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**THE RELATIONSHIP BETWEEN FAMILY FUNCTIONING AND SIBLING
ADJUSTMENT IN FAMILIES WITH A CHILD WITH A
DEVELOPMENTAL DISABILITY**

by

CAROLYN A. SGANDURRA

A dissertation submitted to the Graduate Faculty in Educational Psychology in
partial fulfillment of the requirements for the degree of Doctor of Philosophy,
The City University of New York

2001

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Abstract**THE RELATIONSHIP BETWEEN FAMILY FUNCTIONING AND SIBLING
ADJUSTMENT IN FAMILIES WITH A CHILD WITH A DEVELOPMENTAL
DISABILITY**

by

CAROLYN A. SGANDURRA**Advisor: Professor Marian C. Fish**

This study is an investigation into the mediational effects of family functioning, specifically adaptability, cohesion, problem-solving communication, and coping/resiliency skills, on the social-emotional adjustment (i.e., self-concept and anxiety) of non-disabled siblings of children with developmental disabilities.

Two groups of families (28 families per group) participated in this study: families raising a child with a developmental disability and families raising children with typical development. Mothers and fathers in both groups each completed standardized measures of family functioning: The Family Adaptability and Cohesion Environment Scale (FACES II), the Family Crisis Oriented Personal Scales (F-COPES), and the Family Problem-Solving Communication Scale (FPSC). One parent completed a family profile questionnaire that measured the severity of the disability and the extent of the sibling's household and childcare responsibilities. In addition, non-disabled siblings of children with developmental disabilities and siblings of non-disabled children, ages 8 – 14, completed two measures of social-emotional adjustment: The Piers-Harris

Children's Self-Concept Scale (CSCS) and the Reynolds' Children's Manifest Anxiety Scale (RCMAS).

Results indicate that families of children with and without developmental disabilities show similar family functioning and siblings show similar anxiety and self-concept. Family problem-solving communication significantly predicted siblings' adjustment, and group status also significantly predicted lower self-concept for siblings of children with developmental disabilities as compared to siblings of children with typical development. Information on the severity of the disability and family functioning variables also significantly predicted adjustment. These findings provide support for programs that facilitate effective family problem-solving communication, such as family counseling and support groups, and programs which provide opportunities for siblings to experience positive relationships with the special needs child, such as siblings workshops.

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Table of Contents

Title Page	i
Copyright Page.....	ii
Approval Page	iii
Abstract	iv
Acknowledgements	vi
Table of Contents	viii
List of Tables	xi
List of Figures	xiii
Chapter I. Introduction.....	1
Siblings of Children with Disabilities	3
Chapter II. Review of the Literature	10
Adjustment of Siblings of Children with Disabilities	11
Social-Emotional Adjustment of Siblings.....	24
Family Functioning and Children with Developmental Disabilities	29
Family Systems Theories	36
Circumplex Model of Marital and Family Systems	41
Family Systems and Sibling Adjustment	46
Model of Family Resiliency	51
The Resiliency Model of Family Adjustment and Adaptation And Sibling Adjustment	52
Research Rationale	56

Chapter III. Method	61
Research Participants	61
Instruments	66
Procedure	72
Scoring Procedures	73
Chapter IV. Results	75
Descriptive Analysis	75
Hypothesis Testing	84
Chapter V. Discussion	97
Implications	106
Strengths and Limitations	108
Future Directions	111
Conclusion.....	113
 <u>Appendixes</u>	
Appendix A: Family Cohesion	115
Appendix B: Family Flexibility	116
Appendix C: Family Communication	117
Appendix D: Organization Letters to Parents	118
Appendix E: Announcement to Disability Families	120
Appendix F: Announcement to Non-Disability Families	121
Appendix G: Family Background Questionnaire for Disability Group.....	122
Appendix H: Family Background Questionnaire for Non-Disability Group	124

Appendix I: Family Adaptability and Cohesion Scale (FACES-II)	126
Appendix J: Family Crisis Oriented Personal Scale (F-COPES)	127
Appendix K: Family Problem Solving Communication Scale (FPSC)	129
Appendix L: Permission to Use FACES-II.....	130
Appendix M: Permission to Use F-COPES and FPSC Scales	131
Appendix N: Piers-Harris Children’s Self-Concept Scale (CSCS)	132
Appendix O: Revised Children’s Manifest Anxiety Scale (RCMAS)	134
Appendix P: Instructions for Disability Group.	135
Appendix Q: Instructions for Non-Disability Group.....	136
References.....	137

