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## **Stress, Coping, Adaptation, and Family Hardiness in Families with an Adult Child Who is Developmentally Disabled and Living in the Parental Home**

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STRESS, COPING, ADAPTATION, AND FAMILY HARDINESS IN FAMILIES WITH  
AN ADULT CHILD WHO IS DEVELOPMENTALLY DISABLED AND LIVING IN  
THE PARENTAL HOME

By

Joan M. VanSolkema

A THESIS

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## ABSTRACT

# STRESS, COPING, ADAPTATION, AND FAMILY HARDINESS IN FAMILIES WITH AN ADULT CHILD WHO IS DEVELOPMENTALLY DISABLED AND LIVING IN THE PARENTAL HOME

By

Joan M. VanSolkema

Families who successfully cope and adapt to having a child with a developmental disability are of interest to health professionals. The Typology Model of Adjustment and Adaptation and family hardiness provided the conceptual framework to explore and describe the relationships between family hardiness and family coping and adaptation. Sixty-three families returned a mailed survey that included the Family Hardiness Index, Coping Health Inventory for Parents, and Family Adaptability and Cohesion Evaluation Scales II. Higher levels of family hardiness were associated with better family coping and adaptation. Results of ANOVAs and multiple regression indicate the level of mental retardation of the adult child did not influence family hardiness or adaptation. Some coping patterns were influenced by the child's level of mental retardation and behavior. Parental characteristics did not affect coping patterns. Family hardiness, parents' education, and fathers' health were correlated.

## DEDICATION

This research is dedicated to the families and their members who have shared so much with me. By sharing your joys and sorrows, your hopes and fears, and your wisdom and insight, you have allowed me to grow and learn. Thank you for your trust and willingness to share your family with me.

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## CHAPTER 1

### INTRODUCTION

During the last 20 years, the interest in families who have a child with a developmental disability has increased. Glidden (1993) reported that 21% of the articles published in the *American Journal on Mental Retardation* in 1988 related to research on family issues. This compared to one percent in 1978.

Public policies have changed during this time. Families are now given encouragement and support to maintain their member with a developmental disability at home. Institutions have been closed or reduced in size resulting in the move of those residents into local communities. It is no longer unusual that nurses provide care to individuals who have a developmental disability and to their families.

These families cope and adjust in a variety of ways. Their ability to adapt to the stresses of having an adult child with a developmental disability varies widely. These differences may influence the manner in which services are sought and provided. Some families appear to skillfully balance the everyday challenges and joys of life in addition to meeting the needs of their adult child who is developmentally disabled. Others seem to be driven by their anger or chronic sorrow. For example, distraught and concerned about her daughter's care, a mother took her own and her daughter's life (Kaufman, 1995). The daughter was severely mentally disabled. Some are simply tired of coping.

Parental behavior may be misunderstood by nurses, resulting in inadequate or inappropriate provision of service (Clubb, 1991). Parents who are overwhelmed by their own feelings or by meeting life's daily demands may be ineffective advocates. As a result, all available opportunities for services or health care may not be offered to their

child. Health care professionals may have difficulty interacting appropriately and effectively with parents who seem angry, tired or overly protective. In response they may cause unnecessary pain and fear, either intentionally or unintentionally.

Much of the research about these families has focused on their stress and the impact the child with a developmental disability has had. This perpetuates the idea that a family who has a child with a developmental disability is also a family with a disability. We know that the stress of having a child with a developmental disability affects the physical and emotional health, quality of life, the family's identity, and the marital relationship (Blacher, 1984; Carpinello, Piras, Pariente, Carta, & Rudas, 1995; Crnic, Friedrich, & Greenberg, 1983; Damrosch & Perry, 1989; Dyson, 1993; Intagliata & Doyle, 1984; Kelly & Kropf, 1995; Patterson & Garwick, 1994). What we do not know is what enables some of these families to adapt effectively, survive, and indeed, thrive. The intent of this study is to increase understanding of this phenomenon.

The specific purpose of this study is to describe the relationships between family hardiness, family coping and adaptation in families who have an adult child who is developmentally disabled and living in the parental home. This study used a partial replication of previous studies of these variables with a more homogeneous sample (Failla & Jones, 1991; McCubbin, 1989). These data could be used by professionals to assist families in achieving the skills that foster effective coping and adaptation.

## CHAPTER 2

### CONCEPTUAL FRAMEWORK AND LITERATURE

#### Conceptual Framework

This study was guided by two conceptual frameworks. They were (a) the Typology Model of Adjustment and Adaptation and (b) hardiness.

Typology Model of Adjustment and Adaptation. Family stress theory has been used to guide research on families encountering normative transitions as well as major life changes or illness. A version of family stress theory, the Typology Model of Adjustment and Adaptation (McCubbin, Thompson, Pirner, & McCubbin, 1988) was selected to guide this study. This model was chosen because it addresses family stressors or demands, family coping, family hardiness, and family adaptation. In addition, it recognizes the roles that family appraisal and family strengths and capabilities play in family functioning.

The Typology Model of Adjustment and Adaptation (McCubbin et al., 1988) is an expansion of McCubbin and Patterson's Double ABCX Model (1983). The Double ABCX Model focused on the stressor, the resistance resources of the family, and the family's appraisal of the stressor event. The Typology Model expanded on those components and added the components of family types and levels of vulnerability.

McCubbin et al. (1988) define stressor as a life event or transition such as parenthood, which affects the family unit and either changes or has the potential to change the family social system. The family's resistance resources are the family's resources, capabilities, and strengths that facilitate problem-solving and promote adjustment. The family's appraisal of the stressor event is the family's

definition of the seriousness of the stressor, the difficulties it presents, and the effect on the family. This appraisal is influenced by the family's culture and values. Family typologies are a set of basic attributes of the family and its internal processes which help explain how a family typically appraises, operates, and behaves. Vulnerability, as defined by McCubbin and Thompson (1987), is the interpersonal and organizational condition of the family system. Vulnerability is influenced by the accumulation of demands on the family and its life cycle stage.

Family research using the Typology Model is based on four fundamental assumptions about family life. The assumptions include:

(1) Families face hardships and changes as a natural and predictable aspect of family life over the life cycle; (2) families develop basic strengths and capabilities designed to foster growth and development of family members and the family unit and to protect the family from major disruptions in the face of family transitions and changes; (3) families develop basic and unique strengths and capabilities designed to protect the family from unexpected or non-normative stressors and strains and to foster the family's adaptation following a family crisis or major transition and change; and (4) families benefit from and contribute to the network of relationships and resources in the community, particularly during periods of family stress and crises (McCubbin et al., 1988, p.4).

The Typology Model describes two phases in a family's response to life changes and catastrophes: the adjustment phase and the adaptation phase (McCubbin & Thompson, 1987). The adjustment phase is a short-term response by families to a routine change, transition, or demand which does not lead to a family crisis or major change in family functioning. The family's response is determined by the interactions of the stressor, the family's vulnerability, the family typology, the family's resistance resources, the appraisal of the stressor, and the problem-solving and coping responses of the family.

McCubbin and Thompson (1987) characterize the adaptation phase by the occurrence of a major shift in the manner in which the family unit normally operates in response to a crisis. The family's response to this crisis is determined by the interactions of the accumulation of demands the family encounters, the family's regenerativity or their ability to manage and recover, the typology of the family, the family's strengths, the family's appraisal of the situation, the family schema or beliefs and assumptions regarding relationships, the family's community support, and the family's problem-solving and coping responses.

**Hardiness.** The concept of hardiness was introduced by Kobasa (1979). Hardiness is defined as "a constellation of personality characteristics that function as a resistance resource in the encounter with stressful life events" (Kobasa, Maddi, & Kahn, 1982, p. 169). Based on existential psychology, hardiness is composed of three dimensions: (a) control, (b) commitment, and (c) challenge. These dimensions are interrelated and together constitute a positivity and resiliency in facing life.

Kobasa (1979) explains control as the belief that one is able to control or influence the events of one's experience. An internal, rather than external, locus of control allows one to recognize one's ability to participate or "handle things" rather than seeing oneself as the victim of circumstance.

Commitment, according to Kobasa (1979), is reflected by the recognition of one's beliefs, values, goals, and capabilities and a belief in their importance. This leads to a sense of purpose and involvement rather than a sense of alienation.

Kobasa (1979) describes challenge as an active involvement with one's environment. It is characterized by vigorousness rather than vegetativeness. Those strong in challenge believe fulfillment is to be found in continual growth rather than in comfort and security.

The hardiness concept has been related only to the individual until recently. The construct of family hardiness was guided by that of individual hardiness (McCubbin &

Thompson, 1987). McCubbin and Thompson describe family hardiness as the internal strengths and durability of the unit which function to buffer or mediate the effects of stressors or demands. Family hardiness is composed of four interrelated components: (a) co-oriented commitment, (b) confidence, (c) challenge, and (d) control.

McCubbin and Thompson (1987) explain co-oriented commitment as the family's working together to handle difficulties. Confidence is defined as the family's sense of being able to handle problems and endure hardships. Challenge is described as the family's ability to view hardships as challenges. Control is explained as the family's sense of being in control of life rather than victims of circumstance. In other words, family hardiness is based on a family working together to manage difficulties; believing in their ability to resolve problems; seeing difficulties as challenges; and having a sense of control of family life rather than being controlled by life situations.

### Literature Review

Family is the societal unit most affected by having a child who has a developmental disability. The family may be affected by both chronic and acute stressors. In spite of the unique stressors associated with having a child who is developmentally disabled, some families seem to have abilities and resources that allow them to adapt effectively. As the foundation for examining the relationships between family hardiness, family coping, and family adaptation, studies on parental stress, parental coping, adaptation and hardiness were reviewed. A summary and critique of these studies follows each topic.

Parental stress. Several studies on parental stress in families having a child with a handicap were examined. In one, Minnes (1988) explored the relationship between parental perceived stress associated with a retarded child, internal and external family resources, and characteristics of the child in order to focus on the multiple factors that may mediate stress and facilitate coping. The sample included 60 mothers of children who were mentally retarded and attending an outpatient clinic in Toronto, Ontario. The predictor variables were the family crisis-meeting resources, parent characteristics, and

child characteristics. Included in the family crisis-meeting resources were family relations, social support, spiritual support, and professional support. Parent characteristics were defined by marital and socioeconomic status. Type of handicap, degree of handicap, and age comprised the child characteristics. The dependent variables were the parents' perceptions of the stress associated with dependency and management, cognitive impairment, physical limitations, financial concerns, terminal illness, lack of personal reward, and family disharmony. Stepwise multiple linear regression analyses were completed to determine the predictive contributions of these variables. Family crisis-meeting resources were shown to be significant predictors of stress. They accounted for 32% of the variance in stress that was associated with dependency and management, 40% with family disharmony, 18% with lack of personal reward, and 10% with terminal illness. Child characteristics was the only significant predictor of the stress associated with cognitive (31% of the variance) and physical impairments (28%). Minnes noted that traditionally the child's type of handicap or diagnosis had been shown to influence the amount of parental stress. In this study, the type of handicap was a significant predictor of stress in only one of the regression analyses. Conversely, a significant inverse relationship between the degree of handicap and parental stress was demonstrated in several analyses.

Hayden and Goldman (1996) studied 105 families of adults with mental retardation to determine if the stress they experienced was a function of the caregiver's characteristics, the family member's characteristics, or service needs. The families, recruited from waiting lists of service agencies in Minnesota, had a family member with mental retardation who was at least 20 years old. In addition, they were waiting for at least one type of support service. Stress was measured on the Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members (Short Form). Marital status was the only significant caregiver characteristic associated with level of stress  $F(1, 103) = 7.90, p < .01$ . The adult family member's level of mental



retardation  $F(2, 102) = 14.50, p < .001$ , health status  $F(2, 102) = 7.35, p < .01$ , and frequency of maladaptive behaviors  $F(1, 103) = 22.18, p < .01$  demonstrated significant relationships with level of stress. Family's level of stress was also related to the number of services needed  $F(1, 103) = 6.15, p < .001$  and amount of personal care and supervision required by the adult member  $F(5, 99) = 19.34, p < .01$ .

In another study on parental stress, McCubbin (1989) examined the differences in stressors, demands, family types, family resources, coping patterns, and children's health outcomes between single-parent and two-parent families who have a child with cerebral palsy. The sample consisted of 27 single-parent and 27 two-parent families who lived in a five state area in the upper midwest. The two groups of families were matched on the severity of the child's handicap as well as the parents' age and gender. Although McCubbin hypothesized that there would be a greater number and severity of stressors in single-parent families, no significant differences were found in the accumulation of family stressors and demands and resource strains. This study found one critical difference between the two groups: single-parent families were more adaptable and flexible in response to normative and situational stress.

McKinney and Peterson (1987) examined the effect of child diagnoses, type of early intervention program, social support network, and perceived control on stress. Sixty-seven mothers of children who were aged 7 to 41 months and had a developmental disability were recruited from early intervention programs in the Chicago area. Five hypotheses were tested. The first was that mothers of children with a developmental disability would report higher levels of stress than mothers of nonhandicapped children (based on the sample used to standardize the instrument). As hypothesized, the Child Characteristics domain scores of the Parenting Stress Index were higher for the study subjects ( $n = 67, M = 122.13, SD = 23.05$ ) than the standardization sample ( $n = 534, M = 112.77, SD = 21.48$ )  $t(439) = 9.79, p < .001$ . This indicated that the characteristics of the child with a disability represented a greater stressor to the mother than the

characteristics of a nonhandicapped child. A 2 x 2 analysis of variance demonstrated, as hypothesized, mothers of children with Down syndrome had lower mean child-related stressor scores than the mothers of children with cerebral palsy or other motoric disorders. The difference, however, was not significant  $F(1, 62) = 2.90, p < .094$ . The third hypothesis was that fewer stress symptoms would be reported by mothers who received early intervention services in groups rather than individually. No significant effects from type of intervention were detected. The fourth hypothesis was that subjects reporting a higher degree of social support would report fewer stress symptoms. T-tests were performed on mean differences between the high and low social support groups. No significant differences were found. The fifth hypothesis, that mothers with a high degree of perceived control would report fewer symptoms of stress, was supported. This study showed child diagnosis and type of intervention did not have a significant effect on stress measures, however, it suggested that the mothers' assessment of child characteristics had a significant effect.

Seltzer and Krauss (1989) examined the well-being of aging mothers of mentally retarded adults living at home. The sample was comprised of 203 mothers 55 years or older who had an adult child with mental retardation who was living at home. Data were collected by interview and self-report questionnaires. Although data were obtained regarding several variables, the data of interest is that of perceived maternal stress. Independent variables included five domains: maternal characteristics, characteristics of the adult with retardation, family social climate, mother's social support network, and formal supports. Statistically significant inverse correlations between stress and the level of retardation ( $r = -.343, p < .001$ ), the diagnosis ( $r = -.213, p < .001$ ), and the child's physical health ( $r = -.203, p < .01$ ) were reported. A statistically significant positive correlation was reported between stress and functional level ( $r = .405, p < .001$ ). In multiple regression analysis, these factors accounted for 25% of the variance of parental stress, while family social climate accounted for 17%. Seltzer and Krauss noted that

mothers who reported more parenting stress perceived less cohesion, more conflicts, less independence, and less organization in their families.

