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Relationships between Cohesion and Depression in Parents of Children with Developmental Disabilities

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Relationships between Cohesion and Depression in Parents of Children with Developmental Disabilities

by

Amy Leigh Bailey Giauque

A thesis submitted to the faculty of

Brigham Young University

In partial fulfillment of the requirements for the degree of

Educational Specialist

Department of Counseling Psychology and Special Education

Brigham Young University

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of a thesis submitted by

Amy Leigh Bailey Giauque

This thesis has been read by each member of the following graduate committee and by majority vote has been found to be satisfactory.

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As chair of the candidate’s graduate committee, I have read the thesis of Amy Leigh Bailey Giauque in its final form and have found that (1) its format, citations, and bibliographical style are consistent and acceptable and fulfill university and department style requirements; (2) its illustrative materials including figures, tables, and charts are in place; and (3) the final manuscript is satisfactory to the graduate committee and is ready for submission to the university library.

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ABSTRACT

Relationships between Cohesion and Depression in Parents of Children with Developmental Disabilities

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This research study examined the relationship between family cohesion and depression in mothers and fathers of children with disabilities. One hundred and six two-parent families who had a child with a disability provided information on their feelings of cohesion through Bloom’s cohesion subscale and depression through the Center for Epidemiological Studies Depression scale (CES-D). Analyses indicated that mothers and fathers of this sample are not significantly more depressed than the general population. However, there was a correlation between mothers’ and fathers’ depression, indicating that when mothers’ depression increased, fathers’ depression increased. Negative correlations were found between mothers’ and fathers’ self-reported levels of cohesion and depression indicating that when there were high levels of depression there were low levels of cohesion. Limitations, implications, and further research ideas are presented.
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INTRODUCTION

When husbands and wives begin a family there is much anticipation leading to the arrival of their new child. Many plans are made before the baby arrives. Emily Pearl Kingsley penned this adventure with the following words:

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans: the Coliseum. Michelangelo's David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, ‘Welcome to Holland.’

‘Holland??’ you say. ‘What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.’ But there's been a change in the flight plan. They've landed in Holland and there you must stay. … So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met … It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around..., and you begin to notice that Holland has windmills..., and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say ‘Yes, that's where I was supposed to go. That's what I had planned.’ And the pain of that will never, ever, ever, ever go away..., because the
loss of that dream is a very, very significant loss. But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland (p. 116-117, as cited in Hansen, 2005).

Much like the feelings of this parent, when other parents discover that their child has a disability, an array of emotions may occur. Parents may grieve for the child they planned on having. Parents may wonder what they did wrong and blame themselves for their child’s disability. They may deny that their child has a disability and search for second opinions. Parents may experience a bit of confusion because they do not know what their child’s disability is and how it will impact the family. Parents may feel overwhelmed with the task of caring for their child with a disability. Some may become inquisitive and conduct their own research to know how to best help their child and know what resources are available to them. Some parents may experience a sense of embarrassment because their child is not like other children. Other parents may be quick to accept the child’s disability because a family member has a similar difficulty. No matter what the emotional reaction may be, parents need support in learning how to cope with the added stresses that a child with a disability brings to family life.

Some theoretical models provide insight in how families react and learn how to adjust to the demands that may accompany raising a child who has a disability. David H. Olson’s Circumplex Model of Marital and Family Systems examines the importance of family cohesion, flexibility, and communication in family dynamics. In further examination of cohesion, Olson describes families as being disengaged, enmeshed, separated or connected. Olson’s work has been used by family practitioners to help
families work toward healthy levels of functioning (2000). This model has also been used in research with families who have children with disabilities, though such research is sparse (Curtiss, Klemz, & Vanderploeg, 2000).

Other researchers have focused on the strengths and capabilities a family possesses to work through the adversity that it encounters. McCubbin, McCubbin, Thompson, and Thompson (1995) developed the Resiliency Model of Family Stress, Adjustment, and Adaptation to conceptualize these ideas. McCubbin et al.’s model has been used for research with children who have physical disabilities and also for work with resiliency in ethnic families because of its emphasis on family resources and strengths that facilitate adaptation and adjustment to stressors.

While McCubbin et al. look at the resiliency of families amidst adversity, Olson’s model categorizes families along a continuum of present functioning. McCubbin examines the process of family changes over time due to present stressors, paradigms, schema coherence and problem-solving resources, while Olson’s model takes a snapshot of how the family functions and provides information to practitioners on how to work with that particular family.

Olson’s and McCubbin’s models both use cohesion as important factors in family functioning. In general, cohesion is viewed as forces that act on individuals to keep them in a particular group (Festinger, Schaachter, & Back, 1950). More specifically, cohesion in the family is the emotional bonding that the family has between its members and can be considered a resource to help families work through stressful situations (Olson, 2000).

Research in the area of family cohesion has increased over the years. Many studies have been conducted with cohesion as a resource for creating a more functional
family. Even more specifically, studies have been conducted with families who have a child with a disability. Research has shown that family cohesion is perceived differently between parents when there is a child with a disability: mothers view the family as more cohesive and fathers less cohesive (Krauss, 1993). Other researchers have shown that families who have a child with a disability perceive that the family is more cohesive than a family who does not have a child with a disability (Mahoney & O’Sullivan, 1992). However, other studies have indicated that the relationship between parents may not be as cohesive when there is a child with a disability (Bristol, Gallagher, & Schopler, 1988).

There still appears to be limited research conducted looking at personal resources that affect cohesion in families who have a child with a disability.

McCubbin et al.’s model describes personal resources that help families adapt to stressors. One of the personal resources to examine is mental health. Lack of depression in family members may be considered a resource toward healthy functioning. If a father or mother feels depressed, it may be difficult for him or her to expend the needed energy to raise a child with a disability.

Numerous studies have been conducted with families and the stress that they feel when they have a child with a disability (Beckman, 1991; Cummings, 1976; Dyson, 1991, 1993; Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986; Mahoney & O’Sullivan, 1992; McLinden, 1990). Often times this information has been gathered through reports from the mother and not the father (Mahoney & O’Sullivan, 1992; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999). However, the research conducted with fathers is growing. Also, studies have examined depression levels of mothers who have a child with a disability (e.g., Down syndrome, Willi-Prader
syndrome), but research is limited with depression levels in fathers and children who have developmental disabilities (Bristol et al., 1988). Research is also limited in examining the relationship between depression levels felt by mothers and fathers of a child with a developmental disability and the levels of cohesion felt by mothers and fathers.

