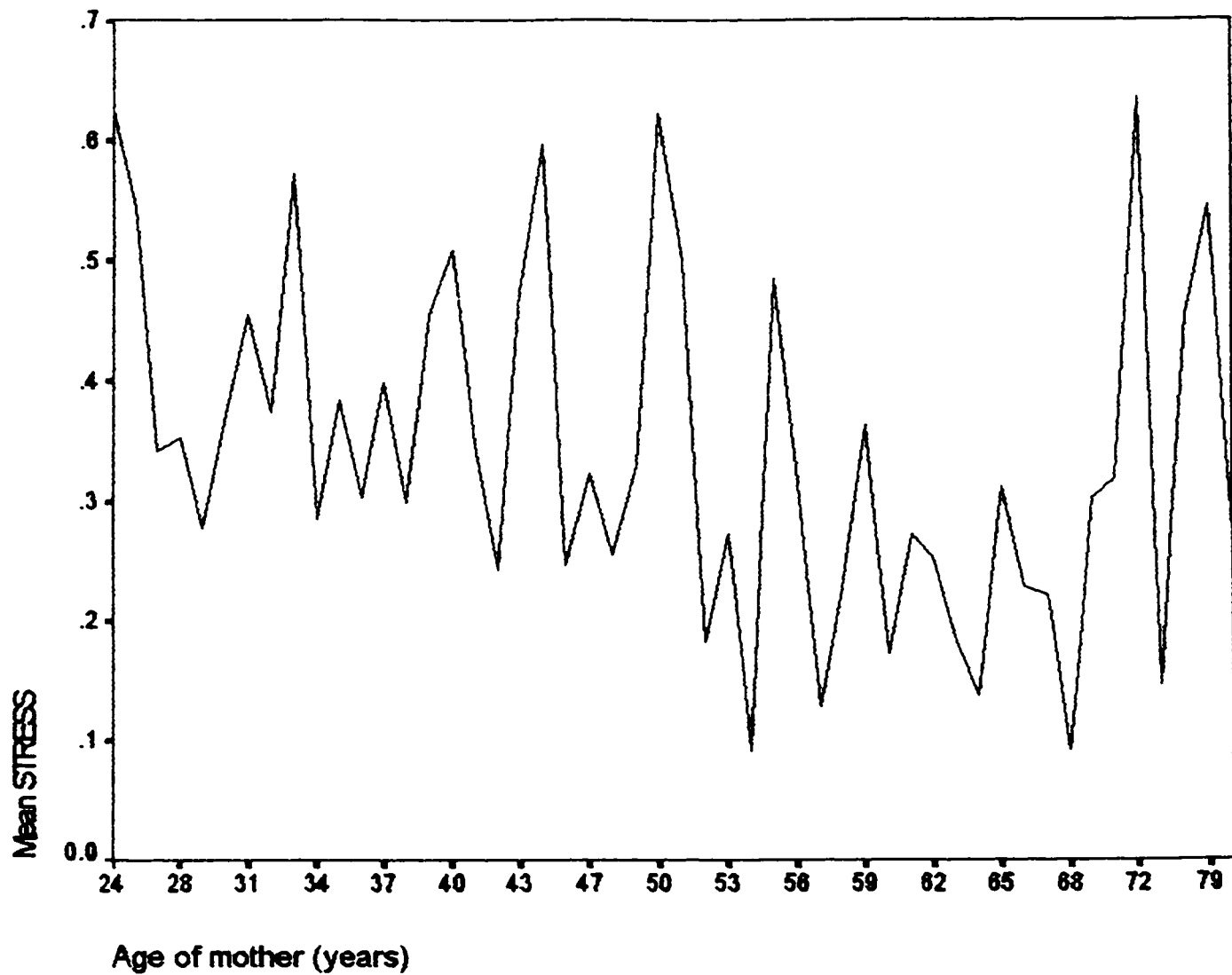


Figure 4

Mean stress level as a function of mother's age

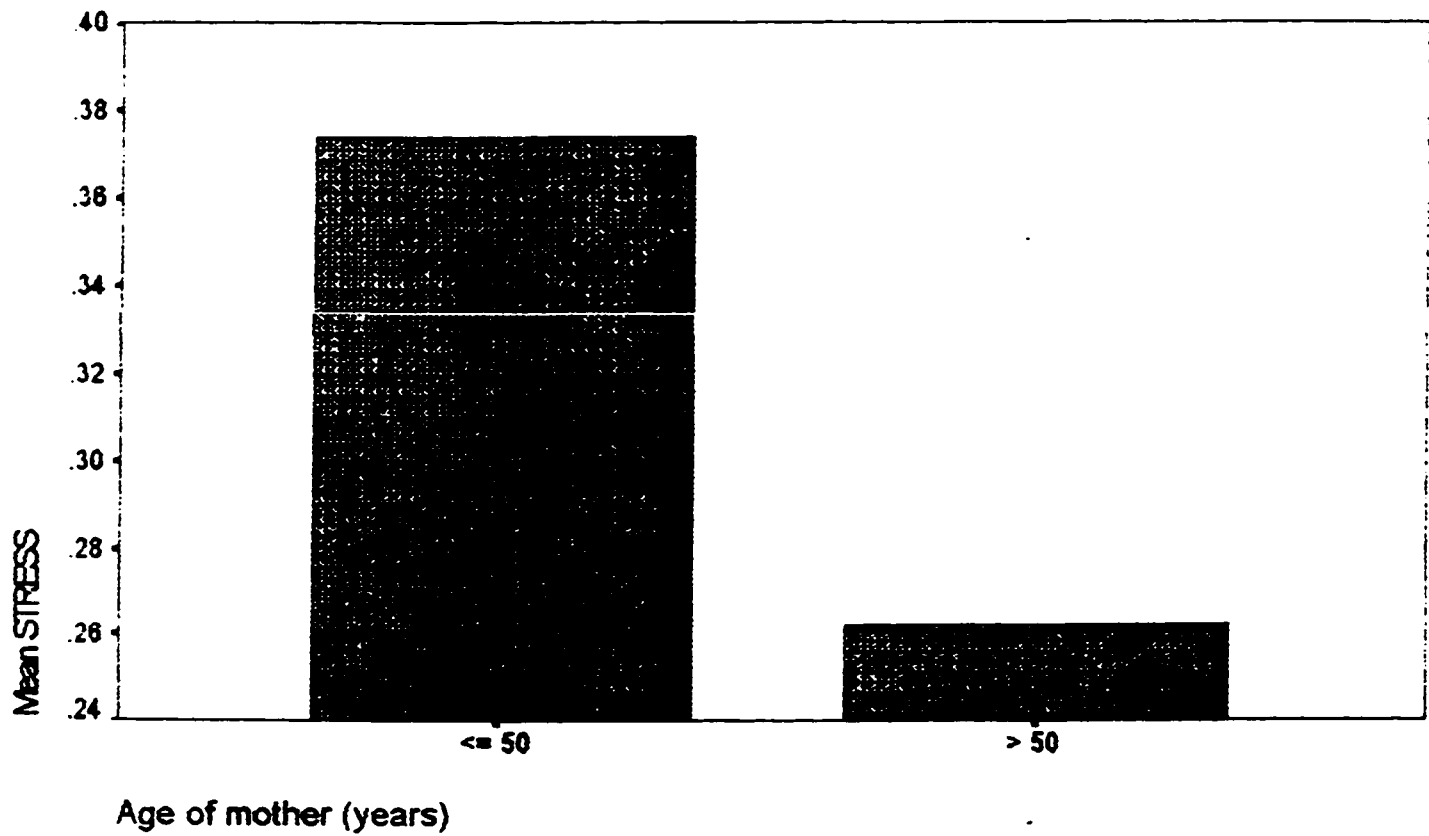


Figure 5

Mean stress level as a function of mother's age group

illustrates the mean stress reported by mothers for the two age groups. This latter figure suggests a negative relationship between maternal stress and maternal age, and this difference was significant at an alpha level of .001. Hence, younger mothers reported experiencing more stress than older mothers.

In summary, these findings provide partial support for the first hypothesis. As expected, the level of maternal stress decreased as a function of both the developmentally disabled individual's increasing age and the mother's increasing age. Contrary to expectations, fluctuations occurred at almost all ages.

#### Predictors of Maternal Stress

Across son/daughter's age. Means and standard deviations for the reformulated measures were calculated for the six age groups and are presented in Table 6. For sons/daughters aged 5 to 9 years and 14 to 19 years, mothers generally reported more negative outcomes than positive outcomes (i.e., mean ratio score greater than 0.5) on the stressor measure, and more positive outcomes than negative outcomes (i.e., mean ratio score less than 0.5) on all the other measures. For all of the other age groups, mothers reported more positive outcomes than negative outcomes for all the measures.

Separate standard multiple regression analyses were performed to assess the relative contribution of (a) the stressor measure, (b) the resource measures (interpersonal, financial, and social support), and (c) the perception measure in predicting maternal

Table 6

Means and standard deviations of the ABCX measures across son/  
daughter's age

Measure	<u>M</u>	<u>SD</u>
5-9 years of age		
STRESSOR-R-C/A	0.68	0.17
TRESOURCE-R	0.37	0.18
IIS	0.24	0.19
IFS	0.48	0.25
ESSS	0.42	0.20
PERCEPTION-R	0.33	0.22
STRESS-R-C/A	0.46	0.29
10-13 years of age		
STRESSOR-R-C/A	0.59	0.15
TRESOURCE-R	0.26	0.13
IIS	0.16	0.16
IFS	0.33	0.21
ESSS	0.30	0.18
PERCEPTION-R	0.25	0.16
STRESS-R-C/A	0.38	0.22



## 14-19 years of age

STRESSOR-R-C/A	0.57	0.23
TRESOURCE-R	0.30	0.14
IIS	0.16	0.15
IFS	0.38	0.24
ESSS	0.36	0.14
PERCEPTION-R	0.24	0.14
STRESS-R-C/A	0.33	0.25

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## 20-29 years of age

STRESSOR-R-C/A	0.39	0.22
TRESOURCE-R	0.28	0.16
IIS	0.19	0.20
IFS	0.29	0.17
ESSS	0.37	0.24
