

ABSTRACT

Title of Dissertation: The Relationship of Stress and
Coping to Emotions Among
Adolescents with Disabled Siblings

Ann Swomley Harden, Doctor of Philosophy, 1994

Dissertation directed by: Susan D. Holloway, Ph.D.
Associate Professor
Harvard Graduate School
of Education

This research investigated the relationship of stress and coping to emotions among adolescents with disabled siblings. Potentially, stress comes from three sources: the relationship between the disabled and nondisabled siblings, the relationship between the normal sibling and his parents, and the relationship between the normal sibling and the community-at-large. The strategies used to cope with these potential stresses affects the emotions that the normal sibling has about his disabled brother or sister. The sample consisted of 58 adolescents between the ages of 12 and 17. There were 33 females and 25 males.

The adolescents filled out three self-report questionnaires: Adolescent Perceived Events Scale, Coping Responses Inventory, and Emotional Response Scale. The research found that the most stressful aspects of life for adolescents with disabled siblings were network events and academics. The positive emotions of enjoyment and tolerance were felt to the greatest extent. Of the negative emotions, anger and fear were experienced most by

these adolescents. The coping strategies of problem solving and logical analysis were used most with seeking guidance being the least used coping strategy.

Additionally, the study found that adolescents who felt academic stress were unlikely to feel enjoyment and tolerance in their relationships with their disabled siblings. Adolescents who used more coping strategies were likely to feel anger, embarrassment, fear, neglect about their disabled siblings than those who used fewer coping strategies. Also, in spite of their coping efforts, adolescents who felt stress in the area of their boyfriend/girlfriend relationships were less likely to have positive emotions about their disabled siblings. Finally, adolescents who felt stress from family relationships were still likely to have negative emotions about their disabled siblings, even after taking into account their attempts to cope with their problems. Implications for policy and practice are discussed.

THE RELATIONSHIP OF STRESS AND COPING TO EMOTIONS
AMONG ADOLESCENTS WITH DISABLED SIBLINGS

by

Ann Swomley Harden

M.D.

C.

Dept. of Human Development

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Advisory Committee:

Professor Jean Hebel
Associate Professor Charles Flatter, Advisor
Associate Professor Susan Holloway, Chairperson
Associate Professor Allan Wigfield
Assistant Professor Kathryn Wentzel

LD3231.M70d Harden, A.S.

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DEDICATION

This dissertation is dedicated to my family who have taught me so much - to my brother, Steve, from whom I have learned compassion and tolerance, to my two children, Dave and Amy, who have instructed me as they have grown to maturity, and to my beloved husband, Dick, who has been my companion as we have searched for and found the meaning of life.

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Chapter I

Introduction

The sibling relationship is a powerful one which exerts great influence in the lives of the brothers and sisters. It is usually the longest and most enduring of the family relationships. The permanence of the relationship makes it possible for the two individuals to have considerable influence over each other throughout a lifetime of interactions (Seligman, 1989). In describing the sibling relationship, Bank and Kahn (1982) have stated,

As long as one has a brother or sister alive, there is always another human being who has known one as a child, who has experienced one in a unique and intimate way over which one has had little control, who has been a mirror, however distorted of one's childhood and youth - someone in short, who has been a child of, and has shared the same parents. (p. 336)

The sibling relationship develops, because there is high access between the siblings, a need for a meaningful personal identity, and insufficient parental influence (Bank & Kahn, 1982).

The mobile and complex world of today has made a significant impact on contemporary family life in which the sibling bond may be even more important than in past decades. Because family size is decreasing with the birth

of fewer children, siblings may have more intense contact with each other. With the increase in longevity of the life span, the relationships may be a source of support for each person throughout the life cycle. Additionally, many siblings are confronted with the disintegration of the family through divorce and remarriage. This change has affected the nature of the sibling relationship. In families where there are frequent changes in location, which may affect the formation of friendships, siblings may rely on each other. Finally, parental stress with both people working may limit their availability to interact both physically and emotionally with their children (Bank & Kahn, 1992). With all of these factors, brothers and sisters may turn to each other for the stability and nurturing that is needed.

However, the sibling relationship takes on an added dimension when one of the siblings is disabled. Then, siblings no longer have equal status within the family, because one of them is "special". There are a variety of issues that become pertinent under these circumstances. These include dealing with siblings who are different by society's standards, added caretaking and household responsibilities, and differing roles and lifestyles. This study investigates the relationship between the sibling and the "special" brother or sister. It will focus specifically on the stress, coping strategies, and emotions of the nondisabled sibling as the result of the

presence of a child with significant intellectual, physical, emotional, and behavioral delays in the family. An additional technical definition of "disabled" will be provided in the Methods section. The research on the issues surrounding the sibling who has a disabled brother or sister will be conceptualized within the stress and coping framework, which includes the characteristics or nature of stress, resources available to the sibling, methods of coping, and resulting emotions.

Stress

Stress has been conceived of as a transaction between the person and the environment, and it takes into account both the characteristics of the person and the nature of the environment and the stressor events. Psychological stress has been defined as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p. 19 cited in Gamble & Woulbroun, 1993). This judgment as to whether the interaction between the person and the environment is stressful hinges on cognitive appraisals, or the individual's own evaluation of what is stressful. Thus, a stressful event has 1) a cognitive component, the evaluation of what is happening in the environment and whether it is threatening to the individual, and 2) an affective component of the

individual's emotional response to the situation. These two components are essential ingredients of stress.

Change is an inherent component of stress, and adolescence is a period which is characterized by changes on many different levels, including biological functioning, cognitive development, social roles, and social environment (Compas, Davis, & Forsythe, 1985). Thus far, the relationship of both major life events and daily stressors with a range of symptoms has been well documented in adults but is more limited in studies with children and adolescents (Compas, Davis, Forsythe, & Wagner, 1987). Although research in this area is expanding, little is still known about the daily activities and hassles that children and adolescents with disabled brothers and sisters go through, which presumably may give rise to emotional and behavioral problems (McHale & Gamble, 1989).

In reviewing the literature on the relationship between the disabled and nondisabled siblings, certain themes prevail that could potentially be linked to the occurrence of stress for the nondisabled brother or sister. Potentially stress come from three sources: the relationship between the siblings, the relationship between the normal child and his parents, and the relationship between the nondisabled child and the community-at-large. In the relationship between the two siblings, stress possibly comes from several areas. The

first is the way in which emotions are expressed. The disabled child may not be capable of understanding or reciprocating appropriately to the emotions directed toward him. There may be parental expectations and sanctions that prohibit the expression of hostility. The extent to which the "normal" sibling finds satisfactory means of expressing emotion may affect the degree of stress experienced. Secondly, the provision of direct services to the disabled sibling may be stressful. The additional household and child care responsibilities demand a maturity often beyond the nondisabled child's years, especially if these duties interfere with other activities that are appropriate for his or her years. Lastly, the sibling needs to deidentify himself to some extent from his disabled brother or sister and create his own identity and capabilities (Gamble & Woulbroun, 1993).

The stressors which may be associated with the parent-child relationship revolve around the communication patterns of the family and the need for information by the sibling, the parents' discrepant expectations and perceptions, and the parents' personal adjustment. Siblings need information about the disabled child's handicap, but because of inhibited communication, they may be afraid to ask questions. They also need training in intervention strategies that will help them in their interactions with the disabled child as well as others in the community (Gamble & Woulbroun, 1993).

The parents may have differing views from the siblings as to the effect the disabled child has had on the family and the expectations for a near normal relationship. There is often a double standard for compliance with rules. There also may be an incorrect assumption on the part of the parents that the sibling is as involved in the needs and progress of the disabled child as they are, when, in fact, he has a broad range of interests (Gamble & Woulbroun, 1993).

The parents themselves undergo a lifetime of adjustment with stresses as they cope with the "loss" of a normal child and go through the grief cycle. Their own emotional turmoil and added burden may translate into parenting that is neglectful or inconsistent with siblings (Gamble & Woulbroun, 1993).

There are also possible stresses for the siblings with regard to their relationship with their friends and the community-at-large. They may be unsure of how to communicate the information to their peers and to those they are dating. They may not know how to deal with teasing that occurs or how to include the disabled sibling in peer interactions. They may also be concerned with the rejection by classmates or stigmatization when the disabled child attends the same school (Gamble & Woulbroun, 1993). Thus, the siblings experience a variety of possible stresses associated with having a disabled

brother or sister which impinge upon relationships both within and outside the family.

A major research issue in the area of stress and coping has been whether stress emanates from major life events that take place in life or from the frustrations that occur on a daily basis. In a study Wagner, Compas, & Howell (1988) proposed a combination of the major life event and daily hassle into an integrative model. In their research, the hypothesis was substantiated that negative daily events mediated the relationship between major life events and psychological symptoms. In other words, major life events influence daily events, and daily events give rise to symptoms. In the relationship between two siblings in which one is disabled, a major life event is the birth of the disabled child. This impacts the nondisabled child in a number of ways, including hassles, such as additional caregiving and household responsibilities, an awkwardness in including the disabled sibling in peer relationship as well as a wide variety of other daily events. This study will be one of the first to use this integrative model of major life events and daily hassles to look at the sources of stress for siblings with disabled brothers and sisters.

Adolescent girls are more distressed than boys in response to stressors affecting others in their social network (Compas & Grant, 1993; Wagner & Compas, 1990).

These findings are consistent with the literature on siblings of the disabled. Research indicates gender differences may be due, in part, to differing role expectations. Typically, sisters have more caregiving responsibilities than do brothers (Boyce & Barnett, 1993). These responsibilities include more sibling caregiving and greater involvement in household tasks (McHale & Gamble, 1989). In general, females often have more extensive and long term involvement with the disabled sibling (Edmundson, 1985). Thus, older female siblings are usually the ones most negatively affected by the presence of the disabled child (Powell & Gallagher, 1993), because they assume the "other mother" role.

With the increased caretaking responsibilities and thus greater involvement with the disabled child, females tend to have an increase in sibling conflict, a decrease in positive sibling interaction, and a decrease in peer interaction and activities outside the home (Stoneman, Brody, Davis, & Crapps, 1988). These factors may lead to a higher rate of depression, role tension and anxiety (Lobato, Barbour, Hall, & Miller, 1987), lower levels of self-worth (Gamble & McHale, 1989), and even an increase in psychiatric disorder (Gath, 1973, 1974). Thus, females seem to be more vulnerable than males regarding the negative impact they experience when having a disabled brother or sister. An interest of this study is on the gender differences associated with the various sources of

stress and the feelings that adolescents have concerning their disabled brothers and sisters.

The potential stress that the normal sibling experiences is related to the disabled child's direct and indirect impact on the relationships within the family as well as those outside of the family. The stress may affect the feelings that the nondisabled sibling has about his disabled brother or sister. In fact, stress may intensify the negative feelings so that little pleasure is derived from the relationship because of the day-to-day hassles. On the other hand, the sibling may be dealing well with the stress because of adequate coping skills and feel that having a disabled child in the family is a worthwhile experience.

Coping

When confronted with possible stressors in the relationship with their disabled brother or sister, parents or the community-at-large, siblings will attempt to cope with them in some manner. These include changing their perceptions of the situation or regulating the emotional distress; these are termed emotion focused strategies (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1985). However, they may endeavor to change the situation itself using problem focused strategies (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1985). Thus, coping is a process whose function is to resolve a problem and/or regulate the emotional distress.

Research has suggested that children as young as six-years-old can describe their own efforts to cope, which includes responding to everyday events (Band & Weisz, 1988; Elwood, 1987). Studies show that children use a wide variety of responses and different forms of coping over time. It seems as if children take an active approach to dealing with stress in their lives (Gamble & Woulbroun, 1993). However, the nature of their coping responses may depend on the available resources as well as their ability to apply these resources to the problem (Crnic & Leconte, 1986).

Studies have shown that children and adolescents use a variety of coping strategies that fit into either the emotion-focused or problem-focused categories. These include support seeking in which the person talks to a friend or parent about the problem, physical aggression or verbal aggression, which may be either problem-focused or emotion-focused, and direct problem solving, including information selection, direct behavioral actions, and cognitive efforts to solve the problem. Children use other coping mechanisms, including avoidance/distraction, doing nothing, physical exercise, and cognitive restructuring/self-soothing, such as trying to see the good side of things (Band & Weisz, 1988; Elwood, 1987; Gamble & Woulbroun, 1993). The management of emotions aroused by the stressors is often included in the conceptualizations of coping (Gamble & Woulbroun, 1993).

Possibly, the kind of coping responses used may be a missing link in the understanding of the effect of the stress which is associated either directly or indirectly with disabled siblings. There are a variety of responses that adolescents may use when confronted with some of the daily hassles, such as the pressure to get good grades in school or the frustrations of caregiving. Some coping strategies will bring about changes that are beneficial to the adolescents while other types of coping strategies may only exacerbate an already difficult situation. The success of their coping responses may certainly have an effect on the way that the adolescents feel about their sibling relationship. Therefore, it is important to understand both the kinds of stressful events that the adolescents encounter and the coping skills which are most effective in dealing with them.

In a recent study, Gamble & McHale (1989) focused on coping with the stress involved in the relationship of children with disabled and nondisabled siblings. There was no significant difference found in the composite stress score, although there were differences in several of the subscales. As far as coping strategies, self-directed cognitions were found to be positively related to well-being whereas environment-directed cognitions were negatively related to these measures. Additionally, all children with disabled siblings and girls with normal siblings reported using environment-directed cognitions,

such as thoughts about the people and situation, more frequently than did children with nondisabled siblings and boys.

Research needs to expand the impact of stressors beyond the sibling interaction to include those associated with other family members, peers, and the community-at-large. Additionally, there are a wide variety of emotions possible which may be the result of the relationship between the disabled and nondisabled siblings, and studies need to address other feelings in addition to anger such as neglect, embarrassment, and enjoyment.

Emotions

Adolescence has traditionally been described as a period of turmoil, identity confusion, and stress, accompanied by an intense range of emotions. Empirical studies have refuted this idea to some extent and instead have emphasized the continuity of development from childhood through adulthood. However, most everyone agrees that adolescence, in general, is a period of great physical, social, and emotional change with early adolescence, in particular, being a time of developmental transition (Siegel & Brown, 1988).

Within stress research dealing with the period of adolescence, stress has most often been characterized as a depressed mood and/or anxiety. Current research supports the belief that negatively rated circumstances are important contributors to depressed mood and anxiety

(Cohen, Burt, & Bjorck, 1987; Compas & Grant, 1993; Siegel & Brown, 1988). Compas, Howell, Phares, Williams, & Guinta (1989) also found that stress is associated with internalized problems of anxiety and depression and, additionally, with externalized behavior problems. This may have been due, in part, to the inclusion of daily stress as well as major life events. Swearington & Cohen (1985) have suggested that the rapidly occurring developmental changes in early adolescence may influence the ability of the adolescent to place chronic strain in perspective.

Chronic stress may indeed be a part of the life of an adolescent with a disabled brother or sister, resulting in a range of feelings. The emotional involvement of the nondisabled teenager with the disabled sibling is a complex one and appears to involve a variety of negative as well as positive emotions. While research findings in this area are only beginning to emerge, anecdotal accounts suggest that the following emotions may exist for the nondisabled sibling. There is a feeling of neglect at all of the time and attention that the parents give to the disabled child (Crnic & Leconte, 1986; Dyson, Edgar, & Crnic, 1989; Hannah & Midlarsky, 1985; Pearson & Sternberg, 1986; San Martino & Newman, 1974; Schild, 1971). Embarrassment may be felt at the obvious differences between the disabled child and normal brothers and sisters and by the unusual things that the disabled

sibling does (Featherstone, 1980; Meyer, Vadasky, & Fewell, 1985; Pearson & Sternberg, 1990). There may be a feeling of anger at the alterations in family roles and lifestyles (McHale & Gamble, 1989; Pearson & Sternberg, 1986; Seligman, 1989; Wilson, Blacher, & Baker, 1989). Guilt may be the result of wondering why they are normal when their sibling is disabled (Trevino, 1979) and questioning if they contributed to the child's disabilities (Crnic & Leconte, 1986; Meyer, Vadasky, & Fewell, 1985; San Martino & Newman, 1974; Schild, 1971; Seligman, 1989; Trout, 1983). The siblings may feel pressured to compensate for the disabled child and have to deal with excessively high parental expectations (Crnic & Leconte, 1986; Dyson, Edgar, & Crnic, 1989; Hannah & Midlarsky, 1990; Schild, 1971; Trevino, 1979). Because there are no "real" brothers or sisters to share life experiences with, there may be feelings of loneliness and isolation from the community-at-large at the differentness of the family (Featherstone, 1990; Meyer, Vadasky, & Fewell, 1985; Seligman, 1989). There may also be a sense of fear in catching the disability (Pearson & Sternberg, 1986) and of ridicule from others about the disabled sibling.

There are, however, some positive feelings that may be derived from the sibling relationship. The siblings may enjoy being with their disabled brothers and sisters (Wilson, Blacher, & Baker, 1989) and feel a sense of pride

in their accomplishments, especially if they have played a part in the mastering of skills (Lobato, Barbour, Hall, & Miller, 1987; Meyer, Vadasky, & Fewell, 1985). There may be a feeling of competence in their ability to do things the disabled child is unable to do (McHale & Gamble, 1989). Importantly, the sibling may gain a sense of tolerance and compassion as they develop insight into human differences and similarities (Carr, 1988; Crnic & Leconte, 1986; Grossman, 1972; Seligman, 1989). Lastly, the sibling may feel that his life and the life of his family have been enriched as the family has mobilized resources to deal with the disabled child (Carr, 1988; Fischer & Roberts, 1983; Grossman, 1972; Lobato, Barbour, Hall, & Miller, 1987; Wilson, Blacher, & Baker, 1988).

These emotions have been derived in large part from conversations with small groups of siblings who are involved in support groups. Further research needs to be done to establish the generalizability of these feelings and the relationship that they have with stress and coping. Many siblings with disabled brothers and sisters share similar circumstances, but they cope with them in different ways and, therefore, have different emotional reactions. No one has sorted out how different coping mechanisms mediate the relationship between the stressors and these emotions.

Research Questions

The present study is designed to address the following research questions:

Question 1. To what extent are various sources of stress experienced by adolescents with disabled siblings?

Question 2. To what extent are a variety of emotions felt by adolescent siblings about their disabled brothers and sisters?

Question 3. Is there a relationship between the various sources of stress experienced by adolescents and the feelings they have about their disabled siblings?

Question 4. To what extent are a variety of coping strategies used by adolescents with disabled siblings?

Question 5. Is there a relationship between the coping strategies used by adolescent siblings and the feelings they have about their disabled brothers or sisters?

Question 6. To what extent do the coping strategies used by adolescents with disabled brothers and sisters moderate the relationship of the various sources of stress to the feelings that they have about their disabled siblings?

Definition of Terms

Coping: "A stabilizing factor that may help individuals to maintain psychological adaptation during stressful periods" (Holahan & Moos, 1987, p. 946) or "Any effort at stress management or the things that people do to avoid being harmed by life's strains" (Holahan & Moos, 1987, p. 946).

Handicapped Students: "Those students who have been determined through appropriate assessment as having temporary or long-term special education needs arising from cognitive, emotional, or physical factors, or any combination of these. Their ability to meet general educational objectives is impaired to a degree whereby the services available in the general education program are inadequate in preparing them to achieve their educational potential (Code of Maryland Regulations, Supplement 10; p. 122).

Stress: "A particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984, p. 19 cited in Gamble & Woulbroun, 1993).

Chapter II

Literature Review

From the time Roger began going to physicians and consultants, it seemed to me that I carried a five-hundred-pound lead weight around in front of my brain. Never out of my mind was the idea that my brother was special, needed special attention, needed special care, and I had to provide some of it.

Powell & Gallagher, 1993, p. 3.

Having a disabled sibling is a significant source of possible stress across the lifespan (Crnic & Leconte, 1986). The siblings have the potential of a triple burden - stress generated from their sibling relationship with increased responsibility for the disabled sibling (Hannah & Midlarsky, 1985), stress generated from their relationship with their parents and decreased parental support, and stress generated from the relationship with the community-at-large. In the literature on siblings of the disabled, research has tried to determine the reactions of siblings to a disabled brother or sister and what characteristics may account for the differences in their adjustment. Studies has often been directed at certain variables that include the characteristics of the disabled sibling, characteristics of the nondisabled sibling, and the characteristics of the parents and family. Although the stress and coping model has not been

used in actually formulating much of the research that has been done in the past on the issues that are relevant to the siblings of disabled children, this theoretical framework will be used to interpret the findings to date. Recent efforts in the research on stress have focused on the following directions: characteristics or nature of stressful events, resources available, efforts at coping, and emotional impact.

Stress

Characteristics of Stressful Events

Positive/Negative Change

The first component of stress research is the characteristics of the life events which may influence the degree of stressfulness and therefore may be associated with potential disorder for the individual. There was an initial feeling that life change per se, whether it was positive or negative, required readjustment. Early studies showed that the greater the number of life events and the greater the degree of personal adjustment required by the events, the higher the risk of illness. Life events, whether desirable or undesirable, were conceived of as life change requiring adjustment and thus producing stress. Stress was viewed as a condition of perceived imbalance between the demands of the change and the capability of the individual to meet these demands (Rowlinson & Felner, 1988). Studies like that of Rutter (1981), which dealt with stress, coping, and development,

investigated the effect of hospitalization, birth of a sibling, and parental divorce. They based on the premise that any change, either good or bad, produced stress. The Coddington Scales that were developed in the mid-seventies pursued this belief that both positive and negative events required adjustment and were therefore stressful (Swearington & Cohen, 1985). Even today more popular psychology books written on stress and the child promote the idea that any change, whether positive or negative, is a source of stress (Hart, 1992). Other studies found that negative life events, not positive life events, account for the variance between life events and dysfunction (Rowlinson & Felner, 1988; Vinokur & Selzer, 1975). A study was done on whether response biases could account for the relation between negative events and psychological symptoms. This was not substantiated, giving further credence that negative life events play a significant role in symptom development (Lakey & Heller, 1985).

The birth of a baby is usually considered a positive event. It changes family life for everyone and possibly produces some short term stress. However, this stress often dissipates as family members integrate the child into the family, resulting in pleasure. In contrast, the birth of a disabled child is considered a negative life event and often produces stress that intensifies as the child grows older.

Hassles Versus Life Events

Another characteristic of stress under investigation is the relative contribution of the two possible sources of stress, major life events and the ongoing strains of daily hassles. Many of the earlier studies have dealt with the issue of whether stress emanates from the major events that occur in one's life or from the frustrations that take place on a daily basis. Major events can be described as "events that have had a large effect on your life or led to changes in how you feel about yourself, your health, your well-being or your relationship with other people" (Compas, Davis, Forsythe, & Wagner, 1987, p. 535). A related term that is less frequently used is "distal", meaning that these events often require extensive change in an individual's life, require prolonged adaptation (Rowlinson & Felner, 1988), are less psychologically immediate, and are a major life event (Wagner, Compas, & Howell, 1988).

Hassles are described as "events that irritate, annoy or upset you and can cause problems, difficulties or pressures" (Compas, Davis, Forsythe, & Wagner, 1987, p. 535). They are also defined as "irritating, frustrating, distressing demands and troubled relationships that plague us day in and day out" (Dohrenwend, Dohrenwend, Dodson, & Shrout, 1984, p. 223). A related term is "proximal", those events in which there is an ongoing level of stress

in the environment (Rowlinson & Felner, 1988) and are manifested in the immediate context of thought, feeling, and action (Wagner, Compas, & Howell, 1988). There has been some dispute as to what makes a daily event or a major life event. In the Wagner, Compas, & Howell (1988) research, frequency was the deciding factor. Major events were perceived as having low frequency and high impact whereas daily events were seen as having low impact and high frequency.

In research on the impact of major life events and daily hassles, Rowlinson & Felner (1988) found that daily hassles remained significantly related to the outcome of stress, even after the effect of major life events had been removed. There was a direct association between daily hassles and adjustment difficulties over and above those that could be attributed to major life events. Thus, a distinct correlation between major life negative events and an increase in daily hassles was confirmed.

Wagner, Compas, & Howell (1988) combined the issues of daily hassles and major life events into an integrative model of psychosocial stress. Measures of major life events, daily hassles, and psychological symptoms were administered to 58 older adolescents three times during the transition from high school to college. The hypothesis was substantiated that negative daily events mediated the relationship between major life events and psychological symptoms. Results indicated that the

pathway from major life events to daily events and from daily events to psychological symptoms were significant, but the direct pathways from major events to symptoms were not significant at any point. Major life events influenced daily events and daily events gave rise to symptoms. Major life events led to an increase in daily stress which in turn led to increased psychological symptoms. Daily events are simultaneously a dependent and an independent variable. Furthermore, there is a cyclical quality to all of this. Symptoms and daily stress may be reciprocally related. Psychological symptoms may exacerbate or change the meaning of ongoing daily events or actually give rise to new events which, then, intensify the symptoms.