While there have been many studies citing cohesion as a factor for healthy family functioning, there have been limited studies concerning cohesion and families who have a child with a disability. Information gathered about depression in families who have a child with a disability has been limited with more emphasis on stress and using mothers as the primary informant. The relationship between cohesion and depression and families who have a child with a disability still requires further examination. This thesis will review two theoretical frameworks for studying family adaptation to a child with a disability. In particular, this study will focus on the Resiliency Model of Family Stress, Adjustment, and Adaptation to analyze the stresses a child with a disability may present to a family. This paper will consider the relationship of cohesion as a family resource and mental health or lack of depression as a personal resource that will facilitate family adaptation to a child with a disability.
LITERATURE REVIEW

Children with disabilities have often been considered strains on family life, but recent studies demonstrate the resiliency of families who have a child with a disability. Theoretical frameworks have been created to understand why some families thrive in the face of challenges and why others seem to crumble under seemingly small pressures. Family cohesion has been considered a family resource while mental health has been considered a personal resource to work through aversive situations that happen in family life.

Theoretical Frameworks for Studying Family Adaptation

In the past decade, research has increased in the area of stressors placed on families. During this time theories have been developed to better understand how some families function well as they work through stressors and how others seem to experience more difficulty. McCubbin and Patterson (1983) questioned “why some families are able to cope with ease and may even thrive on life’s hardships, while other families, faced with similar if not identical stressors or family transitions, give up in the face of seemingly minor life changes” (p. 6).

Two models in particular will be discussed to describe the adaptation and resiliency of families with children who have disabilities, namely, Olson’s Circumplex Model of Marital and Family Systems and McCubbin’s Resiliency Model of Family Stress, Adjustment, and Adaptation.

Circumplex Model of Marital and Family Systems. David H. Olson is a researcher who developed the Circumplex Model of Marital and Family Systems. In this model he examines the interplay between family cohesion, flexibility, and communication.
Specifically, he developed this model to help practitioners better serve their clientele to move toward healthy family functioning (Olson, 2000).

Olson (2000) defined family cohesion as “the emotional bonding that family members have towards one another” (p. 145). Family cohesion examines the amount of independence and connectedness experienced by each member. According to Olson’s model, there are four levels of family cohesion: disengaged, separated, connected, and enmeshed. Disengaged and enmeshed are the extreme family types. Family members in a disengaged family are those who value their independent interests. They may find it difficult to give each other support in other activities. The enmeshed family is one in which family members are dependent on each other with family being the main focus of their lives. There are few relationships with individuals outside the immediate family.

Separated and connected relationships are generally more balanced family types because these individuals are able to function with or without each other. Individuals in a separated relationship are those who spend more time apart but come together to make decisions and give support. The connected relationship is where there is an emotional bond. Time together is valued more than time alone. Family members have friends that are both shared and are different that are not within the family structure. For example, the mother and father are friends with other couples, but the mother and father also have friends of their own. Based on this model, Olson presumes that families who are characterized more as separated or connected are better able to adapt to the changes that come with family life, including the demands that a child with a disability has. Generally, families who are in the more balanced range (separated or connected) are more likely to consider alternatives and manage stressful experiences when they come.
The Circumplex Model recognizes that families will experience stressful
situations and will need to change and adapt. This can occur during typical life or family
cycle events such as marriage, having a new baby, or at unexpected or unplanned
stressful events such as having a child with a disability.

The Circumplex Model has been used to analyze different facets of family
functioning and provide interventions for further growth. Some of these studies include
Kawash and Kozeluk’s (1990) research with family relationships including cohesion in
connection with adolescent self-esteem and Coco and Courtney’s (1998) use of the
Circumplex Model to develop an intervention plan to reduce adolescent runaway
behavior. Other studies have been conducted to examine the effects of a family member
with traumatic brain injury on the rest of the family (Curtiss et al., 2000) and families
who have a child with chronic illness (McCubbin, 1988). These studies use the
Circumplex Model to contextualize their findings.

Researchers have also used the Circumplex Model to explain the functioning of
families with individuals who were schizophrenic or neurotic (Clarke, 1984). Though
there have been studies conducted that use this model, the research is sparse in the
context of families who are raising a child with a disability.

One of the benefits of this model is that it focuses on the family system and
provides practitioners with a model to conceptualize their clients’ life experiences,
circumstances, and levels of functioning. From this point, the practitioner can help the
family work towards change. There is an important focus on cohesion, flexibility and
communication, which have been noted in the literature to contribute to healthy family
functioning (Beavers & Hampton, 1990; Benjamin, 1977; Epstein, Baldwin, & Bishop,
1983 as cited in Olson, 2000). Olson also recognizes that family systems change according to the situational stressors.

However, this model does not fully consider the events, experiences or processes that a family has had that contributed to the way in which a family works through a stressful life event. It provides a definition for the family type and the way it functions, but it is lacking in its ability to examine the resources and skills that the family has to work through stressful situations.

*Resiliency Model of Family Stress, Adjustment, and Adaptation.* McCubbin, McCubbin, Thompson, and Thompson (1995) developed the Resiliency Model of Family Stress, Adjustment, and Adaptation after the evolution of Reuben Hill’s ABCX Model, the Double ABCX Model, FAAR (Family Adjustment and Adaptation Response) Model, and the Typology Model of Family Adjustment and Adaptation. It extends these earlier models and focuses on the resiliency of families despite the stressors that are placed upon them. The current model uses culture and ethnicity as a facilitating factor in helping the family achieve balance and harmony amidst a crisis situation. It looks at the protective factors that a family has which bring adjustment and the recovery factors leading to adaptation in a crisis situation.

The Resiliency Model (McCubbin et al., 1995) is broken into two phases: the adjustment phase and the adaptation phase. In the adjustment phase, a family is presented with a *stressor* (A). How extreme the stressor is to the family is dependent on how much it threatens the present family unit. The stressor has the potential to change the family and this change can affect all aspects of family life.
The stressor interacts with the family’s vulnerability ($V$). This vulnerability is created by a pile-up of stressors. Whether a family has a high or low degree of vulnerability is dependent on the pile-up of stressors and also the stage of life that the family is in. For example, a family may be moving to a new town because the father got a new job. If the children are young, the pile-up of stressors may not be as great as when the children are adolescents and have established friends and other activities outside the family (McCubbin et al., 1995).

The family’s vulnerability interacts with the family typology ($T$), which refers to the way that a family typically acts or functions. In a transition period, families who are resilient tend to be those who have a sense of cohesiveness, but are also flexible. M.A. McCubbin found that children who have chronic illness typically have a more positive outcome when the family has a cohesive and adaptive pattern of functioning (1988). This study suggests that when family members are cohesive but also flexible, they are more likely to adapt to the stresses that a child with a disability can present.