PERCEPTION-R	0.23	0.15
STRESS-R-C/A	0.28	0.21

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## 30-39 years of age

STRESSOR-R-C/A	0.40	0.19
TRESOURCE-R	0.27	0.15
IIS	0.21	0.20
IFS	0.27	0.19
ESSS	0.33	0.18
PERCEPTION-R	0.22	0.16
STRESS-R-C/A	0.26	0.19

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40-53 years of age		
STRESSOR-R-C/A	0.47	0.15
TRESOURCE-R	0.32	0.19
IIS	0.23	0.21
IFS	0.29	0.20
ESSS	0.36	0.26
PERCEPTION-R	0.26	0.17
STRESS-R-C/A	0.30	0.18

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Note. STRESSOR-R-C/A = Reformulated Stressor Scale for children/adults, TRESOURCE-R = Reformulated Total Resource Scale, IIS = Intrafamilial Interpersonal Subscale, IFS = Intrafamilial Financial Subscale, ESSS = Extrafamilial Social Support Subscale, PERCEPTION-R = Reformulated Perception Scale, and STRESS-R-C/A = Reformulated Stress Scale for children/adults.

stress for the six groups. The results of these analyses are presented in Table 7.

In general, this model was statistically significant across the groups, except for mothers of adults aged 40 and older, where none of the variables proved to be statistically useful in predicting stress. For this group, the model only accounted for 43.3% of the variance in reported stress. For mothers of children aged 5 to 9 years, the stressor measure was the only statistically significant predictor of stress. For these mothers, the model accounted for 49.7% of the variance in stress. For mothers of children aged 10 to 13 years, the stressor measure and the interpersonal resource measure were the only statistically significant predictors of stress. For these mothers, the model accounted for 67.3% of the variance in stress. For mothers of children aged 14 to 19 years, the stressor measure and the perception measure were the only statistically significant predictors of stress. For these mothers, the model accounted for 81.6% of the variance in stress. For mothers of adults aged 20 to 29 years, the stressor measure and the perception measure were the only statistically significant predictors of stress. For these mothers, the model accounted for 51.9% of the variance in stress. For mothers of adults aged 30 to 39 years, the stressor measure was the only statistically significant predictor of stress. For these mothers, the model accounted for 61.3% of the variance in stress. Hence, the relative importance of the predictor variables in predicting stress varied across the groups.