In a later study, Compas, Howell, Phares, Williams, & Ledoux (1989) extended the work on this issue and assessed major and daily stressful life events and psychological symptoms in a sample of young adolescents and their parents. Studying stress processes between individuals in a family was believed to be important. The relation between major life events and symptoms was mediated by daily stressors for parents and their young adolescent children. Children's emotional and behavioral problems were associated with fathers' psychological problems but not with mothers symptoms. Both mothers' and fathers' symptoms were associated with their sons' daily stressors,

but girls' daily stressors were related only to mothers' symptoms.

In recent research, Compas & Grant (1993) studied the effects on adolescents when parents were diagnosed with cancer. Adolescent girls reported more total major and minor stressful events than adolescent boys at the time of their parents' diagnosis. Adolescent boys and girls did not differ in their reports of social network, intimacy, or academic stressors, but girls did report more family stressors related to increased responsibilities and burdens. This is consistent with other findings suggesting that adolescent girls are more distressed than boys in response to stressors affecting others in their social network (Wagner & Compas, 1990). Compas believes that the model used could be applied to understanding the impact of other acute stressors faced by children and adolescents, such as parental divorce, as well as the source of chronic stressors in families, such as parental conflict. This model could also be extended to include the chronic stress in families where there is a disabled child.

Controversy

There was an ongoing argument between several key researchers in this field in the mid-1980s as to whether the items in the inventories that were being used to measure stress were confounded. It revolves around the basic issue of whether stress should be measured simply in

environmental terms or whether it lies in the appraisal of the individual involved. After polling 371 psychologists, Dohrenwend, Dohrenwend, Dodson, & Shrout (1984) found that there were items on the inventories being used that could be symptoms of physical or mental illness. Thus, the presence of these items confounded the measurement of stress with the measurement of health outcomes.

Lazarus, DeLongis, Folkman, & Gruen (1985) responded that the appraisal process cannot be removed from the measurement of psychological stress. Stress lies not in the environment but in the person's appraisal of the situation. In their estimation, stress refers to the "operation of many variables and processes in situations in which the demands tax or exceed the person's resources, and the person appraises the encounter as relevant to well-being, engages in coping processes, and responds cognitively, affectively, and behaviorally to feedback about what is happening" (Lazarus, DeLongis, Folkman, & Greun, 1985, p. 777).

In rebuttal, Dohrenwend & Shrout (1985) wanted to measure stress in pure environmental events, uncontaminated by perceptions, appraisals, or reactions. The key question is whether stress is determined by the objective characteristics of the event and situation as opposed to personal variables or some complex interaction between the two. Thus, it appears it would be important to measure the objective characteristics of the events and

the social situations related to them, the individual's perceptions of these events, and the relevant personality variables.

Interactions

The interactions between siblings are an important aspect of the relationship and provide many opportunities for hassles to occur as roles change and caregiving increases. The interactions have certain characteristics that are important to understand in the disabled-nondisabled relationship. The patterns of interaction between the two siblings include role relationships, social engagement, and affective tone.

Role relationship between siblings.

An important aspect of the sibling interactions is role relationship. Role relationships between individuals differ in their degree of symmetry. In general, sibling role relationships during childhood are asymmetrical with older brothers and sisters having a more powerful and dominant role than younger brothers and sisters. With age, these role relations between siblings grow increasingly symmetrical, becoming more like that found between peers and friends. However, when one of the sibling pair has a disability this normal pattern becomes skewed (Stoneman & Brody, 1993). The research done by Stoneman, Brody, Davis, & Crapps (1989) with older siblings of children with mental retardation found that the role relations for these children became less and not

more symmetrical as the years progressed. Older siblings frequently assumed the teacher, helper, and manager roles. This probably leads to adult relationships that are dominated by the nondisabled siblings (Zetlin, 1986).

When the nondisabled sibling is the younger one, there is a "role crossover" that occurs when the younger sibling becomes more competent than the older one with mental retardation. The parents often assign roles, such as caregiving, for these younger children whose siblings are disabled (Brody, Stoneman, Davis, & Crapps, 1991; Stoneman, Brody, Davis, Crapps, & Malone, 1991). In dyads where there was one Down's syndrome child, the nondisabled child led the interactions whether they were the older or the younger (Miller & Cantwell, 1976). This was demonstrated as early as the preschool years where sisters had more childcare responsibilities (Lobato, Barbour, Hall, & Miller, 1987). Thus, the change in the normal role relationships provide fertile ground for possible stress.

Social engagement of siblings.

Another component of the sibling interaction is social engagement, which is defined as the amount of time that siblings spend in play or other activities with each other or the frequency of visits or phone contact between adult siblings (Stoneman & Brody, 1993). In current research, siblings were actively involved with each other, and normal siblings were adept at choosing activities or

toys that could be shared with the disabled siblings in a meaningful way (Stoneman & Brody, 1993; Stoneman, Brody, & Crapps, 1987).

Further research found that while siblings with and without disabled children in the family spent the same amount of time in sibling activities, children with disabled siblings spent more time in caregiving activities and less in play (Gallagher & Powell, 1989; McHale & Gamble, 1989; Powell & Gallagher, 1993; Wilson, Blacher, & Baker, 1989). Determining factors in time spent caregiving were the amount of help required and the siblings' self-esteem (Hannah & Midlarsky, 1990).

Siblings can also be used as teachers in a variety of settings (Gallagher & Powell, 1989). Siblings can be involved in structured programs as therapists for their disabled siblings with positive results. They can help to teach new skills and provide consistency by creating a united front with parents and teachers (Miller & Cantwell, 1976). With the siblings focused on appropriate behavior, there is an increase in positive interactions, self-esteem, and pride in the accomplishments of the disabled brothers or sisters (Hannah & Midlarsky, 1985). However, the added caregiving and possible teaching roles create opportunities for frustrations for the nondisabled sibling.

Affective tone between siblings.

The final aspect of the sibling relationship is the affective tone. In some of the research there were few differences found in the relationships between siblings in which one had mental retardation and comparison pairs. This was true in both positive and negative interactions and during naturalistic, in-home studies and semistructured observations (Brody, Stoneman, Davis, & Crapps, 1991; Stoneman, Brody, & Crapps, 1987; Stoneman, Brody, & Davis, 1989).

However, some studies have shown that sibling interactions were more positive when one of them was disabled. Parents rated their older siblings as kinder when the younger brother or sister was disabled. This positive affect was seen as a reflection of the siblings feeling of involvement with the disabled child (Gallagher & Powell, 1989). In another study, there was an affect neutrality with less intimacy, less competition, less perception of similarity, and less admiration. It is hard to be intimate with someone with a limited language ability (Begun, 1989). Although the affective tone may be more positive, there may be underlying pressures which prohibit the nondisabled siblings from expressing the negative emotions they have.

Characteristics of the Nondisabled Sibling

The nature of stress that is specific to the impact of a disabled child on a sibling includes both the

characteristics of the nondisabled sibling and the characteristics of the disabled sibling. The following characteristics of the nondisabled sibling appear to be relevant: gender, age, age spacing, and relative birth order.

Gender

Of particular interest in previous research, especially that of Compas, are the findings about the vulnerability of females. Gender of the nondisabled sibling has been the most frequently investigated variable. There are differences in reactions to the "special" brother or sister which may be due in part to gender role expectations. It has been found in several studies that older female siblings were the ones most negatively affected by having a disabled child in the family (Gath, 1973, 1974; Powell & Gallagher, 1993). They may be exposed to greater domestic and caregiving responsibility than others their age (Boyce & Barnett, 1993), often relieving parents of some of the supervision (Fischer & Roberts, 1983). This occurred even at the preschool age (Lobato, Barbour, Hall, & Miller, 1987). Older sisters' responsibilities are associated with an increase in observed sibling conflict, a decrease in positive sibling interaction, and a decrease in peer contact and activities outside the home (McHale & Gamble, 1989; Stoneman, Brody, Davis, & Crapps, 1988).

However, brothers of persons with disabilities also perform caregiving (Boyce & Barnett, 1993). Although they did not spend a comparable amount of time as girls with disabled siblings, boys did spend as much time in caregiving as girls with nondisabled siblings. In some ways then, boys who have a disabled brother or sister are encouraged to engage in nontraditional activities (McHale & Gamble, 1989). In general, female siblings often have more extensive and long term involvement with the disabled sibling (Edmundson, 1985). They maintain a close relationship with the disabled brother or sister and often choose helping careers. Males, on the other hand, who have limited contact during childhood and lack information about the sibling's disability are fearful of producing a retarded offspring of their own (Zetlin, 1986). Thus, it appears that females experience more possible stress due to the added caregiving and household responsibilities.

Age

There are some indications that developmental stage affects the reactions of siblings (Boyce & Barnett, 1993). Adolescent sisters reported more conflicts with their brothers and sisters with mental retardation than did adult sisters (Begun, 1989). Also, middle age siblings with stable life styles were better supporters of their mentally retarded siblings than young adults who were away at college or who lived "free" lifestyles (Zetlin, 1986).

There seems to be a difference in how younger or older siblings adjust to their sibling situation. Older school age children have fewer psychological problems while younger children of preschool and kindergarten age have more problems, perhaps because of their lack of understanding of sibling's disability. Younger children are also more dependent on the family for stability and happiness and have not developed outside contacts and interest (Lobato, 1990). On the other hand, as the circle of children widens to include awareness of peers, neighbors, and the world, then shame, hostility, and embarrassment may increase (Hannah & Midlarsky, 1985). In general, there may be especially adverse reactions in developmental periods when conformity is valued (Featherstone, 1980).

Age Spacing

Some research has demonstrated that the closer in age the disabled and the nondisabled child are the greater the adjustment problems will be. The wider the age difference, the greater the likelihood that the sibling will be well-adjusted (Schreiber & Feeley, 1965; Trevino, 1979). Breslau, (1982) also found that as the differences in age increased, there were fewer indications of adjustment problems. This was especially true for males. The closeness in age spacing may cause identity problems, because siblings must adjust their identities to a person

who does not act age appropriate (Powell & Gallagher, 1993).

Relative Birth Order

Social stressor has been defined as any set of circumstances that requires a change in the individual's life style. In families a stressor is a crisis provoking situation for which the family has little or no preparation (Gallagher, Beckman, & Cross, 1983). It seems that families of disabled children are particularly vulnerable to stress. The birth of a child certainly produces change for everyone in that family, and if the baby is disabled, the event can certainly be classified as a negative one. It is plausible that there would a difference in the effect on siblings, depending on whether they were older and a part of the family, or younger and not a part of the family when the disabled child was born.

There have been mixed findings on the effect of relative birth order on siblings of the disabled. The younger could possibly be more vulnerable because of the need for more parental time and attention, while the older may be more responsible for additional caretaking and household responsibilities and feel the disruption to family life (French, 1984). One study found no increased risk for those who were born earlier than the disabled child with the exception of the oldest female (Gath, 1973). However, there was an additional risk for those children born after the disabled child, apparently because

they were expected to make up for the disappointment of the child and were exposed to greater parental pressure (Gath, 1973). In a subsequent study, no effect of birth order was seen in boys (Gath, 1974). However, Breslau (1982) found an interaction effect of gender and birth order. Males who were younger than the disabled child showed greater psychological impairment than those older, but females who were older were at greater risk. These results were contrary to those found in another study in which younger females and older males were more at risk (Hannah & Midlarsky, 1985).

In more recent research, relative birth order did not influence the outcome measures of self-concept (Boyce & Barnett, 1993), overall time use (Boyce & Barnett, 1993), attitudes toward children with mental retardation (Boyce & Barnett, 1993), or vulnerability to deviant behavior (Gath & Gumley, 1987). Additionally, this characteristic did not affect sibling acceptance, hostility, support, or embarrassment as reported by the mother (Boyce & Barnett, 1993). There was one exception in that the younger siblings felt greater rejection of their disabled brother or sister than did older siblings (Boyce & Barnett, 1993).

Characteristics of the Disabled Sibling

The characteristics of the disabled sibling which may impact the stress on the "normal" sibling include the type and severity of the disability, age, gender, place of

residence, onset and prognosis, and behavioral characteristics.

Type of Disability

Type of disability does not seem to be a crucial factor in the adjustment of siblings. Age, sex, and parental attitudes may affect the sense of well-being of the siblings more than the type of disability (Powell & Gallagher, 1993). However, one exception may be that in high SES families, siblings seem less well-adjusted when the brother's or sister's disability is ambiguous or undefined (Gallagher & Powell, 1989).

Severity of Disability

The severity of the disability may be defined as the amount of help a child needs in toileting, eating, dressing, and mobility (Hannah & Midlarsky, 1985). Some researchers found that siblings were more adversely affected when the child's disability was severe and thus required more care (Gath & Grumley, 1987). They may feel a sense of neglect and pressure to achieve (Hannah & Midlarsky, 1985). This is affected by the socioeconomic condition of the family in which lower SES families had less resources. They had less money for sitters, respite care, and special camps, and therefore, more burden fell on the siblings for care (Gallagher & Powell, 1989; Powell & Gallagher, 1993).

However, other research did not substantiate this with findings that there was no connection between the

level of severity of disability and the well-being of the sibling. In fact, one study found that siblings had a more difficult time adjusting when there was a mild disability. The child may not appear to be disabled, and thus, the extra time and attention was regarded as favoritism (Hannah & Midlarsky, 1985). When the child with the disability was higher functioning, the sibling relationship was closer but more competitive (Begun, 1989), and the sibling may be more likely to identify with the disabled brother or sister (Crnic & Leconte, 1986). McHale & Gamble (1989) found no direct connection between the level of competence of the disabled child and sibling well-being as measured by depression, anxiety, and self-competence. Because of the conflicting evidence, there are probably additional factors that interact with severity to account for the difference in adjustment (Lobato, 1990).

Gender

While the gender of the nondisabled child is an important variable in adjustment, the gender of the disabled child per se does not have the same impact. More importantly, the issue is whether the siblings are of the same sex. It appears that same sex siblings may be more vulnerable to adjustment problems (Ferrari, 1984; Gath & Grumley, 1987; Grossman, 1972; Trevino, 1979). Siblings were more embarrassed when the disabled child was of the same sex and close in age (Grossman, 1972).

Age

Additionally, the developmental stage of the child with the disability appears to have an influence on the adjustment of the sibling. As the disabled child grows older, the discrepancy between the chronological age and the cognitive/functioning age increases. The differences between the siblings become more obvious. The disabled child may also become increasingly more difficult to manage behaviorally and with self-care skills, leading the sibling to have slightly higher levels of adjustment problems (Gallagher & Powell, 1989; Lobato, 1990; Powell & Gallagher, 1993).

Place of Residence

Times have changed as to the philosophy of placing disabled children in institutions. With all of the educational and other supportive services, parents are keeping children at home who once would have been institutionalized. Early studies had conflicting results as to whether residential placement was favorable for the siblings. Some research failed to support the idea that residential placement was the better option for the nondisabled brother or sister (Lobato, 1990). Younger siblings may wonder if they too will be institutionalized (Fischer & Roberts, 1983). Male siblings who spent more time outside the home may receive greater attention from their parents, thus creating tension (Fischer & Roberts, 1983). Others hypothesized it may benefit female siblings

who helped to care for the disabled brother or sister (Fischer & Roberts, 1983). With fewer children being placed in institutions full time, the real issue today may be the residentially placed child who reappears in the home on weekends and holidays (Lobato, 1990).

Onset and Prognosis

The time of detection of an illness or disability is one of intense stress and turmoil for the family. If the siblings were a part of the family at that time, they may have experienced some problems before the initial shock gave way to a more predictable routine (Grossman, 1972; Lobato, 1990). As to the prognosis of the disability or disease, the very limited research did not show any difference in siblings who faced a fatal illness as compared to those whose brothers or sisters had more predictable, less threatening problems (Ferrari, 1984; Lobato, 1990).

Behavioral Characteristics

Generally children who cope well with their disability tend to have siblings who do so as well. On the other hand, disabled children who have symptoms of poor adaptation, such as behavioral problems, are more likely to have siblings who have similar characteristics (Gath, 1992, 1993; Gath & Grumley, 1987; Lobato, 1990).

In conclusion, the nature of stress has some overall characteristics that research had addressed which include the issues of change in general versus negative

experiences, daily hassles versus major life events, and measurement in environmental terms versus personal appraisal. It also has some specific characteristics that are related to the demographic characteristics of the nondisabled and disabled siblings such as age, gender, relative birth order, type and severity of disability. How the siblings deal with the stress that is indigenous to their particular situations may depend in part upon the resources available to them.

Resources

The second area of interest in the stress research are the resources, the personal and situational variables that are believed to make an impact on life stress. There are a wide variety of resources, but those that are most relevant to this study are social support, positive experiences, and parental life stress.

Social Support

Social support has been a key variable, because it may buffer the negative effects of stress (Hart, 1992; Rowlinson, 1988). Social support provides emotional support, tangible assistance, and informational guidance. The presence of social resources are associated with physical and mental health, the likelihood of remaining healthy when under stress, and the speed of recovery from illness (Holahan & Moos, 1987). In studies on stress resistance, Holahan & Moos findings were consistent with the idea that family support is important, especially for

children and women, whereas avoidance coping is more important for men. Family support along with the feelings of self-confidence, an easy going disposition, and not using avoidance coping operate jointly to protect individuals from the negative psychological consequences of life stress (Holahan & Moos, 1985, 1986, 1987). These factors function prospectively as coping resources by fostering positive beliefs about the ability to deal successfully with the experience, and providing a context for exploring options and evaluating effectiveness (Holahan & Moos, 1990).

It is important to look at the network of people who provide the support and the conditions under which it is activated (Dohrenwend, Dohrenwend, Dodson, & Shrout, 1984; Sandler & Barrera, 1984). There seems to be a positive effect when people perceive that they are receiving the appropriate amount of support. Additionally, the sheer quantity of support may not be the critical feature of social support but rather whether there is a conflicted or unconflicted network (Sandler & Berrera, 1984). A large network does not compensate for having those who are nonsupportive in the network (DeLongis & Folkman, 1988). An important issue may be the individual's ability to use the assistance effectively (Sandler & Berrera, 1984) and when it is to be activated. The support network is more likely to be activated when the individual requires information but less likely in those instances involving

possible loss of self-esteem for the person (Folkman, Lazarus, Dunkel-Schetter, & DeLongis, 1985).

Although social support has acquired a prominent place as a moderating variable, it has failed to receive confirmation in some studies. The discrepancy may be due to the differing aspects of social support that are being measured (Sandler & Barrera, 1984). In a study of adolescents, it was found that both the direct and stress buffering effects of social support were inconclusive.

Family Size

Social support for siblings of disabled children may take two forms: other siblings within the family and family social support. Siblings from larger families were better adjusted than those from smaller families provided that there were adequate financial resources (Gallagher & Powell, 1989; Lobato, 1990; Powell & Gallagher, 1993). When siblings had at least one other "normal" child with whom they could relate as companions, then they were less likely to be affected. In families with only two children, there was an increase in risk, perhaps because the one normal child had to bear the burden of the parents' hopes (Gath 1973).

Family Social Support

Support by the family's social network is assumed to serve as a protection against stress and in general a moderator of life stress. Holahan & Moos (1987) did find that family support is important for children. Most

relevant to the siblings is the social support provided by the grandparents and other relatives. There seems to be a negative correlation between the support given with siblings' self-perception of anxiety. However, excessive support from the same resources reduces self-confidence in physical appearance and academic ability (Dyson, Edgar, & Crnic, 1989). When parents perceived little support from their partners, extended family, or friends, they were more likely to show signs of depression and fatigue, which impacted upon their relationship with their children (Lobato, 1990). An earlier study found that the most important variable in families where there was a disabled child was the number of parents in the home. However, the social support of outside relationships, such as friends, relatives, and parents of other disabled children, were the means through which the parents could perceive acceptance or rejection (Gallagher, Beckman, & Cross, 1983). It is clear that extended family and friends can be a major source of support for siblings and families.

Positive Experiences

Along with social support, positive experiences are another resource that act as a possible buffer. The hypothesis is that positive experiences serve as a buffer by generating positive feelings that facilitate adaptation to stress and improve the person's ability to cope by providing a breather from negative experiences (Siegel & Brown, 1988). The accumulation of stressful circumstances

with the interpretation of few positive experiences was found to be related to poor physical and mental health (Siegel & Brown, 1988). Another study found the stress protective role of positive events only with respect to girls' self-esteem (Cohen, Burt, & Bjorck 1987), but Swearington and Cohen (1985) in their work with young adolescents did not find this effect longitudinally. However, their study did not include a self-esteem measure.

Developmentally there may be a difference in the way in which adults and adolescents deal with the effect of positive experiences. For adults who have some real control over their environment, positive experiences may induce an active, success oriented, cognitive set that improves coping ability. This may not be true for children and adolescents who have less control over the events surrounding their lives (Swearington & Cohen, 1985). In a study of personal causation and life events, it was found that people with many prior negative experiences greatly benefitted from positive experiences they had initiated, both in terms of increased pleasantness and reduced distress (Reich & Zautra, 1981).

Religion

Within the context of families with disabled children, religious beliefs may be a positive experience that offers a buffer against possible stress. The birth of a child with a disability usually means a crisis in the

family at which time the parents evaluate their theological beliefs. Religious beliefs affect the parents' responses to the birth of a disabled child which in turn may affect the adjustment of the siblings. There has been a moderate but positive correlation between the religious background and acceptance of the disabled child. Catholic families tended to be more accepting of a mentally retarded child than either Jewish or Protestant families, perhaps because of the explicit definitions supporting home and family that the Catholic Church has. A recent study found that mothers who were more involved in religious activities used more coping strategies for dealing with the stress involved with a disabled child (Powell & Gallagher, 1993).

Socioeconomic Status

There is an effect of socioeconomic status on the resources of a family which in turn affects the sibling relationship. Siblings whose families were from a lower socioeconomic class were at a greater risk because of more limited financial resources (Gath, 1973; Grossman, 1972; Powell & Gallagher, 1993). These families had to rely more on resources within the family for caretaking and other practical responsibilities (Featherstone, 1980; Lobato, 1990; Seligman, 1989; Wilson, Blacher, & Baker, 1988). Middle class families had greater resources to utilize outside services, such as medical, educational, and recreational for the disabled child and for themselves

(Fischer & Roberts, 1983). More educated parents placed fewer responsibilities on the siblings and encouraged greater participation in outside activities (Powell & Gallagher, 1993).

Parental Life Stress

Still another resource that offers a potential buffer for adolescent stress is parental life stress or lack of it. Parental life stress may serve as a significant predictor of psychological functioning of the adolescent. Again, there are conflicting results. Holahan & Moos (1987) found parental dysfunction, especially maternal risk factors, to be significantly related to distress in children, but Cohen, Burt, & Bjorck (1987) did not find the expected relationship between parental life stress and young adolescents' self-reports of depression, anxiety, or self-esteem. Compas, Howell, Phares, Williams, & Guinta (1989) did not find a significant relationship between parents' stressful events and children's self-reports of emotional and behavioral problems. However, the emotional and behavioral problems were mediated by the level of psychological symptoms displayed by the parents, especially the father. Their own self-reported stressful events impacted the emotional and social behavior of their sons and daughters. In a later study Compas & Grant (1993) found that adolescent girls were more distressed than boys in response to stressors affecting others in their social network. This is consistent with an earlier

study (Wagner & Compas, 1990) in which females experienced more stress than males related to negative events in the lives of others. Similarly, Thomson & Vaux (1986) did not find an association between parents' reports of daily stressors and children's depression or affect, but they did find a significant relation between paternal major life events and children's affective balance.

In families where there is a disabled child, the parents are going through a cycle of grief similar to those who have lost a child through death. However, their loss is for the "normal" child whom they will never have (Post-Kammer & Nickolai, 1985). The manner in which the parents deal with the grief and potential stress will impact upon the rest of the family through attitudes and interactions. In considering hypothetical paths of causative effect of childhood disability on normal siblings, two paths have been proposed. One involves the physical and mental health of the mother, which may affect the relationship of the mother with the normal sibling. Breslau & Prabucki (1987) suggested that the mothers' psychological distress might be the mechanism which connected the chronic stress in the family to their children's problems. The other alternative is that the normal sibling may be directly affected in the form of body image and learned behavior (Ferrari, 1984). The stress may affect the child by giving rise to emotional problems (Breslau & Prabucki, 1987; McHale & Gamble, 1989)

or lower psychosocial behavior (Breslau & Prabucki, 1987; Lobato, Barbour, Hall, & Miller, 1987).

Family Interactions

Families who have positive modes of interacting, including good communication, affection, adequate means of conflict resolution, and tolerance will foster good psychological adjustment for normal siblings. These families offer a critical buffer for the stress that is involved in having a disabled brother or sister (Dyson, Edgar, & Crnic, 1989; Lobato, 1990) while less family cohesion and expressiveness are related to adjustment problems (Dyson, Edgar, & Crnic, 1989).

Parental Reactions

Siblings' attitudes and feelings tend to be similar to those of their parents (Fischer & Roberts, 1983; Lobato, 1990; Powell & Gallagher, 1993). Children model the behavior of their parents in many areas of their lives and acceptance/rejection of the disabled child is one of them. If parents are warm and accepting or resentful and depressed, siblings pick up on these attitudes which will then affect their responses to the disabled child (Lobato, 1990). Siblings of middle class families had a range of positive and negative feelings that were reflective of their parents' attitudes. Middle class families also had problems lowering their expectations for their disabled child (Powell & Gallagher, 1993).