Dyson (1993) explored parental stress and family functioning in families with a child with disabilities in comparison to families who did not have child with a disability. This study was a follow up to a previous study and included 74 of the 110 families who had participated four years earlier. All families had a child aged 5 to 11 years. Disorders identified in the group with disabilities included: speech disorders, seizure disorders, learning disabilities, mental retardation, and developmental delay. Families were matched by the children's ages and by socioeconomic status. Parental stress was measured on the Questionnaire on Resources and Stress-Short Form. A 2 x 2 multivariate analysis of variance demonstrated no significant interaction for the total stress scores. Dyson reported this indicated any changes in stress over time were the same for both groups. A significant main effect  $F(1, 70) = 57.08, p < .0001$  indicated a difference between groups. This did not change from the initial study. The group with children with disabilities scored significantly higher parent stress. Univariate tests revealed significant effect on Parent/Family Problems and Pessimism subscales. There was a 23% increase in Parent/Family Problems and a 27% increase for Pessimism over the four years. Family functioning was measured on the Family Environment Scale. A 2 x 2 multivariate analysis of variance was completed on the individual subscales of the Family Environment Scale. Univariate tests found a significant interaction effect on Expressiveness. The family group with children with disabilities scored lower than the group with children without disabilities  $F(1, 68) = 5.35, p < .05$ . Although the multivariate effect for group was not significant, univariate tests revealed differences on Achievement Orientation, Intellectual-Cultural Orientation, Moral-Religious, and Control subscales ( $p < .05$ ). A stepwise multiple regression was completed to identify predictors of parental stress. Variables included: disability status, domains of family functioning, relationship, personal growth, and systems maintenance. Forty-three

percent of the variance for parental stress was accounted for by disability status  $F(1, 68) = 51.39, p < .0001$  and family relationship accounted for an additional 7%  $F(1, 67) = 10.03, p < .002$  at follow up. The results of this study suggest parental stress and family functioning are stable over time and that differences between families with and without a member with a disability persist.

In summary, stress is a universally acknowledged factor in the lives of families. In families who have a member with a developmental disability, more stress may be evident (Dyson, 1993). Studies which examined the stress in families having a child with mental retardation, cerebral palsy, or Down syndrome, and living at home are included in this review. Only two of the studies reviewed (Seltzer & Krauss, 1989; Hayden & Goldman, 1996) focused on adult children. Seltzer and Krauss found slightly lower stress scores in their sample. The length of time they had cared for the child and their ability to develop adequate coping skills may have contributed to lessening the stress of having a child with a disability.

Considerable effort has been focused on determining the factors that may be predictive of these families' unique stressors. Several factors were examined in the studies reviewed. Some included family resources, child diagnoses and characteristics, and social support. Family resources, diagnostic characteristics such as poor health and limited functional skills were found to be significant factors in parental stress. Social support was positively correlated with lower stress levels by Seltzer and Krauss while McKinney and Peterson (1993) did not find a significant relationship.

Although Seltzer and Krauss (1989) included 203 subjects and Hayden and Goldman (1996) included 105 subjects, other studies are limited by their small sample sizes, cross-sectional design (with one exception), and reliance on data from only mothers. The subjects were recruited through service providers, potentially having an effect on study results. There is little consistency among the variables studied. Studies that focused on adult children with developmental disabilities were limited. A strength

of Dyson's (1993) study was its reexamination of the subjects at a later time and comparison of matched families with and without a child with a disability. All of these studies highlight the need for longitudinal research to study parental stress over time, more homogeneous groups for comparison, and the inclusion of families of adult children.

Parental coping. All families have normative and situational stresses with which they must cope. Families who have an adult child with a developmental disability may have unique demands and stressors with which they must cope. Parental Coping is the second factor examined for the current study. In one study, the relationship between parental attitudes toward their children's epilepsy and parental coping patterns was examined (Austin & McDermott, 1988). A convenience sample of 27 persons parenting a child aged 6 to 16 years old and diagnosed with a seizure disorder comprised the study sample. The children were being treated at a large university outpatient clinic. Parental coping was measured on the Coping Health Inventory for Parents. The coping pattern of "Maintaining Family Integration, Cooperation, and an Optimistic Definition of the Situation" was found to be most helpful. The coping patterns of "Maintaining Social Support, Self-Esteem, Psychological Stability" and "Understanding the Medical Situations Through Communication with Other Parents and Consultation with Medical Staff" were in the range between minimally to moderately helpful. The Pearson product moment correlation was used to examine the relationship between parental attitude and demographic, seizure, and coping variables. In examining the relationships of demographic and seizure variables with parental attitude and coping patterns, only one significant relationship was found. The length of time the epilepsy had been diagnosed was positively correlated with attitude ( $r = .32, p < .05$ ), suggesting parents may develop a positive attitude over time. Statistically significant positive correlations were found with parental attitude and the coping patterns of "Maintaining Family Integration, Cooperation, and Optimistic Definition of the Situation" ( $r = .42, p < .02$ ) and

"Maintaining Social Support, Self-Esteem, and Psychological Stability" ( $r = .32, p < .05$ ).

These findings supported the belief that those with a positive attitude utilize more positive coping behaviors in addition to sharing their problems and in turn receiving support, which helps maintain self-esteem.

The second study reviewed on parental coping was one conducted by Friedrich, Wiltuner, and Cohen (1985). In this study, the relationship between parental coping and coping resources was examined. The coping resources included: utilitarian resources, energy/morale/health, general and specific beliefs, and social support. The sample was comprised of 140 mothers of children with mental retardation aged 3 to 19 years in the Seattle area. Multiple regression was performed to analyze how the coping resource variables were related to the criterion variable. Four of the five coping resource variables were significant and accounted for 64% of the variance: social support; beliefs; health, energy, and morale; and child variables. Utilitarian resources was not a significant predictor. A second hierarchical regression was performed with behavior problems added as an independent variable. This accounted for an additional 10% of the variance. A follow up study that included 104 of the original mothers was performed after ten months. Although an increase in depression and an increase in family or parental problems were noted, the second study validated the findings from the original study. Friedrich, Wiltuner, and Cohen determined that the severity of the child's disability as well as behavior problems had a direct relationship with the parents' problems. They noted this study demonstrated the interrelatedness of the variables: A parent who is depressed, dealing with a child with behavior problems, would have more difficulty coping effectively.

In another study on parental coping, VanCleve (1989) explored how parents coped with their child's chronic illness. The sample was comprised of 100 parents of children aged 2 months to 18 years who had spina bifida, and were cared for at a university medical center clinic. The sample was divided into a group with low coping and one

with high coping. No significant differences in the stressor scores between the high coping and the low coping groups were found. This suggested they deal with comparable stressors. There were significant differences in scoring on coping strategies although both groups used similar coping strategies. Those with high coping used more coping strategies and seemed to use outside resources more frequently and more freely than those with low coping. A high coping level was found to be significantly positively related to marital satisfaction ( $r = .50, p < .001$ ) and the quality of the relationship between husband and wife ( $r = .56, p < .001$ ). This study found that parental beliefs and attitudes about their child's condition were not associated with coping. VanCleve noted this finding may have been a result of a problem with the instrument measuring attitude. A significant positive relationship between coping and attending a parent's support group ( $r = 0.24, p < .01$ ) was found. In an exploratory stepwise regression using demographic variables, higher income  $F(1, 93) = 6.97, p < .01$  and increased parental age  $F(2, 92) = 5.79, p < .01$  were predictive of parental coping.

In addition to examining parental stress, McCubbin (1989), in the study previously described, examined family strengths and parental coping. Parental coping was measured on the Coping Health Inventory for Parents. The coping pattern of "Maintaining Family Integration, Cooperation, and an Optimistic Definition of the Situation" was significantly lower in single-parent families ( $t = 2.69, df = 23, p = .01$ ). These mothers were less able to utilize helpful coping strategies, engage in activities with the child, or have an optimistic outlook in order to enhance family unity. No significant differences were demonstrated with the two other coping patterns. There were no significant differences found in family types (based on cohesion and adaptability) or the family resources of esteem/communication, mastery/health, and social support between single-parent and two-parent families. McCubbin noted that although the single parents scored lower on the family integration coping pattern, their scores demonstrated more family adaptability.

In summary, parents of children with developmental disabilities may have unique demands and stressors with which they must cope. Studies examined included parental coping with a child who has spina bifida, mental retardation, epilepsy, or cerebral palsy. Studies focusing on the coping of parents who have adult children with a developmental disability were not located. The Coping Health Inventory for Parents was used to measure parental coping by Austin and McDermott (1988) and McCubbin (1989). Austin and McDermott found the coping pattern of "Maintaining Family Integration, Cooperation, and an Optimistic Definition of the Situation" to be of the most help. Parents rated the other two patterns regarding psychological stability and health care in the range between minimally and moderately helpful. Marital satisfaction, positive attitude, the coping resources of beliefs, social support, and morale were found to be correlated with adequate coping. VanCleve found that parents with high coping used more coping strategies and used outside resources more frequently and freely than those with lower coping. These studies highlight the number and interrelatedness of factors that influence parental coping.

These studies are limited by their small sample sizes and including subjects who parent children of a large age range. In addition, all the children of subjects were receiving services which may have influenced their coping. Only VanCleve (1989) included coping strategies which may not be seen as positive. Another weakness is the use of cross-sectional design. A strength of the Friedrich et al. (1985) study was the validation of the original analysis by a reexamination of the subjects at a later date.

Hardiness. Hardiness was the third area reviewed for this study. Hardiness has been identified as an attribute thought to contribute to healthy adaptation. Kobasa (1979) studied personality as a conditioner of the effects of stressful life events on the onset of illness. The sample was comprised of two groups of middle and upper level executives who had comparably high degrees of stressful life events in the previous three years. One group ( $n = 86$ ) endured high stress without becoming ill, while the second group ( $n = 75$ )



became ill after enduring high stress. Mean differences in demographic, personality, and perception variables between the two groups were evaluated by t-test. None of the demographic variables and only one of the perception variables showed significant differences. The group differences were further evaluated by discriminant function analysis on all the personality variables in addition to the one perception variable that had a significant t-score. These data supported the prediction that in comparison, executives with high stress and low illness have more hardiness than executives with high stress and high illness. Those with more hardiness were characterized by their sense of commitment to self, an attitude of vigorousness about life, a sense of meaningfulness, and an internal locus of control.

In another study of individual hardiness, Kobasa, Maddi, and Kahn (1982) tested the hypothesis that hardiness functions to decrease the effect of life events in producing symptoms of illness. The study was based on a sample of 259 middle and upper level management personnel in a public utility company and covered a five year period of time. A principal components factor analysis was performed on the six scales presumed to measure hardiness. With the exception of those involving cognitive structure, all correlations were substantial and highly significant. In evaluating the role of hardiness in health status, a pair of two-way analyses of covariance were performed. Stressful life events were associated with increased symptoms, however, hardiness decreased the symptom onset. This supported the hypothesis that hardiness functions to buffer the effects of stress.

The final study on individual hardiness reviewed was conducted by Ganellen and Blaney (1984). They examined social support and the hardy personality, their relationship, and the role each plays in buffering the effects of life stress. The subjects were 83 female undergraduate students. One issue explored by Ganellen and Blaney was the relationship between aspects of hardiness and social support. The subscales used to measure hardiness included alienation from self, nihilism, vegetativeness, powerlessness,

adventurousness, and internal locus of control. With the exception of internality and powerlessness, the other hardiness subscales were significantly negatively correlated with support. This negative correlation was expected if the relationship between social support and hardiness was positive. The results suggested that commitment and challenge were strongly associated with social support, while control was not. Ganellen and Blaney noted that overall, this supported the hypothesis that social support and hardiness are not independent. In addition, they explored the importance of hardiness and support as buffers of stress and their interaction in a series of three-way analyses of variance. In each analysis, the Beck Depression Inventory score was the dependent variable. The independent variables in each were stressful life event scores, social support, and a measure of a component of hardiness. Significant main effects were found for stressful life events  $F(1, 82) = 6.90, p < .01$ , social support  $F(1, 82) = 4.22, p < .05$ , and two hardiness measures, alienation from self  $F(1, 82) = 5.22, p < .05$ , and vegetativeness  $F(1, 82) = 6.34, p < .02$ . Although the hardiness dimensions of challenge and commitment were represented in the main effects, control was not. The interaction of life stress and social support was nonsignificant  $F(1, 82) = .24$ . Alienation from self did interact with life stress  $F(1, 82) = 5.19, p < .05$ . No other component of hardiness interacted significantly with stress. There was no significant interaction of hardiness and support.

Milne, Sacco, Cetinski, Browne, and Roberts (1994) examined the characteristics and use of respite services of caregivers of elders with severe cognitive impairments. The sample consisted of 64 caregivers recruited from the referrals to a senior day program. The elderly persons with a moderate to severe cognitive impairment, had some difficulty with toileting, dressing, bathing, and eating, and were relatives of the caregivers. Caregivers were assigned to one of four groups by their use of the day program: Enrolled, Refusers, Institutionalized, and Waiting. Caregivers were surveyed regarding their purpose-in-life, caregiver burden, use of services for their impaired

relative, meaning given to illness, hardiness, support, and sociodemographic variables. High levels of social support and purpose, moderate levels of hardiness, favorable meaning, and perceived burden were reported by caregivers. Stepwise regression revealed the most important variable explaining purpose-in-life was hardiness ( $r = .69, p < .000001$ ). Hardiness was also correlated with social support ( $r = .25, p < .05$ ) and favorable meaning given to illness ( $r = .32, p < .05$ ). Milne et al. indicated perceptions, attitudes, and meaning given to illness impact resilience and well-being. They recommended caregivers increase their sense of control, and find commitments and challenges in life in spite of the burden of providing care.

Three studies were reviewed that examined family hardiness. In the first, Failla and Jones (1991) examined the relationship between family hardiness, family stressors, family appraisal, coping, social supports, and satisfaction with family functioning. Additionally, they questioned which of those variables and measures of family demographics are predictive of satisfaction with family functioning. The study sample was a convenience sample of 57 mothers who had a child aged 6 years or younger, with a developmental disability. This study was part of a larger study on the functioning of families with children with developmental disabilities. Pearson correlations indicated a small, nonsignificant negative relationship between family hardiness and family stressor. Family hardiness was found to have significant positive relationships with family coherence, functional support, and satisfaction with family functioning measures. Multiple regression analysis was conducted. Over 42% of the variance in predicting satisfaction with family functioning was accounted for by family hardiness, total functional support, family stressors, and the parental age. This study demonstrated that higher levels of family hardiness were associated with coping behaviors that strengthen family relationships and family life.