Table 7

Regression analyses on the ABC measures for predicting maternal stress as a function of son/daughter's age

Measure	<u>B</u>	<u>SE B</u>	Beta	<u>F</u>
5-9 years of age: $R^2 = 0.497$				
STRESSOR-R-C/A	1.072	0.339	0.637	9.979**
IIS	0.526	0.516	0.352	1.040
IFS	-0.087	0.305	-0.075	0.080
ESSS	-0.200	0.380	-0.140	0.277
PERCEPTION-R	-0.049	0.442	-0.037	0.012
10-13 years of age: $R^2 = 0.673$				
STRESSOR-R-C/A	0.622	0.232	0.449	7.220*
IIS	0.532	0.253	0.387	4.444*
IFS	0.021	0.177	0.020	0.014
ESSS	-0.275	0.160	-0.227	2.962
PERCEPTION-R	0.356	0.254	0.261	1.960
14-19 years of age: $R^2 = 0.816$				
STRESSOR-R-C/A	0.549	0.155	0.500	12.610***
IIS	0.593	0.316	0.363	3.531
IFS	-0.117	0.157	-0.113	0.555
ESSS	-0.254	0.199	-0.140	1.641
PERCEPTION-R	0.551	0.260	0.303	4.499*

20-29 years of age:  $R^2 = 0.519$

STRESSOR-R-C/A	0.514	0.092	0.556	31.103****
IIS	-0.135	0.128	-0.134	1.115
IFS	0.236	0.125	0.195	3.546
ESSS	-0.137	0.097	-0.159	1.994
PERCEPTION-R	0.558	0.172	0.556	10.465***

30-39 years of age:  $R^2 = 0.613$

STRESSOR-R-C/A	0.655	0.134	0.639	23.951****
IIS	-0.080	0.143	-0.082	0.317
IFS	0.226	0.151	0.222	2.238
ESSS	0.001	0.152	0.001	0.000
PERCEPTION-R	0.248	0.193	0.208	1.649

40-53 years of age:  $R^2 = 0.433$

STRESSOR-R-C/A	0.066	0.337	0.054	0.039
IIS	-0.054	0.412	-0.062	0.017
IFS	-0.130	0.278	-0.144	0.218
ESSS	-0.020	0.284	-0.029	0.005
PERCEPTION-R	0.828	0.442	0.761	3.508

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .005$ , \*\*\*\*  $p < .001$

Note. STRESSOR-R-C/A = Reformulated Stressor Scale for children/adults, IIS = Intrafamilial Interpersonal Subscale, IFS = Intrafamilial Financial Subscale, ESSS = Extrafamilial Social Support Subscale, and PERCEPTION-R = Reformulated Perception Scale.

Across mother's age. Means and standard deviations for the reformulated measures were calculated for the two age groups and are presented in Table 8. More negative than positive outcomes were reported by mothers aged 24 to 50 years for the stressor measure. This group of mothers also reported more positive than negative outcomes on all the other measures. More positive outcomes than negative outcomes were reported by mothers aged 51 to 91 years for all the measures.

Separate standard multiple regression analyses were performed to assess the relative importance of (a) the stressor measure, (b) the resource measures (interpersonal, financial, and social support), and (c) the perception measure in predicting maternal stress for the two groups. In general, this model was statistically significant at the .001 alpha level for both age groups. The model accounted for 59.1% of the variance in stress for younger mothers, and 44.6% of the variance in stress for older mothers. Moreover, the relative significance of the predictor variables to the model varied between the two groups. For younger mothers, stressors ( $F(5, 88) = 54.63, p < .001$ ), social support resources ( $F(5, 88) = 4.10, p < .05$ ), and perception of stressors ( $F(5, 88) = 5.12, p < .01$ ) were all important in predicting stress. On the other hand, for older mothers, only stressors ( $F(5, 85) = 29.00, p < .001$ ) and perception of stressors ( $F(5, 85) = 14.77, p < .001$ ) were useful in predicting stress.

In summary, these findings provide partial support for the second hypothesis. As expected, stressors, resources, and

Table 8

Means and standard deviations of ABCX measures across mother's age

Measure	<u>M</u>	<u>SD</u>
25-50 years of age		
STRESSOR-R-C/A	0.57	0.22
TRESOURCE-R	0.31	0.15
IIS	0.19	0.18
IFS	0.37	0.22
ESSS	0.37	0.20
PERCEPTION-R	0.27	0.17
STRESS-R-C/A	0.37	0.24
51-91 years of age		
STRESSOR-R-C/A	0.39	0.19
TRESOURCE-R	0.28	0.16
IIS	0.20	0.20
IFS	0.28	0.19
ESSS	0.34	0.22
PERCEPTION-R	0.23	0.16
STRESS-R-C/A	0.26	0.20

Note. STRESSOR-R-C/A = Reformulated Stressor Scale for children/adults, TRESOURCE-R = Reformulated Total Resource Scale, IIS = Intrafamilial Interpersonal Subscale, IFS = Intrafamilial Financial Subscale, ESSS = Extrafamilial Social Support Subscale, PERCEPTION-R = Reformulated Perception Scale, and STRESS-R-C/A = Reformulated Stress Scale for children/adults.

perception of stressors were all significant in predicting maternal stress, even though the relative importance of these predictors varied according to the developmentally disabled individual's age and the mother's age. The aforementioned three predictors were only significant in predicting stress in younger mothers. For the most part, the stressor measure was the only significantly consistent predictor of stress across the six groups of offspring. Resources and/or perceptions were only useful in predicting stress at specific points throughout the family's life cycle.