Coping

Coping processes are a central aspect of contemporary theories of stress. Coping has been defined in a variety of ways. It is a "stabilizing factor that may help individuals to maintain psychological adaptation during stressful periods." (Holahan & Moos, 1987, p. 946) or "any effort at stress management or the things that people do to avoid being harmed by life's strains" (Holahan & Moos, 1987, p. 946). Coping is further defined as "efforts, both action oriented and intrapsychic to manage (master, tolerate, reduce, minimize) environmental and internal demands and conflicts among them which tax or exceed a person's resources" (Rutter, 1981, p. 336).

Types of Coping

Research in coping has fallen in two general areas: types of coping processes and influence of coping processes on adjustment. Coping can be classified in a number of ways for adults. There are those problem-focused approaches that are active in nature and oriented toward confronting the problem (Holahan & Moos, 1987). These may also be called primary control coping (Band, 1988). Those approaches that reduce tension by avoiding dealing with the problem may be called relinquishment (Band, 1988; Holahan & Moos, 1987). Emotion-focused strategies or secondary control coping attempt to regulate the emotional distress by lowering expectations so as to minimize future disappointment or reinterpret negative

events to try to find meaning in them (Band, 1988; Holahan & Moos, 1987; Taylor, 1983). It is thought that successful coping may depend on flexibility, adaptability, and using a variety of strategies to deal with life's stress (Rutter, 1981).

Gamble & McHale (1989) conducted a study on coping with stress in the sibling relationship. In comparing the two groups of siblings, those with and without disabled brothers and sisters, the researchers found that all children with disabled siblings and girls with normal siblings reported using coping strategies of cognitions about other people or the situation more frequently, such as placing blame. There were no significant differences found for the composite stress score on the Sibling Relationship Measure. Comparisons on the measure of anger, which was the only emotion measured, revealed that the siblings of the disabled were angry more often when the child was sick or hurt. In contrast, the children with nondisabled siblings became more angry when their siblings were physically aggressive toward them.

Coping Strategies

In a classification of coping strategies available to children and adolescents, the following coping categories have been identified: support seeking from peers and parents, physical aggression and verbal aggression, which may be problem-focused or emotion-focused, direct problem solving, which includes information selection, direct

behavioral actions, and cognitive efforts to solve problems, avoidance/ distraction, doing nothing, physical exercise, cognitive structuring/self-soothing, which may include fantasy and relaxation activities (Band & Weisz, 1988; Elwood, 1987; Gamble & Woulbroun, 1993).

Influence on Adjustment

Within these categories of coping it has been found that adaptive coping is positively related to higher socioeconomic status, self-confidence, and family support. Avoidance coping is associated with fewer personal and environmental resources. In fact, the use of avoidance coping over time may be harmful and is one of the risk factors for stress along with negative life events. For children, there is the additional risk factor of parental emotional and physical distress. Active and avoidance coping are both positively associated with stressful life events, positive and negative ones, but avoidance coping is only related to negative life events (Holahan & Moos, 1987). Resilience develops from confronting stressful experiences and coping with them effectively. The process of dealing with stress may broaden a person's perspective, promote new coping skills, and lead to new personal and social resources (Hollahan & Moos, 1989)

Developmental Aspects

There seems to be a developmental aspect to the coping strategies used. Children as young as elementary school report that they do cope with stress, usually with

active coping and use few relinquishment strategies. Their coping is influenced by the situation and their cognitive development. The styles of coping differ depending upon the situation, with events, such as school failure, evoking primary coping and other events, such as medical stress, involving secondary coping. With increase in age, there is an increase in secondary coping and a decrease in primary coping. This is consistent with the view that secondary coping tends to be hidden from view and more abstract, and therefore demands more cognitive maturity (Band & Weisz, 1988). In the development of a stress and coping scale, Elwood (1987) found that children in Grade 7 described more responses that were dependent on cognitive functioning, such as systematizing and rationalizing, while children in Grade 4 described more avoidant responses. This is compatible with the pattern of developing intellectual functioning in children. Rutter (1981) was interested in the developmental aspect of stress and coping in children and felt it was probable that the long term outcome of stress in children's lives was determined by whether the results of coping with stressful events such as hospitalization, divorce, or the birth of a sibling, were successful or not.

The siblings of disabled children potentially have stress in their lives that emanates from a variety of sources: the relationship with their disabled brothers or sisters, the relationship with their parents, and the

relationship with the community-at-large. The stress for the "normal" siblings originates with the birth of the disabled child in the family as a major life event and then translates into daily hassles, such as feeding their disabled brother or sister, dealing with discrepancy in rules by their parents, or tolerating teasing by their peers because of a "retard" brother. The stress from the presence of a disabled child in the family impacts on the way in which the nondisabled siblings feel about their brothers or sisters. If the normal siblings can manage the daily hassles effectively, then they may feel more positively about the relationship and view it with a degree of maturity. However, if they are overwhelmed by the day-to-day responsibilities, then they may feel that they have an unfair burden and experience a host of negative emotions about the relationship. A key factor will be the coping strategies that are employed. The types of coping and their effectiveness at moderating the stress may have a definite relationship to the emotional component of the sibling interaction. Thus, stress, coping, and feelings are intertwined and appear to be an integral part of the relationship between nondisabled and disabled siblings.

Emotions

The final component of the stress framework is emotions. There is a variety of feelings that the sibling of a disabled brother or sister may have regarding their

sibling situation. These feelings can be conflicting in some situations.

Negative Emotions

The negative emotions that the nondisabled brother or sister may have include the following: neglect, embarrassment, anger, guilt, pressure, fear, loneliness, jealousy.

There is great competition for parents' attention and resources among siblings in general (Crnic & Leconte, 1986). In families where there is a disabled child, parents may overlook the needs of the normal child in deference to the more obvious needs of the disabled sibling (Carr, 1988; Dyson, Edgar, & Crnic, 1989; Pearson & Sternberg, 1986; San Martino & Newman, 1974). The normal child may suffer from a lack of time, attention, and participation in special events (Hannah & Midlarsky, 1985; Schild, 1971).

Siblings may be embarrassed by some of the obvious differences between their own disabled sibling and other people's brothers and sisters. There also may be embarrassment by some of the things the disabled siblings do, especially out in public (Featherstone, 1980; Meyer, Vadasky, & Fewell, 1985; Pearson & Sternberg, 1990).

The alterations in family roles, such as extra caregiving responsibilities, may give rise to anger and lead to conflict with parents (McHale & Gamble, 1989). Anger may also surface, because the disabled child

receives the majority of attention, and the nondisabled sibling needs to be a model child to win parental attention (Pearson & Sternberg, 1986). Siblings may experience anger more intensely and more often than other siblings. This will depend on a number of factors: extent to which the sibling is held responsible for the disabled brother or sister; extent to which the disabled brother or sister takes advantage of the sibling; extent to which there are restrictions on social life; and the extent of time taken by care of the disabled child (Seligman, 1989). Siblings may even respond to the anger with guilt (Wilson, Blacher, & Baker, 1989). In general, the child feels angry at their parents, at the disabled child, at the wider world, and at God (Featherstone, 1980).

Guilt is a major but invisible characteristic of the nondisabled sibling, who may feel some sense of responsibility for causing the illness or disability in the first place. This is especially common among younger children (Crnic & Leconte, 1986; Meyer, Vadasky, & Fewell, 1985; Trevino, 1983). They may have a sense of survivor's guilt over the fact that they are normal and able to participate in many things while their disabled brother or sister cannot (Schild, 1971; Seligman, 1989; Trevino, 1979). Their feelings of rivalry toward a disabled child, who has special needs, may even increase the guilt (McHale & Gamble, 1989).

There is pressure to compensate for the disabled child, because they cannot achieve (Crnic & Leconte, 1986; Dyson, Edgar, & Crnic, 1989; Hannah & Midlarsky, 1985; Trevino, 1979). The "normal" sibling may feel the burden of excessively high aspirations by the parents (Schild, 1971), especially in the area of school achievement.

Fear may take several forms. The siblings may have a fear of catching the disability (Pearson & Sternberg, 1986). They may be fearful of what others may do or say about their disabled brother or sister and feel a sense of responsibility and protectiveness (Pearson & Sternberg, 1986). There is also a fear of what the future may bring to the family, if, for example, the parents can no longer care for the disabled child (Meyer, Vadasky, & Fewell, 1985).

The siblings may experience loneliness as a result of not having a "real" brother or sister to share life experiences with (Featherstone, 1980; Meyer, Vadasky, & Fewell, 1985). Additionally, they may feel isolated within the family because of a lack of communication. They sense that certain subjects are taboo and keep their worries and concerns to themselves (Seligman, 1989).

Because parents are often over involved with their disabled children, there may be jealousy on the part of the nondisabled child about the disproportionate attention given to their disabled brothers and sisters (French, 1992; Meyer, Vadasky, & Fewell, 1985; Trevino, 1979).

Positive Emotions and Competencies

There are also many positive emotions and competencies that may result from the presence of a disabled child in the family. These include maturity, pride, compassion and tolerance, family solidarity, responsibility, and competence.

Siblings learn many things that make them wiser and stronger than their peers (Crnic & Leconte, 1986; Meyer, Vadasky, & Fewell, 1985; "What About Me?", 1990). They may feel that they have learned valuable lessons and that their lives have been enriched (Lobato, Barbour, Hall, & Miller, 1987).

Siblings feel a sense of pride in the accomplishments of their disabled brothers or sisters, because they know the time and effort involved in the mastering of different skills (Meyer, Vadasky, & Fewell, 1985).

Siblings gain compassion and a feeling of tolerance for all people with disabilities (Carr, 1988; Gallo, Breitmayer, Knafl, & Zoeller, 1991; Grossman, 1972; Meyer, Vadasky, & Fewell, 1985). They develop an insight into human similarities and differences (Crnic & Leconte, 1986; Seligman, 1989). These qualities may influence the choice of careers. The continuous act of caring for a disabled brother or sister may become internalized to the extent that it influences career decisions in the direction of a helping profession (Seligman, 1989; "What About Me?", 1990).

The presence of the disabled child may exert an integrative effect on the family, mobilizing the resources of the members and bringing a sense of closeness (Carr, 1988; Fischer & Roberts, 1983; Lobato, Barbour, Hall, & Miller, 1987). The siblings may feel a strong sense of loyalty to the disabled child and to the family (Wilson, Blacher, & Baker, 1988).

Siblings may learn to assume a high degree of responsibility for their disabled brother or sister ("What About Me?", 1990; Wilson, Blacher, & Baker, 1989). Additionally, important family roles may foster maturity and competence in the nondisabled child (McHale & Gamble, 1989). Because of the position of being the sibling of a disabled person, the nondisabled child has the satisfying subidentity of being the normal and competent person (Bank & Kahn, 1982).

Thus, there are a range of positive and negative emotions that may be experienced by the nondisabled siblings. The emotional response of the "normal" siblings depends on the amount of stress in their lives, the resources that are available to them, and the ways in which they cope with the stress.

Methodological Issues

Development of Instruments

Because of a belief that there is a divergence in the manner in which children and adults view the same set of life events, it is challenging to adequately describe the stressful experiences of children and adolescents.

Yamamoto & Felsenthal (1982) found that professionals tended to overestimate the stressfulness of certain experiences for children, such as going to the dentist or having a new baby in the house, and underestimated the other responses, such as receiving a bad report card or being caught stealing.

In an effort to develop an instrument that is relevant to the population which will use it, several inventories have been developed. An early inventory was developed by Sarason, James, & Siegel (1978), the Life Experiences Survey. It rested on the premise that life change requires adaptation on the part of the individual, and persons experiencing a marked degree of life change in the recent past are susceptible to physical and psychiatric difficulties. It was developed for both the general and student population and eliminated certain shortcomings of some previous stress measures by taking into account both positive and negative life experiences.

Swearington & Cohen (1985) developed The Junior High Life Experiences Survey, which was a 39 item self-report

measure with both positive and negative life experiences designed for young adolescents.

Elwood (1987) developed an inventory which was designed to elicit a child's perception of experienced stress rather than the adult's perception of it. The research felt that the lack of major stressors in a child's life did not provide a stress free existence, but inventories needed to take into account daily hassles in order to accurately measure strain experienced by children.

Adolescent Perceived Events Scale

In reviewing the measures that had been developed to assess life events during childhood and adolescence, Compas found that most of the existing measures, such as the Coddington and the Swearington & Cohen survey, focused almost exclusively on major life events and failed to meet the following 4 criteria:

1. The domain of potentially relevant events for the population under study should be adequately sampled and represented.
2. Some form of subjective appraisal should be obtained to account for individual differences in the perception of the events.
3. Scale must be adequately reliable.
4. Concurrent and predictive validity must be established.

The development of the Adolescent Perceived Events Scale by Compas, Davis, & Forsythe (1985) represents an improvement in the assessment of life events during adolescence. In the development of the scale several studies were conducted. In study 1, 658 adolescents answered an open-ended questionnaire about daily hassles and major events in their lives. In study 2, 71 college students were asked to categorize the events as to daily hassles or major events, positive or negative value, and the content category. The researchers found that adolescents were clearly aware of events that had occurred recently in their lives. Data indicates that the adolescents may differ in the degree to which they are influenced, not by the objective characteristics of the events, but by their own cognitive appraisal.

Several other studies were done before the Adolescent Perceived Events Scale (APES) was finalized in 1987, including the assessment of the reliability and validity. The APES has been used in research in which the relationship between adolescent stress to behavior problems and psychological symptoms has been addressed. It has also been utilized in an investigation of the role of daily stressors as mediators of the relation between major life events and psychological symptoms as well as the role of parental stress due to cancer in the lives of adolescents.

Problems of Previous Research

Although much has been written about the relationship between disabled and nondisabled siblings, most of the work has been highly fragmented. Studies which apparently focused on the same topic varied considerably in theoretical framework, outcome variables, and measures used to operationalize variables (Barnett, 1993). Many of the studies were not embedded in any conceptual framework, but they simply looked at characteristics that might influence the degree of adjustment. Some of the articles were based on conversations with small groups of nondisabled siblings, or observations of the interactions between the nondisabled and disabled siblings. However, the limited numbers and skewed samples often drawn from clinical populations leave doubts as to how much of the reactions and activities can be generalized. If, indeed, there was a conceptual framework, few studies explored the it with any depth or follow through on previous research.

Furthermore, there were shortcomings in research design as far as operationalizing the variables. Outcome variables were often taken as measures of well-being, such as depression or a lower self-concept, but the relationship between well-being and what was being studied was infrequently made clear. The measures used to operationalize the variable were inconsistent across the studies done. This leads to the conclusion that there was a meager array of instruments available to measure the

important constructs which are involved when there is a disabled child in the family.

Few studies on the relationship between a nondisabled and disabled sibling have been done within the stress and coping framework. The one most closely associated conceptually was the Gambel & McHale study in 1989. However, the inventory used only dealt with the stress directly related to the interactions of the two siblings and did not try to assess the impact of that relationship on others, both inside and outside the family. Furthermore, the research did not explore any emotions other than that of anger when there are a wide variety of other possible feelings.

The most important question that research in this area needs to answer is "Why do some siblings feel that having a disabled brother or sister has been a positive experience while others do not?" The nature and number of stressors experienced by the siblings who have disabled brothers and sisters and their efforts to cope with the stressors will play a vital role in their adjustment. These factors will ultimately impact how they feel about their sibling relationship. It is these important issues that this research will address.

Chapter III

Method

Subjects

The sample consisted of 58 adolescents between the ages of 12 and 17. There were 33 females and 25 males. They were siblings of students who were disabled and attended school in a county in central Maryland. There were two prerequisites for participating in the study: the adolescents must be between the ages of 12 - 17, and they must live at home, either part time or full time, with their disabled siblings. The disabled brothers and sisters were students receiving special education services through the public school system. The settings for their special education included: Level 2, regular classroom with special education services up to 5 hours per week; Level 4, special class within a general education facility; Level 5, special class or wing within a general education facility, or a day school; Level 6, instruction in a residential setting with 24 hour personal care (Disabled students whose siblings participated in the study went home for the weekends.); Level 7, home instruction (Code of Maryland Regulations, 1992). Because of the limited subject pool, it was not possible to secure an equal distribution.

The disabled students, who had siblings participating in the research, had a variety of disabilities. Many were mentally retarded, which is defined as "significant

subaverage intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period" (Heward & Orlansky, 1980, p. 34). Of those students who were retarded, some were either moderately or severely/profoundly retarded. Moderate retardation is a level of intellectual functioning between three and four standard deviations below the mean with concurrent deficits in adaptive behavior (Code of Maryland Regulations, 1992).

Significant delays in development are usually manifested during the preschool years. Education for these children usually focuses on self-care, communication, and social skills. Severe/profound retardation refers to those who are unable to perform basic skills, such as walking, eating, and toileting. They need instruction in basic self-help, motor, perceptual, social, cognitive, and communication skills (Heward & Orlansky, 1980).

Others disabilities included autism, orthopedically impaired, other health impaired, specific learning disabilities, speech and language impaired, multi-handicapped and are defined in the Code of Maryland Regulations, 1992. Autism refers to "children with a developmental disability that significantly affects verbal and nonverbal communication and social interaction, that is generally evident before the age of three, and that adversely affects educational performance" (Code of Maryland Regulations, 1992, p. 123).

Orthopedic impairment means a severe orthopedic impairment which adversely affects a child's educational performance. It includes impairments caused by congenital anomaly, disease, and other causes, such as cerebral palsy (Code of Maryland Regulations, 1992).

Other health impairment refers to an unlimited number of physical and health conditions which limit strength, vitality, or alertness, due to chronic or acute health problems and adversely affect a child's educational performance (Code of Maryland Regulations, 1992). In this study, other health impaired included two rare syndromes with moderate retardation; injuries due to a car accident with below average cognition; mild cerebral palsy with speech/language deficits and mild retardation; primary hearing impairment with some mild mental retardation; and a surviving twin with three open heart surgeries and chronic lung disease.

Specific learning disability is "a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which manifests itself in an imperfect ability to listen, think, speak, read, spell, or do mathematical calculations" (Heward & Orlansky, 1980, p. 77).

Speech and language impairment refers to a communication disorder, such as stuttering, impaired articulation, a language or voice impairment, which

adversely affects a child's educational performance (Code of Maryland Regulations, 1992).

Multihandicapped means concomitant impairments, such as mentally retarded-blind, mentally retarded-orthopedically impaired, which causes severe educational problems so that the child cannot be accommodated in special education programs which have been developed for just one impairment (Code of Maryland Regulations, 1992).

There were two restrictions regarding the family situation: the family could not be a foster family, and the disabled student must live at home, either all or part time. If there was more than one sibling in the family between the designated ages of 12 - 17, the availability and willingness of the participating sibling was the deciding factor. In a pilot study two years ago, some of the adolescents with brothers and sisters attending the Education Center, a Level V school, answered a preliminary version of the questionnaire on emotions. Because of the limited subject pool of siblings at the Level V school, these adolescents were included in the study as long as they had not participated in an intervention program since the administration of the first questionnaire.

Demographic information was obtained including that pertaining to socioeconomic status (father's and mother's educational level and occupation), marital status of parents, presence of step parents, age, gender, and grade of disabled sibling as well as the adolescent, and the age

and gender of other siblings in family. The birth order of the adolescent sibling to the disabled child was coded from the given information, as well as the difference in age between the disabled and target sibling, and the similarity or difference in gender.

Socioeconomic status was computed using the Hollingshead Four Factor Index of Social Status. The educational and occupational levels for each parent were calculated, then the index for the individual parents were summed, and divided in half to obtain an index of the socioeconomic status of the family ($\bar{x} = 41.79$, S. D. = 12.81). There was a wide range of educational levels, from attending high school to completing doctorates, and a wide range of occupations, from truck drivers and waitresses to pharmacists and college professors.

Additionally, information regarding the disabled student was coded, including level of special education services, type of disability, and a social/behavioral factor. The information for the social/behavioral factor was obtained from the IEP (Individual Education Plan) and the disabled student's teacher. The information was coded into problems mentioned on the IEP, problems mentioned by the teacher, and overall compliance/cooperation. A copy of the demographics page of the questionnaire has been included in the Appendix A.

Subjects were drawn from a county in Maryland area, which is in a slow transition from rural to bedroom

community of Baltimore and Washington. It is composed of a predominantly white population. All but 5 of the 58 adolescents were Caucasian. Table 1 gives an overview of the characteristics of the adolescents who participated in the research.

Table 1

Demographic Characteristics of Adolescents with Disabled Siblings Participating in the Research
Characteristics

Nondisabled Sibling

Gender	Males: 25	Females: 33
Age	Mean: 13.81	SD: 1.57
Grade	Mean: 8.77	SD: 1.59
Middle/High School	Middle: 31	High: 27
Birth Order	Mean: 1.60	SD: .79
Older/Younger	Older: 40	Younger: 18
Differences in Ages	Mean: 3.60	SD: 2.20
Same/Different Gender	Same: 37	Different: 21

Disabled Sibling

Age	Mean: 12.03	SD: 3.96
Gender	Male: 26	Female: 32
Level of Service	Mean: 4.31	SD: .88
	Level II: 3	
	Level IV: 33	
	Level V: 16	
	Level VI: 1	

Table 1, continued	Level VII: 2
	Missing Data: 3
Disability Code	01 (Mentally retarded): 19
	04 (Speech/Language Impaired): 1
	07 (Orthopedically Impaired): 2
	08 (Other Health Impaired): 6
	09 (Learning Disability): 6
	10 (Multihandicapped): 18
	14 (Autistic): 3
	Missing Data: 3
Behavioral/Social	1 (Problems Mentioned on IEP):6
Rating	2 (Problems Mentioned from Teachers Comments): 4
	3 (Compliant) : 35
	Missing Data: 3

Family

Total No. of Children	Mean: 2.86	SD: .93
Socioeconomic Status	Mean: 41.79	SD: 12.81
Family Structure	Mean: 1.59	SD: .94
	Biological: 40	
	2-parent: 2	
	Single: 12	
	Extended: 3	
Lives with Mother	Yes: 54	No: 4
Lives with Father	Yes: 45	No: 13
Lives with Stepmother	Yes: 1	No: 57
Lives with Stepfather	Yes: 2	No: 56

Procedure

Permission was obtained from the county's public school system to conduct this study. Class lists, including names and addresses of all students within Level IV and Level V classes, were obtained from the principals or special education coordinators of the individual schools in which such classes existed. Letters were sent home to the families of these students to explain the purpose of the study and to ask if they had teenagers within the 12 to 17 age range who would be willing to participate in the study. In a few instances, the coordinators looked over the files and sent only the names of students whose families would not be offended by receiving such a letter. Self-addressed stamped envelopes were included for the parents to return the permission forms stating whether they had adolescents who were willing to participate in the study. See Appendix B for permission forms.

In addition to a mass mailing to all students receiving Level IV and V services, calls were made by the researcher to parents of current and former students requesting help in the project. They were asked if they knew of any families which fit the criteria of the research. Calls were made to follow up on these leads, and these parents were asked to recommend other families who might qualify. Additionally, people in the community who were involved in recreation programs with disabled

students, such as the Therapeutic Recreation Council, were contacted as to recommendations for families. These suggestions were also followed up with calls. In most instances, parents had received the general mailing that explained the study but had not responded. Because of the personal contact and explanation, all but two of the 75 families contacted, who had adolescents, agreed to participate in the study. The personal element of the phone call was a key ingredient in securing 47 subjects for the research.

In the mass mailing, there was a total of 355 letters sent out to students in 16 schools, 86 to high school students, 93 to middle school students, 153 to elementary school students, and 23 to regional school students. Of these letters, 11 were returned stating that they had teenagers within the designated ages willing to participate in the study. There were 5 letters returned with no permission given for their teenagers to participate. Several parents included reasons, such as taking the questionnaires would enhance already existing rivalry, and the learning disabled sons were viewed as a gift. A number of letters, 34, were returned stating that there were no children within the 12 - 17 age range. Also, there were 14 letters returned by the post office with incorrect addresses. Between the mass mailing and the personal contact, there were disabled students from 21

schools involved in the study, plus 2 students on home teaching.

When parental permission was obtained, either from a signed consent form or phone conversation, arrangements were made to meet with the student at a convenient time and place. Parents were encouraged to bring their teenagers to the Education Center, the Level V school for the severely disabled, for the administration of the questionnaires. However, if this was not possible, another location was agreed upon. Of the 58 meetings with the adolescents, 39 occurred at the Education Center, 8 at fast food restaurants, such as McDonalds and Roy Rogers, 2 at the local library, 8 at the home of the subject, and 1 in the cafeteria of another school on a weekend. After several families forgot the scheduled appointments, calls were made on the evening prior to the meeting as a reminder. In some cases, it was a simple phone call to set up the meeting. In other cases, repeated phone calls were necessary in order to accommodate busy, changing schedules.