The next component to consider in the adjustment phase is the family’s resistance resources ($B$). These may be defined as the family’s capabilities and strengths. This stage examines what strengths the family has to help work through the stressor and keep the situation from turning into a crisis. In the area of adjustment, the family manages the stress rather than making extreme changes that will alter the way the family typically functions. Some of the resources include “economic stability, cohesiveness, flexibility, hardiness, shared spiritual beliefs, open communication, traditions, celebrations, routines, and organization” (McCubbin et al., 1995, 8).
Resistance resources interact with the *family stressor appraisal (C)* which is the interpretation that the family places on the seriousness of the stressor and the anticipation of possible hardships that the stressor will bring to the family unit. For example, in the case of a child with a disability, the family may see the disability as a challenge leading towards growth rather than a situation that will debilitate them. The family may anticipate the stress that the disability may bring and work to combine resources to work through it. This leads to the next area of the Resiliency Model.

Based on how the family interprets the seriousness of the stressor will determine the way in which the family uses *problem solving and coping (PSC)*. This examines how the family manages the stressor. Problem solving may be defined as the ability to organize the stressor into smaller pieces, identify the different ways to work with each component, initiate steps to bring resolution to the issues, and then develop problem-solving patterns. The coping component refers to the patterns or behaviors that the family has to maintain the family unit. The family may seek for help from professionals or friends as a way to cope. They may do their own research to understand the stressor, such as the disability of the child.

From this point the family moves towards *bonadjustment, maladjustment, or crises (X)*. When a family moves through the stressor with ease it is called bonadjustment. The family is able to continue with little or no changes to the system. Schulman’s research suggests that 85% of families adjust well to stressors that are placed on them (including a child with a disability); (as stated in Donnelly, 1983). However, a family moves towards maladjustment when the stressor demands changes in the system
to bring about necessary stability. However, before stability can be established, the family may experience a crisis while they work towards greater equilibrium.

The crisis can be conceptualized as a “continuous condition of disruptiveness, disorganization, or incapacitation in the family social system” (McCubbin et al., 1995, p. 10). McCubbin et al. caution that when families face crisis situations it does not necessarily indicate that the family is dysfunctional or in need of professional help. The crisis suggests that the family needs to change the pattern of functioning in order to bring balance and harmony back to the system. In order for a maladjusted family to adapt to the stressor, there needs to be a newly established pattern of functioning. This may be obtained through various means, such as increasing the social support to enhance the family resources, emotional support from families and friends, or spiritual support from clergy. It may require obtaining professional help to reframe the way in which the family perceives the stressor.

The degree to which a family adapts to a crisis situation is determined by other contributing factors. The adaptation phase of the Resiliency Model first examines the pileup of demands (AA) that interact with the new pattern of functioning that the family has established from the adjustment phase. The pileup of demands includes the various stressors that a family may be experiencing at the time a particular stressor is introduced. Families are not static and therefore experience different stressors at different times. For example, at the same time a family discovers that their child has cerebral palsy, the family may also be concerned that the father has recently changed jobs and the mother has gone back to work.
The pileup of demands interacts with the family’s resources (BB) which include the strengths and capabilities that the family already has. McCubbin et al. (1995) describe two types of resources: personal resources and family systems resources. Some of the personal resources that they describe are the intelligence of family members, health of family members (spiritual, physical, and emotional health), sense of control over the situation, self-esteem of the family members, and ethnic identity of family members including their cultural background. Mental health, or more specifically, lack of depression in parents may be seen as a personal resource to cope with a child who has a developmental disability. Family system resources may include cohesion, adaptability, family organization, and family hardiness.

As families seek to adjust to a stressful situation, such as a child with a developmental disability, social supports (BBB) may also contribute to healthy family functioning. Community agencies and medical services are examples of social supports. Churches, schools and employers may also contribute to the support of a family in a stressful situation.

An appraisal of the situation (CC) is made based on the stressors and the resources that are available to the family to resolve it. The appraisal is affected by the family paradigms (CCC), family’s sense of coherence (CCCC), and the family’s schema (CCCCC). Family paradigms are defined as specific views or expectations that the family has about life. The views or expectations that the family has directly influence daily life. Family paradigms are influenced by the family’s sense of coherence or the feeling that the family has of order and control in situations. The overall level of appraisal is a family’s schema, which includes the family’s beliefs, expectations, and values.
Ultimately, the resources that a family has and the way in which they appraise the stressful situation interact with the family’s problem-solving repertoire (PSC) to facilitate family adaptation. The ability the family has to problem solve through stressors will ultimately bring about bonadaptation and healthy family functioning.

The Resiliency Model has been used in evaluating stress and the functioning in families who have a child in intensive care units (Board & Ryan-Wenger, 2000), with children who have physical disabilities (McCubbin, 1988), families with children who have asthma (Donnelly, 1994), and mothers returning to the work place (Nichols & Roux, 2004), to name a few.

Of particular note, the Resiliency Model examines the process through which a family may change to accommodate the stresses that a child with a disability may have. The model looks at many interacting parts such as resources, social supports, appraisals, schema, and problem solving abilities that lead to healthy family functioning over time. These factors can be considered when working with families who have children with disabilities.

As McCubbin et al.(1995) demonstrate through the Resiliency Model, families have the ability to adjust and adapt to the stressors that are placed upon them. One of the factors that they mention as a resource that may help families be more resilient amidst aversive situations is cohesion. The following section discusses this point.

Cohesion

Cohesion has been defined as the “total field of forces which act on members to remain in the group” (Festinger et al., 1950, p. 164). Tziner and Zaccaro have more recently operationalized this definition to include various dimensions: social-task,
vertical-horizontal, and individual-group cohesion. Social cohesion is defined as the amount of interaction between the group members while task cohesion explains that individuals are drawn to a group by what the group accomplishes. Vertical cohesion considers that bond between leaders and followers, such as parent to child, and horizontal considers cohesion between peers, such as husband to wife. Individual cohesion contrasted with group cohesion differentiates that the individual is a committed individual rather than to the members of the group (as cited in Gally, 2000).

*Family cohesion.* Researchers have not only considered these types of cohesion, but also the dynamics of family cohesion. Family cohesion has been defined as “the emotional bonding that family members have towards one another” (Olson, 2000, p. 145) and so is a type of group cohesion with vertical and horizontal cohesive components. Though cohesion has been cited as one of the most beneficial family resources, very high levels of cohesion, which may cause family members to become enmeshed with each other and very low levels of cohesion, which causes family members to be detached from one another, can be detrimental (Olson, 2000). There is no perfect amount of cohesion for every family, but there needs to be balance in order for the family to function best.