The second study reviewed on family hardiness assessed families regarding family life events, adult hardiness, and illness occurrence (Bigbee, 1992). The sample was

comprised of 58 randomly selected families in southeastern Wyoming, who had at least one child under 18 years living at home. One hypothesis stated that adult hardiness acts as a moderating factor to reduce the occurrence of family illness. This hypothesis was tested using a combined hierarchical and stepwise approach. Total life events score, negative life events score, positive life events score, and total number of life events were tested as indicators of stress. Each was tested with seriousness of illness and total number of illnesses. Using seriousness of illness as the dependent variable, the only stress indicator with a significant interaction with hardiness, was negative life events score  $F(3, 36) = 9.48, p = .000$ . Using number of illnesses as the dependent variable, the only significant hardiness-stress interaction found was the negative life events score  $F(3, 36) = 7.05, p < .001$ . A series of  $2 \times 2$  analyses of variance were also completed. The only stress indices that produced a significant main effect, while using seriousness of illness as the dependent variable, were the negative life events score  $F(1, 36) = 5.33, p < .03$  and the total number of life events  $F(1, 36) = 5.12, p < .03$ . The interaction effects with hardiness were not significant. The results suggested hardiness may function as a stress moderator in addition to having a direct effect in the stress-illness relationship. Bigbee suggested the discrepancy of findings between the ANOVA and regression analysis may have been due to the small sample size, the effects of reducing the variance by categorization based on median splits, or both.

Family hardiness, family stressors, and family functioning were examined in families of children with asthma by Donnelly (1994). Twenty-seven parents were recruited from a pediatric clinic at an ambulatory health center. Family stress was measured on the Family Stress Index. The most common stressors identified concerned employment issues. The fourth-ranked stressor (44%) was a "family member became seriously ill or injured." Family hardiness was measured on the Family Hardiness Index and family function was measured on the Family Adaptability and Cohesion Evaluation Scales II. Pearson correlations demonstrated a significant positive relationship between

family hardiness and family type ( $r = .56, p = .05$ ). Although levels of stress were low and hardiness was fairly high, no significant correlation was found between family hardiness and family stress ( $r = .07, p = <.05$ ). No other significant correlations were noted. Family types ranged from mid-range to balanced. Donnelly noted the importance of parental perceptions, their knowledge of chronicity, and the meaning of life experiences in assisting families with adaptation to chronic conditions.

In summary, four studies on individual hardiness and three on family hardiness are included in this review. Kobasa (1979) and Kobasa, Maddi, and Kahn (1982) explored the effects of hardiness on stress and illness. Study results supported the belief that hardiness functions to decrease the effect of stress in producing symptoms of illness. In examining the interactions among life stress, social support, and a component of hardiness, only alienation from self moderated the influence of life stress. In examining caregivers well-being, Milne et al. (1994) determined that hardiness has a positive effect on caregivers' purpose-in-life.

Failla and Jones (1991) found that higher levels of family hardiness were associated with coping behaviors that strengthened family relationships and family life. Bigbee (1992) found support for the stress-moderating effect of hardiness.

The generalizability of the results of these studies on individual hardiness may be limited by the reliance on self-report data and the subjects selected: males in middle or upper level management, female undergraduate students, and elderly caregivers. In addition, Ganellen and Blaney (1984) used only one outcome variable, depression. Evaluating the influence of hardiness on adaptation may provide additional information regarding the nature of hardiness and its effects.

The literature focused on family hardiness is limited. Studies reviewed are limited by their small sample sizes. Failla and Jones (1991) and Donnelly (1994) used the Family Hardiness Index to measure hardiness, while Bigbee (1992) used Kobasa and Maddi's scale. To evaluate family hardiness, it may be advantageous to use a measure

such as the Family Hardiness Index in order to evaluate the family as a whole and add to the body of knowledge in this area. Measuring outcomes other than illness may provide more data regarding the effects of hardiness.

Family adaptation. Family adaptation was the fourth area of review. Reviews of four studies on family adaptation or well-being are included. In the first, Bristol (1987) examined family adaptation. The sample was comprised of 45 mothers of children, aged 2 to 10 years, who were autistic or severely communication impaired. They were recruited from new referrals to a free program in North Carolina for families of children with autism or severe communication impairments. One of Bristol's hypotheses was that healthy family adaptation would be positively predicted by greater family cohesion, greater adequacy of informal and formal support, and more adequate coping patterns. This was unequivocally supported only for perceived informal support and more adequate coping patterns. The simple correlation of cohesion with adaptation was positive, however, with multiple predictors cohesion was predictive of less healthy family adaptation ratings. Formal support was not a significant predictor of adaptation. Bristol also hypothesized that healthy family adaptation would be negatively predicted by the severity of the child's handicap, pile-up of other stressors, maternal self-blame, and maternal definition of the handicap as a family catastrophe. Although the hypothesized inverse relationships between the quality of parenting and the pile-up of stresses ( $r = -.32$ ), maternal self-blame ( $r = -.44$ ), and definition as a family catastrophe ( $r = -.58$ ) were demonstrated, each was not a significant predictor of each adaptation measure. The severity of the child's handicap was not a significant predictor of the three adaptation measures. In another hypothesis, Bristol hypothesized that the pile-up of stressors, family resources, beliefs, and coping patterns would account for more family adaptation than severity of handicap. Severity of handicap did not significantly add to the prediction in two of the adaptation measures. In the third measure, marital adjustment, greater severity of handicap was associated with better adaptation ( $r = .24$ ).

Bristol (1987) concluded that family stressors, family resources, and family definition of the stressful event significantly predicted family adaptation. Healthier adaptation was related to perceived adequacy of informal social support and coping patterns. Negative maternal beliefs or self-blame appeared to affect adaptation in a negative manner. Severity of handicap only affected marital adjustment and that was in a positive direction.

In another study on family adaptation, Frey, Greenberg, and Fewell (1989) examined the relationships of child characteristics, family social network, parent belief systems, and coping styles to parent outcome. The sample consisted of 48 mothers and 48 fathers of young children with handicaps. Frey, Greenberg, and Fewell used three indicators of parental outcome: parent's response to the child with a handicap, quality of family interaction, and the psychological functioning of the parents. Parental beliefs were found to be significantly and strongly related to each parental outcome measure. Communication skill, sex of the child, social network, beliefs, and ways of coping were used as predictor variables. In regression analyses, these predictors accounted for 43% of the variance in family adjustment among mothers and for 50% among fathers. The authors suggest that enhancing a parent's perceived control, problem-focused coping, and satisfaction with social support may promote healthier adaptation by families.

In another study reviewed on family adaptation, Trute and Hauch (1988) examined the coping patterns and adjustment of families who had adapted well to the birth of a child with a developmental disability. The sample was comprised of 36 families who received service in Manitoba's central testing and resource center. Trute and Hauch reported the study families perceived they were members of strong families and only 5% saw some aspect of their family as problematic and in the range of family weakness. The study scores on the Family Assessment Measure III were significantly higher than those from the sample of normative families. These were indicative of family strength in the areas of affective expression, involvement, and consistency in family values and norms.

Although mothers and fathers often have differing perceptions regarding the functioning and organization of the family, this does not need to indicate marital distress or pathology. Family functioning did not appear to be related to income level, number of children in the family, child's age, or the degree of disability. Trute and Hauch found that the reported quality of the marital subsystem was directly related to the perceived quality of family functioning ( $r = -.60, n = 31, p < .001$ ). Identification of family weaknesses decreased as the marital quality ratings increased. Although the families in the study reported small social networks, their satisfaction was high (study  $M = 16.6, SD = 3.66$ ; norm  $M = 13.4, SD = 4.83; t = 3.37, p < .001$ ). The social networks of family and friends provided material aid, advice and information, physical assistance, social participation, and respite in addition to emotional support.

Trute and Hauch (1988) identified the well being of the parental subsystem, family strategies for coping with stress, and social network functioning as significant factors in healthy family adaptation. It did not appear family adaptation was affected by the degree of disability or if the child with a disability was an only child in the family.

Seltzer, Begun, Seltzer, and Krauss (1991) studied the relationships between adults with mental retardation and their nonhandicapped siblings and the effect of these relationships on the well-being of aging mothers. The sample was comprised of 411 families who provided in-home care for an adult with mental retardation. The sons and daughters with mental retardation ranged in age from 15 to 66 years. Data on the adults with mental retardation, the family, the mother, and the siblings of the adults with mental retardation were collected over a five year period of time. One area examined in this study was the extent to which different levels of sibling involvement were related with the characteristics of the adult with retardation, the family social climate, and maternal well-being. Three groups of families were compared. They included a group with no other living children, those with involved siblings, and those with siblings not involved with the adult with mental retardation. In the group with no siblings, the adults with



retardation tended to be the oldest, have the lowest functional abilities, and poorest physical health. The families of this group also were less likely to value independence and active recreation than the other groups. The family group with involved siblings had the highest scores of the three groups. This was indicative of high levels of cohesion and expressiveness, more strongly held values regarding independence, achievement, and recreational activities, and higher levels of family organization. The group with no involved sibling was less expressive and cohesive than other families. The well-being of the mothers differed between the three groups. Well-being was assessed by physical health, life satisfaction, burden, and stress. Mothers with no other living child had poorer health and were the least satisfied with their lives. Mothers with no involved child tended to demonstrate the most burden and stress associated with caregiving. The group of mothers with involved children reported the most favorable well-being. With this study, Seltzer et al. demonstrated sibling involvement is related to greater maternal well-being.

Two studies on caregiver well-being are included in the review of family adaptation literature. In one study, Fink (1995) explored the influence of family resources and demands on well-being. The sample consisted of 65 families recruited through a variety of health and community agencies. The families provided care to parents whose ages ranged from 60 to 95. The majority of families did not reside with the recipient of care. Although several variables were studied, the one of interest in this study is that of family well-being. Fink defined family well-being as the members' satisfaction with the functioning of the family unit, their perceptions of their own health and emotional well-being and the family's health. Family well-being was measured by combining four separate measures. These included the Family APGAR, Bradburn Affect Balance Scale, perceived individual and family health. Regression analysis was performed on family well-being with strains, resource variables, and socioeconomic status. As hypothesized, family resources, measured on the Family Hardiness Index,

enhanced family well-being. These variables accounted for 65% of the variance in family well-being. Family strains, social support, and socioeconomic status did not significantly contribute. Fink noted these findings were consistent with previous family research as well as suggesting family confidence in problem solving and ability to work together are important factors in maintaining well-being.

Irvin and Acton (1996) examined perceived stress and well-being in caregivers of cognitively impaired adults to determine if perceived support and self-worth had an effect. The sample consisted of 117 primary caregivers of persons experiencing difficulty with memory, judgment, and problem solving. Basic need status, perceived support, self-worth, stress, and well-being of the caregivers were measured on the Basic Needs Satisfaction Inventory, Personal Resource Questionnaire, Rosenberg Self-Esteem Scale, Memory and Behavior Problem Checklist, and General Health Questionnaire, respectively. As hypothesized, caregivers with higher levels of basic needs satisfaction had higher levels of perceived support ( $r = .63, p < .01$ ) and self-worth ( $r = .54, p < .01$ ). Irvin and Acton also found higher levels of perceived support ( $r = .57, p < .01$ ) and self-worth ( $r = .54, p < .01$ ) were correlated with higher levels of well-being. Multiple regression was performed to analyze the relationships among stress response, self-care resources of perceived support and self-worth, and well-being. Stress response accounted for 12% of the variance of well-being while self-care resources accounted for 31%. A second hierarchical regression was performed reversing the entry order of the variables. Self-care resources accounted for 41% of the variance for well-being while stress response was not significant. Irvin and Acton indicated the change in the variance of well-being by stress response was due to the mediational effect of self-care resources.

The review of family adaptation literature included six studies. Only one study involved families of adult children. Areas that were examined as possible influences on family adaptation or outcome included: stressors, family resources, parental beliefs, sibling involvement, and family cohesion. Family stressors and their accumulation were

noted to impede healthy adaptation. Parental beliefs were significantly correlated with family adaptation. Family resources such as strengths and assets of the family and social support were found to be positively related to healthy adaptation or well-being. Adequate coping patterns and the perception of being able to cope were identified as being important in healthy adaptation.

The only study that examined sibling involvement with maternal well-being was that of Seltzer, Begun, Seltzer, and Krauss (1991). Maternal well-being was correlated with sibling involvement with the adult child with mental retardation. These families were characterized by higher levels of cohesion, expressiveness, stronger values for achievement, and family organization.

Two studies on caregiver well-being were also reviewed. Fink (1995) found that 65% of the variance for well-being was accounted for by family resources. Irvin and Acton (1996) found self-care resources decreased the effect of stress on well-being.

The studies reviewed on family adaptation are limited by their cross-sectional design and reliance on self-report questionnaires. Few studies were found that focused specifically on adaptation in families with an adult with a developmental disability. Further, longitudinal research is needed in this area. The data obtained can be used to assist families who are having difficulty coping and adapting well. The studies reviewed highlight the multifaceted nature of adaptation and the importance of looking at family systems rather than focusing on the medical or behavioral needs of the adult child.

In summary, this literature review pointed to the need for continued research on families of adult children with a developmental disability. It is necessary to remain cognizant that these are families who can successfully adapt and are not families with a disability.

### Definition of Terms

In order to promote clarity, the following terms are defined for this study: family, child, developmental disability, profound mental retardation, moderate mental

retardation, mild mental retardation, stressors, family coping, family hardiness, and family adaptation. Family is defined as a group of individuals sharing a household who hold similar values and participate in shared goals (Fawcett, 1993). Child is the biological offspring of the family, regardless of age. In this study, all children with a developmental disability were over the age of 18 years.

Developmental disability refers to a severe, chronic condition which originates before 22 years of age; is expected to continue indefinitely; poses substantial functional limitations in three or more major life activities such as self-care, language, learning, and mobility; and can be attributed to a mental impairment (such as mental retardation or autism), to a physical impairment (such as cerebral palsy or epilepsy), or both (Mental Health Code, Michigan Public Act 290, 1996). Mental retardation is subaverage intellectual functioning with significant limitations in adaptive functioning in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety (American Psychiatric Association, 1994). The *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (1994) (*DSM-IV*) describes mild mental retardation as a level of intellectual functioning with an intelligence quotient from about 50 to 70. People with this level of impairment typically develop social, communication, and vocational skills, have minimal impairment in sensorimotor areas, but may need supervision and guidance. According to the *DSM-IV*, moderate mental retardation is a level of intellectual functioning with an intelligence quotient from about 35 to 50. People with this level of impairment usually develop communication, personal care, vocational, and social skills. Generally, they will need supervision to adapt well to life. Profound mental retardation is described as a level of intellectual functioning with an intelligence quotient below 20. People with this level of impairment may display significant impairments in sensorimotor functioning, require constant supervision and

may be able to develop some self-care, communication, and simple vocational skills according to the *DSM-IV*.

Stressors are defined as those life events or situations that are perceived as exceeding resources or endangering well-being. Stress is the family's response to the perceived threat caused by the stressor. Family coping is the process of developing or using behavioral and or cognitive resources to reduce the impact of stressor events and to strengthen the family unit (McCubbin, 1991). Family hardiness is defined as the internal strengths and durability of the family unit which are characterized by a sense of control over life events and hardships, a sense of meaningfulness in life, and a commitment to learn and explore (McCubbin, McCubbin, & Thompson, 1991). Adaptation is the outcome of the family's coping efforts or attempts to balance demands and capabilities at the individual to family and family to community level (McCubbin, 1991).