When the parents arrived with the adolescents, they were asked for permission to go into the confidential files of disabled students to look at the IEPs' and psychologists' reports. If that permission was given, then the parents signed additional permission forms. If permission to enter the confidential files was withheld, the adolescents were still eligible to participate in the

study. However, the information was listed as missing. All but three parents signed permission forms for entry into the confidential folders.

The issue of confidentiality was a crucial one for the county public school system. Under the system's guidelines, only the names, but not the addresses, of students receiving special education services were public information. The guidelines were adjusted so that the researcher could obtain the names and addresses of students receiving Level IV and V services. However, information as to the number and ages of siblings was not available. During the course of the study, the school system did receive a written letter of complaint from a parent who felt that their confidentiality had been violated. The deputy superintendent and supervisor of special education of the school system replied to the parent to explain the reason for the information being given and to support the research. However, the researcher was asked to proceed cautiously with the study.

After an initial warm up conversation, including a brief overview of the study, the adolescent was given the demographics page to fill out. After checking this page for completion, the interviewer gave the questionnaires to the subject to complete. The teenager filled out the questionnaires in a self-report format. Please see Appendix C for instructions. The interviewer remained with the sibling and was available to answer questions as

the subject proceeds through the questionnaires. It took between 30 - 60 minutes for the 3 questionnaires to be filled out, with the average length of time being 45 minutes. The questionnaires were administered in the following order: stress (APES), coping (Coping Response Inventory) and feelings (Emotional Response Scale). When possible, the questionnaires were administered to several adolescents at a time for the sake of efficiency. However, most of the time they were given on an individual basis. When the situation permitted, the siblings were given a short break to get a soft drink after the first questionnaire, which was the longest.

Measures

Adolescent Perceived Events Scale.

The Adolescent Perceived Events Scale or the APES was developed to measure stressful events during adolescence. Please see Appendix D for a copy of the scale. This instrument was used to measure the daily hassles and life events of the siblings of disabled children. There are three versions: one for junior high students, one for senior high students, and one for adolescents who have gone to college. The first two, which were the versions used, were slightly modified by deleting several items related to sexual activity due to the conservative nature of the school system. Additionally, the impact and frequency ratings of the high school version were removed at the suggestion of Dr. Bruce Compas, the developer of

APES, so that the junior high and senior high scales would be parallel. The junior high version had 159 items, and the senior high had 197 items.

There were six subcategories in the scale: network (events involving a wider circle of family and acquaintances); intimacy (events surrounding boyfriend/girlfriend relationships); family (aspects of family life and relationships); peer (events taking place with friends); academic (events having to do with actual homework and teachers in the school environment); autonomy (events involving greater independence for the adolescent). Not all of the items fit into one of the subscales. The response options as to the desirability of the event ranged from -4 which was "extremely bad" to +4 which was "extremely good". It was a 9 point scale, including a 0 which was neither good nor bad. Each event was marked to indicate whether or not it had occurred in the last four months.

In scoring the APES, subscale scores were derived by summing the negative events, which represented actual stress in the lives of the adolescents, within each of the 6 stress areas. Any ratings of 0 to +4 reflecting neutral or positive events were not used in any calculations. Only the negative scores were used to compute the stress subscales. Thus, several events that were checked as having occurred in the life of the subject within the last three months and given slightly undesirable ratings would

be given the same score as one event which was given a very undesirable rating. The means for each subscale was computed by adding together the total number of negative scores for each subject, summing the individual totals, and dividing by the total number of subjects.

Development of the scale by Compas and associates involved four separate studies. The first two included identifying an item pool of events that were drawn from open-ended reports of adolescents and identifying a cognitive appraisal scale on which the identified events could be assessed. A third study was conducted to determine the scale's psychometric properties which was a two step process. In the first step, the consistency of reports on the occurrence or nonoccurrence of individual items at a 2 week interval was assessed; correlations ranging from .74 to .89 were obtained. In the second step, the measure was divided into thirds, and scores on each section were compared to scores on the other two. The percentage of agreement was 81% or more for each segment, indicating that there was no significant decrease in reliability as a function of the order of items.

The fourth study was the determination of the validity. It was made through the comparison of subjects' self-reports of recent life events to reports of subjects' life events obtained from individuals in close relationships with them. The rates of agreement between subjects' and others' reports can be used to corroborate

the occurrence and appraisal of events. The percent of agreement for event reports by the two sources was 82%. The percentage of agreement for ratings of desirability, impact, and frequency of events was 87%, 90%, and 91% respectively.

The APES has been administered individually and to small groups of adolescents from 10 - 20 in school settings. Youngsters as young as 11 can complete the measure with little problem. The APES was generated from an item pool from surveys of adolescents in Vermont and may be biased toward stressors experienced by white, middle to low SES, rural and suburban population. Stressors that are confronted by adolescents in other environments, such as minority or urban areas, were not included. The area in which the APES was used is similar to that in which the instrument was developed and was therefore appropriate for the population.

Coping Responses Inventory.

Coping responses were measured by the Coping Responses Inventory-Youth Form (Moos, 1993). Please see Appendix E for a copy. The CRI - Youth can be used with adolescents between the ages of 12 - 18. This inventory was administered in a self-report format. The inventory is a measure of eight different types of coping responses, which are grouped into two main categories of approach coping and avoidance coping. Approach coping contains the subscales of logical analysis, positive reappraisal,

seeking guidance and support, and problem solving. Avoidance coping responses include cognitive avoidance, acceptance or resignation, seeking alternative rewards, and emotional discharge. The first two subscales in each set (logical analysis, positive reappraisal, cognitive avoidance, acceptance or resignation) reflect cognitive coping strategies, and the third and fourth subscales in each set (seeking guidance and support, problem solving, seeking alternative rewards, emotional discharge) reflect behavioral coping strategies. Each of the eight subscales is composed of six items in which the adolescent describes how frequently he or she used a particular coping strategy in response to a recent focal stressor dealing with their disabled sibling. There is a four point scale of 0 - 3 from "not at all" to "fairly often". Subscale scores were derived by summing the relevant items. If only one, two, or three items within the subscale were completed, no score was provided for that subscale. If four or five items were completed, then the values were summed and weighted by a correction factor.

The CRI - Youth was developed in five stages:

1. identification of coping domains, development and reduction of an initial item pool;
2. construction of a preliminary inventory;
3. revision of the inventory based on pilot interviews;
4. the first wave of field trials and further revision on the inventory based on data obtained from a sample of 315 youth, including healthy youth,

depressed youth, youth with conduct disorders, and youth with rheumatic diseases; 5. the second wave of field trials with readministration of the revised inventory to 254 of the 315 youth in a 12-15 month follow-up.

The internal consistency as measured by Cronbach's alpha ranged from .55 - .72 for the total score for boys and from .59 - .79 for the total score for girls. The findings of a validation study examining coping profiles of youth exhibiting a variety of psychiatric symptoms were that depressed youth rely more heavily on avoidance coping responses of Cognitive Avoidance, Acceptance/Resignation, and Emotional Discharge than do the control group; youth with conduct disorder rely more on the avoidance coping responses of Cognitive Avoidance, Seeking Alternative Rewards, and Emotional Discharge than do youth with rheumatic disease; and youth with rheumatic disease were comparable to the controls in both approach and avoidance coping. The consistency of the findings with other research provides evidence in support of the construct validity of the CRI-Youth.

Emotional Response Inventory.

The Emotional Response Inventory was developed two years ago by the researcher and piloted on a group of 25 siblings of disabled students. The original scale consisted of 20 items, 16 of which were "yes", "no", "don't know" answers and 4 open-ended questions. The subscales of emotions were anger, embarrassment, neglect,

fear, pressure, and enjoyment. The questionnaire had an internal consistency of .73. It was believed that the 3 point scale did not allow for enough variability in the answers.

The revised inventory included 6 subscales of four questions each. Four of the subscales deal with negative emotions: fear, anger, embarrassment, neglect, and two with positive emotions: enjoyment, compassion/tolerance. There were no open-ended questions. Responses were indicated on a four point scale, including "always", "often", "sometimes", and "never". Subscale scores were derived by summing the relevant items. For missing items, a mean substitution within the given subscale was calculated. The Emotional Response Scale was the last of the three questionnaires to be administered in a self-report format. Please see Appendix F for a copy of the inventory.

Statistical Analysis

A statistical analysis was done for each of the research questions. The following three questions were answered in a similar manner.

Question 1. To what extent are various sources of stress experienced by adolescents with disabled siblings?

Question 2. To what extent are various emotions felt by adolescent siblings about their disabled brothers or sisters?

Question 4. To what extent are a variety of coping strategies used by adolescents with disabled siblings?

In each questionnaire, items were summed within appropriate subscales. In the Emotional Response Scale and Coping Response Inventory, subscales were checked for internal reliability using Cronbach's alpha. Descriptive statistics were obtained for each subscale variable, including mean and standard deviation. T-tests were used to test the significance of gender and school level differences in the areas of stressors, coping strategies used, and feelings experienced. Bivariate correlations were computed among all the subscale scores; correlations between the demographic variables and the subscale scores were also calculated. Highly correlated subscales were combined in order to reduce the number of variables used in multivariate analysis. The composite scales were checked for internal consistency using Cronbach' alpha, and correlations with the demographic variables were computed.

Question 3. Is there a relationship between the various sources of stress experienced by adolescents and the feelings that they have about their disabled sibling?

A series of multiple regressions were done in which the feelings composites variables were regressed on the stress subscales variables, controlling on family demographics variables. The outcome variables were the composite feelings variables. The predictor variables

were the stress variables, and the control variables were designated demographics variables. The designated demographic variables were dropped from the regression equation, because there were no significant predictors. A stepwise regression was done with the stress subscales that most highly correlated with the positive and negative emotion composite variables.

Question 5. Is there a relationship between the coping strategies used by adolescent siblings and the feelings they have about their disabled brothers and sisters?

A series of multiple regressions were done in which the feeling composite variables were regressed on the coping composite variable, controlling on family demographics. The outcome variables were the feelings composites variables, the predictor variable was the composite coping variable, and the control variables were the designated demographic variables. The designated demographic variables were dropped from the equation, because they were not significant predictors.

Question 6. To what extent do the coping strategies used by the adolescent siblings moderate the relationship of the various sources of stress to the feelings that they have about their disabled brothers and sisters?

A series of stepwise regressions were done with three sets of variables: outcome variables of feeling composites variables, predictor variables of stress variables, and

control variables of demographics and coping composite variable. The designated demographic variables were dropped from the equation, because of there being no significant predictors. Stepwise regressions were done, controlling on the coping composite variable, with the stress subscales that were most highly correlated with the positive and negative emotion composites.

CHAPTER IV

Results

Question 1. To what extent are various sources of stress experienced by adolescents with disabled siblings?

The means and standard deviations of the six stress subscales of the Adolescent Perceived Events Scale were examined. The six subscales are: academics (events having to do with actual class work and teachers in the school environment); autonomy (events involving greater independence for the adolescent); family (aspects of family life and relationships); intimacy (events surrounding boyfriend/girlfriend relationships); network (events in a wider circle of family and acquaintances); peers (events taking place with friends).

The most stressful aspects of life for adolescents with disabled brothers and sisters were network events ($\bar{x} = 9.72$, $SD = 9.94$) and academics ($\bar{x} = 8.26$, $SD = 7.69$). Stress in the areas of peers ($\bar{x} = 6.74$, $SD = 7.15$) and family ($\bar{x} = 6.72$, $SD = 6.09$) were felt to a similar degree. The areas in which stress were least experienced were intimacy ($\bar{x} = 3.72$, $SD = 4.25$) and autonomy ($\bar{x} = .43$, $SD = 1.80$). Table 2 presents the means and standard deviations for the subscales.

To test for differences between males and females, and between students in middle school and high school for sources of stress, t-tests were conducted. In the area of network events, females ($\bar{x} = 12.00$, $SD = 10.95$, $t = -2.06$,

$p < .05$) experienced a greater degree of stress than did males ($\bar{x} = 6.72$, $SD = 7.62$). High school adolescents with disabled siblings felt greater stress in the area of peers ($\bar{x} = 9.93$, $SD = 8.71$, $t = -3.46$, $p < .001$) than did those in middle school ($\bar{x} = 3.97$, $SD = 3.76$). Also, high school adolescents felt more stress academically ($\bar{x} = 11.37$, $SD = 8.16$, $t = -3.08$, $p < .01$) than did adolescents in middle school ($\bar{x} = 5.55$, $SD = 6.20$).

Table 2

Mean and Standard Deviation for Stress Subscales

<u>Stress Subscales</u>	<u>Mean</u>	<u>Standard Deviation</u>
Network	9.72	9.94
Academics	8.26	7.69
Peer	6.74	7.15
Family	6.72	6.09
Intimacy	3.72	4.15
Autonomy	.43	1.8

Note. $n = 58$

The autonomy subscale was dropped from subsequent analyses, because few adolescents experienced stress in that area. No factor analysis was done on the stress subscales. The developer of the scales reported that the items responded to in the inventory only reflected whether the events had taken place in the lives of the adolescents. Therefore, consistency of response, as reflected by an alpha, was not an issue.

In order to examine associations among the various sources of stress, Pearson product-moment correlations were computed among the subscales. As seen in Table 3, significant correlations were found among all the subscales.

Table 3

Correlations of Stress Subscales

Stress

Subscales

Correlations

	Network	Intimacy	Family	Peer
Network				
Intimacy	.63**			
Family	.61**	.66**		
Peer	.48**	.61**	.73**	
Academics	.29*	.46**	.57**	.55**

Note. n = 58

*p < .05 **p < .01 ***p < .001

Correlations were performed between all of the demographic variables and the stress subscale variables. Only 13 of the 90 demographic variables were significant at the .05 level or higher. There was no pattern to the correlations that were significant.

Question 2. To what extent are various emotions felt by adolescent siblings about their disabled brothers and sisters?

The means and standard deviations of the six emotion subscales of the Emotional Response Scale were examined.

The subscales consisted of two positive emotion subscales, enjoyment and tolerance, and four negative emotion subscales, anger, embarrassment, fear, and neglect. Adolescents with disabled siblings felt the two positive emotions of tolerance ($\bar{x} = 11.28$, $SD = 2.61$) and enjoyment ($\bar{x} = 11.05$, $SD = 3.14$) to the greatest extent. Of the negative emotions, anger was experienced most ($\bar{x} = 8.66$, $SD = 3.25$) with fear next ($\bar{x} = 7.62$, $SD = 2.32$). The other two negative emotions, neglect ($\bar{x} = 6.35$, $SD = 2.59$) and embarrassment ($\bar{x} = 6.28$, $SD = 2.41$), were experienced least. Table 4 presents the means and standard deviations for the subscales.

To test for differences between males and females, and between students in middle school and high school for emotional responses, t-tests were conducted. No differences were found among the various emotions due either gender or school level (middle versus high school).

Table 4

Mean and Standard Deviation for Emotion Subscales

<u>Emotion Subscales</u>	<u>Mean</u>	<u>Standard Deviation</u>
Tolerance	11.28	2.61
Enjoyment	11.05	3.14
Anger	8.66	3.25
Fear	7.62	2.32
Neglect	6.35	2.59
Embarrassment	6.28	2.41

Note. $n = 58$

In order to examine associations among the various subscales of emotions, Pearson product-moment correlations were computed among the subscales. As seen from Table 5, adolescents who felt enjoyment also tended to feel tolerance but did not feel embarrassment. As for negative emotions, adolescents who felt anger, embarrassment, fear, or neglect were likely to feel the other three negative emotions as well.

Table 5

Correlations for Emotions SubscalesEmotionSubscalesCorrelations

	Enjoyment	Tolerance	Anger	Fear	Neglect
Enjoyment					
Tolerance	.64***				
Anger	-.18	.08			
Fear	.15	.25	.38**		
Neglect	-.07	-.09	.47***	.39**	
Embarrassment	-.26*	-.10	.54***	.40**	.29*

Note. n = 58

*p < .05 **p < .01 ***p < .001

Reliability coefficients were examined for each subscale. Coefficient alphas for the subscales were: enjoyment .85, tolerance .66, anger .74, fear .39, embarrassment .74, neglect .75. Because of the low alpha, the fear subscale was examined and found to have one question that correlated poorly with the other three

questions. This question, number 4, was removed and a new alpha was obtained for the fear subscale, which was .51.

In order to create composite variables, factor analysis (orthogonal rotation) was performed on the emotion subscales. The negative emotions of fear, anger, neglect, and embarrassment loaded above the .5 level on Factor 1. The eigenvalue was 1.81. The positive emotions of compassion and tolerance loaded above the .5 level on Factor 2. The eigenvalue was 1.43. Table 6 contains the factor loadings for the positive and negative emotions.

Table 6

Factor Loadings for Negative and Positive Emotions

<u>Emotion Subscales</u>	<u>Factor 1</u>	<u>Factor 2</u>
Fear	.61	.39
Neglect	.54	.02
Anger	.79	.05
Embarrassment	.68	-.10
Enjoyment	-.25	.82
Tolerance	-.03	.77

Two composite variables were created based on the findings from the factor analysis. A positive emotion composite was created by summing two items: tolerance and enjoyment. The positive emotion composite variable had an alpha of .84. A negative emotion composite was created by summing four items: anger, fear, embarrassment, neglect. The negative emotion composite variable also had an alpha of .84. The demographic variables were correlated with

the positive and negative emotion composite variables. There were no significant correlations.

Question 3. Is there a relationship between the various sources of stress experienced by adolescents and the feelings that they have about their disabled siblings?

Pearson product-moment correlations were computed between the 5 stress subscales of network, intimacy, family, peer, academics, and the Emotional Response Subscales of fear, neglect, anger, embarrassment, enjoyment, tolerance. Adolescents who experienced stress in network events tended to feel fear in their relationship with their disabled siblings. Adolescents who felt stress in their relationships with boyfriends/girlfriends were likely to feel fear, anger, and embarrassment with their disabled brothers and sisters, but not enjoyment. Those who felt stress from their family interactions were probably experiencing fear, neglect, and embarrassment about their disabled siblings while those who felt stress with their peers tended to feel fear. Teenagers who felt stressed about school were less likely to express enjoyment or a feeling of tolerance about their siblings. Table 7 presents these correlations.

Table 7

Correlations of Stress to Emotional Response Subscales

<u>Stress</u>	<u>Emotional Response Subscales</u>						
	<u>Subscales</u>	Fear	Neglect	Anger	Embarras	Enjoy	Toler
Network		.42***	.12	.14	.19	-.17	-.11
Intimacy		.28*	.18	.30*	.45***	-.31*	-.20
Family		.31*	.31*	.25	.36**	-.24	-.23
Peer		.27*	.26	.08	.20	-.15	-.09
Academic		.04	.05	.03	.11	-.28*	-.27*

Note. n = 58

*p < .05 **p < .01 ***p < .001

Embarras: Embarrassment

Toler: Tolerance

The first set of multiple regressions was designed to examine the predictors of adolescents' positive emotions. The analysis plan was to create two initial models. In Model 1, three demographic variables that have emerged as important predictors in previous literature about disabled siblings were to be entered as predictors. These included age and gender of nondisabled sibling, and family socioeconomic status. In Model 2, the demographic variables plus the 5 stress subscale variables were to be entered as predictors. The difference in variance accounted for by these two models could then be examined, along with the significance of individual predictors.

When Model 1 was run, the model did not reach significance ($F = 1.28$, n.s.), and none of the demographic

variables were significant predictors. Because of the relatively small sample and large number of substantively important predictors to be tested, the demographic variables were dropped from further models of positive emotions.

For Model 2, the 5 stress subscale variables of academics, network, peer, intimacy, and family were entered simultaneously. The overall equation was not significant ($F = 1.45$, n.s.). In order to reduce the number of predictors, and conserve degrees of freedom, the stress subscale variables most highly correlated with positive emotions - academics and intimacy - were selected and entered as predictors in a stepwise multiple regression analysis (Model 3). As seen in Table 8, when the academic subscale variable was entered as a predictor, the equation was significant ($F = 4.96$, $p < .05$). Thus, adolescents who felt stress in the area of school were unlikely to feel positive emotions of enjoyment and tolerance. The other variable, intimacy, did not meet the .20 criterion for entry.

Table 8

Stepwise Regression Assessing Relationship Between
Positive Emotion Composite and Areas of Stress

<u>Variable</u>	<u>Non- Standardized Beta</u>	<u>Standard Error of Beta</u>	<u>T</u>	<u>Significance of T</u>
Academics	-.20	.09	-2.22	.03
Intimacy	-.18	-.17	-1.25	.22

R-Square for Model = .09

Note. The stress subscale "intimacy" did not reach the .20 criterion for entry into the model.

The next set of multiple regressions was designed to examine the predictors of adolescents' negative emotions. The analysis plan was to create two initial models. In Model 1, three demographic variables that have emerged as important predictors in previous literature of disabled siblings were to be entered as predictors. These included age of nondisabled sibling, gender of nondisabled sibling, and family socioeconomic status. In Model 2, the demographic variables plus the 5 stress subscale variables were to be entered as predictors. The difference in variance accounted for by these two models could then be examined, along with the significance of individual predictors.

When Model 1 was run, the model did not reach significance ($F = .75$, n.s.), and none of the demographic variables were significant predictors. Because of the

relatively small sample size and large number of substantively important predictors to be tested, the demographic variables were dropped from further models of negative emotions.

For Model 2, the 5 stress subscale variables of academics, network, peer, intimacy, and family were entered simultaneously. As Table 9 indicates, the overall equation was significant ($F = 3.71, p < .01$).

Table 9

Simultaneous Multiple Regression for Assessing Relationship Between Negative Emotion Composite and Areas of Stress

	<u>Non-</u>	<u>Standard</u>		
<u>Variable</u>	<u>Standardized</u>	<u>Error of</u>	<u>T</u>	<u>Significance of</u>
	<u>Beta</u>	<u>Beta</u>	<u>T</u>	<u>T</u>
Academic	-.25	.16	-1.55	.13
Network	-.09	.13	-.67	.50
Peer	-.17	.21	-.79	.43
Intimacy	.67	.35	1.94	.06
Family	.66	.27	2.43	.02

R-Square for Model = .27

In order to reduce the number of predictors, and conserve degrees of freedom, the stress subscale variables that were most highly correlated with negative emotions were selected and entered as predictors in a stepwise multiple regression analysis (Model 3). As seen in Table 10, the family stress variable entered the equation first,

explaining 18% of the variance in negative emotions. The beta for the family stress variable was significant at the .001 level. The intimacy stress variable entered in Step 2, accounting for an additional 3% of the variance. The beta was not significant for the intimacy stress variable. The other variable - network - did not meet the .20 criterion for entry. The overall F for the equation was 6.84, $p < .002$. Thus, adolescents with disabled siblings who felt stress in the area of their family relationships were likely to feel negative emotions.

Table 10

Stepwise Regression Assessing Relationship Between Negative Emotion Composite and Areas of Stress

<u>Variables</u>	<u>Non-</u>	<u>Standard</u>	<u>T</u>	<u>Significance of</u>
	<u>Standardized</u>	<u>Error of</u>		
	<u>Beta</u>	<u>Beta</u>		<u>T</u>
Step 1				
Family	.55	.16	3.38	.001
R-Square Change for Step 1 = .18				
Step 2				
Intimacy	.44	.31	1.43	.16
R-Square Change for Step 2 = .03				

Note. Intimacy did not meet the .20 criterion for entry.

Question 4. To what extent are a variety of coping strategies used by adolescent siblings with disabled brothers and sisters?

The means and standard deviations of the eight subscales on the Coping Response Inventory were examined. The subscales included logical analysis, positive reappraisal, seeking guidance and support, problem solving, cognitive avoidance, acceptance/resignation, seeking alternative rewards, and emotional discharge. The first four subscales (logical analysis, positive reappraisal, seeking guidance and support, problem solving) relate to strategies that are approach coping, and the last four strategies (cognitive avoidance, acceptance/resignation, seeking alternative rewards, emotional discharge) are related to avoidance coping.

Reliability coefficients were examined for each of the subscales. Coefficient alphas for the subscales were: logical analysis .75, positive reappraisal .74, seeking guidance .57, problem solving .66, cognitive avoidance .55, acceptance/resignation .40, seeking alternative rewards .77, emotional discharge .68.

Adolescents with disabled brothers and sisters used the coping response of problem solving most frequently ($\bar{x} = 9.21$, $SD = 3.96$) followed by logical analysis ($\bar{x} = 8.53$, $SD = 4.08$). The five coping responses of cognitive avoidance ($\bar{x} = 7.84$, $SD = 3.51$), positive reappraisal ($\bar{x} = 7.81$, $SD = 4.14$), seeking alternative rewards ($\bar{x} = 7.77$, $SD = 4.82$), acceptance/resignation ($\bar{x} = 7.77$, $SD = 4.82$), and emotional discharge ($\bar{x} = 7.16$, $SD = 3.83$) were all used to a similar extent. The coping response that was

least used was seeking guidance ($\bar{x} = 5.09$, $SD = 3.28$). Table 11 presents the means and standard deviations for the coping subscales.