*Cohesion and families of children with disabilities.* Much research has been conducted concerning the importance of cohesion in families. Indeed, cohesion is one of the most recognized resources for family functioning by various researchers (Olson, Sprenkle, & Russell, 1979 as cited in McCubbin et al., 1995). Mothers and fathers of a child with a disability may perceive family cohesion differently. Krauss (1993) conducted a study with the mothers and fathers of 121 children who had developmental disabilities, including Down syndrome, motor impairments, and developmental delays that were of an
uncertain origin. The parents were surveyed at the time that early intervention services began with their child. Based on the mother and father reports, Krauss found that the mothers reported having a significantly more cohesive and adaptable family as compared to the reports from the fathers. This study may suggest that mothers and fathers perceive family cohesion and adaptability differently when a child has a disability.

Families may report reduced levels of child-related stress and parenting stress when they feel that the family is more cohesive. In a longitudinal study conducted by Warfield et al. (1999), 79 mothers were recruited through an early intervention program. The mothers were contacted at the beginning of the services. To be eligible to participate, the children had to have Down syndrome, motor impairments, or unspecified but significant developmental delays. The child also had to be 27 months of age or younger. The mothers were assessed through interview and questionnaires at three times: when their child entered into the early intervention program, when the child left the program at age three, and when the child was about to enter kindergarten at age five. The study found that the greater family cohesion when the child was three years of age, the lower the child-related stress. Similarly, at five years of age, family cohesion was a predictor of lower levels of reported child-related stress and parenting stress. Though a causal relationship cannot be concluded, it appears that when mothers feel support within the family unit, the levels of stress that accompany caring for a child with a disability decrease.

Families raising children with disabilities may view their situation as being more cohesive and adaptive than do other families. Researchers contacted professionals belonging to the Council on Exceptional Children: Division of Early Childhood (DEC) to
obtain a sample of 503 mothers who had children with disabilities. The mothers were
selected by the professionals based on the criteria that the child had to be between ages
one and six and have a disability. The children’s disabilities included Down syndrome,
cerebral palsy, mental retardation with medical conditions, developmental delays, and
sensory impairments. In comparison with the normative sample for Moos’s Family
Environment Scale (as cited in Mahoney & O’Sullivan, 1992), the mothers’ responses
indicated these families of children with disabilities have significantly higher rated
responses in the areas of cohesion, expressiveness, moral-religious, and organization. The
normative sample indicated greater emphasis in the areas of achievement orientation and
active-recreational. This may suggest that families with a child who has a disability may
place more value on cohesion than achievement orientation and active-recreational
activities.

Though some studies show that raising a child with a disability emphasizes more
cohesion in the family, research suggests that raising a child with a disability may be
related to difficulties with parents maintaining cohesive relationships. Bristol et al. (1988)
selected 56 two-parent Caucasian families for a study examining adaptation and spousal
support. All the families had to have one son between the ages of two and six years.
Thirty-one of the families had boys with diagnoses of autism and severe communication
impairments and 25 of the families had boys who did not have disabilities. Based on self-
reports, researchers found that fathers of sons with developmental disabilities reported
being at-risk for marital problems as opposed to the fathers of sons without a disability.
Prior to parent intervention, parents of the boys with disabilities reported having more
marital problems than did the parents of boys without disabilities. Mothers in both groups
noted that they felt they received less emotional support from their husbands than their husbands reported receiving from wives. This could lead to a family feeling less cohesive and having more difficulty in adapting to the stressors that are present with a child who has a disability. The Bristol et al. study also revealed that perceived and current spousal supports were found to be the best predictor for family adaptation to child with a disability. The best predictor of quality of parenting was expressive support of spouse (1988).

*Cohesion summary.* In summary, McCubbin et al. identified cohesion as a resource that promotes the resiliency of families (1995). According to research with families who have children with disabilities, family cohesion is perceived differently by mothers and fathers (Krauss, 1993). Families raising children with disabilities may actually report higher levels of cohesiveness and adaptation than other families (Mahoney and O’Sullivan, 1992); however, there have also been studies to show that parents have difficulties maintaining a cohesive marital relationship (Bristol et al., 1988). Families may also have a tendency to be more cohesive when child-related and parenting stress is reduced (Warfield et al., 1999). The reverse may also be true, when parents feel increased levels of stress they may feel less cohesion in the family and more difficulty adapting to the disability.

*Depression*

Just as cohesion may be viewed as a resource for a family who has a child with a disability, lack of depression or the mental health in a mother and/or father may also be considered a personal resource for resiliency amidst a pileup of stressors. It would seem that lack of depression would allow parents to better care for the needs of their child with
a disability. In the *Diagnostic Statistical Manual of Mental Disorders (DSM-IV-TR)* (American Psychiatric Association [APA], 2000) a Major Depressive Episode is described as a depressed mood or loss of pleasure in typical activities. The episodes last for most of the day during at least a two-week period of time. During that time there is also impairment in daily functioning in the workplace, school, or social activities. An individual may manifest this depressive episode through having a sad or depressed mood for most of the day or losing interest in most activities that the individual usually enjoys. The individual may experience weight loss or gain and have difficulty sleeping or difficulty staying awake at night. Individuals may be observed being restless, having less energy to perform daily tasks, and showing excessive guilt or feelings of worthlessness. Individuals may have difficulty with thinking or concentrating, and thoughts about death may permeate their daily functioning.

Women experience major depressive episodes twice as much as men do in the United States (APA, 2000). When a major depressive episode occurs, it generally lasts at least four months if it is not treated. Symptoms often go into remission, but there are some cases where only some of the symptoms go into remission.

While some individuals may experience occasional depressive episodes, others may have multiple episodes that lead to Major Depressive Disorder. Major Depressive Disorder is defined by two or more Major Depressive Episodes. Generally there are two months between the depressive episodes to be considered Major Depressive Disorder.

Average age of onset of Major Depressive Disorder is generally in a person’s 20s; however, the age of onset has been decreasing over the years. Of those individuals who experience a Major Depressive Episode, research suggests that two-thirds of those
individuals will experience only one episode during their life while another third will continue to experience partial or full depressive episodes throughout their life time. It appears that the percentage of women who experience Major Depressive Disorder is between 5 and 9% while the percentage of men who experience Major Depressive Disorder is only between 2 and 3% (APA, 2000).

Studies suggest that some stressors like loss of a job or financial hardship may actually play a part in the development of major depressive episodes that lead to Major Depressive Disorder (APA, 2000). Another such stressor may be the birth of a child with a disability.

*Stress and families of children with disabilities.* Many studies have been conducted to examine the stress felt by parents who have a child with a disability. Recent research has shown that families who have a child with a disability generally feel more stress than families who do not have a child with a disability. In a longitudinal study conducted by Dyson in 1991 and 1993, she examined 72 families of primarily middle socioeconomic status and where both parents were in the home. Thirty-six families had a child with a disability and 36 of the families had a child who did not have a disability between the ages of five and eleven years. The children had an array of disabilities including mental retardation, physical disabilities, sensory impairments, developmental delays, speech disorders, and learning disabilities. Dyson found that for families with children who have disabilities, their stress was statistically more significant than families who did not have a child with a disability. However, the difference between the stresses felt at time one and time two by the families who had a child with a disability were not significant. In other words, the stress that mothers and fathers felt did not significantly
change over time. Dyson’s study also found that the child’s disability was the best predictor of family stress.