#### Overall Relationship Among the Measures

Hierarchical regression analyses were then run on the pooled data to determine the unique proportion of variance in the outcome variable stress that is explained by each of the predictor variables. Toward this end, each predictor variable was removed from the model one at a time and then put through a regression analysis. The results are presented in Table 9. Overall, this model was statistically significant,  $R^2 = .548$ ,  $F(5,180) = 43.56$ ,  $p < .001$ . The model accounted for 54.8% of the variance in mothers' reported stress levels, with 23.2% of this variance explained redundantly. Of the five predictor variables, only two variables, namely the stressor measure and the perception measure, made significant unique contributions to the prediction model. Specifically, the stressor measure uniquely explained 24.7% ( $p < .001$ ) of the variance in stress once all the other predictors had been partialled out of stressor. Similarly, the perception



Table 9

Summary of hierarchical regression analyses for the predictors of maternal stress for the combined sample

Measure	<u>B</u>	<u>SE B</u>	Beta	<u>F</u>	Change <u>R<sup>2</sup></u>
STRESSOR-R-C/A	0.548	0.055	0.540	98.167*	0.247
IIS	0.080	0.084	0.067	0.910	0.002
IFS	0.078	0.062	0.072	1.565	0.004
ESSS	-0.124	0.065	-0.112	3.652	0.009
PERCEPTION-R	0.441	0.096	0.320	21.344*	0.054

\*  $p < .001$

Note. STRESSOR-R-C/A = Reformulated Stressor Scale for children/adults, IIS = Intrafamilial Interpersonal Subscale, IFS = Intrafamilial Financial Subscale, ESSS = Extrafamilial Social Support Subscale, and PERCEPTION-R = Reformulated Perception Scale.

Prediction equation: Stress = -0.052 + 0.548 (Stressor) + 0.080 (Interpersonal resource) + 0.078 (Financial resource) - 0.124 (Social support) + 0.441 (Perception)

measure uniquely explained 5.4% of the variance in stress once all the other predictors had been partialled out of perception.

To find the most parsimonious and complete model for predicting stress in mothers of sons/daughters with mental delays, a forward and backward hierarchical regression was run with an entry alpha level of .05 and an exit level of .10. Both regression analyses yielded the same model, thereby increasing confidence in this model. The following model was obtained:  
Stress = -0.063 + 0.551 (stressor) + 0.470 (Perception).

The aforementioned model indicates that both stressors and perceptions play a role in the prediction of stress for this population of mothers. In order to determine whether perceptions had a moderating influence on stress, mothers were divided into four groups: mothers who reported a low ratio of stressors and a low ratio of negative perceptions (low stressor-low negative perception, n = 93), mothers who reported a low ratio of stressors and a high ratio of negative perceptions (low stressor-high negative perception, n = 6), mothers who reported a high ratio of stressors and a low ratio of negative perceptions (high stressor-low negative perception, n = 78), and mothers who reported a high ratio of stressors and a high ratio of negative perceptions (high stressor-high negative perception, n = 9). A low ratio of stressors was defined as a mean score of 0.5 or less on the stressor measure, and a high ratio of stressors was defined as a mean score above 0.5 on the stressor measure. A low ratio of negative perceptions was defined as a mean score of 0.5 or less on the perception measure, and a high ratio of negative perceptions

was defined as a mean score above 0.5 on the perception measure. The mean stress score was then calculated for each of the four groups.

If mothers' perceptions of stressors has a moderating influence on stress, then mothers in the low stressor-high negative perception group should have a higher mean stress score than mothers in the low stressor-low negative perception group. Similarly, mothers in the high stressor-high negative perception group should have a higher mean stress score than mothers in the high stressor-low negative perception group.

Comparisons among the four groups revealed that mothers in the low stressor-high negative perception group had a higher mean score ( $M = 0.36$ ,  $SD = 0.23$ ) than mothers in the low stressor-low negative perception group ( $M = 0.19$ ,  $SD = 0.16$ ). The difference in mean stress scores between these two groups of mothers, however, was not statistically significant ( $t = 1.88$ ,  $p < .10$ ). Mothers in the high stressor-high negative perception group had a higher mean score ( $M = 0.69$ ,  $SD = 0.20$ ) than mothers in the high stressor-low negative perception group ( $M = 0.42$ ,  $SD = 0.20$ ). The difference in mean stress scores between these two groups of mothers was statistically significant ( $t = 3.86$ ,  $p < .001$ ). Thus, the degree of negative perceptions did not have a moderating effect on maternal stress when the ratio of stressors was lower than 0.5, but it did have a moderating effect when the ratio of stressors was higher than 0.5.

In summary, these findings do not provide support for the third hypothesis. Once the confounds within the scales had been

controlled for, the overall relationship among the measures differed from that proposed by McCubbin and Patterson's Double ABCX model. Contrary to McCubbin and Patterson's model, none of the three types of resources made a statistically significant contribution to the prediction of stress. Moreover, the moderating influence of perceptions on stress was conditional upon the stressor score.

## CHAPTER IV

## DISCUSSION

The present study is unique in that it assessed maternal stress associated with caring for offspring with developmental delays across the lifespan. Furthermore, this study attempted to ensure that the measures employed to address this issue were relatively free of confounds, that is, that the measures were relatively independent of one another. However, some of the measures were still highly intercorrelated with each other. Items were only included in a measure if they adhered to the operational definition of that measure. Hence, only items measuring life events or situations that could be potentially stressful to the mothers and their families were included in the stressor scale. Only items measuring psychological, interpersonal or social characteristics of the mothers, their families, and their communities that help lessen the impact of a stressor were included in the resource scale. Only items measuring mothers reports of their families' perceptual orientation toward stressors and their means of managing or resolving them were included on the perception scale. Only items measuring the mothers' psychological and/or physical response(s) to stressors were included on the stress scale. The reformulated resource scale was unique in the sense that it differentiated among interpersonal, financial, and social support resources.

The reformulated measures yielded results similar to those of Cameron et al. (1990) in that mothers of adults with mental delays reported less stress than mothers of children with mental delays.

This similarity of findings suggests that these reformulated scales were an adequate measure of maternal stress for this population. Moreover, when stressors, resources, perceptions, and stress were differentiated into separate scales, a more positive outlook on these mothers was obtained as mothers reported experiencing a more positive than negative outcomes in their lives. Thus, the ratio score calculated for each of the measures shifted the focus solely from the negative effects of caring for a child who is developmentally delayed to a focus that took both positive and negative effects into consideration. In this respect, mothers were only considered to be experiencing high stress if the degree of negative outcomes outweighed the degree of positive outcomes.

In general, maternal stress decreased as a function of the increasing age of the individual with the developmental delay and the increasing age of the mother. This was expected as there is a high positive correlation between age of the mother and age of the son/daughter with the mental delay.