To test for differences between males and females, and between students in middle school and high school for coping strategies, t-tests were conducted. Among adolescents with disabled siblings, females used coping strategies of logical analysis ($\bar{x} = 9.72$, $SD = 4.24$, $t = -2.47$, $p < .05$) to a greater extent than males ($\bar{x} = 7.08$, $SD = 3.55$). Adolescent females also used seeking guidance ($\bar{x} = 5.94$, $SD = 3.25$, $t = 2.12$, $p < .05$) more than adolescent males ($\bar{x} = 4.04$, $SD = 3.24$). No differences were found due to school level for coping strategies.

Table 11

Mean and Standard Deviation for Coping Subscales

<u>Subscales</u>	<u>Mean</u>	<u>Standard Deviation</u>
Problem Solving	9.21	3.96
Logical Analysis	8.53	4.08
Cognitive Avoidance	7.84	3.51
Positive Reappraisal	7.81	4.14
Seeking Alter Rewards	7.77	4.82
Acceptance/Resignation	7.59	3.29
Emotional Discharge	7.16	3.83
Seeking Guidance	5.09	3.28

Note. $n = 52-56$

In order to examine associations among the various coping strategies, correlations were computed among the

subscales. As seen in Table 12, significant correlations were found among all the subscales with the exception of positive reappraisal and emotional discharge.

Table 12

Correlations Between Coping Response Subscales

<u>Subscales</u>	<u>Correlations</u>						
	Log Ana	Pos Reap	Seek Guid	Prob Solv	Cog Avoid	Accept Resig	Seek Reward
Log							
Ana							
Pos	.64***						
Reap							
Seek	.52***	.31*					
Guid							
Prob	.52***	.50***	.37**				
Solv							
Cog	.46***	.30*	.30*	.32*			
Avoid							
Accept	.50***	.40**	.44***	.30*	.53***		
Resig							
Seek	.46***	.49***	.36**	.55***	.32*	.45***	
Reward							
Emot	.40**	.15	.38**	.38**	.56***	.35*	.44***
Disc							

Note. n = 57-58

*p < .05 **p < .01 ***p < .001

Log Ana: Logical Analysis

Pos Reap: Positive Reappraisal

Seek Guid: Seeking Guidance and Support

Prob Solv: Problem Solving

Cog Avoid: Cognitive Avoidance

Accept Resig: Acceptance or Resignation

Seek Reward: Seeking Alternative Rewards

Emot Disc: Emotional Discharge

A factor analysis was done on the coping subscales scores. It was found that all the subscales loaded above the .5 level on Factor 1. The eigenvalue was 3.47. Therefore, all items were combined into a single composite; it had a coefficient alpha of .90. The single composite of total coping contained all of the coping strategies, including approach coping and avoidance coping strategies. Table 13 contains the factor loadings for the total composite variable. Correlations were performed between the demographic variables and the coping composite variable. No significant correlations were found.

Table 13

Factor Loadings for Coping Composite Variable

<u>Variables</u>	<u>Factor 1</u>
Logical Analysis	.79
Positive Reappraisal	.69
Seeking Guidance	.58
Problem Solving	.65
Cognitive Avoidance	.62
Acceptance/Resignation	.65
Seek Alternative Rewards	.67
Emotional Discharge	.61

Question 5. Is there a relationship between the coping strategies used by adolescent siblings and the feelings they have about their disabled brothers and sisters?

Pearson product-moment correlations were computed between the Coping Response Subscales of logical analysis, positive reappraisal, seeking guidance, problem solving, cognitive avoidance, acceptance/resignation, seeking alternative rewards, emotional discharge, and the feelings subscales of anger, enjoyment, embarrassment, fear, neglect, tolerance. As seen in Table 14, adolescents who used the coping skills of logical analysis tended to feel fear and tolerance about their disabled siblings, while those who used positive reappraisal were likely feeling fear, neglect, enjoyment, and tolerance. Adolescents who used the strategy of seeking guidance probably felt fear,

neglect, anger about their disabled brothers and sisters, while those who used problem solving may have experienced anger. Those who used cognitive avoidance tended to feel fear, neglect, and anger about their sibling relationship, and adolescents with the coping skill of acceptance/resignation likely felt fear. Teenagers with disabled siblings who used seeking alternative rewards tended to feel anger about their brothers and sisters, and those using emotional discharge tended to use neglect and anger. Correlations were also performed between the coping composite variable and the emotion composite variable. As seen in Table 14, those adolescents who used coping strategies were likely to have feelings of fear, neglect and anger.

Table 14

Correlations Between Coping and Emotional ResponseSubscales

<u>Coping Subscales</u>	<u>Emotional Response Subscales</u>					
	Fear	Neglect	Anger	Embarras	Enjoyment	Tolerance
Log	.45***	.19	.14	-.04	.18	.26*
Ana						
Pos	.28*	.29*	.17	-.15	.28*	.28*
Reap						
Seek	.29*	.35**	.37**	.18	.08	.05
Guid						
Prob	.06	.16	.32*	-.09	.01	.13
Solv						
Cog	.32*	.29*	.26*	.01	-.13	-.08
Avoid						
Accept.	.48***	.17	.26	.12	.16	.17
Resig						
Seek	.14	.07	.29*	-.14	.03	.17
Reward						
Emot	.13	.33**	.32*	.06	-.22	-.12
Disc						
Total	.39**	.32*	.37**	-.03	.07	.16

Note. n = 57-58

*p < .05 **p < .01 ***p < .001

Log Ana: Logical Analysis

Pos Reap: Positive Reappraisal

Seek Guid: Seeking Guidance
Prob Solv: Problem Solving
Cog Avoid: Cognitive Avoidance
Accept/Resig: Acceptance or Resignation
Seek Rewards: Seeking Alternative Rewards
Emot Disc: Emotional Discharge
Total Coping: Coping Composite

Correlations were performed between all of the demographic variables and the coping composite variable. None of them had any significant correlations with the emotion composite variables or coping composite variable. However, because of the role played by age and gender of the nondisabled sibling in previous literature, these variables plus family socioeconomic status were included in the multiple regression.

The first set of multiple regression were designed to examine the predictors of adolescents' positive emotions. The analysis plan was to create two initial models. In Model 1, the three demographic variables were to be entered as predictors. In Model 2, the demographic variables plus the coping composite variable were to be entered as predictors. The difference in variance accounted for by these two models could then be examined, along with the significance of the individual predictors.

When Model 1 was run, the model did not reach significance ($F = 1.28$, n.s.), and none of the demographic variables were significant predictors. Because of the

relatively small sample size and large number of substantively important predictors to be tested, the demographic variables were dropped from further models of positive emotions. In Model 2 the coping composite variable was entered as the sole predictor. This equation did not reach statistical significance ($F = .57$, n. s.).

The second set of multiple regressions were designed to examine the predictors of adolescents' negative emotions. The analysis plan was to create two initial models. In Model 1, the three demographic variables emerging from previous literature were to be entered as predictors. In Model 2, the demographic variables plus the coping composite variable were to be entered as predictors. The difference in variance accounted for by these two models could then be examined, along with the significance of the individual predictors.

When Model 1 was run, the model did not reach significance ($F = .75$, n.s.), and none of the demographic variables was a significant predictor. Because of the relatively small sample size and substantively important predictors to be tested, the demographic variables were dropped from further models of negative emotions. Model 2, therefore, included only one predictor, the total coping composite. As indicated in Table 15, the overall equation was significant ($F = 7.67$, $p < .01$). Although counterintuitive, adolescents who used more coping strategies were likely to feel negative emotions about

their disabled siblings than those who used fewer coping strategies.

Table 15

Multiple Regression Assessing Predictors of Negative Emotions

<u>Variable</u>	<u>Non-Standardized Beta</u>	<u>Standard Error of Beta</u>	<u>T</u>	<u>Significance of T</u>
Coping	.13	.05	2.77	.008

R-Square for Model = .13

Question 6. To what extent do the coping strategies used by the adolescent siblings moderate the relationship of the various sources of stress to the feelings that they have about their disabled brothers and sisters?

The first set of stepwise regression analyses were designed to examine whether the sources of stress remained significant predictors of adolescents' positive emotions after controlling on the use of coping strategies. The analysis plan was to create two initial models. In Model 1, the three demographic variables that have emerged as important predictors in previous literature on disabled siblings were to be entered as predictors. These included age of nondisabled sibling, gender of nondisabled sibling, and family socioeconomic status. In Model 2, the demographic variables plus coping composite variable were to be entered as a block, followed by the stress scale

variables that were most highly correlated with positive emotions.

When Model 1 was run, the model did not reach significance ($F = 1.28$, n.s.), and none of the demographic variables was a significant predictor. Because of the relatively small sample size and large number of substantively important predictors to be tested, the demographic variables were dropped from further models of positive emotions.

In Model 2, the total coping composite variable was entered first, followed by the two stress subscale variables, academics and intimacy. As Table 16 reveals, the coping composite variable was not a significant predictor ($\beta = .02$, n.s.). The intimacy stress subscale variable entered on Step 2 and was significant ($\beta = -.34$, $p < .02$). The academic stress subscale variable was not significant ($\beta = -.20$, n.s.) but entered the equation on Step 3. The overall equation reached significance ($F = 2.87$, $p < .05$). Thus, in spite of their coping efforts, adolescents who felt stress in the area of their relationships with boyfriends and girlfriends were less likely to have positive feelings about their disabled siblings.

Table 16

Stepwise Regression Assessing Relationship Between
Positive Emotions, Coping, and Areas of Stress

<u>Variables</u>	<u>Non- Standardized Beta</u>	<u>Standard Error of Beta</u>	<u>T</u>	<u>Significance of T</u>
<u>Step 1</u>				
<u>Coping</u>	.02	.03	.75	.45
R-Square Change for Step = .01				
<u>Step 2</u>				
<u>Intimacy</u>	-.41	.17	-2.44	.02
R-Square Change for Step = .10				
<u>Step 3</u>				
<u>Academic</u>	-.13	.10	-1.38	.17
R-Square Change for Step = .03				

The second stepwise regression analyses were designed to examine whether the sources of stress remained significant predictors of adolescents' negative emotions after controlling on the use of coping strategies. The analysis plan was to create two initial models. In Model 1, the three demographic variables that have emerged as important predictors in previous literature on disabled siblings were to be entered as predictors. These included age of the nondisabled sibling, gender of nondisabled sibling, and socioeconomic status of the family. In Model 2, the demographic variables plus the coping composite variable were to be entered as a block, followed by the

stress scale variables that were most highly correlated with negative emotions.

In Model 1, no significant correlations were found between the three designated demographic variables and the negative emotion composite, which had an $F = .75$, n.s. Because of the relatively small sample size and large number of substantively important predictors to be tested, the demographic variables were dropped from further models of negative emotions.

In Model 2, the total coping composite variable was entered first, followed by the three stress subscale variables (family stress subscale, network stress subscale, and intimacy stress subscale). From Table 17 it can be seen that the coping composite variable was a significant predictor ($\beta = .13$, $p < .01$). The family stress subscale variable entered on Step 2 and was significant ($\beta = .47$, $p < .01$). The overall F for the equation was 8.68 at the .01 level. The other two stress subscales variables, network stress subscale and intimacy stress subscale, did not meet the .20 criterion for entry into the model. Thus, adolescents who felt stress from family relationships were still likely to feel negative emotions about their disabled siblings, even after taking into account their attempts to cope with their problems. Therefore, while coping did enter the equation as a significant predictor, it did not moderate the relationship between family stress and negative emotions.

Table 17

Stepwise Regression Assessing Relationship Between
Negative Emotions, Coping, and Areas of Stress

<u>Variables</u>	<u>Non- Standardized Beta</u>	<u>Standard Error of Beta</u>	<u>T</u>	<u>Significance of T</u>
Step 1				
Coping	.13	.05	2.77	.008
R-Square Change for Step = .13				
Step 2				
Family	.47	.16	2.93	.005
R-Square Change for Step 2 = .13				

Chapter V

Discussion

The final chapter of this research will include three sections, a discussion of the major findings of the study, limitations of the study, and suggestions for further research plus implications for practice.

Discussion of the Present Study

Question 1 addresses the degree to which stress is felt in various areas in the lives of the adolescents with disabled siblings.

In this study, adolescents with disabled siblings felt the greatest stress coming from the areas of network and academics, an intermediate amount of stress coming from peer and family, and the least amount of stress coming from intimacy and autonomy. Very few adolescents experienced stress regarding autonomy, and it was eliminated from further analyses. The comparison of these stress subscales based on means should be approached cautiously, because of the different number of items in each subscale.

The greatest amount of stress for the adolescents who participated in this research was in the area of network, which included events such as family member or relative having an emotional problem or a brother/sister getting engaged or married. Females experienced a much larger degree of stress in this area than did males. This is consistent with recent findings that adolescent girls are

more distressed than boys regarding negative events affecting others in their social network (Compas & Grant, 1993; Wagner & Compas, 1990). The differences may be, indeed, in part due to gender role expectations (Boyce & Barnett, 1993).

The adolescents in this study felt stress coming from the area of academics, with high school students feeling greater stress than middle school students. Academics included those events that directly related to classes in school, such as understanding homework, doing poorly on tests, having good classes or teachers, and did not involve any extracurricular activities. The teenagers may feel pressured to compensate for their disabled sibling who cannot achieve. They may have to deal with excessively high expectation from parents, which confirms the suggestions of previous literature (Crnic & Leconte, 1986; Dyson, Edgar, & Crnic, 1989; Hannah & Midlarsky, 1990; Schild, 1971; Trevino, 1979). Students in high school may feel greater stress academically than those in middle school, because of impending decisions about college placement or work situations.

The adolescents felt an equal amount of stress from the areas of peer and family. Peer included events such as talking on the phone, change in relationship with friends, having few or no friends, talking or sharing feelings with friends, while family involved pressures or expectations by parents, getting punished by parents, not

spending enough time with family members. High school students felt greater pressure in the area of peers than middle school students.

Stress that emanates from the area of peers may be due to a variety of circumstances. They may be unsure of how to communicate the information about their disabled sibling to their friends and may not know how to deal with teasing. Also, they may be concerned about possible rejection by classmates or stigmatization by teachers if the disabled student attends the same school (Gamble & Woulbroun, 1993). They may be embarrassed about bringing friends home or not know how to include the disabled sibling in activities with peers.

High school adolescents felt greater stress in the area of peer events than those in middle school. It may be that middle school students are still involved in the life of the family where as high school students have a greater desire to broaden their independence from their families. They may tend to look to their peers for support at a time when the family may need their increasing help with the disabled child, thus causing conflict.

It has been a prevailing belief that the family is a source of stress for siblings when there is a disabled child in the family. There is often an increase in burdens and responsibilities, which may affect females to a greater extent than males. Although the family did

provide a source of stress for the adolescents, there were no gender differences found. These findings of no gender differences are contrary to the results of research done by Wagner & Compas (1990) where females experiences greater stressors than males in families in which a parent had just been diagnosed with cancer.

Intimacy was the source of least stress for these adolescents. Intimacy included events having to do with romance and boyfriend/girlfriend situations, such as arguments with a boyfriend/girlfriend and falling in love. The finding that intimacy was the source of least stress is contrary to the suggestion that possible stress emanates from the dating situation, especially about communicating information about the sibling's disability to a potential boyfriend or girlfriend. (Gamble & Woulbroun, 1993). It is reasonable that once the information is communicated and accepted by the person the adolescent is dating, it is no longer a source of stress.

In recent research by Compas and associates (Compas & Grant, 1993; Wagner & Compas, 1990), there was a similar pattern to the amount of stress experienced by adolescents in the different areas. Among adolescents with parents who had recently been diagnosed with cancer, network was the area of greatest stress for both males and females. Stress from the area of intimacy was experienced least by females, and family stress was least felt by males. (Peer was not among the areas of stress reported.) In another

study with a general population of adolescents, network events were the greatest source of stress for junior high males and females and for high school females. Intimacy events were the source of least stress for both males and females in junior high and high school.

The stress subscales were all intercorrelated so that if the adolescents felt stress in one area, they were likely to feel stress in all areas. It is possible that the effect of the disabled child on the sibling and family was so pervasive that stress invaded all areas. However, events in the stress inventory were not specifically related to situations involving a disabled brother or sister. Therefore, it is not possible to draw firm conclusions as to whether the stress was directly related to the presence of the disabled sibling or emanated from other sources.

Question 2 deals with the extent to which a variety of emotions are felt by adolescent siblings about their disabled brothers and sisters.

The study found that the two positive emotions of tolerance/compassion and enjoyment were felt to a greater extent than any of the negative emotions. Generally, past literature has concentrated on the negative aspects of the sibling relationship and the inherent negative emotions, such as anger or neglect. This research demonstrates that positive emotions of enjoyment and tolerance are an important part of the relationship between "normal"

siblings and their disabled brothers and sisters. Previous research has mentioned that positive emotions play a role (Carr, 1988; Gallo, Breitmayer, Knafl, & Zoeller, 1991; Grossman, 1972; Meyer, Vadasky, & Fewell, 1985), but not to the extent that this study demonstrates.

The siblings have developed a sense of compassion and tolerance for those with disabilities and for all people with differences, which is in agreement with others (Crnic & Leconte, 1986; Seligman, 1989). This quality may even influence career decisions in the direction of a helping profession (Seligman, 1989; "What About Me?", 1990). In general, the adolescents felt that the positive gains from having disabled siblings outweighed the negatives and that their lives have been enriched (Carr, 1988; Fischer & Roberts, 1983; Grossman, 1972; Lobato, Barbour, Hall, & Miller, 1987; Wilson, Blacher, & Baker, 1988).

Enjoyment was the other positive emotion that was felt to a great extent. The adolescents liked to help with their disabled siblings, play with them, teach them new skills, and even take their places. This agrees with past literature that siblings may enjoy being with their disabled brothers and sisters (Wilson, Blacher, & Baker, 1989) and feel pride in their accomplishments, especially if they have been a part of the mastery process (Lobato, 1983; Lobato, Barbour, Hall, & Miller, 1987; Meyer, Vadasky, & Fewell, 1985). Interestingly, correlations revealed that enjoyment and embarrassment were negatively

related so that those siblings who enjoyed helping, playing, teaching their siblings did not feel embarrassment. Intuitively, it seems logical that those siblings who choose to be with their disabled brothers and sisters are not embarrassed by them.

This study also revealed that the negative emotion of anger was the most prevalent with fear being next. The siblings were angry about the burdens, such as extra jobs at home, not spending enough time with friends, and the inequality of treatment in areas of punishment and assistance required. This confirms past literature that the siblings may feel anger at the alterations in family roles and lifestyles (McHale & Gamble, 1989; Pearson & Sternberg, 1986; Seligman, 1989; Wilson, Blacher, & Baker, 1989).

Also, fear was felt by the adolescents in this study, fear of others making fun of their disabled sibling, fear of getting angry with the disabled sibling because of what parents might say, and fear of the future when parents may not be able to care for the disabled child. This confirms suggestions made in previous literature (Meyer, Vadasky, & Fewell, 1985; Pearson & Sternberg, 1986).

Neglect and embarrassment were the least felt emotions with approximately one-third of the adolescent reporting that they never experienced these feelings. Some of the adolescents failed to feel that they did not get their fair share of time, attention, or material

resources, an emotion which had been suggested by others (Carr, 1988; Dyson, Edgar, & Crnic 1989; Hannah & Midlarsky, 1985; Pearson & Sternberg, 1986; San Martino & Newman, 1974; Schild, 1971). Many of the adolescents (70%) who participated in this research came from two parent, intact families, and this may contribute to not feeling neglect. This confirms an earlier study that the most important variable in families where there was a disabled child was the number of parents in the home (Gallagher, Beckman, & Cross, 1983). Also, adolescents may be at a stage that they do not desire as much parental involvement in their lives, and thus do not resent any perceived lack of attention.

To a great extent these adolescents did not feel embarrassed by the actions of their disabled siblings or about having friends come to the house, which had been implied in past articles (Featherstone, 1980; Meyer, Vadasky, & Fewell, 1985; Pearson & Sternberg, 1990). They also would not feel embarrassed if their disabled sibling attended the same school. It is possible that the increased exposure of disabled students to regular schools and community situations has lessened the feelings of embarrassment for "normal" siblings. However, in another sense, this lack of embarrassment seems unusual, because teenagers are at a point where they wish to conform and look to their peers for approval.

Question 3 deals with the relationship between the various sources of stress experienced by the adolescents and the feelings that they have about their disabled brothers and sisters.

None of the demographic information consistently correlated with any of the stress, coping, or emotion variables used. The demographic variables included those relating to the nondisabled sibling: age, grade, gender, middle versus high school, birth order, older/younger than disabled sibling, differences in ages, same/different gender. Also, the demographic variables included information about the disabled sibling: age, gender, level of service, disability code, behavioral/social rating. Additional demographic information of interest related to the family: total number of children, parental occupations, family structure, presence of parents/stepparents.

Up until this point, much of the research has dealt with the characteristics of the family, characteristics of the nondisabled sibling, and characteristics of the disabled sibling. However, in this research, none of these characteristics appeared to have any bearing on the issues of stress, coping, or emotions. It has been suggested that family factors may be more predictive of sibling outcomes than the individual characteristics. Families are comprised of complex systems of relationships that mutually influence one another. The "personality" of

the family, its mode of communication, nurturing, and affection, may be an important element in the adjustment of the siblings.

The study found that adolescents who felt stress in the area of school were not likely to feel positive emotions of enjoyment and tolerance about their disabled siblings. This confirms past literature that siblings with disabled brothers and sisters are pressured to compensate for them and to excel academically. Since their disabled siblings can not achieve in school, the "normal" sibling feels he has to succeed.

An important finding in this research is that adolescents who felt stress in the area of family were likely to express negative emotions about their disabled siblings. Many researchers believe that the family is a primary source of stress for siblings who have disabled brothers and sisters. Potential stress can come from the interactions of the siblings, especially if the demands of the disabled sibling places an extra burden on the adolescent. Stress may be generated by the interactions of the parents with the nondisabled sibling, especially if there is a lack of meaningful communication about the issues involved in the family. Parenting may be inconsistent or neglectful as they go through their own grief cycle to cope with the loss of a "normal" child (Gamble & Woulbroun, 1993; Post-Kammer & Nickolai, 1985). Not only does this cycle fluctuate as the parents work

through many difficult issues, but it is affected by the stage in life of the disabled child.

Question 4 deals with the extent to which coping strategies are used by adolescents with disabled brothers and sisters.

In filling out the Coping Responses Inventory, the adolescents had to target a problem that they had with their disabled sibling. These problems included: health related issues, such as seizures (7); inability of the disabled sibling to do certain things, such as read (3); violation of personal or family things, such as taking things that do not belong to them (11); interference with social plans, such as the need to baby-sit when the adolescent wanted to go out (4); inappropriate behavior, especially in public, such as undressing in front of people (5); parental attitudes, such as a lack of attention (4); and personal disposition of the disabled sibling, such as being stubborn, argumentative, aggressive (24).

Problem solving and logical analysis were the two most frequently employed strategies with seeking guidance used least by the adolescents in this research. Logical analysis and problem solving are both approach coping responses. In general, approach coping is problem focused and covers both cognitive and behavioral efforts to master or resolve life stressors. It is active in nature and oriented toward confronting the problem. Logical analysis

is an example of a cognitive type of approach coping while problem solving is an example of a behavioral type of approach coping. In the CRI - Youth, logical analysis strategies included: thinking of different ways to deal with the problem; trying to step back from the problem and thinking about it. Problem solving strategies included: deciding on one way to deal with the problem and doing it; knowing what had to be done and trying hard to make things work. Approach coping is positively related to high socioeconomic status, self-confidence, and family support, while avoidance coping is associated with fewer personal and environmental resources (Holahan & Moos, 1987). The findings of this study confirm previous research. Many of these adolescents are from intact families (70%) and may have a lot of family support.

The least used strategy was also approach coping of a behavioral nature, seeking guidance. Past research has shown that people seek less social support in encounters involving their self-esteem. This may be due to shame or embarrassment (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1985). Although embarrassment was not one of the emotions strongly felt, perhaps some of the adolescents were embarrassed by situations involving their disabled siblings, such as undressing in front of strangers. They may have decided not to seek out other people, who may not understand their situation. In this study, females used logical analysis and seeking guidance

more than males. The use of the seeking guidance strategy by females confirms past studies that there is a gender difference in relation to going to other people for help. Women tend to seek guidance, whereas men tend to withdraw. This may be a function of conventional patterns of sex roles in our society (Holahan & Moos, 1985).

When the adolescents used one coping strategy they tended to use them all. This is consistent with Rutter (1981) who suggested that successful coping may depend on flexibility, adaptability, and using a variety of strategies to deal with life stresses. Coping studies have revealed that children and adolescents identify a wide variety of coping responses and use different coping responses over time (Gamble & Woulbroun, 1993). However, the use of a wide variety of responses is contrary to other research in which one type of coping response was used extensively.

Question 5 deals with the relationship between coping strategies and emotions for these adolescents with disabled siblings.

This study found that adolescents who used more coping strategies were likely to feel negative emotions about their disabled siblings than those who used fewer coping strategies. Although this appears to be counterintuitive, it is possible that those adolescents who used more coping strategies had greater amounts of stress in their lives to deal with than those who used

fewer coping strategies. Even after coping with the stress, they still had negative emotions about their disabled siblings. It is also possible that the coping strategies used only served to accentuate the stress rather than to decrease it. Perhaps the strategies chosen were inappropriate or ineffective for the stressful situations and did nothing to allay the negative feelings the adolescent had about the disabled sibling.