Characteristics of the child’s disability also contribute to the stress felt by parents of children who have Prader-Willi syndrome. Hodapp, Dykens, and Masino (1997) studied stress levels of 39 mothers and 3 fathers that responded. The researchers discovered that the age, IQ, Body Mass Index, or sex of the child did not significantly contribute to the stress that parents felt in raising their child with Prader-Willi Syndrome. However, the child’s scores on Achenbach’s Child Behavior Checklist (CBCL) maladaptive scales were highly correlated with the reported levels of stress that the parents felt. This suggests that the degree of the child’s maladaptive behavior contributed to the stress that was felt by the parent. Parents may have felt better prepared to work with some of the characteristics of a child with Prader-Willi syndrome (i.e., child’s age, IQ, and Body Mass), but not to handle the maladaptive behaviors that are manifested.

While the child’s age or IQ did not contribute to the distress felt by parents of children who had Prader-Willi syndrome, one sample of mothers and fathers had more distress when the disabled child was a boy. Frey, Greenberg, and Fewell (1989) collected data from 48 fathers and 48 mothers of children with Down syndrome, cerebral palsy, multi-sensory handicaps, William syndrome, and Trisomy-19. The children were between 32 months and 168 months of age with a mean age of 83 months. Both sets of parents reported higher levels of stress when the child with a disability was a boy and had communication difficulties. They found that the child’s ability to communicate was highly correlated with the fathers’ reported levels of distress. It appears that the less the child was able to communicate, the higher the stress felt by the father. The distress that
fathers felt when their disabled child was a boy may be due to the difficulty that fathers have with knowing how to interact with their son with a disability rather than through play and sport. This finding is similar to those found by Bristol et al. (1988).

Depression and families of children with disabilities. Bristol et al. (1988) studied 31 mothers and 31 fathers of sons who had autism or a severe communication disorder and compared them to 25 mothers and 25 fathers who had sons without a disability. These researchers found that the families who had a son with a disability had a higher mean on the Center for Epidemiologic Studies Depression Scale (CES-D) than did parents of sons without disabilities; however, the difference was not statistically significant. A higher mean scored on this scale indicates that an individual has a greater likelihood of depression. Parents of children with a disability were not statistically more depressed than parents who did not have a child with a disability. Also, mothers did not report more depressive symptoms than the fathers. Though this study brings to light interesting findings with depression in parents of children who have disabilities, there are limitations to this study. It was only conducted with white families who had male children with a specific disability. Male and female children with differing disabilities may present different results. Also, the results may not have been statistically significant due to the small sample size. The results also may have been different between other ethnic groups and cultures.

Another study using the CES-D scale to measure depression levels focused on the mothers of children with disabilities. Smith, Innocenti, Boyce, and Smith (1993) discovered contradicting findings from Bristol et al.’s (1988) work. In their research with 48 mothers of children between ages 39 and 59 months (24 boys and 24 girls) with severe
developmental delays, Down syndrome, cerebral palsy, and motor or sensory impairments, Smith et al. found that the mothers in their sample scored above the mean on the Center for Epidemiological Studies Depression Scale (CES-D), which was in the clinical range as compared to the general population. Also, these mothers were nearly one standard deviation above the mean suggesting that they demonstrated statistically significant symptoms for depression. The differences between Bristol et al.’s and Smith et al.’s findings could be attributed to the nature of the children’s disabilities or possibly the difference in the sample sizes.

A larger sample was used to assess the levels of depression felt by mothers of children with autism and mothers of children with an intellectual disability. Olsson and Hwang (2001) conducted a study with 207 mothers and 167 fathers of children with a diagnosis of autism or an intellectual disability without autism with 204 mothers and 185 fathers of children who did not have a disability in the control group. They discovered that the mothers who had a child with a disability reported higher levels of depression than mothers in the control group. The fathers in the sample reported more depression when their child had autism, which supports Bristol et al.’s 1988 findings. Mothers of children with autism have been found to have higher levels of depression than mothers of children with an intellectual disability. This study also found that the mothers who had a child with a disability reported higher levels of depression than the fathers of children with disabilities.

Similarly, the mothers of children with autism reported significantly more anxiety than did the fathers. The mothers also reported higher levels of depression than did the fathers though it was not significant (Hastings, 2003). The lack of statistical significance
could be due to the smaller sample size (18 mothers and 18 fathers) or possibly because 10 of the 18 children were actually living in residential treatment centers.

Over the years there has been contradicting research concerning the level of stress and depression experienced by mothers and that experienced by fathers who have a child with a disability. In 1976, Cummings conducted research concluding that fathers feel more stress with having a child who has a disability and have fewer ways in which they can relieve that stress. Goldberg et al. (1986) conducted a study with fathers and mothers of children who had developmental delays. This study found that fathers reported fewer stress-related symptoms than mothers. However, Olsson and Hwang reported that mothers reported higher levels of depression than fathers (2001).

Beckman’s (1991) research supports parents of children with disabilities experiencing more stress than parents of children without disabilities. She also found that mothers experiencing greater levels of depression than fathers. She studied 27 mothers and 27 fathers of children with a disability and 27 mothers and 27 fathers of children without a disability to evaluate stress levels. The children were between 18 and 72 months of age. The disabilities of the children included cerebral palsy, autism, multiple disabilities, developmental delay, and general delays. The study found that on the scales that addressed depression, mothers of children with disabilities reported more difficulty in the area of depression than did the fathers. Fathers were significantly more concerned in the area of attachment. Overall, parents of children with disabilities reported more depression than families who did not have children with disabilities.

Depression and resources of families of children with disabilities. While much research has focused on levels of stress and depression felt by families of children with
disabilities, research has also been conducted to discover which types of personal or family resources help decrease levels of stress that a family may feel. Some researchers have reported that the amount of stress that families report is often correlated with the social support that they receive. The more social support a family feels, the levels of stress are reported to be lower (Beckman, 1991). Similarly, Warfield et al. (1999) noted in their study with 79 mothers who had children with Down syndrome, motor impairments, or significant developmental delays that the key predictors of parenting and child related stress had less to do with the characteristics of the child and more to do with less family support, lower amount of income, and low family cohesion.