The higher stress levels experienced by mothers of younger children could be due to the new challenges and problems faced by these mothers as their child fails to acquire many of the skills that other children who are not developmentally delayed are acquiring. Moreover, for many of these mothers this is the first time that they are faced with these kinds of problems so they might not as equipped with the means of managing or resolving these problems as are mothers of older children. However, mothers of 20 to 39 year olds who report lower stress levels have had a

number of years to develop the skills necessary to take care of their child. In addition, they are less likely to be faced with new challenges as this is a period of relative stability for their children in the sense that the children are not going through any major developmental milestones. The slight increase in stress levels for mothers of children aged 40 to 53 years, although not significant, may reflect increased concerns regarding the child's future as the mothers are faced with their own failing health. Thus, it is possible that stress levels may increase significantly beyond this age group. If that were the case, then maternal stress would vary nonlinearly with increasing age of the child with the mental delay.

The finding of a negative relationship between maternal stress and age is consistent with the findings of other researchers. For example, Whittick (1988) found that mothers of children with mental delays reported experiencing higher levels of stress than mothers of adults with mental delays. Moreover, Kaufman et al. (1990) found that older mothers reported lower stress levels than did younger mothers.

In contrast, the present results contradicted those of Dyson (1993) and Flynt and Wood (1989), both of whom found no significant differences in maternal stress regardless of the age of the individual with the developmental disability. However, as mentioned previously, these differences could be due to the limited age range of Dyson's sample, and to the lack of offspring in nontransition periods in the Flynt and Wood study. Alternatively, the disparity in results could be due to

differences in the way stress was measured. Both Dyson and Flynt and Wood used the QRS-SF to measure stress, a measure that the present author determined to be highly confounded with other variables such as stressors.

The ratio of stressors reported by mothers was the only consistent predictor of maternal stress, regardless of the age of mentally delayed individual or the age of the mother. Contrary to McCubbin and Patterson's model, resources and/or perceptions only made significant contribution(s) to the prediction of maternal stress at specific periods of development.

Consistent with the findings of Bristol (1987) and Seltzer et al. (1995), perception had a moderating effect on maternal stress. However, this moderating influence only held true when stress was relatively high. Consequently, having a positive outlook and a positive means of dealing with stressors protected these mothers from experiencing high levels of stress when there were a high number of stressors present.

In general, resources did not contribute to the prediction of maternal stress for this sample of mothers. These results are contrary to those of Petersen (1984), in which he found that mothers with high stressors but high resources reported fewer outcome problems than those mothers with high stressors but low resources. Thus, for Petersen's sample of mothers, resources acted as a powerful moderator variable in buffering mothers from stress related problems. However, Petersen's definition of resources included physical and emotional support, encouragement and praise from significant individuals, satisfaction with the



division of labor related to the care of the child, sufficient financial ability to meet medical costs, presence of love and affection in the home, and satisfaction with community services. Moreover, he defined stress in terms of marital adjustment and the presence of physical symptoms in the mother. Consequently, the disparity in results between Petersen's findings and the present findings could simply be due to differences in how these two variables were operationally defined.

Similarly, it is possible that the resource measures used in this study did not reflect the resources relevant to this population of mothers. Support for this hypothesis is provided by Hall, Orr, Cameron, and Hakim-Larson (in press) as they found that the FIRM failed to assess the resources that mothers of adults with developmental delays found useful. Therefore, it is likely that the reformulated total resource measure, which was created using the FIRM, would also fail to tap into the resources relevant to the mothers in this study.

Alternatively, this disparity could be due to the fact that the reformulated resource measures used in this study were moderately to highly intercorrelated with the reformulated perception measure. Thus, the resources measures were not seen as making a significant contribution to the prediction of maternal stress over and above that predictability afforded by the stressor and perception measure.

The interpretation of these results has to be tempered by the fact that this was not a longitudinal study. Therefore, developmental changes can not be evaluated directly and must be

inferred from the cross-sectional data. Cross-sectional data may be biased by individual differences or by the confounding of age and time of birth. Moreover, despite efforts to generate relatively independent measures, some of the reformulated measures were still highly intercorrelated with other measures. In addition, the reformulated scales were not standardized so the validity and reliability of these scales have not been determined. The lack of a standardized sample against which to compare the results made it impossible to determine whether the stress scores obtained from this sample differed in any way from the stress scores one would expect for a sample of mothers of offspring who do not have developmental delays. However, the measures were selected in a manner so as to maximize the content validity of these scales.

This study represents another step toward an understanding of how maternal stress varies across the lifespan. However, longitudinal research is clearly needed to assess intraindividual developmental changes in maternal stress across the life cycle. Preliminary results suggest that efforts to lower maternal stress associated with caring for a son/daughter with a developmental disability should be focused on different aspects of the family, depending on the age of the mother and the age of her son/daughter. For example, mothers of early adolescent children with mental delays should be focused on lowering the number of stressors the family is exposed to and by improving the interpersonal resources of the family.

Additionally, there is a need for the further development of unconfounded scales which are created on the basis of very specific operational definitions. Further investigation is needed to uncover the stress reducing potential of other moderator variables, especially for mothers of older adults with mental delays. It is possible that, for these mothers, variables such as maternal health and the division of labor may prove to be more fruitful in predicting stress.

It is hoped that studies such as this one will lead to the creation of new developmental theories of family stress that more adequately predict maternal stress for this population. The number of families caring for a son/daughter with a developmental delay is increasing. Therefore it is imperative that researchers continue to strive toward a better understanding of the causes of stress, as this will facilitate the development of more adequate support services.

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## FOOTNOTES

<sup>1</sup> The terms developmentally disabled, developmentally delayed, developmentally challenged, and mentally delayed are all used interchangeably. These terms refer to mental retardation or other related neurological and developmental conditions that constitute a substantial cognitive limitation and can be expected to be enduring.

<sup>2</sup> A stressor differs from a daily hassle in that hassles are annoying minor everyday events as opposed to major life altering events. However, it is important to note that the cumulation of relatively minor insignificant daily hassles can still result in significant psychological distress (Crnic & Acevedo, 1995).

<sup>3</sup> A moderator variable is any variable that acts to influence how a given event will be experienced, interpreted, and reacted to (Petersen, 1984).