This research also found that adolescents with disabled siblings who felt anger, embarrassment, fear, and neglect used a variety of approach and avoidance coping strategies. These findings are a reminder of early controversy in the stress and coping literature in which any change, whether positive or negative, was believed to be a source of stress. However, later studies, including one with adolescents (Siegel & Brown, 1988) found that it was negatively rated circumstances that caused stress. Logically, it appears that stress probably leads to the use of coping responses.

The model that has been used in this research assumes that coping is a response to the stressful circumstances in the lives of the adolescents with disabled siblings. This coping then leads to certain emotions, either negative or positive. In this study though, stress, coping, and emotions are being measured at the same time. It is possible that adolescents with disabled siblings, who feel very emotional, tend to use certain types of

coping strategies or a greater amount of coping to deal with the stress. Thus, the emotional component of the model is not the result of the stress and coping, but rather plays a greater role in the decision of what coping strategies are to be used and to what extent.

Question 6 The last research question deals with the relationship of stress, coping, and emotions among adolescents with disabled siblings.

This study found that in spite of their coping efforts, adolescents who felt stress in their relationships with boyfriends and girlfriends were less likely to have positive feelings of enjoyment and tolerance about their disabled siblings. Past literature has suggested that there may be stress involved with dating, because of the difficulties in explaining a disabled sibling to a new person. Although not suggested elsewhere in literature, it may be that the adolescents over invest emotionally in a dating relationship to compensate for the lack of attention at home.

It is interesting to note the effect of coping on the areas of stress and emotions in this final question. Coping did not enter the equation as a significant predictor of adolescent's positive emotions about their disabled siblings, but it seemed to have an affect on which of the stress variables were significant. In the simpler model, academics entered as a significant predictor of positive emotions, but intimacy was not

significant. However, when coping entered the equation, intimacy became a significant predictor, but academics did not. In the relationship between areas of stress and negative emotions, family stress was a significant predictor of anger, fear, embarrassment, and neglect. When coping entered the equation, it was a significant predictor, but it did not moderate the relationship between family stress and negative emotions. In subsequent research, the role of coping in moderating the relationship between stress and emotions needs to be clarified.

An important finding of the research was that the family was the primary source of stress for these siblings. Adolescents who felt stress from family relationships were still likely to feel negative emotions of anger, embarrassment, fear, and neglect about their disabled siblings, even after taking into account attempts to cope with their problems. It was the relationship with family members that was a major contributor to the stress of adolescents with disabled siblings and resulted in the negative emotions explored in this study. Issues involved may be discrepant expectations, lack of communication, double standards for compliance with rules, and a need for further information. Although these issues were not specifically tapped in the stress inventory, they may cause stress within the family. This stress then spills

over to more general events, such as arguments with parents and not spending enough time with family members.

Limitations of the Study

The findings and conclusions of this study should be regarded cautiously for several reasons. First, the study was limited by the biases and confounding factors that are inherent in self-report data. The data are vulnerable in several ways: the tendency by some adolescents to respond in a socially desirable manner, a tendency in some of the adolescents to respond carelessly, and the overall responses being affected by the variations in willingness of the adolescent to participate.

Secondly, the generalizability of the findings is limited by the small sample size and the type of respondents. Although an effort was made to contact every family who had students in Level IV and Level V setting in the county, families with siblings who participated in the research shared some qualities. They were all volunteers who made an effort to participate in the study. Many of them were strong advocates for their disabled children and had knowledge about the kind of educational services available, both within the context of the school day and in the community-at-large. All but 10% of the siblings were Caucasian, which is representative of the county, and 70% of the siblings were still in their original families, which is contrary to national figures for families with disabled children.

Furthermore, the type of information may be restricted by the choice of standardized psychometric instruments. As noted in the next section, the stress and the coping questionnaires were instruments to be used with the general population and contained no specific references to the life experiences of these adolescents with disabled siblings. There was no way of knowing if the stresses they experienced were related to the presence of a disabled sibling in the family or the general stress of any group of adolescents. Additionally, the stress questionnaire, although concrete and easy to understand, took 15-30 minutes to complete. The questions on the coping questionnaire were difficult for some of the adolescents to relate to the problems targeted with their disabled siblings.

Although both of the questionnaires developed by major researcher in the field were designed for adolescents between the ages of 12 - 18, the age range was a wide one. Teenagers in middle school may have different stresses than those in high school and differ in ways of coping with them. However, except for the areas of peers and academics in which high school students demonstrated greater stress than middle school students, no other differences were found between the two levels.

Last, because of the relatively small pool of siblings available, there was a wide variety of disabilities and levels of service among the students with

disabilities. The disabilities ranged from learning disability to profound retardation, and from instruction in a regular classroom with special education services to part time residential placement or home teaching. Although past research has found issues involved for each level of disability, these may not be apparent with such a wide range of disabilities.

Suggestions for Future Research

The stress scale used in this research was developed for general use to identify large and small events that may cause stress in the lives of adolescents. There was no inclusion of possible events that may cause stress for adolescents with disabled siblings. In general, there has been a failure to identify and evaluate specific events that may cause stress for siblings in these situations. Further research is needed to identify these day-to-day stressors, their frequency, and intensity (Gamble & Woulbroun, 1993). The domain of stressors should include problems arising not only with disabled siblings but additional family members, peers, and others outside the home. Also, examining persistent stressors over time for these siblings may reveal further information about the process of stress, coping, and developmental status (Gamble & McHale, 1989).

The coping scale used in this research was a general one relevant to any type of problem that adolescents might encounter. There may be coping responses used by siblings

to reflect unique strategies for their situations that are not addressed on this scale. Further studies are needed on the variety of coping responses used by siblings with disabled brothers and sisters. This investigation will help to clarify the differences between those who are generally well adjusted from those who have more adjustment problems. Furthermore, the information obtained from most coping assessments is of a self-report nature and may not represent the child's actual coping strategies (Gamble & Woulbroun, 1993). Research is needed on the actual methods of coping used by the "normal" sibling as opposed to what they think they should or would do in the stressful situation.

Another area for further research is to investigate the stress and coping responses of siblings within the context of a family adaptation to stressors associated with the presence of a disabled child. How closely do siblings mirror their parents' reactions to stress and subsequent coping strategies? It is important to remember that the parents like the siblings will often have varied and conflicting emotions depending on their own stage of life as well as the stage of the disabled child.

The stress and coping framework is a valuable paradigm to use for the investigation of the relationship between disabled and nondisabled siblings. Although the term "stress" is not one that is usually associated with sibling relationships, it is an appropriate word to

characterize many of the interactions and roles between brothers and sisters, especially if one of them is disabled. There has been much variability in the functioning of siblings who have disabled brothers and sisters with little understanding of the differences. Further studies documenting what constitutes stress and coping for these nondisabled siblings will not only aid in the development of a theoretical framework, but also in the design of effective prevention and intervention programs (Gamble & Woulbroun, 1993).

Implications for Practice

Although this is only one small study, it confirms previous beliefs about adolescents with disabled siblings. They have unique situations in their lives that need to be taken into account if they are to be understood. Within the context of their education, classroom teachers should realize that they may have pressures and/or added responsibilities at home that other students may not have. It would be helpful if they could be encouraged to relate their sibling experiences through projects, such as a research paper on Down's Syndrome. In this way they are exploring issues that are vital to their lives. As more disabled students are entering regular classrooms through the process of integration, the special role of these "normal" siblings will become apparent.

Additionally, school counsellors need to be aware of the fact that students with disabled siblings are often in

need of support to work through their life situation. Many times they do not even know that other students within the school face similar challenges. Ideally, the formation of sibling support groups provides opportunities for them to interact with other siblings who face similar problems and experience similar feelings, and to give and receive help from them as well as the counsellor (Featherstone, 1980; Gallagher & Powell, 1993; Lobato, 1990; Post-Kammer & Nickolai, 1985). The video "What About Me?" about adolescents with disabled brothers and sisters provides an excellent view of the dynamics of such a group.

A number of articles have been written on siblings as a result of conversations with them. Common themes have been raised as to the needs of these adolescents with special brothers and sisters (Chinitz, 1981; Featherstone, 1980; French, 1992; Lobato, 1990; Meyer, Vadasky, & Fewell, 1985; Post-Kammer & Nickolai, 1985; Wasserman, 1983). This research underlines the importance of these issues, and sibling or parent support groups should certainly focus on them. The themes include the following:

Open and honest communication about the disability of the child and the impact on the family. Children hesitate to reveal their private, negative emotions, but doing so can help to alleviate tensions and anxieties, both within the individual and within the family. The adolescents in

this study who felt stress from family relationships were still likely to feel negative emotions about their disabled sibling, even after they have attempted to deal with the problems. Therefore, the issue of communication is a particularly valuable one as the sibling and family work through many of the difficult issues.

Coping strategies in dealing with the issues of their disabled sibling and their family, peers, and community-at-large. They need to know how to communicate with their family and friends about the disability. The adolescents in this research used a variety of coping strategies when dealing with the negative emotions involved with their disabled siblings.

Information about the disability, such as prognosis, inheritability, and transmissibility. This may be increasingly important as the siblings become older and begin the process of dating and marriage. This was confirmed in this study. In spite of their coping efforts, adolescents who felt stress in the area of intimacy were less likely to have positive feelings of enjoyment and tolerance about their disabled brothers and sisters.

Encouragement to develop their own identity. The development of personal identity is especially important at certain stages, such as adolescence and preadolescence. Being similar to or different from the disabled brother or sister is a vital issue for the siblings to resolve. The

siblings who fail to establish an independent identity may be vulnerable to developing symptoms similar to the disabled brother or sister. They need to pursue their own lives, which includes a recognition of their own strengths and weaknesses.

Quality time with parents on an individual basis.

The adolescents need to share their feelings and concerns about their own lives, independent of their disabled brothers and sisters. Despite the fact that one-third of the adolescents in this research did not feel neglect, others felt that they did not receive their fair share of time and attention.

If the needs of adolescents with disabled siblings are properly addressed, both inside and outside of the family, one day they, too, may echo the following words -

To conclude, I want to relate that I, myself, and my other siblings all agree that despite the challenges and hassles of having a brother with autism, we feel we've benefited from the experience. We've learned to appreciate our blessings of health and to be compassionate toward others less fortunate. Certainly, we've learned to not mind being different.

Powell & Gallagher, 1993, p. 35.

APPENDIX A
DEMOGRAPHIC INFORMATION

Please answer the following questions:

1. How old are you? _____
2. What grade are you in? _____
3. Are you male or female? (circle one)
4. How old is your disabled brother or sister? _____
5. What is his/her gender (male or female)? (circle one)
6. What school does he/she attend? _____
7. Please list the age and gender (male or female) of any other brothers and sisters:
 - 1.
 - 2.
 - 3.
8. What is your father's occupation? _____
9. What is your father's highest grade completed in school?
 1. ___ Went to high school
 2. ___ Graduated from high school
 3. ___ Went to college
 4. ___ Graduated from college
 5. ___ Has a master's or doctorate degree
10. What is your mother's occupation? _____
11. What is your mother's highest grade completed in school?
 1. ___ Went to high school
 2. ___ Graduated from high school
 3. ___ Went to college
 4. ___ Graduated from college
 5. ___ Has a master's or doctorate degree
12. List what adults are currently living with you at home?
 1. mother ___
 2. father ___
 - other adults such as stepmother (please specify relationship to you)
 - 3.
 - 4.

Thank you for taking the time to complete the following questionnaires.

APPENDIX B

September, 1993

Dear Parents,

As a part of my doctoral work at the University of Maryland, I am doing a study on the impact on siblings of having a disabled child in the family. My interest stems from my 8 years of teaching at the Carroll County Education Center as well as from my personal experiences as the sister of a disabled individual. I have done a pilot study on this subject and will be expanding my research to include the feelings, stress and coping that are related to having a disabled brother or sister for teenagers ages 12 - 17.

If you have a teenager between the ages of 12 - 17 who has a disabled brother or sister and agree to participate in this study, three questionnaires will be administered to your teenager. The questionnaire on stress deals with possible stress that may arise in any adolescent's life. The other two questionnaires assess the coping strategies and emotional issues that are directly related to having a disabled brother or sister. If you agree to participate in the study, I will contact you to set up a convenient time and place to meet with your teenager. I will remain with your teenager as he/she fills out the questionnaires which should take about 45 minutes.

From the pilot study which was done there was little emotional reaction from the teenagers when the questionnaire was given. Recently all of the guidance counsellors in Carroll County schools were informed of the many issues involved in having a disabled brother or sister. They are available if your teenager would like to speak to someone.

Your cooperation would be greatly appreciated in permitting your teenager to participate in this study. Once permission is given, you may withdraw your consent at any time.

I have received the permission and cooperation of the Carroll County School System to conduct this research. The results of the questionnaires will be kept confidential; neither your name nor that of your teenager will appear on any document.

Return the permission slip on the next page to the enclosed envelope if your child is a student there or in C.C.E.C. if your disabled child is in another school. Please feel free to call me at 876-3871 if you have any questions.

Sincerely,

Ann S. Harden

APPENDIX B

**The Relationship of Stress and Coping to Emotions
Among Adolescents with Disabled Siblings**

*The study to which this form relates was explained
in the attached letter.*

PERMISSION FORM

Directions: Please check your responses to the questions in the appropriate boxes below. Thank you.

Do you have a teenager between the ages of 12 - 17 who has a disabled brother or sister?

Yes

No

Mrs. Ann Harden's research will focus on the Stress, Coping and Emotional Issues of Adolescents with a Disabled Sibling. Teenagers with disabled siblings will be asked to complete three questionnaires. I understand that the answers will be confidential and will be used only for the purpose of this research.

My teenager has my permission to participate.

My teenager does not have my permission to participate.

I am interested but would like more information.

Disabled Student's Name: _____

School: _____

Teenager's Name: _____

School: _____

Parent Signature: _____

Date: _____ Telephone Number: _____

APPENDIX B

**The Relationship of Stress and Coping to Emotions
Among Adolescents with Disabled Siblings**

*The study to which this form relates was explained
in the attached letter.*

PERMISSION FORM

Directions: Please check your responses to the questions in the appropriate boxes below. Thank you.

To gain information regarding the exact nature of the disabled child's handicapping condition, Mrs. Harden will review the psychologist's evaluation in the child's confidential folder.

I give permission for Mrs. Harden to review the psychologist's evaluation.

I do not give permission for Mrs. Harden to review the psychologist's evaluation.

Disabled Student's Name: _____

School: _____

Teenager's Name: _____

School: _____

Parent Signature: _____

Date: _____ Telephone Number: _____

APPENDIX B

September, 1993

PARENT COPY

Dear Parents,

As a part of my doctoral work at the University of Maryland, I am doing a study on the impact on siblings of having a disabled child in the family. My interest stems from my 8 years of teaching at the Carroll County Education Center as well as from my personal experiences as the sister of a disabled individual. I have done a pilot study on this subject and will be expanding my research to include the feelings, stress and coping that are related to having a disabled brother or sister for teenagers ages 12 - 17.

If you have a teenager between the ages of 12 - 17 who has a disabled brother or sister and agree to participate in this study, three questionnaires will be administered to your teenager. The questionnaire on stress deals with possible stress that may arise in any adolescent's life. The other two questionnaires assess the coping strategies and emotional issues that are directly related to having a disabled brother or sister. If you agree to participate in the study, I will contact you to set up a convenient time and place to meet with your teenager. I will remain with your teenager as he/she fills out the questionnaires which should take about 45 minutes.

From the pilot study which was done there was little emotional reaction from the teenagers when the questionnaire was given. Recently all of the guidance counsellors in Carroll County schools were informed of the many issues involved in having a disabled brother or sister. They are available if your teenager would like to speak to someone.

Your cooperation would be greatly appreciated in permitting your teenager to participate in this study. Once permission is given, you may withdraw your consent at any time.

I have received the permission and cooperation of the Carroll County School System to conduct this research. The results of the questionnaires will be kept confidential; neither your name nor that of your teenager will appear on any document.

Return the permission slip on the next page to C.C.E.C. if your disabled child is a student there or in the enclosed envelope if your child is in another school. Please feel free to call me at 876-3871 if you have any questions.

Sincerely,

Ann S. Harden

APPENDIX B

**The Relationship of Stress and Coping to Emotions
Among Adolescents with Disabled Siblings**

*The study to which this form relates was explained
in the attached letter.*

PERMISSION FORM

Directions: Please check your responses to the questions in
the appropriate boxes below. Thank you.

Do you have a teenager between the ages of 12 - 17 who
has a disabled brother or sister?

Yes

No

Mrs. Ann Harden's research will focus on the Stress,
Coping and Emotional Issues of Adolescents with a
Disabled Sibling. Teenagers with disabled siblings
will be asked to complete three questionnaires. I
under that the answers will be confidential and will
be used only for the purpose of this research.

My teenager has my permission to participate.

My teenager does not have my permission to
participate.

I am interested but would like more information.

Disabled Student's Name: _____

School: _____

Teenager's Name: _____

School: _____

Parent Signature: _____

Date: _____ Telephone Number: _____

APPENDIX B

The Relationship of Stress and Coping to Emotions
Among Adolescents with Disabled Siblings

The study to which this form relates was explained
in the attached letter.

PERMISSION FORM

Directions: Please check your responses to the questions in
the appropriate boxes below. Thank you.

To gain information regarding the exact nature of the
disabled child's handicapping condition, Mrs. Harden
will review the psychologist's evaluation in the child's
confidential folder.

- I give permission for Mrs. Harden to review the
psychologist's evaluation.
- I do not give permission for Mrs. Harden to review
the psychologist's evaluation.

Disabled Student's Name: _____

School: _____

Teenager's Name: _____

School: _____

Parent Signature: _____

Date: _____ Telephone Number: _____

APPENDIX C

Instructions to the Siblings

Introductory statements made before the interview begins.

Hi, How are you today? My name is Mrs. Harden and I teach at the Carroll County Education Center. I appreciate your meeting with me. I am going to ask you to fill out some questionnaires about the impact of having a brother or sister like _____ (name of disabled sibling) in your family. I am interested not only because I teach children like your brother or sister, but because I also have a disabled brother. I have contacted your parents, and they have given me permission to talk to you today.

The first thing I am going to have you do is fill out some basic information about your family. You will notice that no where on the form does it ask for your name or the name of anyone in your family. All of the information that you give me, including the responses to the questionnaires, will be confidential. You have the right to withdraw from this study at any time without any penalty. Please bring this paper back when you have finished it. (The interviewer will check to make sure all the information is complete when form is returned.)

Now I am going to give you three questionnaires, one at a time. You are to take each questionnaire back to

APPENDIX C

your seat, fill it out, and bring it back to me. I will then give you another one. The first questionnaire deals with some of the stresses that you may have in your life as a teenager. Some of these events may have happened to you and some may not. Please read each of the 159 (or 197) question carefully and decide if it has happened to you in the last three months. If so place an "X" on the line marked EVENT HAS HAPPENED in front of the event. For each event that has happened to you, please fill in your rating of how good or bad it was when it happened. The scale goes from - 4 which is extremely bad to +4 which is extremely good. Think about how you described the event at the time that it happened when filling out the scale.

The next questionnaire has to do with how you deal with important problems that come up in your life. I want you to think about a problem or stressful event that has happened in the last 12 months that is related to having a disabled brother or sister. Briefly describe the problem in the space provided in Part I of the answer sheet. Then answer the 10 questions about the problem or situation by circling the appropriate answer. In Part II there are 48 questions. Read each item carefully and indicate how often you took that action to deal with the problem you described in Part I. The possible answers include: N if your response is No, not at all; 0 if your response is Yes, once or twice; S if your response is Yes, sometimes;

APPENDIX C

and F if your response is Yes, fairly often; NA is the item does not apply to you. Please answer each question as accurately as possible. Note that the answers are numbered across in rows on Part II of the answer sheet. Please bring the questionnaire back to me when you are finished.

In the last questionnaire about feelings there are 25 questions about some of the ways we can feel about things that happen because we have a disabled brother or sister. Sometimes we feel good about them and sometimes we feel bad about them. The questions can be answered by circling one of the 4 numbers on the scale which range from "never" which is number 1 to "always" which is number 4. Remember, there is no right or wrong way to feel. It is just important to be honest. Thank you for answering these questions.

I am doing a study for my doctorate on the stress, coping and feelings of teenagers who have disabled brothers and sisters. You have helped me a lot by answering these questionnaires, and I appreciate it. The guidance counsellor in your school has received a lot of information about the issues involved in having a disabled brother or sister and would be glad to speak with you if you would like to talk to someone. Do you have any questions that I can help you with? Thanks for coming here this evening (or afternoon).

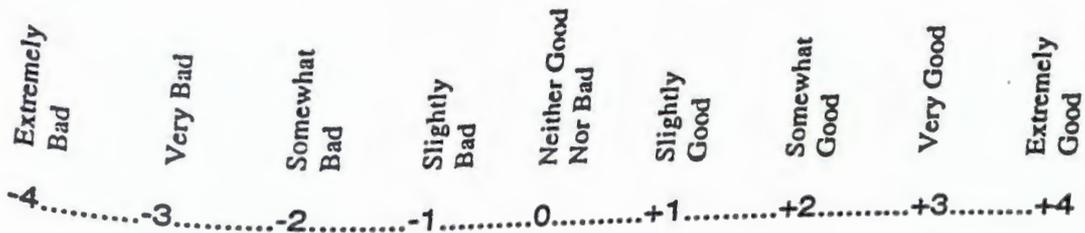
APPENDIX D

Life Events

Junior High

Instructions: The following pages contain a list of events which may or may not have happened to you. Please read each item carefully. If the event has happened to you in the past 3 months, please place an "X" on the line marked **EVENT HAS HAPPENED** in front of the event. For each event which has happened please fill in your rating of the desirability of the event (how good or bad it was when it happened).

Desirability Rating: Good (desirable) events are ones which are pleasant or make us happy while bad (undesirable) events are ones that upset us or make us feel scared, sad, or angry. Using the numbers below, write in the blank space marked **GOOD/BAD RATING** the number which best describes how desirable or undesirable the event was when it happened to you.