Other resources were discovered in Sloper and Turner’s study based upon reports from 98 mothers and 72 fathers of children who had severe motor disabilities and were between the ages of 6 months and 13 years (1993). They found mothers reported less distress which was associated with lesser degree of the disability, less engagement with wishful thinking, fewer financial problems, and the use of informal emotional supports. Mothers were less likely to feel distressed when they had employment outside the home. Fathers felt less stress when there was support in the family relationships like having high cohesion and little conflict. In this study the lesser degree of the child’s disability, fewer financial problems, high levels of cohesion, and little conflict were a few of the resources to families who had a child with a disability.

**Depression summary.** In summary, according to McCubbin et al.’s Resiliency model, depression or stress can be viewed as contributing to the pile-up of demands that come with a child who has a disability (1995). As researchers have examined the effects of a child with a disability on the family, some studies suggest that families who have a
child with a disability report higher levels of stress or exhibit more depressive symptoms than those families who have a child without a disability (Dyson 1991, 1993; Smith et al., 1993). However, another study indicates that while families with a child who has a disability may exhibit increased stress, they are not significantly more depressed than other families (Bristol et al., 1988).

There are also contradicting findings about the levels of stress felt by mothers and fathers with some saying that fathers report more stress and others reporting the mother with more stress though these levels of stress may be due to the gender and/or severity of the disability for the child (Beckman, 1991; Cummings, 1976; Frey et al., 1989; Goldberg et al., 1986; Hastings, 2003). In some studies the nature of the disability is correlated with the stress level felt by the parents (Cummings, 1976; Goldberg et al., 1986; Hodapp et al., 1997; Sloper & Turner, 1993).

Other studies have indicated personal and family resources to cope with the stresses that a child with a disability presents (Beckman, 1991; Sloper and Turner, 1993; Warfield et al., 1999). While there have been studies conducted on coping resources for a family who has a child with a disability, there is less research on the correlation between depression and family cohesion as resources for parents who have a child with a disability.

*Statement of the Problem*

Though researchers have begun to examine the effects of caring for a child with a disability on both the mother and the father, much of the research has been conducted with mothers as the primary informants. Studies have also been conducted concerning cohesion in the family who has a child with a disability. Stress and distress have often
been examined as stressors that families experience when they have a child with a disability. This study seeks to further investigate the influence of a child with a disability on both the mother and father. In particular it looks at the influence of family cohesion as a family resource and lack of depression as a personal resource to cope with the demands of a child with a disability.

Statement of Purpose

The purpose of this research is to study the relationship between family cohesion and depression in families raising a child who has a disability. Specifically, this study will address the following questions:

1. Is there a significant difference in self-reported levels of depression in a sample of parents who have children with disabilities as compared to a normative sample of adults on the CES-D scale?

2. Is there a significant difference in self-reported levels of depression in a sample of mothers of children with disabilities as compared to a normative sample on the CES-D scale?

3. Is there a significant difference in self-reported levels of depression in a sample of fathers of children with disabilities as compared to a normative sample on the CES-D scale?

4. Is there a significant difference in self-reported levels of depression between mothers and fathers in a sample of families who have children with disabilities?

5. What is the correlation between self-reported levels of depression in mothers and fathers in a sample of families who have children with disabilities?
6. What is the correlation between self-reported levels of depression in mothers and their self-reported estimate of family cohesion in a sample of families who have children with disabilities?

7. What is the correlation between self-reported levels of depression in fathers and their self-reported estimate of family cohesion in a sample of families who have children with disabilities?
METHOD

This study used an existing dataset to answer the research questions. Data were collected previously by researchers in the Family Adaptation to Disability and Chronic Conditions Research Project at Brigham Young University. Therefore, the methods of gathering data are reported based upon work that was previously completed.

Participants

All participants were from two-parent families and both mothers and fathers responded to both the CES-D scale and Bloom’s Cohesion subscale (N = 106 families). Mothers in the study had a mean age of 38.13 years (SD = 7.49) and an average of 14.76 years of education (SD = 1.96). The fathers had an average age of 40.12 years (SD = 7.95) and an average of 15.56 years of education (SD = 2.19). Participating families had an average of 3.88 (SD = 1.71) children. Ninety-six percent of the fathers (102) and 40% (43) of the mothers were employed either full or part-time. Of the mothers who were employed, they spent an average of 14.13 hours working in a week (SD = 16.21) and fathers spent an average of 45.40 hours working in a week (SD = 11.83). Over 72% (77) of the participating households had incomes of more than $35,000 per year.

The children with disabilities ranged in age from 0 to 18 years, with an average age of 6.9 years. Fifty-eight percent of the children were 6 years of age or younger (N = 62). Of the 106 children, 73 (68.9%) were male and 31 (29.2%) were female and data were missing for two of these children. The majority of these children were Caucasian (N = 86, 81.1%), while four were Hispanic (3.8%), one child was of oriental origin and another of Caucasian-Hawaiian origin. Information pertaining to the child’s race was missing for 14 children. The children with disabilities in these families all qualified for
federally-mandated early intervention, early childhood special education programs or school special education programs. For the purposes of this study, the Individuals with Disabilities Education Act (IDEA) classifications were used to categorize the children’s disabilities. Thirty-three children had mental retardation (31.1%), 22 of the children had a diagnosis of autism (20.8%), 15 had an orthopedic impairment (14.2%), 14 had multiple disabilities (13.2%), 6 had a communication disorder (5.7%), 3 had a traumatic brain injury (2.8%), 3 other children had developmental delays (2.8%) and the remaining children had hearing impairments, emotional disabilities, specific learning disabilities or other health impairments.

Procedure

Parents were contacted through early intervention, early childhood special education programs, educational conferences, and through snowball sampling (one family who had a child with a disability referred another family they knew who had a child with a disability). Once parents agreed to participate, two sets of questionnaires and an information page were hand-delivered to each family with specific instructions for the mothers and fathers to complete the questionnaires separately. The parents were provided with a self-addressed, pre-stamped envelope to return the questionnaires. Some parents were given follow-up telephone calls to remind them to finish the surveys. Once the surveys were completed, each family received $25.00 for their volunteer participation.

Measures

Demographic questionnaire. Each family provided information on the Family Information Questionnaire regarding their ethnicity, family composition (one-parent, two-parent, step-family, etc.), age of mother and father, years of education for mother and
father, occupation of mother and father, number of hours mother and father spent at
work, religious preference, family income, and a description of the child’s disability (See
Appendix A).

Two separate instruments were used to measure family cohesion and depression.
Both are self-report measures.