#### Research Question and Hypotheses

The research question in this study was what are the relationships between family stress, family hardiness, family coping, and family adaptation in families who have an adult child with a developmental disability who lives in the parental home. It was hypothesized parents who have an adult child with a developmental disability and score higher in family hardiness would also have higher levels of family coping and family adaptation, regardless of their stress level. Although stress is an acknowledged variable in the lives of families, hardiness, coping, and adaptation are the variables of interest in this study. Therefore the presence of stress will be assumed, but not measured. It was also hypothesized the level of disability of the adult child would not influence the relationship between family hardiness, and family coping and family adaptation.

## CHAPTER 3

### METHODOLOGY

#### Study Design

A descriptive correlational design was used to examine the relationships between family hardiness and family coping and family adaptation. The purpose of this study was to describe and to explore the differences and similarities in family hardiness, coping, and adaptation in families who have an adult child with a developmental disability residing with the family. It was hypothesized, regardless of their stress, families who had higher levels of family hardiness would also have higher levels of coping and adaptation. A second hypothesis was the level of disability of the adult child would not influence the relationship between family hardiness and family coping and family adaptation. The independent variables in this study were the family stress of having an adult child who has a developmental disability and the level of family hardiness. These were not amenable to manipulation.

Research designs assist in controlling extraneous variables (Polit & Hungler, 1991). In this study, situational contaminants, time factor, and constancy of condition must be addressed. Study subjects completed the instruments in their homes. Although this was a natural setting, emotional and role factors may have influenced the subjects' responses. To control the time factor and constancy of conditions, all study participants received the same written information regarding the study and written instructions for completing the instruments in a letter (see Appendix A). All data were collected during the same time period.

It was necessary to provide for the control of intrinsic factors such as the characteristics of the child and the child's level of impairment in this study. Methods useful in controlling intrinsic factors are randomization, blocking, homogeneity, and matching (Polit & Hungler, 1991). Randomization was not possible in this study, however, the use of homogenous groups was. Three distinct groups were used. The groups included the families of adults who are: (a) severely or profoundly mentally retarded, (b) moderately mentally retarded, and (c) mildly mentally retarded. Additionally, each child lived with his or her family.

### Sample and Setting

Research packets were mailed to the families of 142 adult children with a developmental disability who were believed to be residing with either one or both parents. This included 41 families with an adult with mild mental retardation, 59 with moderate mental retardation, and 42 with severe/profound mental retardation. The adult children's ages ranged from 18 to 59 with a mean age of 36 years. Fifty-two percent of the adult children were male and 48% were female. Overall, 69 packets (49%) were returned. Sixty-three returned packets (44%) provided usable data. This represented a non-probability convenience sampling procedure.

The subjects in this study were selected from families who were receiving services from a private, non-profit agency that provides case management services to persons with developmental disabilities and their families under a contract with a county Community Mental Health Board in a midwestern state. Services are provided in a variety of settings: client's homes, the agency offices, day programs, schools, and at the locales of other service providers. The agency acts as the gatekeeper for services to people with a developmental disability.

The criteria used to select subjects included being the biological or step-parent of an adult child with a developmental disability and being able to read, write, and understand English. The child was required to be 18 years or older, reside with the

parents, and be either severely or profoundly, moderately, or mildly mentally retarded. These classifications, based on intellectual as well as adaptive functioning, were determined by the agency. Families were excluded from the study if the child had an identified mental illness.

### Characteristics of Subjects

Data were obtained from 36 fathers and 60 mothers in the 63 sample families. Parental ages ranged from 40 to 86. Educational levels ranged from less than high school to completion of graduate school. The majority were not employed. The ethnicity of the subjects was primarily white. The majority rated their health as good. Most families rated their income as adequate for meeting family needs.

The majority (65%) of the adult children with a developmental disability were male. Ages ranged from 18 to 58 (mean age = 35). The health of the majority was rated as good and was expected to stay the same. Behavior was rated as either "no problem" or a "mild problem" by most respondents. The majority of adult children were away from the parental home some of the time: The hours ranged from 5 to 56 per week. Most families did not have help come into their home to assist in the care of the child with a disability.

### Instruments

Three instruments were used in the study. They included: the Coping Health Inventory for Parents (CHIP); the Family Hardiness Index (FHI); and Family Adaptability and Cohesion Evaluation Scales II (FACES II).

Coping Health Inventory for Parents (CHIP). The CHIP (see Appendix B), used with permission (Appendix C) was developed to assess parents' perceptions of their response to managing family life when they have a child who is seriously and/or chronically ill. There are 45 items on this self-report questionnaire. The CHIP uses a "not helpful" (0) to "extremely helpful" (3) Likert scale to rate coping behaviors (McCubbin, 1991). Scores are computed by summing unweighted ratings from the items



in each pattern. Scores can range from 0 to 57 on Pattern I, from 0 to 54 on Pattern II, and from 0 to 24 on Pattern III.

Construct validity of the CHIP revealed three coping patterns that account for 71.1% of the variance (McCubbin, 1991). Coping Pattern I, Family Integration, Co-operation, and an Optimistic Definition of the Situation is composed of 19 behaviors that focus on strengthening family life and the parental outlook. Coping Pattern II is composed of 18 items involving relationships with others, activities that enhance self-worth, and behaviors that manage pressures. It is named Maintaining Social Support, Self Esteem, and Psychological Stability. Understanding the Health Care Situation Through Communication with Other Parents and Consultation with the Health Care Team is Coping Pattern III. This pattern is composed of eight behaviors that involve developing an understanding of the illness or disability and mastering treatment regimens.

Concurrent validity assessments of the CHIP were done using the Family Environment Scale (McCubbin, 1991). The mother's use of the three coping patterns was associated with the family interpersonal relationship dimensions of family life as measured on the Family Environment Scales. Coping Patterns I and III were positively associated with cohesion ( $r = .21, p < .01$ ;  $r = .19, p < .05$ , respectively). Coping Pattern II was positively associated with family expressiveness ( $r = .19, p < .05$ ). The use of Coping Pattern I by the fathers was also positively associated with family cohesion ( $r = .36, p < .01$ ) and inversely related to family conflict ( $r = -.21, p < .05$ ). In fathers' coping, both Patterns I and III were positively associated with system maintenance dimensions of family life.

McCubbin, McCubbin, and Thompson (1991) reported an internal reliability of .79 for both Patterns I and II, and .71 for Pattern III. A second study with only mothers reported internal reliabilities of .95 for Pattern I, .93 for Pattern II, and .91 for Pattern III (McCubbin, 1989). Austin and McDermott (1988) reported coefficient alphas that

ranged from .84 to .89. In this study, the overall coefficient alpha was .90 with .86 for Pattern I, .76 for Pattern II, and .77 for Pattern III.

Family Hardiness Index (FHI). Hardiness is a characteristic that helps families resist stress and cope. The FHI (see Appendix D), used with permission (Appendix C), was developed to measure this characteristic (McCubbin, McCubbin, & Thompson, 1991). The FHI is a 20 item instrument using a "false" (0) to "totally true" (3) Likert scale that families score to rate hardiness. The FHI consists of four subscales: (a) Co-oriented commitment, (b) Confidence, (c) Challenge, and (d) Control. Scoring is accomplished by summing the values of the items in each subscale. Scores can range from 0 to 24 on Co-oriented commitment, from 0 to 12 on Confidence, from 0 to 15 on Challenge, and from 0 to 9 on Control, and from 0 to 60 on the complete FHI.

McCubbin, McCubbin, and Thompson (1991) described the four subscales as follows. The eight item Co-oriented commitment subscale measures the family's sense of their dependability and ability to work together. The Confidence subscale measures the family's sense of being able to plan ahead, ability to endure hardships, and ability to experience life with interest. It consists of four items. The five item Challenge subscale measures the family's attempts to be innovative, active, and learn. The family's sense of being in control of family life is measured by the Control subscale which consists of three items.

McCubbin, McCubbin, and Thompson (1991) reported the overall internal reliability for the FHI using a Cronbach's alpha is .82. Failla and Jones (1991) reported a standardized alpha of .80. In this study, the overall coefficient alpha was .89. On the Co-oriented commitment subscale, Failla and Jones (1991) reported a standardized alpha of .77, .71 on the Confidence, .49 on the Challenge, and .58 on the Control subscales. In this study the internal reliability on the Co-oriented commitment subscale was .81, with .88 on the Confidence, .63 on the Challenge, and .76 on the Control subscales.

Construct validity was established by factor analysis (McCubbin, McCubbin, & Thompson, 1991). Concurrent validity was examined by McCubbin, Thompson, and Pirner as cited in McCubbin, McCubbin, and Thompson. Criterion indices included family flexibility, family time and routines, and quality of family life. The correlations were .22 for family flexibility as measured on the Family Adaptability and Cohesion Evaluation Scales and .23 for family time and routines as measured on the Family Time and Routines scale ( $p = < .05$ ). The correlations ranged from .11 to .20 on family satisfaction, marital satisfaction, and community satisfaction as measured on the Quality of Family Life scale ( $p = < .05$ ). Other reliability and validity statistics are not available according to McCubbin, McCubbin, and Thompson.

Family Adaptability and Cohesion Evaluation Scales II (FACES II). FACES II (see Appendix E), used with permission (Appendix C), was the third instrument used in this study. It was designed to measure family adaptability and family cohesion, factors identified as critical to understanding family systems and their ability to adapt to family stress and crises. In this study, adaptation was defined as the outcome of the family's attempts to balance demands and capabilities (McCubbin, 1991). Cohesion and adaptability measure this outcome.

Family cohesion is the bonding or separateness that family members have toward each other (Olson, Bell, & Portner, 1992). FACES II includes 16 items regarding cohesion. The items assess concepts such as emotional bonding, family boundaries, coalitions, friends, time space, and decision-making. Family adaptability is the ability of a family system to change its power structure, role relationships, and relationship rules in response to stress (Olson et al.). FACES II has 14 items that assess the adaptability concepts of assertiveness, leadership, discipline, negotiations, roles, and rules. Each item, rating how frequently a behavior occurs in the family, is scored on a 5-point Likert scale ranging from "almost never" (1) to "almost always" (5).

Olson, Bell, and Portner (1992) reported an internal consistency of .87 for cohesion and .78 for adaptability. The test-retest after four to five weeks was reported as .83 for cohesion and .80 for adaptability. Concurrent validity assessment of FACES II was done using the Dallas Self-Report Family Inventory. The coefficient alpha for cohesion was .93 while for adaptability it was .79 ( $p < .01$ ) (Hampson, Hulgus, & Beavers, 1991). In this study, the overall coefficient alpha was .84 while the coefficient alpha was .71 for cohesion and .78 for adaptability.

Scoring FACES II is accomplished by summing the scores of the items that represent each dimension in order to obtain total cohesion and total adaptability scores. Each of these scores is used to determine the description of each dimension. Cohesion scores can range from 16 to 80 and adaptability scores can range from 14 to 70. Interpretations of family cohesion range from very connected to disengaged and those of adaptability range from very flexible to rigid. These dimension scores are then used to determine one of eight family types from balanced to extreme (Olson & Tiesel, 1991). The adaptability and cohesion levels and family types are presented in Table 1. In this study, raw scores from each dimension were used for additional data analysis.

Table 1

FACES II Family Types

Family Type Score	Family Type	Adaptability Dimension	Cohesion Dimension
8 7	Balanced	Very Flexible	Very Connected
6 5	Moderately Balanced	Flexible	Connected
4 3	Mid-Range	Structured	Separated
2 1	Extreme	Rigid	Disengaged

Family information. Data regarding the characteristics of the family (see Appendix F) were also collected. These data included: parental ages, employment, education, ethnicity, health, and income. Data regarding the characteristics of the child with a disability included: age, types of disability, health, behavior, the child's activities, and the use of outside assistance.

#### Procedure

Permission to conduct this study was obtained from the Grand Valley State University Human Subjects Review Committee (see Appendix G). Following this approval, the proposal was submitted to the county Community Mental Health Research Committee for approval (see Appendix G).

After permission was granted by the Grand Valley State University Human Subjects Review Committee and the county Community Mental Health Board, a letter was sent to potential subjects (see Appendix A). The letter included information regarding the nature and importance of the research and possible risks and benefits. The questionnaires and stamped, addressed, return envelopes were enclosed with the letter. One week later, a handwritten post card reminder (see Appendix A) was mailed to all potential subjects.

Two areas of potential risk to the subjects were identified. The first was a breach of confidentiality. This risk was minimized as the questionnaires were mailed without coding and the only contact with families was through the mail and subject initiated phone calls. The second potential risk was that of emotional distress. Families were assured that participation was voluntary, anonymous, and without obligation or effect on their services from the agency. The investigator offered to discuss with families issues raised by completing the instruments and to assist with referrals for professional intervention, as needed. No referrals were requested. The agency's professional staff were made aware of the study, although not the identity of subjects, in order to provide additional emotional support or intervention for families if they requested it.

## CHAPTER 4

### DATA ANALYSIS

The purpose of this study was to describe and examine the relationships between family hardiness, family coping, and adaptation in families who have an adult child who is developmentally disabled and living in the parental home. The Family Hardiness Index was used to measure the independent variable, family hardiness. Family coping, a dependent variable was measured on the Coping Health Inventory for Parents. The other dependent variable, family adaptation, was measured on the Family Adaptability and Cohesion Evaluation Scales II. All data were collected by self-administered questionnaires. Data analysis was accomplished using the Statistical Package for Social Sciences (SPSS/Windows) software.

#### Sample Characteristics

Descriptive data were collected on 96 individual parents from 63 families. Data regarding the father, mother, and adult child with a developmental disability were analyzed. Based on the adult child's level of mental retardation, groups of families were established. Instruments were completed by fathers in four families (6%), mothers in 47 families (75%), and by both mother and father in 11 families (18%). One family did not provide this information. In the families of those with mild mental retardation, instruments were completed by two fathers (12%), by both parents in three families (18%), and by 12 mothers (71%). In the families of those with moderate mental retardation, instruments were completed by the father in one family (5%), by both parents in three families (14%), and by mothers in 18 families (82%). Instruments were completed by one father (4%), five by both parents (22%), and 17 mothers (74%) in

families with an adult child with severe/profound mental retardation. The groups were similar in education, ethnicity, health and income. However, the parents of children with a severe/profound impairment tended to be younger and more worked over 20 hours a week. As an oversight, data regarding parents' marital status was not collected. A summary of the descriptive data about the parents is presented in Table 2.

The sample families also included 63 adult children with mental retardation. The sample was comprised of 41 males (65%) and 20 females (33%). Gender was not indicated by two families. The ages of the adult children ranged from 18 to 58 with a mean age of 35. Among the groups based on the adult child's level of mental retardation, one similarity was health status ratings. However, several differences were noted among the groups. The group with severe/profound mental retardation tended to be younger, have more problems with behavior, and had more individuals for whom the parents anticipated a decline in the health of the adult child. Cerebral Palsy and Epilepsy were diagnosed in a larger percentage of the group with severe/profound mental retardation. In addition, the only individuals diagnosed with Autism were in this group. Only 22 adult children had a specific diagnosis. A summary of the data describing the adult children is presented in Table 3.