<sup>4</sup> For the purposes of the present study, each condition/event outlined in questions 9, 10, 12, and 16 of the DEMO used in the Orr et al. study and questions 12, 13, 16, and 20 of the DEMO used in the Cameron et al. study, was considered as a distinctive question on the reformulated measures.

<sup>5</sup> The sample size was reduced due to missing data.

## APPENDIX A: Reformulated measures

Based on the operational definitions provided below the following scales were generated. The origin of each item is indicated in brackets at the end of the item, followed by the original item number.

Stressor - any life event or situation that could be potentially stressful to the mother and her family.

Resource - any psychological, interpersonal, or social characteristic of the mother, her family, and/or her community that helps lessen the impact of the stressor on the mother and her family.

1. Interpersonal resources - characteristics of the immediate family such as family cohesion, flexibility, organization, and communication.
2. Financial resources - aspects of the immediate family's financial status, such as available income and property owned.
3. Social support resources- social support networks outside the immediate family along which information and services are exchanged.

Perception and coping - this includes the family's perceptual orientation towards stressors and their means of managing or resolving stressors as reported by the mothers.

Stress - any psychological and/or physical responses to the stressor, for instance, irritation, worry, depression, fatigue, and illness.



## REFORMULATED STRESSOR SCALE

- Indicate whether the following apply to your situation as a parent [DEMO, 9 or 12]:
  - Financial problems
  - Poor health
  - Serious health problems in other family members
  - Elderly person in household
  - Another handicapped person in household
- Indicate the following conditions that apply to your son/daughter [DEMO, 12 or 16]:
  - Developmental delay
  - Frequent seizures
  - Hyperactivity
  - Physical handicap requiring special adaptive equipment (e.g., wheelchairs, etc)
  - Severe emotional problem
  - Severe behavioral problem
  - Severe visual problem
  - Severe hearing problem
- Indicate if your son/daughter does any of the following [DEMO, 16 or 20]:
  - Physically harms others
  - Harms self (bites, pinches, hits, . etc)
  - Destroys property or objects
  - Interferes with sleep of others in household
  - Is sexually aggressive with others
  - Irritates other household members

- Having only one person in the family earning money is (or would be) a problem in our family [FIRM, 6]
- One or more working members of our family are presently unemployed [FIRM, 28].
- When my child wants something, my child usually keeps trying to get it [PSI, 1].

OR I am able to leave \_\_\_\_\_ alone in the house for an hour or more [QRS-SF, 2.2].

- Compared to most, my child has more difficulty concentrating and paying attention [PSI, 4].

OR \_\_\_\_\_ is aware of who he/she is (for example, male 14 years old) [QRS-SF, 2.4].

- My child will often stay occupied with a toy for more than 10 minutes [PSI, 5].

OR It is easy to keep \_\_\_\_\_ entertained [QRS-SF, 1.5].

- My child wanders away much more than I expected [PSI, 6].

OR \_\_\_\_\_ would be in danger if he/she could get out of the house or yard [QRS-SF, 2.1].

- My child is much more active than I expected [PSI, 7].

OR Because \_\_\_\_\_ uses special equipment and facilities, it is difficult to take him/her out [QRS-SF, 8.6].

- I feel that my child is very moody and easily upset [PSI, 20].

OR \_\_\_\_\_ is very irritable [QRS-SF, 1.6].

- In some areas my child seems to have forgotten past learnings and has gone back to doing things characteristic of younger children [PSI, 22].

OR \_\_\_\_\_ knows his/her own address [QRS-SF, 2.3].

- My child doesn't seem to learn as quickly as most children [PSI, 23].

OR \_\_\_\_\_ can describe himself/herself as a person [QRS-SF, 2.6].

- My child is not able to do as much as I expected [PSI, 26].

OR \_\_\_\_\_ doesn't do as much as he/she should be able to do [QRS-SF, 1.4].

- My child has more health problems than I expected [PSI, 45].

OR I worry about what will happen to \_\_\_\_\_ when I can no longer take care of him/her [QRS-SF, 4.1].

- My child turned out to be more of a problem than I expected [PSI, 47].

OR I worry about what will be done with \_\_\_\_\_ when he/she gets older [QRS-SF, 4.5]

- My child is always hanging on me [PSI, 49].

OR Outside activities would be easier without \_\_\_\_\_ [QRS-SF, 3.6].

- My child seems to be much harder to care for than most [PSI, 48].

OR As the time passes I think it will take more and more to care for \_\_\_\_\_ [QRS-SF, 7.2].

- My child makes more demands on me than most children [PSI, 50].

OR \_\_\_\_\_ demands that others do things for him/her more

than is necessary [QRS-SF, 1.1.].

- Most of my life is spent doing things for my child [PSI, 68].

OR In the future, \_\_\_ will be more able to help himself/herself [QRS-SF, 7.5]

#### REFORMULATED TOTAL RESOURCE SCALE

##### Intrafamilial Interpersonal Subscale

- I have a feeling of being loved or cared about from my spouse or partner [SSI, I.1].
- I feel I am valued or respected for who I am and what I can do by my spouse or partner [SSI, II.1].
- I have a sense of trust or security from the "give-and-take" of being involved with my spouse or partner [SSI, III.1]
- When I need to talk or think about how I'm doing with my life, I feel understood and get help from my spouse or partner [SSI, IV.1].
- We have to nag each other to get things done [FIRM, 3]
- It seems that members of our family take each other for granted [FIRM, 7].
- Certain members of our family do all the giving, while others do all the taking [FIRM, 9].
- Family members understand each other completely [FIRM, 12]
- Many things seem to interfere with family members being able to share concerns [FIRM, 14].
- Most of the money decisions are made by only one person in

- our family [FIRM, 15].
- There are times when family members do things that make other members unhappy [FIRM, 16].
  - In our family some members have many responsibilities while others don't have enough [FIRM, 18].
  - No one could be happier than our family when we are together [FIRM, 19].
  - It is hard to get family members to cooperate with each other [FIRM, 23].
  - There are times when we do not feel a great deal of love and affection for each other [FIRM, 34].
  - In our family we understand what help we can expect from each other [FIRM, 39].
  - In our family it is "okay" for members to show our positive feelings about each other [FIRM, 50].
  - It is "okay" for family members to express sadness by crying, even in front of others [FIRM, 53].
  - We discuss our decisions with other family members before carrying them out [FIRM, 55].
  - We get great satisfaction when we can help one another in our family [FIRM, 58].
  - The members of our family respect one another [FIRM, 62].
  - Members of our family are encouraged to have their own interests and abilities [FIRM, 65].
  - The members of our family are known to be good citizens and neighbors [FIRM, 67].