*Family cohesion.* The cohesion subscale from Bloom’s self-report measure of
family functioning was used (Bloom, 1985) (See Appendix A). Only 20 questions of the
original 38 questions were used for the Family Adaptation to Disability and Chronic
Conditions Research Project at Brigham Young University. This complete scale has
demonstrated strong valid (.90 cronbach alpha) and reliable (.86 test-retest reliability)
psychometric properties (Bloom & Naar, 1994). The cohesion sub-scale is a 20-item
questionnaire where mothers and fathers can respond independently to questions such as
“family members really help and support one another” and “we really get along with each
other.” There is a 4-point Likert-type scale to answer from “certainly applies” to
“certainly does not apply.” Higher scores on this scale indicate greater family cohesion
(Bloom & Naar, 1994). For this study items 1, 3, 5, and 7 are specifically related to
cohesion and thus were used to measure family cohesion. The internal consistency for
these items was good for both mothers and fathers (respectively .73 and .75 cronbach
alpha).

*Depression.* The Center for Epidemiological Studies Depression Scale (CES-D) is
a measure for depressive symptoms in the general population, and differs from other
scales that are used for diagnoses of depression (See Appendix A). The CES-D has
shown high internal consistency (.85 alpha for the general population) and acceptable
test-retest reliability (.57). This scale has also demonstrated its validity as correlations were made with other self-report depression measures such as the Beck and Zung. The CES-D is a 21-item, 4-point Likert-type scale from “rarely or none of the time” to “most or all of the time.” Respondents are asked to answer questions such as “I was bothered by things that usually don’t bother me” and “I felt lonely.” Higher scores on this scale indicate greater likelihood of depression. The mean score for the CES-D normative population is 16.0; scores greater than 16 are considered in the clinical range (Radloff, 1977).

Data Analysis

Descriptive analyses were conducted to define characteristics of the sample. Single-sample $t$-tests were be used to compare the study sample to the normative sample from the CES-D scale. A paired $t$-test was used to examine the difference between mothers’ and fathers’ reported levels of depression. Pearson correlations were used to evaluate the correlation between levels of depression reported in mothers and fathers, levels of family cohesion and depression reported by mothers, and levels of family cohesion and depression reported by fathers. The level of statistical significance was $< .05$. Statistical analyses were conducted using SPSS 13.0 version.
RESULTS

The Family Adaptation to Disability and Chronic Conditions Research Project began with 188 participating families. For this thesis, 160 of these families were two-parent families. Of those 160, only 106 of the families provided information on cohesion and depression from both the mother and the father. Only data from these 106 cases were analyzed in order to determine the correlation between levels of depression and cohesion in mothers and father who have children with disabilities. Of the participating families, a single sample *t*-test compared the mean score in self-reported levels of depression in parents of children with disabilities to the mean score of 16.0 on the CES-D scale. No significant difference was found (*t*(105) = -1.286, *p* > .05). The sample mean for depression in parents was 15.03 (SD = 7.7) suggesting that the average level of depression for this sample of parents who have a child with a disability is not different than the normative population.

A single sample *t*-test was used to compare the mean score of mothers of children with disabilities to the normative mean score on the CES-D scale. There was no significant difference found (*t*(105) = .510, *p* > .05). The sample mean of 16.51 (SD = 1.01) for mothers was not significantly different from the normative population. A similar single sample *t*-test was used to compare the mean score of fathers of children with disabilities and the mean score on the CES-D scale. There was a significant difference found for the sample of fathers (*t*(105) = -3.159, *p* < .01). The sample mean of fathers of children with disabilities at 13.54 (SD = 7.99) was significantly lower for depression than the normative population.
A paired-samples *t*-test was calculated to compare the mean depression score of mothers to the mean depression score for fathers. There was a significant difference found (*t*(105) = -2.952, *p* < .01). There was a significant correlation between mothers’ and fathers’ reported levels of depression (*r*(104) = .395 (*p* < .01). It is interesting to note that even though the fathers indicated lower levels of depression than the mothers, the mothers’ and fathers’ levels of depression were significantly correlated. This suggests that as a mother’s level of depression is higher in a family the father’s depression tends to be higher too.

The correlation between mothers’ self-report on family cohesion and depression was analyzed using a Pearson correlation. A significant correlation was found between these two variables (*r* = -.259, *p* < .01). As a mother’s level of depression is higher, her feelings of family cohesion are lower. The correlation between fathers’ sense of family cohesion and depression were also significant (*r* = -.302, *p* < .01). This suggests that as a father’s depression is higher, his sense of family cohesion is lower.
DISCUSSION

This study was constructed to examine family cohesion and depression of mothers and fathers of children who have disabilities. Data was considered within the context of McCubbin et al.’s Resiliency Model of Family Stress, Adjustment, and Adaptation. Lack of depression in mothers and fathers, or mental health, may be considered a personal resource in coping with the demands that a child with a disability may present to the family system. Family cohesion may be a family resource that contributes to bonadaptation or healthy adjustment for a family with a child who has a disability.

Depression in Mothers and Fathers of Children with Disabilities

Studies have indicated that families who have a child with a disability generally feel more stress than families who do not have a child with a disability (Dyson 1991; 1993). Though parenting a child with a disability may place additional stressors on the family, mothers and fathers of children with disabilities in this sample were not significantly more depressed than the normative sample of the CES-D scale, suggesting that these parents are not significantly more depressed than the general population. These findings are also similar to those in Dyson’s sample which has similar demographics (i.e., Caucasian, middle-class, well-educated). Findings in the present study are also commensurate with Bristol et al.’s findings, where the parents of sons who had autism or a severe communication disorder were not significantly more depressed than the normative population on the CES-D (1988).

Results from this study are contrary to Smith et al.’s (1993) findings with their sample of mothers of children who had developmental delays, Down syndrome, cerebral palsy or motor or sensory impairments. Smith et al.’s sample of mothers reported a
significant amount of depression as compared to the CES-D normative population. Though the self-reported scores of the mothers in the present study were above the mean for depression, it was not statistically significant. This could be attributed to the diversity of the disabilities of the children in the present study, which presents a variety of demands. The difficulties that a child with mild disabilities has may not be like those of a child with more significant disabilities, such as autism. Indeed, studies have shown that the more severe the disability, the more stressed or depressed the mother may feel (Hodapp et al., 1997; Mahoney & O'Sullivan, 1992; Olsson & Hwang, 2001).

The non-significant level of depression among mothers in the present sample may also be due to the diversity in age of the children in the sample. Smith et al.’s sample of mothers had children who were under the age of seven. Forty percent of the children in the present sample were seven years or older. When a child with a disability grows older, the demands of caring for that child may change. As parents gain greater knowledge about the nature of the disability and the changes that may occur over time, they may develop better coping skills to help their child. Also, having the children involved in special education programs may have contributed to greater social supports leading to less feelings of depression.

Though scores for mothers and fathers in the sample were not significant for depression, there was a significant correlation between mothers’ reports of depression and fathers’ reports of depression. This is consistent with Trute’s research indicating that depression reported in one spouse is significantly correlated with depression in the other spouse (1995). This finding suggests that when mothers are feeling depressed, fathers are more likely to feel depressed. This has important implications for therapists and other
professionals who work with families and children who have disabilities, which will be discussed in the implications section.