### Hypotheses

Hypothesis 1. It was hypothesized that parents who had an adult child with a developmental disability and higher levels of family hardiness would also have higher levels of family coping and family adaptation, regardless of their levels of stress. The relationship between the subjects' family hardiness and their adaptation was examined to determine if a significant relationship existed.

The Family Hardiness Index scores were used as the measure of family hardiness while FACES II dimensions of adaptability and cohesion were used to measure family adaptation (see Table 4 for scores on all instruments). The FACES II family type was

Table 2

Family Characteristics by Level of Mental Retardation (N = 96; 63 families)

Variable	<u>Mild</u> (17 families)		<u>Moderate</u> (23 families)		<u>Sev/Prof.</u> (23 families)	
	Father	Mother	Father	Mother	Father	Mother
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Employment						
Not employed	7 (41)	11 (65)	8 (35)	17 (74)	6 (26)	14 (61)
Employed < 20 hr/wk	1 ( 6)	1 ( 6)	---	2 ( 9)	---	2 ( 9)
Employed > 20 hr/wk	2 (12)	3 (18)	3 (13)	4 (17)	11 (48)	5 (22)
Education						
< than high school	2 (12)	2 (12)	---	2 ( 9)	---	---
Some high school	1 ( 6)	3 (18)	2 ( 9)	3 (13)	---	1 ( 4)
High school	9 (53)	6 (35)	15 (65)	8 (35)	15 (65)	14 (61)
Some college	4 (24)	4 (24)	4 (17)	6 (26)	5 (22)	4 (17)
College grad.	1 ( 6)	2 (12)	1 ( 4)	2 ( 9)	1 ( 4)	3 (13)
Grad. school	---	---	1 ( 4)	2 ( 9)	2 ( 9)	1 ( 4)
Ethnicity						
African American	1 ( 6)	1 ( 6)	3 (13)	4 (17)	1 ( 4)	2 ( 9)
American Indian	---	---	---	---	---	1 ( 4)
Spanish	---	---	---	1 ( 4)	---	---
White	9 (53)	15 (88)	8 (35)	18 (78)	16 (70)	19 (83)
Health						
Excellent	1 ( 6)	3 (18)	1 ( 4)	4 (17)	5 (22)	5 (22)
Good	6 (35)	10 (59)	5 (22)	13 (57)	7 (30)	13 (57)
Fair	1 ( 6)	2 (12)	3 (13)	4 (17)	3 (13)	4 (17)
Poor	1 ( 6)	---	1 ( 4)	2 ( 9)	2 ( 9)	---
Income						
< than adequate		2 (12)		3 (13)		4 (17)
Adequate		13 (77)		20 (87)		17 (74)
> than adequate		2 (12)		---		2 ( 9)
Age Range	40-81	42-75	51-83	39-84	43-86	40-73
Mean Age (SD)	65.6 (10.6)	63 (9.1)	65.2 (7.6)	65.5 (10.1)	59.5 (11)	55.7 (9.8)



Table 4

Scores on Study Instruments for Total Group and by Level of Mental Retardation of Adult Child

Instrument	Total group	Mild	Moderate	Severe/Profound
	<i>M (SD) (Range)</i>	<i>M (SD) (Range)</i>	<i>M (SD) (Range)</i>	<i>M (SD) (Range)</i>
FHH	<i>n</i> = 63	<i>n</i> = 17	<i>n</i> = 23	<i>n</i> = 23
Commitment	19.37 ( 3.85) ( 8-28)	19.00 ( 4.47) ( 8-25)	19.21 ( 3.36) (14-24)	19.78 ( 3.95) (13-28)
Confidence	8.11 ( 3.95) ( 0-12)	8.29 ( 4.28) ( 0-12)	7.61 ( 4.22) ( 0-12)	8.48 ( 3.52) ( 0-12)
Challenge	9.95 ( 2.80) ( 4-15)	10.06 ( 3.27) ( 5-15)	9.82 ( 3.20) ( 4-15)	10.00 ( 2.02) ( 7-14)
Control	5.62 ( 2.59) ( 0- 9)	5.94 ( 2.77) ( 1- 9)	5.52 ( 2.64) ( 0- 9)	5.48 ( 2.48) ( 1- 9)
Total	43.05 (10.46) (18-60)	43.29 (12.77) (18-59)	42.17 (10.41) (23-60)	43.74 ( 8.94) (23-60)
FACES II	<i>n</i> = 56	<i>n</i> = 17	<i>n</i> = 18	<i>n</i> = 21
Cohesion	62.25 (10.92) (35-80)	60.65 (12.10) (35-77)	62.28 (12.02) (37-80)	63.52 ( 9.15) (48-80)
Adaptability	46.79 ( 7.59) (27-62)	45.59 ( 8.40) (32-59)	48.28 ( 6.24) (40-61)	46.47 ( 8.10) (27-62)
CHP	<i>n</i> = 33	<i>n</i> = 8	<i>n</i> = 9	<i>n</i> = 16
Pattern I: family	36.21 (10.16) (16-51)	27.75 ( 8.73) (16-39)	37.00 (11.62) (18-51)	40.00 ( 7.66) (25-50)
Pattern II: support	30.56 ( 7.99) (11-44)	29.25 ( 5.55) (20-39)	29.11 (11.85) (11-43)	31.94 ( 6.62) (20-44)
Pattern III: medical	16.75 ( 4.85) ( 7-24)	14.33 ( 5.03) (10-24)	15.44 ( 5.13) ( 7-23)	18.61 ( 4.08) (10-24)

Table 4

Scores on Study Instruments for Total Group and by Level of Mental Retardation of Adult Child

Instrument	Total group	Mild	Moderate	Severe/Profound
	<i>M (SD) (Range)</i>	<i>M (SD) (Range)</i>	<i>M (SD) (Range)</i>	<i>M (SD) (Range)</i>
FII	<i>n</i> = 63	<i>n</i> = 17	<i>n</i> = 23	<i>n</i> = 23
Commitment	19.37 ( 3.85) ( 8-28)	19.00 ( 4.47) ( 8-25)	19.21 ( 3.36) (14-24)	19.78 ( 3.95) (13-28)
Confidence	8.11 ( 3.95) ( 0-12)	8.29 ( 4.28) ( 0-12)	7.61 ( 4.22) ( 0-12)	8.48 ( 3.52) ( 0-12)
Challenge	9.95 ( 2.80) ( 4-15)	10.06 ( 3.27) ( 5-15)	9.82 ( 3.20) ( 4-15)	10.00 ( 2.02) ( 7-14)
Control	5.62 ( 2.59) ( 0- 9)	5.94 ( 2.77) ( 1- 9)	5.52 ( 2.64) ( 0- 9)	5.48 ( 2.48) ( 1- 9)
Total	43.05 (10.46) (18-60)	43.29 (12.77) (18-59)	42.17 (10.41) (23-60)	43.74 ( 8.94) (23-60)
FACES II	<i>n</i> = 56	<i>n</i> = 17	<i>n</i> = 18	<i>n</i> = 21
Cohesion	62.25 (10.92) (35-80)	60.65 (12.10) (35-77)	62.28 (12.02) (37-80)	63.52 ( 9.15) (48-80)
Adaptability	46.79 ( 7.59) (27-62)	45.59 ( 8.40) (32-59)	48.28 ( 6.24) (40-61)	46.47 ( 8.10) (27-62)
CHIP	<i>n</i> = 33	<i>n</i> = 8	<i>n</i> = 9	<i>n</i> = 16
Pattern I: family	36.21 (10.16) (16-51)	27.75 ( 8.73) (16-39)	37.00 (11.62) (18-51)	40.00 ( 7.66) (25-50)
Pattern II: support	30.56 ( 7.99) (11-44)	29.25 ( 5.55) (20-39)	29.11 (11.85) (11-43)	31.94 ( 6.62) (20-44)
Pattern III: medical	16.75 ( 4.85) ( 7-24)	14.33 ( 5.03) (10-24)	15.44 ( 5.13) ( 7-23)	18.61 ( 4.08) (10-24)

determined as well. The FHI, FACES II adaptability and cohesion, and CHIP coping pattern scores are displayed by the eight FACES II family types in Table 5. A two-tailed Pearson correlation revealed a significant relationship between family hardiness and family adaptability ( $r = .59, df = 56, p = .000$ ) as well as between family hardiness and cohesion ( $r = .51, df = 56, p = .000$ ). Thus family hardiness accounts for 35% of the variance in family adaptability and 26% in cohesion. These indicate that higher family hardiness scores are correlated with higher levels of adaptation and support the first hypothesis.

A one-way ANOVA was completed to determine if a difference existed among the family types and FHI scores  $F(6, 49) = 6.76, p = .000$ . A post hoc analysis was done using the Scheffe. Significant differences in the mean FHI scores among family types 2, Extreme, and 6, Moderately Balanced; 2, Extreme, and 7, Balanced; and 2, Extreme, and 8, Balanced were detected. This indicates that family hardiness scores are significantly higher with higher levels of adaptation and supports the first hypothesis.

The CHIP scores were used as the measure of family coping (see Table 3). Only 36 families (57%) who participated in this study completed some portion of the CHIP. This may have been related to the format of the instrument, its placement in the packet sent to parents, or other factors. Thirty-three families (52%) completed Pattern I items, 34 families completed Pattern II items and Pattern III was completed by 36 families (36%). Twenty-six families (41%) did not complete any of the instrument. The CHIP scores were examined in relation to the FHI to determine if families with higher hardiness also had higher levels of coping. The median FHI score was used to divide the families into two groups, one with lower hardiness and one with higher hardiness. Subsequent t-tests were completed to determine the differences between the scores of the two groups on the CHIP Patterns of Coping (see Table 6). Although statistical significance was achieved only with Pattern III, each coping pattern demonstrates higher

Table 5

Instrument Scores by FACES II Family Type

FAMILY TYPE		FII	CIII Pattern I	CIII Pattern II	CIII Pattern III	Adaptability	Cohesion
(n)		M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)
Balanced							
8	( 4)	57.75 ( 2.06)	45.00 ( 8.49)	35.33 ( 7.77)	18.33 ( 6.03)	60.00 ( 1.83)	76.75 ( 2.75)
7	( 8)	47.38 ( 8.52)	42.00 ( 6.08)	27.33 ( 7.51)	18.67 ( 1.53)	53.13 ( 4.32)	73.38 ( 3.62)
Moderately Balanced							
6	(14)	48.57 ( 7.43)	39.71 ( 8.30)	34.25 ( 5.85)	18.56 ( 4.59)	50.57 ( 3.11)	66.79 ( 5.52)
5	(12)	42.42 ( 7.30)	35.89 (11.85)	27.44 (10.24)	16.11 ( 4.70)	44.42 ( 2.15)	63.33 ( 2.87)
Mid-Range							
4	( 6)	41.33 ( 4.50)	38.75 ( 6.50)	33.67 ( 5.13)	17.25 ( 5.06)	45.50 ( 4.59)	52.00 ( 6.20)
3	( 6)	43.17 ( 9.77)	33.20 ( 6.65)	31.00 ( 8.34)	15.60 ( 6.35)	40.00 ( 2.53)	51.50 (10.21)
Extreme							
2	( 6)	30.67 ( 8.26)	24.67 ( 4.04)	19.00 ( 2.65)	11.00 ( 1.73)	33.50 ( 4.04)	46.00 ( 6.26)
1	( 0)	---	---	---	---	---	---

scores achieved by families with higher hardiness. In addition, Pattern I neared statistical significance ( $p = .058$ ). This also supports the first hypothesis.

Table 6

Coping Health Inventory for Parents Scores by Level of Hardiness

Variables	Low Hardiness		High Hardiness		<i>t</i>
	<i>M (SD)</i>	<i>n</i>	<i>M (SD)</i>	<i>n</i>	
Pattern I (Fam)	33.17 (10.02)	18	39.87 (9.37)	15	-1.97
Pattern II (Sup)	29.76 ( 7.74)	17	31.35 (8.38)	17	-.57
Pattern III (Med)	15.11 ( 4.27)	18	18.39 (4.96)	18	-2.12*

\*  $p < .05$

Hypothesis 2. A second hypothesis was that the level of mental retardation of the adult child would not influence the relationship between family hardiness and family coping and adaptation. One-way ANOVAs were completed to examine the relationships between the level of mental retardation of the adult child and the measure of family hardiness, the FHI (see Table 3). No significant differences were found among the groups' mean scores of the total FHI  $F(2, 60) = .13, p = .88$  and its subscales co-oriented commitment  $F(2, 60) = .22, p = .80$ , confidence  $F(2, 60) = .30, p = .74$ , challenge  $F(2, 60) = .04, p = .96$ , and control  $F(2, 60) = .18, p = .84$ . This indicates no significant difference among groups. One-way ANOVAs were completed to examine the relationships between the level of mental retardation and the measure of family adaptation, the FACES II adaptability and cohesion subscales (see Table 3). No significant differences were found among the groups' mean adaptability scores  $F(2, 53) = .57, p = .57$  or cohesion scores  $F(2, 53) = .32, p = .73$ . This indicates no significant difference among groups.

The relationships among the CHIP's Coping Patterns and the family groups based on the level of mental retardation of the adult child were examined using one-way

ANOVAs. A significant difference was found among mean scores of Coping Pattern I  $F(2, 30) = 4.86, p = .01$ . Post hoc analysis with the Scheffe demonstrated that this difference was between family groups with an adult child who is mildly mentally retarded and family groups with an adult child who is severely/profoundly mentally retarded. No significant differences were found among the groups' scores on Pattern II  $F(2, 31) = .49, p = .61$  or on Pattern III  $F(2, 33) = 3.09, p = .059$ .

A multiple regression analysis using family hardiness, family coping and adaptation as well as other sample characteristic variables (including level of mental retardation) was done. Two equations were run using each measure of family adaptation as the dependent variable. A stepwise procedure was used. The resulting equations are displayed in Tables 7 and 8. The only difference in the two equations is the addition of CHIP Pattern II for cohesion. Level of mental retardation did not load into the regression equation and, therefore, did not affect the relationships among family hardiness and family coping and adaptation. Based on the ANOVA analysis, level of mental retardation may affect CHIP Pattern I.

Table 7

Regression Equation for FACES II: Adaptability

Variables	<i>b</i>	<i>t</i>	<i>p</i>
FHI	.37	3.13	.004
CHIP Pattern I (family)	.28	2.82	.009
Constant	= 19.53		
<i>R</i>	= .69		
<i>R</i> <sup>2</sup>	= .47		
<i>F</i>	= 13.34		
<i>p</i>	= .000		

Table 8

Regression Equation for FACES II: Cohesion

Variables	<i>b</i>	<i>t</i>	<i>p</i>
FHI	.51	2.87	.008
CHIP Pattern II (support)	- .78	-3.46	.002
CHIP Pattern I (family)	.64	3.59	.001
Constant	= 38.45		
<i>R</i>	= .74		
<i>R</i> <sup>2</sup>	= .55		
<i>F</i>	= 11.31		
<i>p</i>	= .000		

Based on these findings, the second hypothesis is partially supported. The level of the adult child's mental retardation does not affect the relationship between family hardiness and family adaptation. It may, however, have some effect on the family's coping. This requires exploration in future study.