Intrafamilial Financial Subscale

- We have money coming in from our investments (such as rental property, stocks, bonds, etc) [FIRM, 1].
- We depend almost entirely upon financial support from welfare or other public assistance programs [FIRM, 10].
- We depend almost entirely on income from alimony and/or child support [FIRM, 21].
- We own land or property besides our place of residence [FIRM, 31].
- We own (are buying) a home (single family, condominium, townhouse, etc.) [FIRM, 33].
- If a close relative were having financial problems we feel we could afford to help them out [FIRM, 35].
- We feel we have a good retirement income program [FIRM, 37].
- We seem to have little or no problem paying our bills on time [FIRM, 40].
- We would have no problem getting a loan from the bank if we wanted one [FIRM, 42].
- We feel we have enough money on hand to cover small unexpected expenses (under \$100) [FIRM, 43].
- The member(s) who earn our family income seem to have good employee benefits (such as paid insurance, stocks, car, education, etc.) [FIRM, 45].
- We feel we are able to eat out occasionally without hurting our budget [FIRM, 47].
- It seems that we need more insurance than we have [FIRM, 49].

- We feel we are able to make financial contributions to a good cause (needy people, church, etc) [FIRM, 51].
- When we need something that can't be postponed, we have money in savings to cover it [FIRM, 54].
- We worry about how we would cover a large unexpected bill (for home, auto repairs, etc. for about \$100) [FIRM, 57].
- In our family we feel it is important to save for the future [FIRM, 59].
- We have written cheques knowing there wasn't enough money in the account to cover it [FIRM, 61].
- We save our extra spending money for special things [FIRM, 63].
- We feel confident that if our main breadwinner lost his/her job, (s)he could find another one [FIRM, 64].
- We feel we are financially better off now than we were 5 years ago [FIRM, 69].

#### Extrafamilial Social Support Subscale

- Indicate which of the following services your son/daughter is now receiving [DEMO, 10 or 13]:
  - Special services at home
  - Counselling or psychotherapy
  - Social or recreational program
  - School
  - Day program
  - Speech therapy
  - Physiotherapy

- Residential treatment

- Friends seem to enjoy coming to our house for visits [FIRM, 36].
- Our relatives seem to take from us, but give little in return [FIRM, 41].
- We try to keep in touch with our relatives as much as possible [FIRM, 48].
- Our relatives are willing to listen to our problems [FIRM, 56].
- The working members of our family seem to be respected by their co-workers [FIRM, 60].
- Our relatives do and say things to make us feel appreciated [FIRM, 66].
- We make an effort to help our relatives when we can [FIRM, 68].

When we face problems or difficulties in our family, we respond by:

- Sharing our difficulties with relatives [F-COPES, 1].
- Seeking encouragement and support from friends [F-COPES, 2].
- Seeking information and advice from persons in other families who have faced the same or similar problems [F-COPES, 4].
- Seeking advice from relatives (grandparents, etc.) [F-COPES, 5].
- Seeking assistance from community agencies and programs designed to help families in our situation [F-COPES, 6].



- Receiving gifts and favors from neighbors (e.g. food, taking in mail, etc.) [F-COPES, 8].
- Seeking information and advice from the family doctor [F-COPES, 9].
- Asking neighbors for favors and assistance [F-COPES, 10].
- Attending church services [F-COPES, 14].
- Sharing concerns with close friends [F-COPES, 16].
- Exercising with friends to stay fit and reduce tension [F-COPES, 18].
- Doing things with relatives (get-togethers, dinners, etc.) [F-COPES, 20].
- Seeking professional counseling and help for family difficulties [F-COPES, 21].
- Participating in church activities [F-COPES, 23].
- Asking relatives how they feel about problems we face [F-COPES, 25].
- Seeking advice from a minister [F-COPES, 27].
- Sharing problems with neighbors [F-COPES, 29].
- Having faith in God [F-COPES, 30].

#### REFORMULATED PERCEPTION SCALE

- We do not plan too far ahead because many things turn out to be a matter of good or bad luck anyway [FIRM, 4].
- Our family is as well adjusted as any family in this world can be [FIRM, 5].
- Sometimes we feel we don't have enough control over the direction our lives are taking [FIRM, 8].

- We seem to put off making decisions [FIRM, 11].
- If our family has faults we are not aware of them [FIRM, 24].
- Many times we feel we have little influence over the things that happen to us [FIRM, 26].
- We have the same problems over and over- we don't seem to learn from past mistakes [FIRM, 27].
- There are things at home we need to do that we don't seem to get done [FIRM, 29].
- We feel our family is a perfect success [FIRM, 30].
- When we make plans we are almost certain we can make them work [FIRM, 38].
- When we face a problem, we look at the good and bad of each possible solution [FIRM, 44].
- No matter what happens to us, we try to look at the bright side of things [FIRM, 46].
- We seem to be happier with our lives than many families we know [FIRM, 52].

When we face problems or difficulties in our family, we respond by:

- Knowing we have the power to solve major problems [F-COPES, 3].
- Knowing that we have the strength within our own family to solve our problems [F-COPES, 7].
- Facing the problems "head-on" and trying to get the solution right away [F-COPES, 11].
- Showing that we are strong [F-COPES, 13].

- Accepting stressful events as a fact of life [F-COPES, 15].
- Knowing luck plays a big part in how well we are able to solve family problems [F-COPES, 17].
- Accepting that difficulties occur unexpectedly [F-COPES, 19].
- Believing we can handle our own problems [F-COPES, 22].
- Defining the family problem in a more positive way so that we do not become too discouraged [F-COPES, 24].
- Feeling that no matter what we do to prepare, we will have difficulty handling problems [F-COPES, 26].
- Believing if we wait long enough, the problem will go away [F-COPES, 28].