**Family Cohesion in Mothers and Fathers of a Child with a Disability**

Findings from this study demonstrated a significant negative correlation between mothers and fathers self-reported levels of depression and family cohesion. Warfield et al.’s (1999) findings noted that when higher levels of family cohesion were reported by mothers of children enrolled in early intervention programs, lower levels of stress were reported. There was a negative correlation, which is similar to this study’s findings. When mothers felt more depressed, their feelings of family cohesion were lower. Fathers who sensed more depression also had a lower sense of family cohesion. Because this was a correlation, it is not known if a higher level of depression actually causes the feelings of less family cohesion. It also is difficult to ascertain if feelings of higher family cohesion would actually create lower depression levels felt by parents.

**Limitations**

Though this study contributes to past research conducted with families who have a child with a disability, there are still some limitations. The present sample is homogenous as most were Caucasian, well-educated, two-parent, middle-class families. Because of the homogeneity of the sample, the results cannot be generalized to all populations. The diversity of the children’s disabilities and the varying ages of the children may create outliers that make it difficult to adequately interpret the results. Mothers and fathers may have had higher levels of depression if the children were younger and the disabilities were more severe (Radloff, 1980; Smith et al., 1993).

**Implications for Application**
There are implications for additional research. More longitudinal research needs to be conducted to examine the depression levels of mothers and fathers raising a child with a disability over time (Dyson, 1993; Warfield et al., 1999). It would be interesting to study the correlation between levels of cohesion and depression in parents over time in order to better understand more stressful periods or critical times in raising a child with a disability.

Additional research is needed to study the levels of cohesion and depression of parents who do not have a child with a disability as compared to families who do have a child with a disability. Up to this time, studies have examined the depression levels in parents of children with disabilities compared to depression levels in parents of children without disabilities. However, little has been done to study the correlation between depression and cohesion in families who have children with disabilities with families who have children without disabilities (Bristol et al., 1988; Olsson & Hwang, 2001).

Based on the present findings, therapists and other professionals working with families who have a child with a disability may be aware that if the mother in the family is feeling depressed, there is a chance that the father is feeling depressed. Parents may benefit from exploring these feelings with a professional therapist. Also, as many children are initially identified with a disability in the school setting, it may be important for school professionals to be aware of the emotional reaction of parents to their child’s disability. School professionals could provide additional resources to the parents to facilitate skill development and growth in working with their child who has a disability.

To assist in skill development in working with a family with a child who has a disability, therapists may use a family systems approach. Family therapy may provide an
environment where family members can express themselves openly about the concerns or questions they have about their child or sibling who has the disability. Parenting classes and sibling classes could promote family understanding and togetherness. Therapists may help the family get involved with whole family activities that would be appropriate with the child with the disability that may promote increased togetherness.
REFERENCES


APPENDIX A

Instruments
Family Information Questionnaire  (One per family)  

(1)  Today’s Date _____________________
(2)  Family ethnicity ___________________
(3)  Ethnicity of child with disability (if different from family) ___________________
(4)  Family Composition: (circle one)
   1. Two Parent Family
   2. Single Parent Family
   3. Step Parent Family
   4. Other Family Type ___________________
   5. Other adults besides parent living at home? Yes No
   6. If yes, who? __________________________
(5)  Age of Parents: ________ Father ________ Mother
(6)  How many years of education has husband completed? ___________________ years
(7)  How many years of education has wife completed? ___________________ years
(8)  What is husband’s current occupation? (job title)________________________
    Please briefly describe husband’s duties ______________________________________
    _________________________________________________________________________
(9)  What is wife’s current occupation? (job title)________________________
    Please briefly describe wife’s duties _________________________________________
    _________________________________________________________________________
(10) If husband has been employed outside of the home during this past year, has the 
     employment generally been full time or part time? ___________________
    ______Number of hours husband works per week.
(11) If wife has been employed outside of the home during this past year, has the employment 
     generally been full time or part time? ___________________
    ______Number of hours wife works per week.
(12) __________________________ Husband’s religious preference.
(13) __________________________ Wife’s religious preference.
(14) __________________________ Husband’s religious preference.
(15) __________________________ Wife’s religious preference.
(16) (Optional) What is your total family income?
    1. Under $7000  3. $15001 - $25000  5. $35001 - $50000
    2. $7000 - $15000  4. $25001 - $35000  6. Over $50000
(17) Please describe your child’s disability ________________________________________
    _________________________________________________________________________
Bloom’s Family Functioning Cohesion Subscale

Below is a series of statements about families. Please write the number that best describes how well each statement applies to your family. Please respond to each statement.

3 2 1 0
Certainly applies  Applies  Does not apply  Certainly does not apply

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

Below are a series of statements about how you felt last week. Please write the number that best describes how often you felt this way.

<table>
<thead>
<tr>
<th></th>
<th>Rarely or none of the time</th>
<th>Some of the time</th>
<th>Occasionally</th>
<th>Most or all of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I was just bothered by things that usually don’t bother me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>I did not feel like eating; my appetite was poor.</td>
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<tr>
<td>3</td>
<td>I felt that I could not shake off the blues even with help from family or friends.</td>
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<tr>
<td>4</td>
<td>I felt that I was just as good as other people.</td>
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<tr>
<td>5</td>
<td>I had trouble keeping my mind on what I was doing.</td>
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<tr>
<td>6</td>
<td>I felt depressed.</td>
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<tr>
<td>7</td>
<td>I felt that everything I did was an effort.</td>
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<tr>
<td>8</td>
<td>I felt hopeful about the future.</td>
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<tr>
<td>9</td>
<td>I thought my life had been a failure.</td>
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<tr>
<td>10</td>
<td>I felt fearful.</td>
<td></td>
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<tr>
<td>11</td>
<td>My sleep was restless.</td>
<td></td>
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<tr>
<td>12</td>
<td>I was happy.</td>
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<tr>
<td>13</td>
<td>I talked less than usual.</td>
<td></td>
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<tr>
<td>14</td>
<td>I felt lonely.</td>
<td></td>
<td></td>
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<tr>
<td>15</td>
<td>People were unfriendly.</td>
<td></td>
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<tr>
<td>16</td>
<td>I enjoyed life.</td>
<td></td>
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<tr>
<td>17</td>
<td>I had crying spells.</td>
<td></td>
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<tr>
<td>18</td>
<td>I felt sad.</td>
<td></td>
<td></td>
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<tr>
<td>19</td>
<td>I felt that people disliked me.</td>
<td></td>
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</tr>
<tr>
<td>20</td>
<td>I could not “get going.”</td>
<td></td>
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</tbody>
</table>