Other Findings

Coping Health Inventory for Parents (CHIP). The CHIP Pattern I was rated as most helpful by 19 families (54%). This pattern focuses on strengthening family life and the parental outlook. Nine families (26%) indicated Pattern II which focuses on supportive relationships and enhancing self-esteem while seven families (20%) indicated Pattern III as most helpful. Pattern III focuses on knowledge about medical conditions and relationships centered on medical or health issues.

Pearson correlations were used to determine relationships between CHIP Patterns and other variables (see Tables 9,10, and 11). A small, significant correlation was found between Pattern II and the adult child's behavior ( $r = .35$ ,  $df = 33$ ,  $p = .04$ ). Relationships were found between the adult child's level of mental retardation and Pattern I ( $r = .48$ ,  $df = 33$ ,  $p = .005$ ) and Pattern III ( $r = .39$ ,  $df = 36$ ,  $p = .02$ ). A moderate, significant correlation was found between Coping Pattern III and the commitment dimension of the

FHI ( $r = .41$ ,  $df = 36$ ,  $p = .01$ ). No significant correlations were found between CHIP Coping Patterns and parental characteristics.

The CHIP was completed by fewer study participants than either the FHI or FACES II. Several comments on returned, but incomplete CHIP forms may explain this to a degree. These include: "I don't feel this is [sic] appropriate questions or has any value to having a retarded child," "don't understand & stupid, doesn't apply," "Sorry I can't respond. It's much too long and involved for me now."

Table 9

Correlations Among Instruments and Child Characteristics

Variable	Level of MR	Child's Health	Child's Behavior
Level of MR			
Health	.06		
Behavior	.10	.05	
CHIP I	.48**	-.13	.16
CHIP II	.16	-.32	.35*
CHIP III	.39*	-.28	.24
FHI	.02	-.15	-.02
Commitment	.08	-.00	-.05
Confidence	.03	-.05	.05
Challenge	-.01	-.42**	-.06
Control	-.07	-.07	-.03
Adaptation	.04	-.14	.03
Cohesion	.11	.05	.00

\*  $p \leq .05$  \*\*  $p \leq .01$



Table 10

Correlations Among Instrument Scores

Variable	CHIP I	II	III	FII	Commit	Confid	Challenge	Control	Adapt	Cohes
CHIP I (Fam)		.59*** (n = 32)	.74*** (n = 33)	.34 (n = 33)	.33 (n = 33)	.31 (n = 33)	.25 (n = 33)	-.06 (n = 33)	.55*** (n = 33)	.41* (n = 33)
CHIP II (Supp)			.65*** (n = 34)	.21 (n = 34)	.14 (n = 34)	.14 (n = 34)	.25 (n = 34)	.06 (n = 34)	.32 (n = 34)	-.05 (n = 34)
CHIP III (Med)				.33* (n = 36)	.41** (n = 36)	.25 (n = 36)	.21 (n = 36)	-.05 (n = 36)	.38* (n = 36)	.25 (n = 36)
FII					.78*** (n = 63)	.88*** (n = 63)	.69*** (n = 63)	.78*** (n = 63)	.59*** (n = 56)	.51*** (n = 56)
Commitment						.52*** (n = 63)	.44*** (n = 63)	.39*** (n = 63)	.52*** (n = 56)	.50*** (n = 56)
Confidence							.45*** (n = 63)	.77*** (n = 63)	.40** (n = 56)	.35** (n = 56)
Challenge								.37** (n = 63)	.57*** (n = 56)	.40** (n = 56)
Control									.26* (n = 56)	.24 (n = 56)
FACES Adaptability										.64*** (n = 56)
FACES Cohesion										

\*  $p \leq .05$  \*\*  $p \leq .01$  \*\*\*  $p \leq .001$

Family Hardiness Index (FHI). Pearson correlations were used to explore the relationships between the FHI and other study variables (see Tables 9, 10, and 11). The only characteristic of the adult children to reach significance was health. Children's health was negatively correlated with the challenge dimension of the FHI ( $r = -.42, df = 61, p = .001$ ). This suggests that families of adult children who are healthy tend to be more actively involved in life and new experiences than those families with adult children who have poorer health. Several significant correlations between the subscales of the FACES II and the FHI were revealed. Adaptability was positively correlated with

Table 11

Correlations Among Instruments and Parental/Family Characteristics

Variable	Ftr Age	Mtr Age	Ftr Educ	Mtr Educ	Income
Father's Age					
Mother's Age	.68***				
Father's Educ	-.19	-.18			
Mother's Educ	-.11	-.22	.32*		
Income	.10	.13	.10	.02	
FHI	-.18	-.12	.38**	.27*	.09
CHIP I (Fam)	-.03	.00	-.03	-.14	-.01
CHIP II (Sup)	-.25	-.29	-.09	.21	-.03
CHIP III (Med)	-.15	-.10	-.01	-.15	.08
FACES Adaptability	-.01	.05	.26	.09	.20
FACES Cohesion	.20	.11	.27*	.07	.23

\*  $p \leq .05$  \*\*  $p \leq .01$  \*\*\*  $p \leq .001$

the FHI ( $r = .59, df = 56, p = .00$ ), and the FHI dimensions of co-oriented commitment ( $r = .52, df = 56, p = .00$ ), confidence ( $r = .40, df = 56, p = .002$ ), challenge ( $r = .57, df = 56, p = .00$ ), and control ( $r = .26, df = 56, p = .005$ ). Significant correlations were also

revealed between cohesion and the FHI ( $r = .51, df = 56, p = .000$ ), and the FHI dimensions of confidence ( $r = .35, df = 56, p = .008$ ), challenge ( $r = .40, df = 56, p = .002$ ), and co-oriented commitment ( $r = .50, df = 56, p = .000$ ).

Fathers' education level was positively correlated with the total FHI score ( $r = .38, df = 63, p = .002$ ), co-oriented commitment ( $r = .26, df = 63, p = .04$ ), confidence ( $r = .39, df = 63, p = .002$ ), and control ( $r = .37, df = 63, p = .003$ ). Fathers' health was negatively correlated with the FHI score ( $r = -.39, df = 36, p = .02$ ), confidence ( $r = -.47, df = 36, p = .004$ ), and control ( $r = -.53, df = 36, p = .001$ ). Relationships were also found between mothers' education level and the FHI score ( $r = .27, df = 63, p = .03$ ), and the FHI dimensions of confidence ( $r = .30, df = 63, p = .016$ ), and control ( $r = .31, df = 63, p = .01$ ). These findings indicate higher education levels, especially in fathers, and better health in fathers are associated with higher family hardiness.

Family Adaptability and Cohesion Evaluation Scales (FACES II). Pearson correlations were used to explore relationships between FACES II and other study variables (see Tables 9,10, and 11). No significant relationships were detected between FACES II subscales and characteristics of the adult children. Significant correlations were revealed between adaptability and CHIP Pattern I ( $r = .55, df = 33, p = .001$ ) and Pattern III ( $r = .38, df = 36, p = .02$ ). Significant correlation was noted between cohesion and CHIP Pattern I ( $r = .41, df = 33, p = .02$ ).

The only relationship noted with parental characteristics was with fathers' education. Fathers' education level was positively correlated with adaptability ( $r = .26, df = 56, p = .05$ ) and cohesion ( $r = .27, df = 56, p = .04$ ).

Family data. Families were also asked to identify what was most helpful for their adaptation to having a child with a disability. Eight (13%) of the 63 families provided no answer and two (3%) indicated "nothing" was helpful. Ten families (16%) reported faith, God, or prayer as the most helpful. School or teachers and time/experience were each reported as most helpful by five of the families (8%). Love and others with a child with a

disability were each reported by three families (5%). Four (6%) listed the mental health agency which provided the names of families for this study.

Families were also asked what was least helpful for their adaptation. Twenty-nine (46%) families did not answer and four (6%) indicated "nothing." Four (6%) indicated lack of support from friends and/or family. Teachers/school, outside advice, and doctors were each identified by three families (5%) as the least helpful.

Families were surveyed about the strengths that assisted their family to adjust. Eleven (17.5%) provided no answer and one (2%) indicated "nothing." Religion and/or faith was indicated by 27 families (43%) as a strength. Fourteen (22%) reported love and/or caring as a family strength. Four (6%) indicated help from family members.

Data were also collected regarding their family weaknesses that hindered adjustment. Twenty-four (38%) did not answer and 11 (17.5%) indicated "nothing." Too many demands and too few hours were reported by five (8%) of the families. Five (8%) also indicated others in the family being ill or disabled as a weakness.

### Summary

Data analysis indicates parents who report higher levels of family hardiness tend to report higher levels of family coping and adaptation, thus supporting the first hypothesis. It also reveals the adult child's level of mental retardation has no influence on the relationship between family hardiness and family adaptation. The adult child's level of mental retardation has some influence on family coping. Therefore, the second hypothesis is partially supported. The factors found to be predictive of family adaptation include: CHIP Patterns I and II, and the FHI.

## CHAPTER 5

### DISCUSSION AND IMPLICATIONS

#### Discussion Related to Hypotheses

The findings of this study support the hypothesis that parents who have an adult child with a developmental disability and have higher levels of family hardiness also have higher levels of family coping and family adaptation regardless of their levels of stress. Family adaptation was measured using a scale for both adaptability and cohesion. Although there was only moderate correlation between family hardiness and the two scales measuring family adaptation, 25% of the variance of cohesion and 35% of the variance of adaptability were accounted for by family hardiness. Family coping was only different for families with high and low levels of hardiness on Pattern III of the CHIP. CHIP Pattern I was moderately correlated with adaptability and cohesion. It accounted for 30% of the variance of adaptability and 17% of the variance of cohesion. Pattern II accounted for 14% of the variance of adaptability.

Another hypothesis was that the level of mental retardation of the adult child would not influence the relationship between family hardiness and family coping and family adaptation. Level of mental retardation did not influence the relationship between family hardiness and adaptation. However, one significant difference was noted between the families of those with an adult child with mild mental retardation and those with an adult child with severe/profound mental retardation in coping on CHIP Pattern I. No differences were found among the groups on Pattern II or III. Although level of mental retardation did not effect family hardiness or family adaptation, it may have some effect on family coping. The second hypothesis was partially supported by these findings.

### Discussion Related to Other Findings

Coping Health Inventory for Parents (CHIP). Pattern I, which focuses on strengthening family life and relationships was identified as the most helpful pattern of coping behaviors by the majority of parents in this study. There were significant correlations between this pattern and cohesion and level of mental retardation of the adult child. The correlation between Pattern I and cohesion may be expected since the cohesion scale is a measure of the emotional bonding among family members. Families with adult children who are mildly mentally retarded tended to score significantly lower on Pattern I than the other two groups. This may be a reflection of the particular participants in this study or it may be a difference in coping behaviors brought about by the adult child's unique demands.

Pattern II, which focuses on the parents' efforts to have a sense of well-being obtained through social support, maintain feelings of self-esteem, and deal with psychological strains, was significantly correlated with the adult child's behavior. Parents of children who present more behavioral challenges may find it helpful or easier to use coping skills that facilitate supportive relationships outside of the family. Feeling responsibility for or embarrassment regarding the behavior of the adult child, they may also focus more on maintaining self-esteem.

Pattern III, which focuses on understanding the health care situation and interacting with health care personnel, was correlated with the commitment dimension of the FHI. Commitment is indicative of a sense of meaningfulness and curiosity about life. This correlation may be explained by a family's desire to learn about the child's needs and to focus on mastering them and therefore imparting a sense of meaning to their circumstances.

Family Hardiness Index (FHI). There were no significant differences among the three groups for the scores on the four dimensions of the FHI. The FHI demonstrated significant correlations with the adaptability and cohesion scores of the FACES. This

suggests a positive relationship between a family's beliefs, outlook on life and its challenges and their ability to achieve balance in their emotional bonding and ability to change in response to stress.

The FHI scores were positively correlated with the parents' education level. This suggests family hardiness increases with more education. Correlations were also noted between fathers' education level and the dimensions of confidence, commitment, and control. The mothers' education level was correlated with the dimensions of confidence and control. The experiences one gains from education may increase one's ability to assess life situations, see them as challenges, and feel as if one has control. Negative correlations were noted between fathers' health and FHI, confidence, and control. These indicate better health in fathers is related to higher levels of hardiness, confidence, and control.

#### Relationship of Findings to Conceptual Framework

This study was guided by two conceptual frameworks: the Typology Model of Adjustment and Adaptation (McCubbin, Thompson, Pirner, & McCubbin, 1988) and hardiness (Kobasa, 1979). Both were useful in this study. The Typology Model was helpful in that it includes various factors that influence a family's adaptation. It recognizes family adaptation as a complex and continually changing process. Hardiness provided the definitions of the beliefs and outlook which function to help families achieve healthy adaptation.

This study demonstrated that 47% of the variance of adaptability and 55% of the variance of cohesion were accounted for by family hardiness and various coping methods. The remaining variance may be attributed to other factors included in the Typology Model framework such as the "pile-up" of demands, other family strengths, the family's schema or beliefs, and their problem solving responses which were not addressed in this study.

### Discussion of Findings Related to Previous Findings

Coping. Austin and McDermott (1988) and Failla and Jones (1991) found the CHIP's Pattern I to be most helpful to parents of children with developmental disabilities. This was consistent with the findings of this study. The CHIP's mean scores in this study were somewhat lower than those found by Failla and Jones and by McCubbin (1989). Given the missing data on the CHIP in this study, this may not be an accurate representation of the population.

Hardiness. The mean FHI scores in this study were lower than those reported by Fink (1995) and Donnelly (1994). In this study, family hardiness was not significantly correlated with the CHIP Patterns. This was in contrast to the Failla and Jones (1991) findings. This may be a reflection of the small number of subjects who completed the CHIP in this study. This finding suggests coping and hardiness are two different concepts and behaviors. Both are important in understanding families.

Family hardiness was correlated with family adaptation in this study. This is consistent with previous research that indicated hardiness acts as a resource to diminish the effects of stress, increase social support, and facilitate adaptation (Bigbee, 1992; Donnelly, 1994; Failla & Jones, 1991; Fink, 1995; Ganellen & Blaney, 1984; Kobasa, 1979; Kobasa, Maddi, & Kahn, 1982; Milne et al., 1994).

Adaptation. Austin and McDermott (1988) found parents who had a positive attitude had more positive coping and adaptation. In addition, there was a positive correlation between parental attitude and length of time their child had been diagnosed with epilepsy. These findings are supported by this study. Although the mean scores of the FACES are slightly lower than those reported by Olson, Bell, and Portner (1992) and Donnelly (1994) in the current study, only six of 56 families scored in the extreme range of family types. Given the nature of the adult children's disabilities, the families in this study have been aware of their child's diagnoses for a period of time. Generally, most of these adult children have lived with their parents most of their lives. Time may also have



been a factor influencing family adaptation in this study. It was reported by families as having been helpful in their adaptation.

Level of mental retardation was not correlated with the family adaptation measures in this study. This was consistent with Bristol's (1987) and Trute and Hauch's (1988) findings.

Behavior problems of the adult child was correlated with only CHIP Pattern II (maintaining support and self-esteem). It was not a significant factor in the multiple regression analysis of adaptation in this study. Friedrich, Wilturner, and Cohen (1985) also found a relationship between parental coping and the child's behavior.