#### REFORMULATED STRESS SCALE

- Being physically tired much of the time is a problem in our family [FIRM, 2].
  - Our family is under a lot of emotional stress [FIRM, 13].
  - It seems that we have more illness (colds, flu, etc.) in our family than other people do [FIRM, 17].
  - It is upsetting to our family when things don't work out as planned [FIRM, 20].
  - Being sad or "down" is a problem in our family [FIRM, 22].
  - My child is so active that it exhausts me [PSI, 2].
- OR \_\_\_\_\_ is easy to live with [QRS-SF, 1.3].
- There are some things my child does that really bother me a lot [PSI, 44].

OR If \_\_\_\_\_ were more pleasant to be with, it would be easier to care for him/her [QRS-SF, 1.2].

- As my child has grown older and become more independent, I find myself more worried that my child will get hurt or into trouble [PSI, 46].

OR I don't worry too much about \_\_\_\_\_'s health [QRS-SF, 7.1].

- I feel trapped by my responsibilities as a parent [PSI, 70].

OR It bothers me that \_\_\_ will always be this way [QRS-SF, 4.6].

- Since having this child I have been unable to do new and different things [PSI, 72].

OR There is no way we can possibly keep \_\_\_\_\_ in our home [QRS-SF, 10.3]

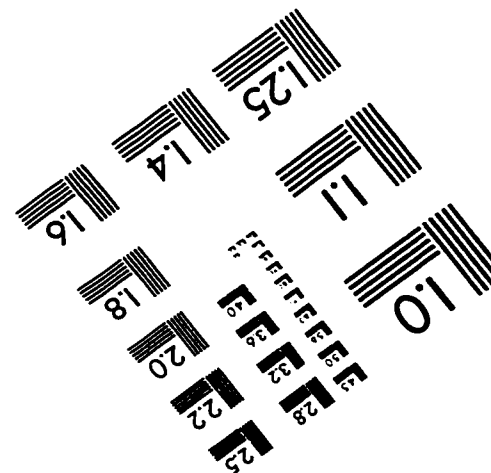
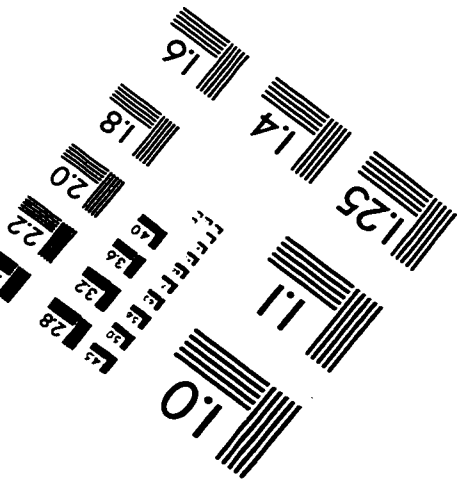
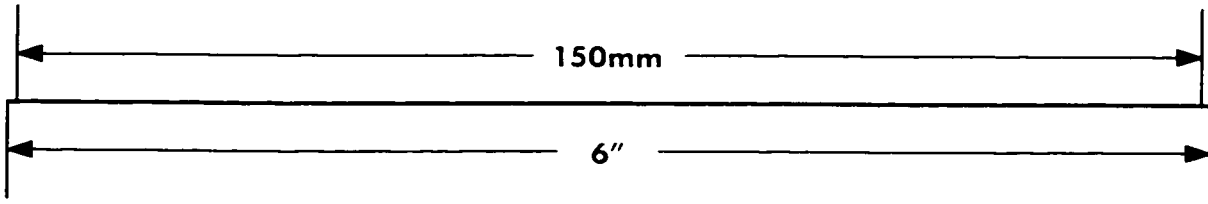
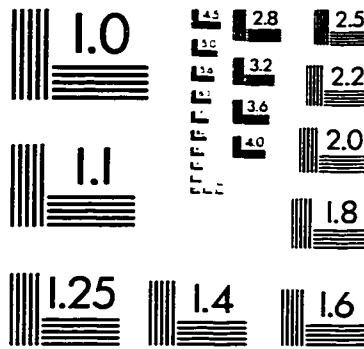
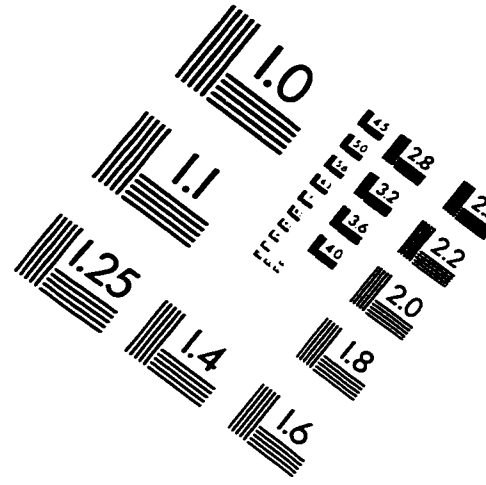
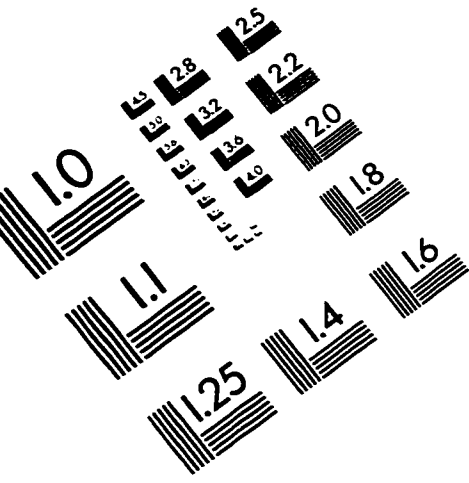
- I don't enjoy things as I used to [PSI, 100].

OR I rarely feel blue [QRS-SF, 11.6].

## VITA AUCTORIS

Nicole Stacey Li was born on July 25, 1974 in St.Kitts. She graduated from St. Ursula's High Shcool in Barbados in 1992. From there she went to the University of Toronto where she obtained an Honours B.Sc. in Psychology in 1995. Nicole is enrolled as a Doctoral candidate in the Developmental Psychopathology Stream of the Clinical/Developmental Program at the University of Windsor, and is currently completing the requirements for a Master of Arts degree in Developmental Psychology.

# IMAGE EVALUATION TEST TARGET (QA-3)



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