APPENDIX D

Junior High--2

	Extremely Bad	Very Bad	Somewhat Bad	Slightly Bad	Neither Good Nor Bad	Slightly Good	Somewhat Good	Very Good	Extremely Good	
	-4	-3	-2	-1	0	+1	+2	+3	+4	
EVENT HAS HAPPENED										GOOD/BAD RATING
24. _____ Work hassles (rude customers, unpleasant jobs, etc.).....										_____
25. _____ Liking someone who doesn't like you.....										_____
26. _____ Doing poorly on an exam or paper.....										_____
27. _____ Talking or sharing feelings with friends.....										_____
28. _____ Change in personal health or fitness.....										_____
29. _____ Arrest of a family member.....										_____
30. _____ Getting in trouble or being suspended from school.....										_____
31. _____ Hassles, arguments, or fights with other students or persons.....										_____
32. _____ Financial troubles or money worries.....										_____
33. _____ Getting bad grades or progress reports.....										_____
34. _____ Having bad classes or teachers.....										_____
35. _____ Worry about school performance.....										_____
36. _____ Worry about sports performance.....										_____
37. _____ Change in moral or religious beliefs.....										_____
38. _____ Not getting enough sleep.....										_____
39. _____ Dieting or keeping track of weight.....										_____
40. _____ Having a good talk with a teacher or other adult.....										_____
41. _____ School interfering with other activities.....										_____
42. _____ Emotional worries (feeling depressed, moody, angry, insecure, etc.).....										_____
43. _____ Being assaulted.....										_____
44. _____ Buying new clothes.....										_____
45. _____ Eating.....										_____
46. _____ End of school year.....										_____

APPENDIX D

Junior High--5

Extremely Bad	Very Bad	Somewhat Bad	Slightly Bad	Neither Good Nor Bad	Slightly Good	Somewhat Good	Very Good	Extremely Good
-4.....	-3.....	-2.....	-1.....	0.....	+1.....	+2.....	+3.....	+4
EVENT HAS HAPPENED								GOOD/BAD RATING
93.	Change in privileges or responsibilities at home.....							_____
94.	Change in health of a family member or relative.....							_____
95.	Change in health of a friend.....							_____
96.	Change in number of friends (make new friends or lose friends).....							_____
97.	Parents discovering something you didn't want them to know.....							_____
98.	People interrupting when you are trying to get work done.....							_____
99.	Brother or sister getting engaged or married.....							_____
100.	Brother or sister getting separated or divorced.....							_____
101.	Not spending enough time with family members or friends.....							_____
102.	School or career change of family member (drops out of school, gets job, etc.).....							_____
103.	Advancing a year in school.....							_____
104.	Living with only one parent.....							_____
105.	Talking on the phone.....							_____
106.	Losing job (quitting, getting fired, laid off, etc.).....							_____
107.	Homework or studying.....							_____
108.	Taking care of brothers or sisters.....							_____
109.	Personal achievement at work (getting a raise, promotion, etc.).....							_____
110.	Problems or arguments with teachers or principal.....							_____
111.	Problems or arguments with parents, siblings, or family members.....							_____
112.	Spending time at home.....							_____
113.	Having or making money.....							_____
114.	Change in alcohol or drug abuse.....							_____
115.	Making honor roll or other school achievements.....							_____

APPENDIX D

Junior High--7

Extremely Bad	Very Bad	Somewhat Bad	Slightly Bad	Neither Good Nor Bad	Slightly Good	Somewhat Good	Very Good	Extremely Good	
-4.....	-3.....	-2.....	-1.....	0.....	+1.....	+2.....	+3.....	+4.....	
EVENT HAS HAPPENED									GOOD/BAD RATING

- 139. ___ Parent loses job..... _____
- 140. ___ Problems at work..... _____
- 141. ___ Receiving a gift..... _____
- 142. ___ Sleeping late..... _____
- 143. ___ Wearing contacts..... _____
- 144. ___ Weight change..... _____
- 145. ___ Having teachers favor other students..... _____
- 146. ___ Parents getting divorced..... _____
- 147. ___ Waiting in lines, waiting for people, etc..... _____
- 148. ___ Not getting along with parents of friends..... _____
- 149. ___ Doing well on an exam or paper..... _____
- 150. ___ Spending time/relaxing/going out with friends..... _____
- 151. ___ Participation in extracurricular activities (music, arts, etc.)..... _____
- 152. ___ Friend(s) move away or you move away from friends..... _____
- 153. ___ Getting punished by parents..... _____
- 154. ___ Personal hospitalization..... _____
- 155. ___ Feeling pressed for time..... _____
- 156. ___ Worry about nuclear war..... _____
- 157. ___ Getting up in the morning..... _____
- 158. ___ Being in love or in a relationship..... _____
- 159. ___ Not having a boyfriend/girlfriend..... _____

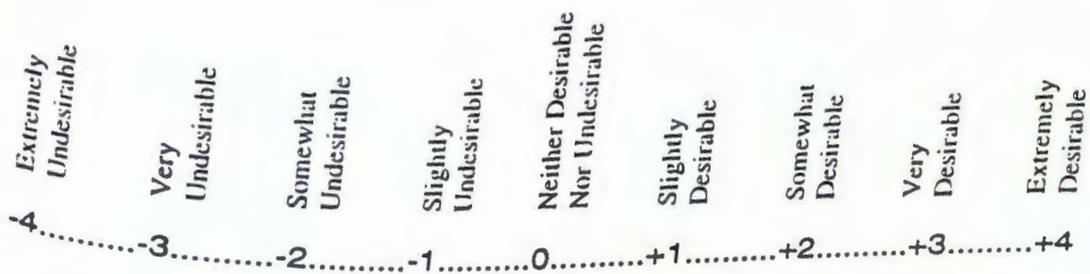
APPENDIX D

Life Events

High School

Instructions: The following pages contain a list of events which may or may not have happened to you. Please read each item carefully. If the event has happened to you in the past 3 months, please place an "X" on the line marked **EVENT HAS HAPPENED** in front of the event. For each event which has happened please fill in your rating of the desirability of the event (how good or bad it was when it happened).

Desirability Rating: Desirable events are ones which are pleasant or enjoyable while undesirable events irritate, annoy, or upset people. Using the numbers below, write in the blank space marked **DESIRABILITY RATING** the number which best describes how desirable or undesirable the event was when it happened to you.



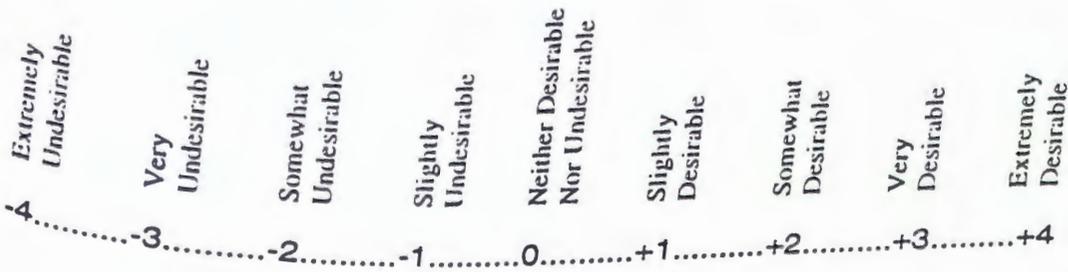
APPENDIX D

Life Events

High School

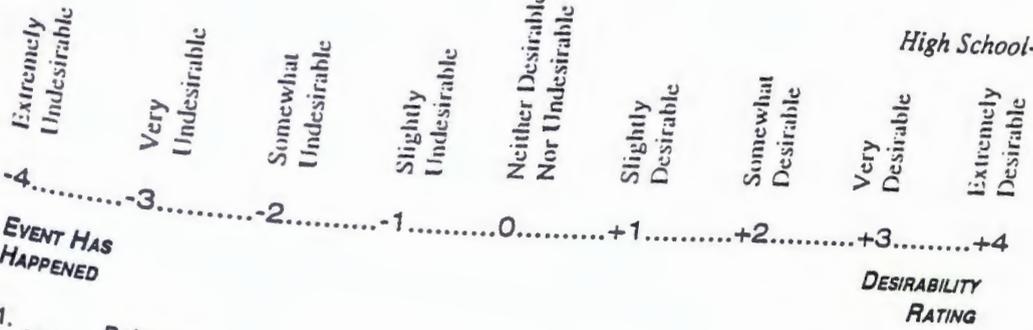
Instructions: The following pages contain a list of events which may or may not have happened to you. Please read each item carefully. If the event has happened to you in the past 3 months, please place an "X" on the line marked **EVENT HAS HAPPENED** in front of the event. For each event which has happened please fill in your rating of the desirability of the event (how good or bad it was when it happened).

Desirability Rating: Desirable events are ones which are pleasant or enjoyable while undesirable events irritate, annoy, or upset people. Using the numbers below, write in the blank space marked **DESIRABILITY RATING** the number which best describes how desirable or undesirable the event was when it happened to you.



APPENDIX D

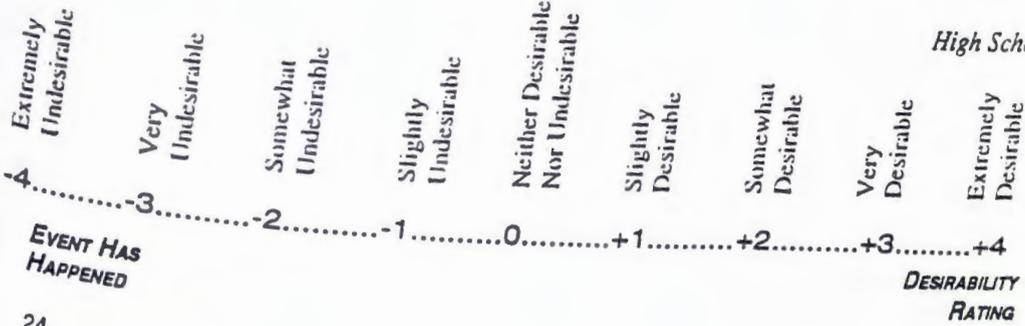
High School--1



1. ___ Being assaulted.....
2. ___ Hospitalization of a family member or relative.....
3. ___ Work hassles (rude customers, unpleasant jobs, etc.).....
4. ___ Worry about school performance.....
5. ___ Worry about sports performance.....
6. ___ Being around people who are inconsiderate or offensive.....
7. ___ Worry about school performance in extracurricular activities (music, arts, etc).....
8. ___ Personal achievement at work (getting a raise, promotion, etc.).....
9. ___ Worry about nuclear war.....
10. ___ Personal hospitalization.....
11. ___ Traffic or parking problems.....
12. ___ Restrictions at home (having to be in at a certain time, etc.).....
13. ___ Good weather.....
14. ___ Someone showing they care.....
15. ___ Trouble with the law.....
16. ___ Poor relationships between family members or friends.....
17. ___ Not spending enough time with family members or friends.....
18. ___ Feeling too young.....
19. ___ Getting a job.....
20. ___ Getting mail.....
21. ___ Getting robbed.....
22. ___ Wearing contacts.....
23. ___ Writing letters.....

APPENDIX D

High School--2



- 24. ___ Getting braces.....
- 25. ___ Wearing braces.....
- 26. ___ Driving.....
- 27. ___ Falling in love or beginning a relationship with boyfriend/girlfriend.....
- 28. ___ Talking or sharing feelings with friends.....
- 29. ___ Getting in trouble or being suspended from school.....
- 30. ___ Getting bad grades or progress reports.....
- 31. ___ Dieting or keeping track of weight.....
- 32. ___ Meeting new people.....
- 33. ___ Putting things off.....
- 34. ___ Smoking cigarettes.....
- 35. ___ Getting or losing a pet.....
- 36. ___ Feeling pressured by friends.....
- 37. ___ Looking for a place to live.....
- 38. ___ Getting complimented.....
- 39. ___ Joining the armed forces.....
- 40. ___ Getting driver's license or learner's permit.....
- 41. ___ Helping other people.....
- 42. ___ Getting up in the morning.....
- 43. ___ Talking on the phone.....
- 44. ___ Marriage or becoming engaged.....
- 45. ___ Losing job (quitting, getting fired, laid off, etc.).....
- 46. ___ Taking care of younger brothers or sisters.....
- 47. ___ Having or making money.....

APPENDIX D

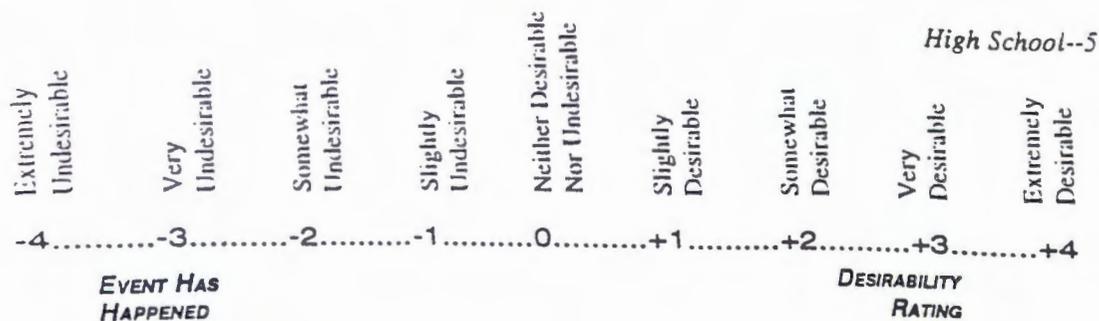
Extremely Undesirable	Very Undesirable	Somewhat Undesirable	Slightly Undesirable	Neither Desirable Nor Undesirable	Slightly Desirable	Somewhat Desirable	Very Desirable	Extremely Desirable
-4.....	-3.....	-2.....	-1.....	0.....	+1.....	+2.....	+3.....	+4
EVENT HAS HAPPENED				DESIRABILITY RATING				
<p>48. ____ Change in alcohol or drug abuse.....</p> <p>49. ____ Making honor roll or other student achievements.....</p> <p>50. ____ Friend getting married or engaged.....</p> <p>51. ____ Having few or no friends.....</p> <p>52. ____ Having to share a room.....</p> <p>53. ____ Having good classes or teachers.....</p> <p>54. ____ Change in relationship with boyfriend/girlfriend.....</p> <p>55. ____ Change in relationship with family member(s).....</p> <p>56. ____ Change in relationship with friend(s).....</p> <p>57. ____ Having plans fall through.....</p> <p>58. ____ Change in church attendance.....</p> <p>59. ____ Having braces removed.....</p> <p>60. ____ Having teachers favor other students.....</p> <p>61. ____ Doctor's or dentist's appointment.....</p> <p>62. ____ Friend(s) move away or you move away from friends.....</p> <p>63. ____ Eating.....</p> <p>64. ____ Friend/family member recovering from illness or injury.....</p> <p>65. ____ Bad weather.....</p> <p>66. ____ Getting divorced.....</p> <p>67. ____ Family move.....</p> <p>68. ____ Having a job.....</p> <p>69. ____ Parent loses job.....</p> <p>70. ____ Taking medication.....</p> <p>71. ____ Taking showers.....</p>								

High School:-3

APPENDIX D

Extremely Undesirable	Very Undesirable	Somewhat Undesirable	Slightly Undesirable	Neither Desirable Nor Undesirable	Slightly Desirable	Somewhat Desirable	Very Desirable	Extremely Desirable	<i>High School-4</i>
-4.....	-3.....	-2.....	-1.....	0.....	+1.....	+2.....	+3.....	+4	
EVENT HAS HAPPENED				DESIRABILITY RATING					
72. ____ Weight change.....									
73. ____ Change in personal appearance.....									
74. ____ Liking someone who doesn't like you.....									
75. ____ Change in personal health or appearance.....									
76. ____ Arrest of a family member.....									
77. ____ Having bad classes or teachers.....									
78. ____ Change in moral or religious beliefs.....									
79. ____ Having a good talk with a teacher or other adult.....									
80. ____ School interfering with other activities.....									
81. ____ Buying new clothes.....									
82. ____ End of school year.....									
83. ____ Change in eating habits.....									
84. ____ Friend getting separated or divorced.....									
85. ____ Having or taking care of pets.....									
86. ____ Moving away from parents' home or living on own.....									
87. ____ Parent getting remarried.....									
88. ____ Hassles with people of the opposite sex.....									
89. ____ Parents discovering something you didn't want them to know.....									
90. ____ Hobbies or activities (watching TV, reading, playing an instrument, etc).....									
91. ____ Friends getting drunk or using drugs.....									
92. ____ Parents getting divorced.....									
93. ____ Going to church.....									
94. ____ Not getting mail.....									

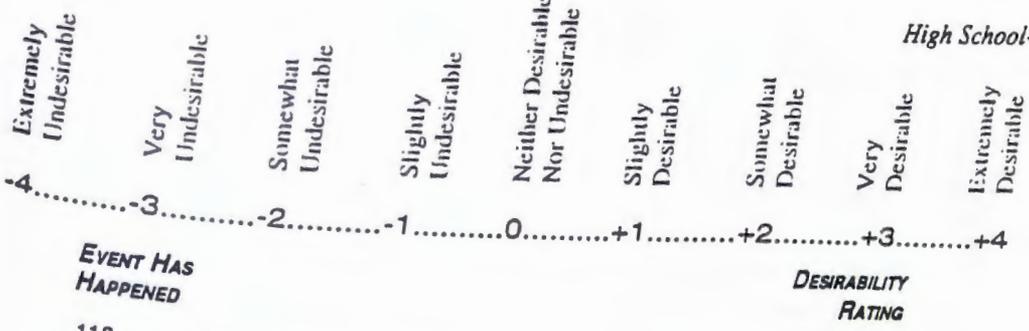
APPENDIX D



- 95. ____ Not attending your high school prom....._____
- 96. ____ Not getting enough sleep....._____
- 97. ____ Not getting driver's license or learner's permit....._____
- 98. ____ Not getting the classes you want....._____
- 99. ____ Going to dances, parties, or concerts....._____
- 100. ____ Obligations at home....._____
- 101. ____ Doing things/spending time with family members....._____
- 102. ____ Going to bed/sleeping....._____
- 103. ____ Understanding classes/homework....._____
- 104. ____ Not getting along with parents or friends....._____
- 105. ____ Being unemployed....._____
- 106. ____ Menstruation....._____
- 107. ____ Not having a boyfriend/girlfriend....._____
- 108. ____ Negative feelings or worry about your appearance....._____
- 109. ____ Negative feelings or worry about your personal health or fitness....._____
- 110. ____ Applying to or waiting to hear from colleges....._____
- 111. ____ Visiting with relatives....._____
- 112. ____ Spending time/relaxing/going out with friends....._____
- 113. ____ Death of a friend....._____
- 114. ____ Car trouble....._____
- 115. ____ Death of a relative....._____
- 116. ____ Death of a family member....._____
- 117. ____ Vacation, trip, or summer break....._____

APPENDIX D

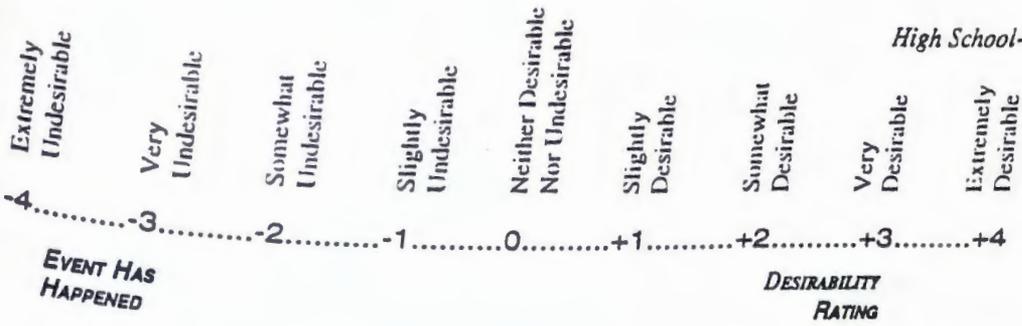
High School--6



- 118. _____ Doing poorly on an exam or paper..... _____
- 119. _____ Minor physical ailments or illnesses(headaches, cuts, bruises, etc.)_____
- 120. _____ Recovering from an accident or illness..... _____
- 121. _____ Brother or sister getting engaged or married..... _____
- 122. _____ Brother or sister getting separated or divorced..... _____
- 123. _____ Homework or studying..... _____
- 124. _____ Pressures or expectation by parents..... _____
- 125. _____ Exercising..... _____
- 126. _____ Hassles, arguments, or fights with other students or peers..... _____
- 127. _____ Major success or failure in sports..... _____
- 128. _____ Major success or failure in extracurricular activities
(music, art, etc.)..... _____
- 129. _____ Discussion with parents..... _____
- 130. _____ Participation in sports or recreation..... _____
- 131. _____ Participation in extracurricular activities (music, arts, etc.)..... _____
- 132. _____ Alcohol or drug use of family members or relatives..... _____
- 133. _____ Problems at work..... _____
- 134. _____ Problems or arguments with parents, siblings, or family members... _____
- 135. _____ Problems with arguments with teachers or principal..... _____
- 136. _____ Problems with transportation..... _____
- 137. _____ Changing schools..... _____
- 138. _____ Sleeping late..... _____
- 139. _____ Emotional worries(feeling depressed, moody, angry, insecure, etc.)_____
- 140. _____ Becoming a year older..... _____
- 141. _____ Spending time alone..... _____

APPENDIX D

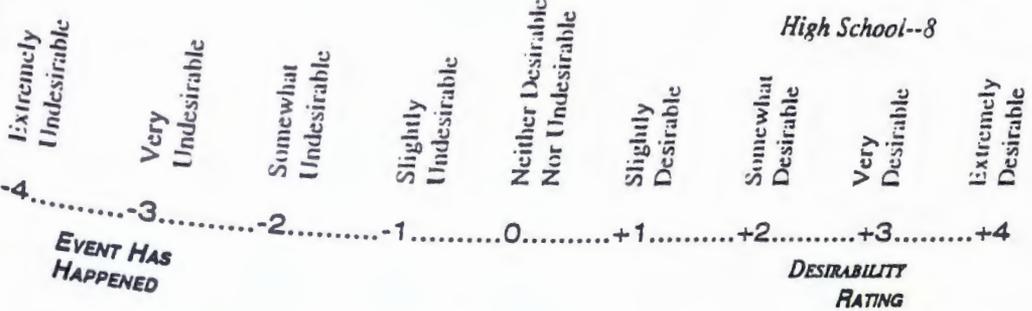
High School--7



- 142. _____ Arguments or problems with boyfriend/girlfriend....._____
- 143. _____ Spending time/talking with boyfriend/girlfriend....._____
- 144. _____ Becoming financially independent....._____
- 145. _____ Spending time at home....._____
- 146. _____ Becoming more independent....._____
- 147. _____ Breaking up with or being rejected by a boyfriend/girlfriend....._____
- 148. _____ Arguments or fights between parents....._____
- 149. _____ Drinking or using drugs....._____
- 150. _____ Visiting a parent who doesn't live with you....._____
- 151. _____ Feeling pressed for time....._____
- 152. _____ Getting a car/motorcycle/truck, etc....._____
- 153. _____ Getting good grades or progress reports....._____
- 154. _____ Getting ready for school....._____
- 155. _____ Getting accepted at one or more colleges....._____
- 156. _____ Getting a traffic ticket or parking ticket....._____
- 157. _____ Waiting in lines, waiting for people, etc....._____
- 158. _____ Getting rejected by, or not being able to attend college....._____
- 159. _____ Getting punished by parents....._____
- 160. _____ Doing household chores....._____
- 161. _____ Receiving a gift....._____
- 162. _____ Attending school....._____
- 163. _____ Financial troubles or money worries....._____
- 164. _____ Listening to music....._____

APPENDIX D

High School--8



- 165. _____ Being involved in a car accident....._____
- 166. _____ Returning to live at parents' home....._____
- 167. _____ Something bad happens to a friend....._____
- 168. _____ Attending your high school prom....._____
- 169. _____ Returning to school after time off....._____
- 170. _____ Free time in school....._____
- 171. _____ Being in love or in a relationship....._____
- 172. _____ Advancing a year in school....._____
- 173. _____ Something good happens to a friend....._____
- 174. _____ Change in participation in extracurricular activities (music, art, etc.)_____
- 175. _____ Change in sleep habits....._____
- 176. _____ Making decisions about career....._____
- 177. _____ Making a major purchase (stereo, bicycle, etc.)....._____
- 178. _____ Change in cigarette use....._____
- 179. _____ Friend becoming pregnant or having a child....._____
- 180. _____ Family member or relative having motional problems....._____
- 181. _____ Change in priveleges or responsibilitles at home....._____
- 182. _____ Change in heath of a family member or relative....._____
- 183. _____ Change in heath of a friend....._____
- 184. _____ Change in number of friends (make new friends or lose friends)....._____
- 185. _____ People interrupting when you are trying to get work done....._____
- 186. _____ School of career change of family member
(drops out of school, gets job, etc)....._____
- 187. _____ People not respecting your privacy or property....._____

APPENDIX E

Part 1

This booklet contains questions about how you deal with important problems that come up in your life. Please think about the most important problem or stressful situation you have experienced **in the last 12 months** (for example, a problem with your parents, a problem at school, a serious illness or accident, or the death of a family member or a friend). Briefly describe the problem in the space provided in Part 1 of the answer sheet. If you have not experienced a major problem, list a minor problem that you have had to deal with. Then answer each of the 10 questions about the problem or situation (listed below and again on the answer sheet) by circling the appropriate response:

Circle **"DN"** if your response is **DEFINITELY NO**.

DN	MN	MY	DY
-----------	----	----	----

Circle **"MN"** if your response is **MAINLY NO**.

DN	MN	MY	DY
----	-----------	----	----

Circle **"MY"** if your response is **MAINLY YES**.

DN	MN	MY	DY
----	----	-----------	----

Circle **"DY"** if your response is **DEFINITELY YES**.

DN	MN	MY	DY
----	----	----	-----------

1. Have you ever faced a problem like this before?
2. Did you know this problem was going to happen to you?
3. Did you have enough time to get ready to deal with the problem?
4. When this problem happened, did you think about how it might harm you?
5. When this problem happened, did you think of it as a challenge?
6. Was this problem caused by something you did?
7. Was this problem caused by something someone else did?
8. Did anything good come out of dealing with this problem?
9. Has this problem or situation been worked out?
10. If the problem has been worked out, did it turn out all right for you?

APPENDIX E

Part 2

Read each item carefully and indicate how often you took that action to deal with the problem you described in Part 1. Circle the appropriate response on the answer sheet:

Circle "N" if your response is NO, Not at all.

Circle "O" if your response is YES, Once or Twice.

Circle "S" if your response is YES, Sometimes.

Circle "F" if your response is YES, Fairly often.

N	O	S	F
N	O	S	F
N	O	S	F
N	O	S	F

There are 48 items in Part 2. Remember to mark all your answers on the answer sheet. Please answer each question as accurately as you can. All your answers are strictly confidential. If you do not wish to answer a question, please circle the number of that question on the answer sheet to indicate that you have decided to skip it. If an item does not apply to you, please write **NA** (Not Applicable) in the box to the right of the number for that item. If you wish to change an answer, make an **X** through your first answer and circle the new answer. Note that answers are numbered across in rows on Part 2 of the answer sheet.

1. Did you think of different ways to deal with the problem?
2. Did you tell yourself things to make yourself feel better?
3. Did you talk with a parent or other family member about the problem?
4. Did you decide on one way to deal with the problem and do it?
5. Did you try to forget the whole thing?
6. Did you feel that time would make a difference—that the only thing to do was wait?
7. Did you get involved in new activities?
8. Did you take it out on other people when you felt angry or sad?
9. Did you try to step back from the problem and think about it?
10. Did you tell yourself that things could be worse?
11. Did you talk with a friend about the problem?
12. Did you know what had to be done and try hard to make things work?
13. Did you try not to think about the problem?
14. Did you realize that you had no control over the problem?
15. Did you try to make new friends?
16. Did you take a chance and do something risky?
17. Did you go over in your mind what you would say or do?
18. Did you try to see the good side of the situation?
19. Did you talk with an adult like a teacher, coach, counselor, clergyman, or doctor?
20. Did you decide what you wanted and try to get it?