#### Limitations and Recommendations for Future Research

The generalizability of the findings of this research study is limited by its small, non-random sample. A research design incorporating random sampling and a larger sample could facilitate generalizability. Enhanced recruitment strategies could improve participation. Moriarty (1990) reports giving parents a sense of control over the process and contacting families in the evening as helpful for recruitment efforts. The sample appears to be reflective of the families served by the agency that helped identify participants for this study. The target population of adult children is comprised of 52% males and 48% females with a mean age of 36 years. The study sample of adult children is comprised of 65% males and 35% females with a mean age of 35 years. The sample obtained for this study tended to be homogeneous in several variables. Eighty-seven percent of the parents in the study sample are at least high school graduates, 86% are white, 76% have good or excellent health, and 86% have incomes that are adequate or more than adequate to meet family needs. Additionally, the sample was drawn from only one site. Although having a homogeneous sample was useful to compare some variables, a more heterogeneous group may provide more data. Use of multiple research sites is recommended.

Another limitation of this study was the reliance on self-report questionnaires that were primarily completed by mothers. A research design incorporating observation and assessment of the families' adaptation as well as collecting data from other household members may provide a more complete description of family coping, hardiness, and adaptation.

Generally, the instruments used in this study tend to reflect values frequently held by the middle and upper classes. For example, personal growth and having an active rather than passive orientation to managing stressful situations may not be held in high regard by those who do not have adequate food, housing, or emotional strength. This was a limitation.

Another limitation of this study was the limited response in completing the CHIP. This may be attributed to the way the study instruments were arranged in a packet or the directions on the instrument form. Fifty-two percent of the families completed this instrument. In addition, the CHIP focuses only on parental coping behaviors that are viewed as adaptive or positive. Therefore, negative coping strategies such as overprotection or withdrawal were not measured.

Another limitation in this study was the failure to obtain complete demographic data. Data regarding the parents' marital status and presence of and role of other siblings in the home were not sought. Pruchno, Patrick, and Burant (1996) and Seltzer et al. (1991) note the importance of siblings involvement in the lives of and planning for adults with disabilities. Limited information was obtained on the adult child's functional abilities and behaviors. A more complete description may have revealed other patterns or relationships.

Although several issues have recently been raised regarding the concept of hardiness, the results of this study encourage future research in family hardiness. At issue are the concept's somewhat judgmental nature, its gender and class bias, and determining if hardiness is a trait that helps mediate stress, or a benefit of having a strong

support network (Jennings & Staggers, 1994; Low, 1996; Tartasky, 1993). Further research is needed to answer these concerns as well as gain additional knowledge on the role family hardiness has in family coping and adaptation. Longitudinal studies of families, their hardiness, coping and adaptation are needed. Additional study is needed to explore the effect level of mental retardation and the presence of the adult child in the parental home have on family coping and family adaptation. The study of family hardiness needs to include families with and without members with disabilities. If family hardiness continues to be seen as a resource for healthy adaptation, future research must focus on fostering family hardiness as well as examining interventions that promote family hardiness.

#### Implications for Nursing

The changes in public policies for the provision of mental health services and managed care ensure that nurses in most health settings will provide care to individuals who have a developmental disability and to their families. While some families have adapted well to having a child with a developmental disability, others have not. This study has supported the relationship between family hardiness, family coping, and adaptation. It also showed level of mental retardation does not affect those relationships. These findings emphasize the importance for nurses to be cognizant of family hardiness and family adaptation.

Nurses providing care to families with adult children with developmental disabilities living in the home must work with them to systematically assess their coping, hardiness, and adaptation. Families at higher risk for poor adaptation must be identified. Some of the instruments used in this study are easily accessible and can be administered without difficulty. They are not too time consuming and can be used in most settings. Nurses must be prepared to help families strengthen their coping efforts. This may be accomplished by referrals for appropriate services or by direct clinical practice for the advanced practice nurse. The advanced practice nurse must be prepared to provide

individual and family counseling for grief and loss issues, anger management, behavioral intervention, and coping strategies in order to promote healthy family adaptation (Heller & Factor, 1993). Support and educational groups could be an effective means for families to learn and share coping skills. However, Krahn (1993) cautions it may be counterproductive to encourage a family, already too stressed to maintain their preexisting supports, to participate in a support group.

Many parents have cared for an adult child with a developmental disability living in their home since the child's birth. This perpetual caregiving may have affected the parents' health, financial, and emotional status. In addition, aging parents may have be experiencing their own age-related struggles at the same time their adult child needs additional functional support as a result of aging (Kelly & Kropf, 1995). In considering the ages of the subjects in this study, it is apparent nurses must be prepared to assist families with their adaptation in relating to an adult child, to aging, and the need to prepare for the future of the adult child with a developmental disability (Hurley & Sovner, 1993; Pruchno et al., 1996; O'Malley, 1996). Griffiths and Unger (1994) report this may be a distressing time for families especially is there are different expectations between parental and sibling expectations.

Although the focus of this research study has been the family, nurses must be prepared to intervene with the individual who has a developmental disability. They too have a full range of emotions and life stage challenges. In addition, there is an increased prevalence of psychiatric disorders in persons with mental retardation (Vitiello & Behar, 1992). How the individual copes and adapts influences the family's adaptation. The advanced practice nurse must be prepared to recognize and participate in the treatment of psychiatric disorders in this population. Individual counseling and group therapy can be effective interventions provided by the advanced practice nurse.

The findings of this study also suggest an educational role for nurses. Nurses need to be prepared to educate the individual, the family, other societal groups, and other

nurses about coping, adaptation, and hardiness. As individuals learn better problem solving and coping, their self-esteem and ability to relate or work with others improves. The advanced practice nurse will be able to educate and consult with other health team members on family coping, hardiness, and adaptation and their effects on families seeking services. In addition, nurses must be sensitive to the impact of aging and developmental disabilities, the impact of each on the other, and be able to educate families and other health care providers (Parkinson & Howard, 1996).

The results of this study are of importance to nurses in administrative roles. The advanced practice nurse may use leadership skills in order to have an active role in determining health care and service provision policies, participate in quality assurance activities, and lead interdisciplinary committees or projects that affect families and their adult children with a developmental disability. The nurses' knowledge of families and their coping and adaptation is crucial. Nurses with this knowledge will be able to assist organizations in determining effectiveness of services and efficacy of service provision.

Nurses also have a role in advocacy. After a systematic assessment of the family, the nurse may determine a need for advocacy. This may focus on an individual or the family. The nurse may assist the family in "allowing" a person with a developmental disability take an appropriate risk in order to facilitate growth and independence rather than continue a family's pattern of overprotection. It may focus on advocating at an administrative level for time to intervene with a family to strengthen their coping skills. Families who are able to cope well are better able to provide health care for their members (McCubbin, 1984).

This study demonstrates the need for nursing to have a role in continuing research on family coping, hardiness, and adaptation. Future research will provide additional knowledge for the foundation of nursing practice as well as on the effectiveness of educational and psychosocial interventions.

Nursing not only promotes health or recovery from illness. Nursing also supports and enhances a family's strengths, assists families in maintaining their support systems, and assists families in evaluating what is best for them given their situation. Family hardiness is a strength families have to manage the impact of stressors and strains. It is an adaptation resource. Family adaptation is a complex, changing process. Nurses have a responsibility to assist families in this process.

## APPENDICES

## APPENDIX A

### Communications to Study Participants



## APPENDIX A

April 25, 1996

Dear Parent:

As you know, many families with a child with a developmental disability experience a greater level of stress than similar families who have a child without a developmental disability. This stress may cause additional difficulties for families. You, as the parent(s) of an adult child who is developmentally disabled, are a very important source of information. You have been randomly selected from a list of families at Kent Client Services to participate in a research study on the ways families with an adult child have dealt with that stress. I hope the information you share will help identify the factors that lead to increased stress and the factors that have helped families adapt successfully. This information will be useful to families as well as nurses and other professional who work with families.

Permission to use this list was given by Kent Client Services and by Kent County Community Mental Health. Every effort will be made to protect your confidentiality. All data will be collected anonymously. Data will only be reported as group data. It is not anticipated you will be harmed in any way by participating in this study. In the event, however, you wish to discuss issues which arise from completing the questionnaires, please feel free to contact me. If you should require a referral to another professional, I will refer you to appropriate resources. I will not accept any financial responsibility for these referrals. Your decision to participate or not participate in this study shall in no way influence or affect the services your family receives from KCS.

A postage-paid return envelope has been provided for you to return the questionnaires. Return of the completed questionnaires indicates consent to participate. I hope you will take the approximately 30 minutes to complete the enclosed questionnaires. I would appreciate you returning the questionnaires by May 10, 1996. If you would like a summary of my findings, please write your name and address on a separate piece of paper and enclose it in the return envelope. PLEASE DO NOT WRITE YOUR NAME ON THE QUESTIONNAIRES.

Your help is very much appreciated. I am conducting this research study in order to fulfill part of the requirements for earning a Master's degree in Nursing through Grand Valley State University. If you have any questions regarding this, please feel free to contact me at Kent Client Services (774-0853).

Sincerely,



Jo VanSolkema, R.N., B.S.N.

## APPENDIX A

5/4/96

Dear Parent:

Thank you so much for completing the survey forms for me. I really appreciate your efforts! If you haven't completed the forms yet, please take a few minutes to do so. Your family's observations are very important to me. Please call me at (616) 774 0853 if you have any questions or concerns. Again, THANK YOU.

Jo VanSolkema

## APPENDIX B

### Coping Health Inventory for Parents

## APPENDIX B



FAMILY STRESS COPING AND HEALTH PROJECT  
1200 Linden Drive  
University of Wisconsin-Madison  
Madison, WI 53706

# CHIP

FORM D  
1983  
H. McCubbin

## COPING-HEALTH INVENTORY FOR PARENTS

### Family Health Program

Hamilton I. McCubbin Marilyn A. McCubbin Robert S. Nevin Elizabeth Cauble

#### PURPOSE

CHIP - The Coping-Health Inventory for Parents was developed to record what parents find helpful or not helpful to them in the management of family life when one or more of its members is ill for a brief period or has a medical condition which calls for continued medical care. Coping is defined as personal or collective (with other individuals, programs) efforts to manage the hardships associated with health problems in the family.

#### DIRECTIONS

- To complete this inventory you are asked to read the list of "Coping behaviors" below, one at a time.
- For each coping behavior you used, please record how helpful it was.

*HOW HELPFUL* was this COPING BEHAVIOR to you and/or your family: Circle ONE number

- 3 = *Extremely* Helpful
- 2 = *Moderately* Helpful
- 1 = *Minimally* Helpful
- 0 = *Not* Helpful

- For each Coping Behavior you did *Not* use please record your "Reason."

Please *RECORD* this by *Checking* ☐ one of the reasons:

Chose not to use it      Not Possible

☐      or      ☐

PLEASE BEGIN: Please read and record your decision for EACH and EVERY Coping Behavior listed below.

COMPUTER CODES: IID ☐☐☐☐ GID ☐☐☐ FAMID ☐☐☐☐

F 4218

# APPENDIX B

COPING BEHAVIORS	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I do not code this way because		For Computer Use Only			
					Chose Not To	Not Possible	F	S	M	
1 Trying to maintain family stability	3	2	1	0			12			
2 Engaging in relationships and friendships which help me to feel important and appreciated	3	2	1	0						
3 Trusting my spouse (or former spouse) to help support me and my child(ren)	3	2	1	0						
4 Sleeping	3	2	1	0						
5 Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center	3	2	1	0						
6 Believing that my child(ren) will get better*	3	2	1	0						
7 Working outside employment	3	2	1	0						
8 Showing that I am strong	3	2	1	0						
9 Purchasing gifts for myself and/or other family members	3	2	1	0						
10 Talking with other individuals/parents in my same situation	3	2	1	0						
11 Taking good care of all the medical equipment at home	3	2	1	0						
12 Eating	3	2	1	0						
13 Getting other members of the family to help with chores and tasks at home	3	2	1	0						
14 Getting away by myself	3	2	1	0						
15 Talking with the Doctor about my concerns about my child(ren) with the medical condition*	3	2	1	0						
16 Believing that the medical center/hospital has my family's best interest in mind	3	2	1	0						
17 Building close relationships with people	3	2	1	0						
18 Believing in God	3	2	1	0						
19 Develop myself as a person	3	2	1	0						
20 Talking with other parents in the same type of situation and learning about their experiences	3	2	1	0						
21 Doing things together as a family (involving all members of the family)	3	2	1	0						
22 Investing time and energy in my job	3	2	1	0						
23 Believing that my child is getting the best medical care possible*	3	2	1	0			34			
24 Entertaining friends in our home	3	2	1	0			36			
25 Reading about how other persons in my situation handle things	3	2	1	0						
26 Doing things with family relatives	3	2	1	0						
27 Becoming more self-reliant and independent	3	2	1	0						
28 Telling myself that I have many things I should be thankful for	3	2	1	0						
29 Concentrating on hobbies (art, music, jogging, etc.)	3	2	1	0						
30 Explaining our family situation to friends and neighbors so they will understand us	3	2	1	0						
31 Encouraging child(ren) with medical condition to be more independent*	3	2	1	0						
32 Keeping myself in shape and well-groomed	3	2	1	0						
33 Involvement in social activities (parties, etc.) with friends	3	2	1	0						
34 Going out with my spouse on a regular basis	3	2	1	0						
35 Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	3	2	1	0						
36 Building a closer relationship with my spouse	3	2	1	0						
37 Allowing myself to get angry	3	2	1	0						
38 Investing myself in my child(ren)	3	2	1	0						
39 Talking to someone (not professional counselor/doctor) about how I feel	3	2	1	0						
40 Reading more about the medical problem which concerns me	3	2	1	0						
41 Talking over personal feelings and concerns with spouse	3	2	1	0						
42 Being able to get away from the home care tasks and responsibilities for some relief	3	2	1	0						
43 Being able to deal with the medical condition when at the medical center or hospital	3	2	1	0						
44 Believing that I am not and always will not	3	2	1	0						
45 Doing things with my children	3	2	1	0						

PLEASE Check all 45 items to be sure you have either circled a number or checked a box for each one. This is important.

FAM ☐ 29  
SUP ☐ 30  
MED ☐ 36

## APPENDIX C

### Permission to Use Instruments

## APPENDIX C



July 11, 1995

Joan M. VanSolkema  
2251 S. Saulk, #203  
Grand Rapids, MI 49506

Dear Ms. VanSolkema:

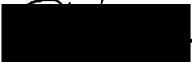
I am pleased to give you my permission to use the **FILE: Family Inventory of Life Events and Changes** (McCubbin, H., Patterson, J., Wilson, L.) and the **CHIP: Coping Health Inventory for Parents** instruments. We have a policy to charge \$5.00 (one time charge only) *per instrument* to individuals who seek permission. We apologize for this necessity. We also ask that you please fill out the enclosed abstract form and return it to this office.

The manual, **Family Assessment Inventories for Research and Practice, Second Edition** should be cited when using the instrument. The publication is currently out of print while a new edition is being compiled. However, we are making packets available for each instrument including scoring, psychometric data and theoretical information at a cost of \$15.00 per packet. It is not advisable to use the **Family Inventories** manual by David Olson to score the instrument due to errors in its scoring section.

A sample copy of each instrument is enclosed. Additional copies can be obtained at this address for 10 cents each. When large quantities are requested, the cost of postage is also added to the order.

If I could be of any further assistance to you, please let me know.

Sincerely,

  
Hamilton I. McCubbin  
Dean

HIM/kme

Enclosures

Office of the Dean  
School of Family Resources and Consumer Sciences

---

1300 Linden Drive    Madison, Wisconsin 53706-1575    608/262-4847    FAX 608/262-5335

## APPENDIX C

October 9, 1995

Joan M. VanSolkema  
2251 S. Saulk, #203  
Grand Rapids, MI 49506

Dear Joan:

You have permission to include a copy of the Coping Health Inventory for Parents (CHIP), the Family Hardiness Index (FHI), the Family Inventory of Life Events and Changes (FILE), and the Family Index of Resiliency and Adaptation-General (FIRA-G) in an appendix of your thesis regarding stress, coping, family hardiness in families with a child with a developmental disability.

Sincerely,

A black rectangular redaction box covering the signature of the sender.



## APPENDIX C



FAMILY STRESS, COPING, AND HEALTH PROJECT  
School of Family, Resources and Consumer Sciences  
University of Wisconsin-Madison  
1300 Linden Drive  
Madison, Wisconsin 53706  
608-262-5712

July 11, 1995

Joan M. VanSolkema  
2251 S. Saulk, #203  
Grand Rapids, MI 49506

Dear Ms. VanSolkema:

I am pleased to give you my permission to use the **Family Hardiness Index**. We have a policy to charge \$5.00 (one time charge only) *per instrument* to individuals who seek permission. We apologize for this necessity. Please fill out the enclosed form and return to the address above.

The manual, **Family Assessment Inventories for Research and Practice, Second Edition** should be cited when using the instrument. The publication is currently out of print while a new edition is being compiled. However, we are making packets available for each instrument including scoring, psychometric data and theoretical information at a cost of \$15.00 per packet.

Also enclosed is a sample copy of the instrument. Additional copies can be obtained at this address for 10 cents each. If a large number of additional copies are ordered, the cost of postage is also added to the order. However, by obtaining permission to use the instrument, you do also obtain permission to Xerox copies.

If I could be of any further assistance to you, please let me know.

Sincerely,

Marilyn McCubbin  
Associate Professor

MM/kme  
Enclosures

## APPENDIX C

### UNIVERSITY OF MINNESOTA

---

*Twin Cities Campus*

*Family Social Science  
College of Human Ecology*

*290 McNeut Hall  
1945 Buford Avenue  
St. Paul, MN 55108  
612-625-7250  
Fax: 612-625-4227*

### PERMISSION TO USE FACES II

I am pleased to give you permission to use **FACES II** in your research project, teaching or clinical work with couples or families. You may either duplicate the materials directly or have them retyped for use in a new format. If they are retyped, acknowledgment should be given regarding the name of the instrument, the developer's name and the University of Minnesota.

In exchange for providing this permission, we would appreciate a copy of any papers, theses or reports that you complete using **FACES II**. This will help us to stay abreast of the most recent developments and research regarding this scale. We thank you for your cooperation in this effort.

In closing, I hope you find **FACES II** of value in your work with couples and families. I would appreciate hearing from you as you make use of this inventory.

Sincerely,



David H. Olson, Ph.D.  
Professor

## APPENDIX C

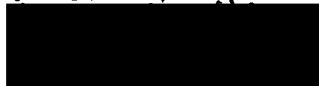
March 11, 1996

Joan M. VanSolkema  
2251 S. Saulk #203  
Grand Rapids, MI 49506

Dear Joan:

You have permission to include a copy of FACES II in an appendix of your thesis regarding stress, coping, adaptation, and family hardiness in families with a child with a developmental disability. I am aware that University Microfilms, Incorporated may supply single copies on demand.

Sincerely,



David H. Olson, Ph.D.  
Professor

## APPENDIX D

### Family Hardiness Index

## APPENDIX D

	Family Stress Coping and Health Project 1300 Linden Drive University of Wisconsin-Madison Madison, Wisconsin 53706	<b style="font-size: large;">FAMILY HARDINESS INDEX ©</b>  Marilyn A. McCubbin    Hamilton I. McCubbin    Anne I. Thompson
---	--	--

**Directions:**

Please read each statement below and decide to what degree each describes your family. Is the statement **False (0), Mostly False (1), Mostly True (2), or Totally True (3)** about your family? Circle a number 0 to 3 to match your feelings about each statement. Please respond to each and every statement.

IN OUR FAMILY .....	False	False	Mostly True	True	Not Applicable
1. Trouble results from mistakes we make	0	1	2	3	NA
2. It is not wise to plan ahead and hope because things do not turn out anyway	0	1	2	3	NA
3. Our work and efforts are not appreciated no matter how hard we try and work	0	1	2	3	NA
4. In the long run, the bad things that happen to us are balanced by the good things that happen	0	1	2	3	NA
5. We have a sense of being strong even when we face big problems	0	1	2	3	NA
6. Many times I feel I can trust that even in difficult times that things will work out	0	1	2	3	NA
7. While we don't always agree, we can count on each other to stand by us in times of need	0	1	2	3	NA
8. We do not feel we can survive if another problem hits us	0	1	2	3	NA
9. We believe that things will work out for the better if we work together as a family	0	1	2	3	NA
10. Life seems dull and meaningless	0	1	2	3	NA
11. We strive together and help each other no matter what	0	1	2	3	NA
12. When our family plans activities we try new and exciting things	0	1	2	3	NA
13. We listen to each others' problems, hurts and fears	0	1	2	3	NA
14. We tend to do the same things over and over .... its boring	0	1	2	3	NA
15. We seem to encourage each other to try new things and experiences	0	1	2	3	NA
16. It is better to stay at home than go out and do things with others	0	1	2	3	NA
17. Being active and learning new things are encouraged	0	1	2	3	NA
18. We work together to solve problems	0	1	2	3	NA
19. Most of the unhappy things that happen are due to bad luck	0	1	2	3	NA
20. We realize our lives are controlled by accidents and luck	0	1	2	3	NA

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## **APPENDIX E**

### **FACES II: Family Version**

## APPENDIX E

<h2 style="margin: 0;">FACES II: Family Version</h2> <p style="margin: 0;">David H. Olson, Joyce Portner &amp; Richard Bell</p>				
1	2	3	4	5
Almost Never	Once in Awhile	Sometimes	Frequently	Almost Always
<b>Describe Your Family:</b>				
<input type="checkbox"/> 1. Family members are supportive of each other during difficult times. <input type="checkbox"/> 2. In our family, it is easy for everyone to express his/her opinion. <input type="checkbox"/> 3. It is easier to discuss problems with people outside the family than with other family members. <input type="checkbox"/> 4. Each family member has input regarding major family decisions. <input type="checkbox"/> 5. Our family gathers together in the same room. <input type="checkbox"/> 6. Children have a say in their discipline. <input type="checkbox"/> 7. Our family does things together. <input type="checkbox"/> 8. Family members discuss problems and feel good about the solutions. <input type="checkbox"/> 9. In our family, everyone goes his/her own way. <input type="checkbox"/> 10. We shift household responsibilities from person to person. <input type="checkbox"/> 11. Family members know each other's close friends. <input type="checkbox"/> 12. It is hard to know what the rules are in our family. <input type="checkbox"/> 13. Family members consult other family members on personal decisions. <input type="checkbox"/> 14. Family members say what they want. <input type="checkbox"/> 15. We have difficulty thinking of things to do as a family. <input type="checkbox"/> 16. In solving problems, the children's suggestions are followed. <input type="checkbox"/> 17. Family members feel very close to each other. <input type="checkbox"/> 18. Discipline is fair in our family. <input type="checkbox"/> 19. Family members feel closer to people outside the family than to other family members. <input type="checkbox"/> 20. Our family tries new ways of dealing with problems. <input type="checkbox"/> 21. Family members go along with what the family decides to do. <input type="checkbox"/> 22. In our family, everyone shares responsibilities. <input type="checkbox"/> 23. Family members like to spend their free time with each other. <input type="checkbox"/> 24. It is difficult to get a rule changed in our family. <input type="checkbox"/> 25. Family members avoid each other at home. <input type="checkbox"/> 26. When problems arise, we compromise. <input type="checkbox"/> 27. We approve of each other's friends. <input type="checkbox"/> 28. Family members are afraid to say what is on their minds. <input type="checkbox"/> 29. Family members pair up rather than do things as a total family. <input type="checkbox"/> 30. Family members share interests and hobbies with each other.				

UNIVERSITY OF MINNESOTA

## APPENDIX F

### Family Information



## APPENDIX F

### FAMILY INFORMATION

**PLEASE COMPLETE THE REQUESTED INFORMATION FOR EACH PARENT WHO LIVES WITH YOUR CHILD WHO HAS A DISABILITY:**

**INDICATE YEAR OF BIRTH OF EACH PARENT:**

Father

Mother

\_\_\_\_\_

\_\_\_\_\_

**Employment: (CHECK WHICH APPLIES FOR EACH PARENT)**

Father

Mother

\_\_\_\_\_

Not employed

\_\_\_\_\_

\_\_\_\_\_

Employed less than 20 hours/week

\_\_\_\_\_

\_\_\_\_\_

Employed 20 or more hours/week

\_\_\_\_\_

\_\_\_\_ Yes \_\_\_\_ No

My employment feels stable

\_\_\_\_ Yes \_\_\_\_ No

**Education: (CHECK HIGHEST LEVEL ACHIEVED FOR EACH PARENT)**

\_\_\_\_\_

Less than high school

\_\_\_\_\_

\_\_\_\_\_

Some high school

\_\_\_\_\_

\_\_\_\_\_

High School

\_\_\_\_\_

\_\_\_\_\_

Some college

\_\_\_\_\_

\_\_\_\_\_

College graduate

\_\_\_\_\_

\_\_\_\_\_

Graduate school

\_\_\_\_\_

**Ethnicity: (CHECK WHICH APPLIES FOR EACH PARENT)**

\_\_\_\_\_

African-American

\_\_\_\_\_

\_\_\_\_\_

American Indian

\_\_\_\_\_

\_\_\_\_\_

Asian

\_\_\_\_\_

\_\_\_\_\_

Mid-Eastern

\_\_\_\_\_

\_\_\_\_\_

Spanish

\_\_\_\_\_

\_\_\_\_\_

White

\_\_\_\_\_

\_\_\_\_\_

Other

\_\_\_\_\_

**Health: (CHECK WHICH APPLIES FOR EACH PARENT)**

\_\_\_\_\_

Excellent

\_\_\_\_\_

\_\_\_\_\_

Good

\_\_\_\_\_

\_\_\_\_\_

Fair

\_\_\_\_\_

\_\_\_\_\_

Poor

\_\_\_\_\_

**Income: (CHECK WHICH APPLIES)**

\_\_\_\_\_

Less than adequate to meet family needs

\_\_\_\_\_

Adequate to meet family needs

\_\_\_\_\_

More than adequate to meet family needs

## APPENDIX F

### DESCRIBE YOUR CHILD WITH A DEVELOPMENTAL DISABILITY:

Year of Birth \_\_\_\_\_

Gender: (CHECK WHICH APPLIES) \_\_\_\_\_ Male \_\_\_\_\_ Female

### Developmental Disability: (CHECK ALL WHICH APPLY)

Autism \_\_\_\_\_

Epilepsy \_\_\_\_\_

Cerebral Palsy \_\_\_\_\_

Mental Retardation \_\_\_\_\_

### Child's Health: (CHECK WHICH APPLIES)

Excellent \_\_\_\_\_

Good \_\_\_\_\_

Fair \_\_\_\_\_

Poor \_\_\_\_\_

### Is his/her health expected to: (CHECK WHICH APPLIES)

Improve \_\_\_\_\_

Stay the same \_\_\_\_\_

Decline \_\_\_\_\_

### Rate your child's behavior: (CHECK WHICH APPLIES)

No problem \_\_\_\_\_

Mild problem \_\_\_\_\_

Moderate problem \_\_\_\_\_

Severe problem \_\_\_\_\_

### PLEASE ANSWER THE FOLLOWING QUESTIONS ABOUT YOUR FAMILY:

How many hours per week is your child in school, work, or other activity? \_\_\_\_\_

How many hours per week does someone come into your home to help with your child's care? \_\_\_\_\_

How many hours per month do you use respite services? \_\_\_\_\_

What helped your family the most to get used to having a child with a developmental disability? \_\_\_\_\_

What helped your family the least to get used to having a child with a developmental disability? \_\_\_\_\_

What family strengths helped your family's adjustment? \_\_\_\_\_

What family weaknesses hindered your family's adjustment? \_\_\_\_\_

### Who completed this form? (CHECK WHICH APPLIES)

\_\_\_\_\_ Father

\_\_\_\_\_ Both Father & Mother

\_\_\_\_\_ Mother

## APPENDIX G

### Permission to Conduct Research

## APPENDIX G

KENT COUNTY  
**COMMUNITY MENTAL HEALTH**  
728 FULLER NE • GRAND RAPIDS, MICHIGAN 49503  
ADMINISTRATIVE SERVICES • (616) 336-3785 FAX (616) 336-3593  
CORNERSTONE 24-HOUR CRISIS CARE • (616) 336-3909



April 22, 1996

Ms. Jo VanSolkema  
Kent Client Services  
1225 Lake Dr. SE  
Grand Rapids, MI 49506

RE: Research Proposal

Dear Ms. VanSolkema,

This letter is to confirm our telephone conversation, wherein I informed you that all Research Committee members who provided us with any information about your proposal were comfortable with client safety aspects. Several committee members had some comments and suggestions they thought might be helpful. You agreed to my request that you contact Lynn Heemstra, Greg Dziadosz, and Michael Walker individually if you wanted to speak with them about those comments and suggestions.

I understand that the research will be conducted without employing any CMH program resources. I also understand that the research will be conducted in a manner that is not disruptive to individual recipient's programming.

We have now addressed all requirements of the CMH Research Policy and I am able to consent to your conducting this research. I hope your project is successful.

Sincerely,

  
Bonnie M. Huntley  
Executive Director

Having reviewed the recommendations of the Research Committee, I consent to the implementation of the research described in the proposal.

  
Ronald J. VanValkenburg, MD, M.P.H.  
Clinical Director

BMH/jsk

**CMH**

## APPENDIX G



1 CAMPUS DRIVE • ALLENDALE MICHIGAN 49401-9403 • 616/895-6611

March 25, 1996

Joan VanSolkema  
2251 S. Saulk #203  
Grand Rapids, MI 49506

Dear Joan:

Your proposed project entitled "*Stress, Coping, Adaptation and Family Hardiness in Families With an Adult who is Developmentally Disabled*" has been reviewed. It has been approved as a study which is exempt from the regulations by section 46.101 of the Federal Register 46(16):8336, January 26, 1981.

Sincerely,

A black rectangular box redacting the signature of Paul Huizenga.

Paul Huizenga, Chair  
Human Research Review Committee

## LIST OF REFERENCES

## LIST OF REFERENCES

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