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21. Did you daydream or imagine things being better than they were?
22. Did you think that the outcome would be decided by fate?
23. Did you begin to read more often for enjoyment?
24. Did you yell or shout to let off steam?
25. Did you think about how things might turn out?
26. Did you keep thinking about how you were better off than other people with the same problems?
27. Did you look for help from other kids or groups with the same type of problem?
28. Did you try at least two different ways to solve the problem?
29. Did you put off thinking about the situation, even though you knew you would have to at some point?
30. Did you accept the problem because nothing could be done to change it?
31. Did you begin to spend more time in fun activities, like sports, parties, and going shopping?
32. Did you cry to let your feelings out?
33. Did you try to make sense out of why this problem happened to you?
34. Did you try to tell yourself that things would get better?
35. Did you ask a friend to help you solve the problem?
36. Did you try to do more things on your own?
37. Did you wish the problem would go away or somehow be over with?
38. Did you expect the worst possible outcome?
39. Did you try to keep busy with school or other things to help you cope?
40. Did you do something that you didn't think would work, but at least you were doing something?
41. Did you think about the new hardships that would be placed on you?
42. Did you think about how this situation could change your life for the better?
43. Did you ask for sympathy and understanding from someone?
44. Did you take things a day at a time, one step at a time?
45. Did you try to deny how serious the problem really was?
46. Did you lose hope that things would ever be the same?
47. Did you find new ways to enjoy life?
48. Did you listen to music as a way to cope?

APPENDIX E

CRI-YOUTH ANSWER SHEET

Form: Actual ___ Ideal ___

Name _____ Date ____ / ____ / ____ Sex ____ Age ____

Grade in School _____ Ethnic Group _____

Part 1

Describe the problem or situation _____

DN = Definitely No MN = Mainly No MY = Mainly Yes DY = Definitely Yes

- 1. Have you ever faced a problem like this before? DN MN MY DY
- 2. Did you know this problem was going to happen to you? DN MN MY DY
- 3. Did you have enough time to get ready to deal with this problem? DN MN MY DY
- 4. When this problem happened, did you think of it as a threat? DN MN MY DY
- 5. When this problem happened, did you think of it as a challenge? DN MN MY DY
- 6. Was this problem caused by something you did? DN MN MY DY
- 7. Was this problem caused by something someone else did? DN MN MY DY
- 8. Did anything good come out of dealing with this problem? DN MN MY DY
- 9. Has this problem or situation been worked out? DN MN MY DY
- 10. If the problem has been worked out, did it turn out all right for you? DN MN MY DY

Part 2

N = No, Not at all O = Yes, Once or twice S = Yes, Sometimes F = Yes, Fairly often

1 N O S F	2 N O S F	3 N O S F	4 N O S F	5 N O S F	6 N O S F	7 N O S F	8 N O S F
9 N O S F	10 N O S F	11 N O S F	12 N O S F	13 N O S F	14 N O S F	15 N O S F	16 N O S F
17 N O S F	18 N O S F	19 N O S F	20 N O S F	21 N O S F	22 N O S F	23 N O S F	24 N O S F
25 N O S F	26 N O S F	27 N O S F	28 N O S F	29 N O S F	30 N O S F	31 N O S F	32 N O S F
33 N O S F	34 N O S F	35 N O S F	36 N O S F	37 N O S F	38 N O S F	39 N O S F	40 N O S F
41 N O S F	42 N O S F	43 N O S F	44 N O S F	45 N O S F	46 N O S F	47 N O S F	48 N O S F

APPENDIX F
Emotional Response Scale

Please circle the number that corresponds to your answer for each of the questions below. There are no right or wrong answers but only how you feel.

Circle 4 if your answer is always.

Circle 3 if your answer is often.

Circle 2 if your answer is sometimes.

Circle 1 if your answer is never.

1. Do you like to help with your handicapped brother or sister? 4 - 3 - 2 - 1
2. Do you feel upset that your parents don't talk to you more about what is wrong with your handicapped brother or sister? 4 - 3 - 2 - 1
3. Do you get embarrassed when your family goes to the mall or on trips because of the way your handicapped brother or sister acts? 4 - 3 - 2 - 1
4. Are you afraid that you will become like your handicapped brother or sister? 4 - 3 - 2 - 1
5. Do you like to be around other people who are different such as handicapped people? 4 - 3 - 2 - 1
6. Do you feel left out when your parents are working with your handicapped brother or sister? 4 - 3 - 2 - 1
7. Do you get tired of doing extra jobs at home because your handicapped brother or sister can't help? 4 - 3 - 2 - 1
8. Do you feel embarrassed about having friends come to the house when your handicapped brother or sister is home? 4 - 3 - 2 - 1
9. Do you feel your parents spend a lot of money on things your handicapped brother or sister needs and don't have enough money to buy you what you want? 4 - 3 - 2 - 1
10. Does having a handicapped brother or sister help you to accept the fact that people are different in many ways? 4 - 3 - 2 - 1

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11. Do you feel angry when your handicapped brother or sister is bad and doesn't get punished? 4 - 3 - 2 - 1
12. Do you like to play with your handicapped brother or sister? 4 - 3 - 2 - 1
13. Do you feel angry when your parents do things for your handicapped brother or sister that he could do for himself? 4 - 3 - 2 - 1
14. Are you afraid that others will make fun of your handicapped brother or sister? 4 - 3 - 2 - 1
15. Do you feel your parents spend too much time with your handicapped brother or sister? 4 - 3 - 2 - 1
16. Are you afraid to get angry with your handicapped brother or sister because of what your parents will say? 4 - 3 - 2 - 1
17. Do you feel embarrassed by some of the actions and sounds that your handicapped brother or sister makes? 4 - 3 - 2 - 1
18. Do you like to teach new skills to your handicapped brother or sister? 4 - 3 - 2 - 1
19. Are you afraid of what might happen in the future if your parents can't take care of your handicapped brother or sister? 4 - 3 - 2 - 1
20. Do you wish that you could spend more time with your friends but can't because of the things you do for your handicapped brother or sister? 4 - 3 - 2 - 1
21. Because you have a handicapped brother or sister, do you think you want to be in a job that helps other people? 4 - 3 - 2 - 1
22. Do you like to take your handicapped brother or sister to special places? 4 - 3 - 2 - 1
23. Would you feel embarrassed if your handicapped brother or sister attended the same school as you do? 4 - 3 - 2 - 1
24. Do you feel your life has been enriched because you have a handicapped brother or sister? 4 - 3 - 2 - 1

REFERENCES

- Abramovitch, Rona, Stanhope, L., Pepler, D., & Corter, Carl (1987). The influence of Down's Syndrome on sibling interaction. Journal of Child Psychology and Psychiatry, 28(6), 865-879.
- Band, Eve, & Weisz, John (1988). How to feel better when it feels bad: Children's perspectives on coping with everyday stress. Developmental Psychology, 24(2), 247-253.
- Bank, S. P., & Kahn, M. D. (1982). The sibling bond. New York: Basic Books.
- Barnett, Steven (1993). Toward a more general model for research on the well-being of siblings of persons with disabilities. In Stoneman & Berman (Eds.), The Effect of Mental Retardation, Disability and Illness on Sibling Relationships (pp. 333- 354). Baltimore: Paul Brookes.
- Begun, Andrea (1989). Sibling relationships involving developmentally disabled people. American Journal of Mental Retardation, 93(5), 566-574.
- Boyce, Glenna, & Barnett, Steven (1993). Siblings of persons with mental retardation. In Stoneman & Berman (Eds.), The Effects of Mental Retardation, Disability, and Illness on Sibling Relationships (pp. 145-184). Baltimore: Paul Brookes.
- Breslau, Naomi (1982). Siblings of disabled children: Birth order and age-spacing effects. Journal of Abnormal Child Psychology, 10(1), 85-96.
- Breslau, Naomi, & Prabucki, Kenneth (1987). Siblings of disabled children: Effects of chronic stress in the family. Arch General Psychiatry, 44, 1040-1046.
- Brody, Gene H., & Stoneman, Zolinda (1986). Contextual issues in the study of sibling socialization. In Gallagher & Vietze (Eds.), Families of Handicapped Persons: Research, Programs and Policy Issues (pp. 197- 217). Baltimore: Paul Brookes.

- Brody, Gene H., Stoneman, Zolinda, Davis, Cathy H., & Crapps, John (1991). Observations of the role relations and behavior between older children with mental retardation and their younger siblings. American Journal on Mental Retardation, 95(5), 527-536.
- Carr, Janet (1988). Six weeks to twenty-one years old: A longitudinal study of children with Down's Syndrome and their families. Journal of Child Psychology and Psychiatry, 29(4), 407-431.
- Chinitz, Susan P. (1981). A sibling group for brothers and sisters of handicapped children. Children Today, 10(6), 21-24.
- Code of Maryland Regulations, Supplement 10 (1992). Virginia: Michie Co.
- Cohen, Laurence, Burt, Charles, & Bjorck, Jeffrey (1987). Life stress and adjustments: Effects of life events experienced by young adolescents and their parents. Developmental Psychology, 23(4), 583-592.
- Compas, Bruce (1987). Stress and life events during childhood and adolescence. Clinical Psychology Review, 7, 275-302.
- Compas, Bruce, Davis, Glen, & Forsythe, Carolyn (1985). Characteristics of life events during adolescence. American Journal of Community Psychology, 13(6), 677- 691.
- Compas, Bruce, Davis, Glen, Forsythe, Carolyn, & Wagner, Barry (1987). Assessment of major and daily stressful events during adolescence: The Adolescent Perceived Events Scale. Journal of Consulting and Clinical Psychology, 55(4), 534-541.
- Compas, Bruce, & Grant, Kathryn (1993). Stress and adolescent depressive symptoms: underlying mechanisms and processes. Paper presented at the biannual meeting of The Society for Research in Child Development, New Orleans, La.
- Compas, Bruce, Howell, David, Phares, Vicky, Williams, Rebecca, & Guinta, Carole (1989). Risk factors for emotional/behavioral problems in young adolescents: A prospective analysis of adolescent and parental stress and symptoms. Journal of Consulting and Clinical Psychology, 57(6), 737-740.

- Compas, Bruce, Howell, David, Phares, Vicky, Williams, Rebecca, & Ledoux, Normand (1989). Parent and child stress and symptoms: An integrative analysis. Developmental Psychology, 25(4), 550-559.
- Crnic, Keith, & Leconte, Judith (1986). Understanding siblings needs and influences. In Fewell, Rebecca & Vadasy, Patricia (Eds.), Families of Handicapped Children: Needs and Support Across the Life Span (pp. 75-98). Texas: Pro-Ed.
- Crouthamel, Carol S. (1988). Siblings of handicapped children: A group support program. Early Child Development and Care, 37, 119-131.
- Davis, Russell (1967). Family processes in mental retardation. American Journal of Psychiatry, 124, 350-350.
- DeLongis, Anita, Folkman, Susan, & Lazarus, Richard (1988). The impact of daily stress on health and mood: Psychological and social resources as mediators. Journal of Personality and Social Psychology, 54(3), 486-495.
- Dohrenwend, Barbara, Dohrenwend, Bruce, Dodson, Margaret, & Shrout, Patrick (1984). Symptoms, hassles, social support, and life measures: Problem of confounded measures. Journal of Abnormal Psychology, 93(2), 222-230.
- Dohrenwend, Bruce, & Shrout, Patricia (1985). "Hassles" in the conceptualization and measurement of life stress variables. American Psychologist, 40, 780-785.
- Dyson, Lily, Edgar, Eugene, & Crnic, Keith (1989). Psychological predictors of adjustment of developmentally disabled children. American Association on Mental Retardation, 94(3), 292-302.
- Edmundson, Kathryn (1985). The "discovery" of siblings. Mental Retardation, 23(2), 49-51.
- Elwood, Sandra (1987). Stressor and coping response inventories for children. Psychological Reports, 60, 931-947.
- The Extended Family: The handicapped child's siblings (1974). In Mann (Ed.), The Human Side of Exceptionality VIII (pp. 212-214). Philadelphia: JSE Press.

- Featherstone, Helen (1980). A difference in the family: Living with a disabled child. New York: Penguin.
- Ferrari, Michael (1984). Chronic illness: Psychosocial effects on siblings-chronically ill boys. Journal of Child Psychiatry and Psychology, 25(2), 459-476.
- Fischer, John, & Roberts, Susan (1983). The effects of the mentally retarded child on his siblings. Education, 103, 399-401.
- Folkman, Susan, Lazarus, Richard, Dunkel-Schetter, Christine, DeLongis, Anita, & Gruen, Rand (1985). Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. Journal of Personality and Social Psychology, 992-1003.
- French, Kelsey (1992). Emotional rehabilitation. The Journal of Head Injury, 1(4), 16-18.
- Gallagher, James, Beckman, Paula, & Cross, Arthur (1983). Families of handicapped children: Sources of stress and its amelioration. Exceptional Children, 50, 10-19.
- Gallagher, Peggy, & Powell, Thomas (1989). Brothers and sisters: Meeting special needs. Topics in Early Childhood Special Education, 8(4), 24-37.
- Gallo, Agatha, Breitmayer, Bonnie, Knafl, Kathleen, & Zoeller, Linda (1991). Stigma in childhood chronic illness: A well sibling perspective. Pediatric Nursing, 17(1), 21-25.
- Gamble, Wendy & McHale, Susan (1989). Coping with stress in sibling relationships: A comparison of children with disabled and nondisabled siblings. Journal of Applied Developmental Psychology, 10, 353-373.
- Gamble, Wendy, & Woulbroun, Jeanne (1993). Measurement considerations in the identification and assessment of stressors and coping strategies. In Stoneman & Berman (Eds.), The Effects of Mental Retardation, Disability, and Illness on Sibling Relationships (pp. 287-319). Baltimore: Paul Brookes.
- Gath, Ann (1972). The mental health of siblings of congenitally abnormal children. Journal of Child Psychology and Psychiatry, 13, 211-218.

- Gath, Ann (1973). The school age siblings of mongol children. British Journal of Psychiatry, 123, 161-167.
- Gath, Ann (1974). Siblings reactions to mental handicap: A comparison of the brothers and sisters of mongol children. Journal of Child Psychology and Psychiatry, 15, 187-198.
- Gath, A, & Gumley, D. (1987). Retarded children and their siblings. Journal of Child Psychology and Psychiatry and Allied Disciplines, 28(5), 715-730.
- Grossman, F. K. (1972). Brothers and sisters of retarded children: An exploratory study. Syracuse, NY: Syracuse University Press.
- Hannah, Mary E., & Midlarsky, Elizabeth (1985). Siblings of the handicapped: A literature review for school psychologists. School Psychology Review, 14(4), 510-520.
- Hannah, Mary E., & Midlarsky, Elizabeth (1990, August). Helping by siblings of the retarded: Demographic and personality correlates. Paper presented at the annual convention of the American Psychological Association, Boston, Mass.
- Hart, Archibald (1992). Stress and your child: Know the signs and prevent the harm. Dallas: Word Publishing.
- Heward, William & Orlansky, Michael (1980). Exceptional children. Columbus, Ohio: Merrill Publishing Co.
- Holahan, Charles, & Moos, Rudolf (1985). Life stress and health: Personality, coping, and family support in stress resistance. Journal of Personality and Social Psychology, 49(3), 739-747.
- Holahan, Charles, & Moos, Rudolf (1986). Personality, coping, and family resources in stress resistance: A longitudinal analysis. Journal of Personality and Social Psychology, 51(2), 389-395.
- Holahan, Charles, & Moos, Rudolf (1987). Risk, resistance and psychological distress: A longitudinal analysis with adults and children. Journal of Abnormal Psychology, 6(1), 3-13.
- Holahan, Charles, & Moos, Rudolf (1987). Personal and contextual determinants of coping strategies. Journal of Personality and Social Psychology, 52(5), 946-955.

- Holahan, Charles, & Moos, Rudolf, (1989). Life stressors, resistance factors, and improved psychological functioning: An extension of the stress resistance paradigm. Journal of Personality and Social Psychology, 58(5), 909-917.
- Hollingshead, A. B. (1975). Four factor index of social status. New Haven, Connecticut: Department of Sociology, Yale University.
- Holroyd, Jean (1974). The questionnaire on resources and stress: An instrument to measure family responses to a handicapped family member. Journal of Community Psychology, 2, 92-94.
- Kaplan, Frances (1969). Siblings of the retarded. In Saravan & Doris (Eds.), Psychological Problems in Mental Deficiency (4th ed., pp. 186-208). New York: Harper & Row.
- Lahey, Brian, & Heller, Kenneth (1985). Response biases and the relation between negative life events and psychological symptoms. Journal of Personality and Social Psychology, 49(6), 1662-1668.
- Lazarus, Richard, DeLongis, Folkman, Susan, & Gruen, Rand (1985). Stress and adaptational outcomes: The problem of confounded measures. American Psychologist, 40, 770-779.
- Lobato, Debra (1983). Siblings of handicapped: A review. Journal of Autism and Developmental Disorders, 13(4), 347-364.
- Lobato, Debra (1990). Brothers and sisters and special needs. Baltimore: Paul Brookes.
- Lobato, Debra, Barbour, Linda, Hall, Laura, & Miller, Carol (1987). Psychosocial characteristics of preschool siblings and nonhandicapped children. Journal of Abnormal Child Psychology, 15(3), 329-338.
- McHale, Susan, & Gamble, Wendy (1989). Sibling relationships of children with disabled and nondisabled brothers and sisters. Developmental Psychology, 25(3), 421-429.
- Meyer, Donald, Vadasky, Patricia, & Fewell, (1985). Living with a brother or sister with special needs: A book for sibs. Seattle: University of Washington Press.

- Miller, Nancy Brown, & Cantwell, Dennis (1976). Siblings as therapist: A behavioral approach. American Journal of Psychiatry, 133(4), 447-450.
- Murphy, Ann, Pueschel, Siegried, Duffy, Trudy, & Brady, Eleanor (1976). Meeting with brothers and sisters of children with Down's Syndrome. Children Today, 20-23.
- O'Neill, Jane (1965). Siblings of the retarded: Individual counseling. Children, 12(6), 226-226.
- Pearson, Judith, & Sternberg, Abby (1986). A mutual-help project for families of handicapped children. Journal of Counseling and Development, 65, 213-215.
- Post-Kammer, Phyllis, & Nickolai, Susanne (1985). Counseling services for the siblings of the handicapped. Elementary School Guidance and Counseling, December, 115-120.
- Powell, Thomas, & Ogle, A (1985). Brothers & sisters: A special part of exceptional families. Baltimore: Paul Brookes.
- Powell, Thomas, & Gallagher, Peggy (1993). Brothers & sisters: A special part of exceptional families (2nd ed.). Baltimore: Paul Brookes.
- Reich, John, & Zautra, Alex (1981). Life events and personal causation: Some relationship with personality and distress. Journal of Personality and Social Psychology, 41(5), 1002-1012.
- Rowlinson, Richard, & Felner, Robert (1988). Major life events, hassles, and adaptations in adolescence: Confounding in the conceptualization and measurement of life stress and adjustment revisited. Journal of Personality and Social Psychology, 55(3), 432-444.
- Rutter, Michael (1981). Stress, coping and development: Some issues and some questions. Journal of Child Psychology and Psychiatry, 44(4), 323-356.
- Sandler, Irwin, & Barrera, Manuel (1984). Toward a multimethod approach to assessing the effects of social support. American Journal of Community Psychology, 12(1), 715-721.

- San Martino, Mary, & Newman, Morton (1974). Siblings of retarded children: A population at risk. Child Psychiatry and Human Development, 4, 168-177.
- Sarason, Irwin, Johnson, James, & Siegel, Judith (1978). Assessing the impact of life changes: Development of the Life Experiences Survey. Journal of Consulting and Clinical Psychology, 16(5), 932-946.
- Schild, Sylvia, (1971). The family of the retarded child. In Koch & Dobson (Eds.), The Mentally Retarded Child and His Family (pp. 436-438). New York: Brunner & Mazel.
- Schreiber, Meyer, & Feely, Mary (1965). Siblings of the retarded: A guided group experience. Children, Nov-Dec., 221-225.
- Seligman, Milton (1989). Effects on siblings. In Darling (Ed.), Ordinary Families, Special Children: A Systems Approach to Childhood Disability (pp. 111-133), New York: Guilford Press.
- Senapati, Roshni, & Hayes, Alan (1988). Sibling relationships of handicapped children: A review of conceptual and methodological issues. International Journal of Behavioral Development, 11(1), 89-115.
- Siblings of children with disabilities (1979). The Exceptional Parent, 9(6), 29-32.
- Siegel, Judith, & Brown, Jonathan (1988). A perspective study of stressful circumstances, illness symptoms, and depressed mood among adolescents. Developmental Psychology, 24(5), 715-721.
- Simeonsson, Rune J., & Bailey, Donald B. (1986). Siblings of handicapped children. In Gallagher and Vietze (Eds.), Families of Handicapped Persons: Research, Programs and Policy Issues (pp. 67-77). Baltimore: Paul Brookes.
- Slade, Jill C. (1988). Why siblings of handicapped children need the attention and help of the counselor. The School Counselor, 36, 107-111.

- Stoneman, Zolinda, & Brody, Gene (1993). Sibling relations in the family context. In Stoneman & Berman (Eds.), The Effect of Mental Retardation, Disability and Illness on Sibling Relationships (pp. 3-30). Baltimore: Paul Brookes.
- Stoneman, Zolinda, Brody, Gene, & Crapps, John (1987). Mentally retarded children and their older same-sex siblings: Naturalistic in-home observations. American Journal of Mental Retardation, 92(3), 290-298.
- Stoneman, Zolinda, Brody, Gene, & Davis, Cathy (1989). Role relations between children who are mentally retarded and their older siblings: Observations in three in-home contexts. Research in Developmental Disabilities, 10, 61-76.
- Stoneman, Zolinda, Brody, Gene, Davis, Cathy, & Crapps, John (1988). Childcare responsibilities, peer relations, and sibling conflict: Older siblings of mentally retarded children. American Journal on Mental Retardation, 93(2), 174-183.
- Stoneman, Zolinda, Brody, Gene, Davis, Cathy, Crapps, John, & Malone, Michael (1991). Ascribed role relations between children with mental retardation and their younger siblings. American Journal on Mental Retardation, 95(5), 537-550.
- Summers, Marcia, Bridge, Jane, & Summers, Carl (1991). Sibling support groups. Teaching Exceptional Children, Summer, 20-25.
- Swearington, Elizabeth, & Cohen, Laurence (1985). Life events and psychological distress: A perspective study of young adolescents. Developmental Psychology, 31(6), 1045-1054.
- Taylor, Shelley (1983). Adjustment to threatening events: A theory of cognitive adaptation. American Psychologist, Nov., 1161-1173.
- Thomson, Brian, & Vaux, Alan (1986). The importation, transmission, and moderation of stress in the family system. American Journal of Community Psychology, 14(1), 39-55.
- Trevino, Fern (1979). Siblings of handicapped children: Identifying those at risk. Social Casework: The Journal of Contemporary Social Work, 488-493.

- Trout, Micheal D. (1983). Birth of a sick or handicapped infant: Impact on the family. Child Welfare, 52(4), 337-348.
- Turnbull, Ann, Summers, Jean Ann, & Brotherson, Mary Jane (1986). Family life cycle: Theoretical and empirical implications and future directions for families with mentally retarded members. In Gallagher & Vietze (Eds.), Families of Handicapped Persons: Research, Programs and Policy Issues (pp. 45-65). Baltimore: Paul Brookes.
- Vinokur, Amiram, & Selzer, Melvin (1975). Desirable versus undesirable life events: Their relationship to stress and mental distress. Journal of Personality and Social Psychology, 32(2), 329-337.
- Wagner, Barry, Compas, Bruce, & Howell, David (1988). Daily and major life events: A test of an integrative model of psychological stress. American Journal of Community Psychology, 16(2), 189-205.
- Wagner, Barry, & Compas, Bruce (1990). Gender, instrumentality, and expressivity: Moderators of the relation between stress and psychological symptoms during adolescence. American Journal of Community Psychology, 18(3), 383-406.
- Wallinga, Charlotte, Paguio, Ligaya, & Skeen, Patsy, (1987). When a brother or sister is ill. Psychology Today, 21(8), 42-43.
- Wasserman, Rona (1983). Identifying the counseling needs of siblings of retarded children. The Personnel and Guidance Journal, June, 622-627.
- What about me? Brothers and sisters of children with disabilities (1990), (videotape). Oregon: Educational Production Inc.
- Wilson, Judith, Blacher, Jan, & Baker, Bruce (1989). Siblings of children with severe handicaps. Mental Retardation, June, 167-173.
- Yamamoto, Kaoru, & Felsenthal, Helen (1982). Stressful experiences of children: Professional judgments. Psychological Reports, 50, 1087-1093.
- Zitlin, Andrea (1986). Mentally retarded adults and their siblings. American Journal of Mental Deficiency, 91(3), 217-225.