List of Tables

Table 1. Developmental Disabilities of Non-Participating Siblings in Disability Group	62
Table 2. Agencies/Special Education Programs Represented by Families. ..	65
Table 3. Ages of Mothers, Fathers, and Participating Siblings in Disability & Non-Disability Groups.	76
Table 4. Ages of Non-Participating Siblings	76
Table 5. Gender of Participating Siblings	77
Table 6. Gender of Non-Participating Siblings	77
Table 7. Birth Order and Gender of Participating Siblings as Compared to Non-Participating Siblings.....	78
Table 8. Total Number of Children in the Family	78
Table 9. Birth Order of Participating Sibling	79
Table 10. Number of Household Responsibilities Assumed by Participating Siblings in Disability and Non-Disability Groups	80
Table 11. Highest Level of Education Attained for Mothers and Fathers	81
Table 12. Ethnicity Identified by Disability & Non-Disability Families.....	81
Table 13. Religious Affiliation for Mothers and Fathers by Group Status	82
Table 14. Income Level for Disability and Non-Disability Families	83
Table 15. Means and Standard Deviations of Mothers' and Fathers' Responses on FACES-II, F-COPES, and FPSC by Group Status... ..	85
Table 16. T-Tests Between Mothers' and Fathers' Scores on Family Measures.....	85
Table 17. Mean Parent Rating on Family Systems Variables by Group Status..	86
Table 18. Mean Parent Rating on Total Family Coping Skills by Group Status	87
Table 19. Mean Parent Ratings on Subscales of the F-COPES	88

Table 20. Correlations and Z-Scores Between Family Cohesion, Adaptability, and Problem Solving Communication and Coping Skills for Disability and Non-Disability Groups.	89
Table 21. Mean Ratings of Siblings' Self-Reported Anxiety & Self-Concept...90	
Table 22. Summary of Regression Analyses for Predicting Siblings' Self-Concept	92
Table 23. Summary of Regression Analyses for Predicting Siblings' Anxiety	93
Table 24. Mean Ratings for Disability Severity Questions	94
Table 25. Summary of Regression Analysis for Disability Group: Main Effect Model for Predicting Self-Concept	95
Table 26. Summary of Regression Analysis for Disability Group: Interaction Model for Predicting Anxiety.	96

List of Figures

Figure 1: Interaction in the Family System38

Figure 2: The Circumplex Model of Marital and Family Systems.....44

Chapter I

Introduction

Sibling Relationships

Research studies have for many years investigated the impact of parents' competence and mental health on children's development (Cicirelli, 1995). Until recently, research has overlooked the importance of sibling relationships on children's development. With the emergence of systemic theories of family functioning, there is renewed interest in sibling relationships as researchers study sibling subsystems and their impact on families.

Cicirelli (1995) defines sibling relationships as:

..the total of the interactions (physical, verbal, and nonverbal communication) of two or more individuals who share knowledge, perceptions, attitudes, beliefs, and feelings regarding each other, from the time that one sibling becomes aware of the other. A sibling relationship includes both overt and covert actions and interactions between the sibling pair as well as the covert subjective, cognitive, and affective components of the relationship. (Cicirelli, 1995, p.4).

Like all relationships, sibling relationships have varying degrees of closeness. Some siblings may be extremely close and have enduring intimacy characterized with interdependency, reciprocity, commitment, and emotional involvement. On the other extreme, some siblings may have

detached, formal relationships with little concern for each other's interests (Circicelli, 1995).

Yet sibling relationships share unique qualities which make them important (Cicirelli, 1995, Seligman, 1991). Sibling relationships are often the longest lasting relationship among all those experienced. These enduring relationships initially develop through daily, close contact in the home supervised by the same parent(s) where many shared experiences contribute to the similarities between siblings. Daily interactions in the home environment help siblings foster behavior and development in socialization, altruism, cooperation, and friendship skills, as well as negative behaviors such as competition and aggression. Throughout the lifespan, siblings may serve as a source of help and sense of security, such as helping a younger sibling learn to play a game, or complete a homework assignment or household chores. In this respect, siblings also learn new roles from one another, roles such as caregiver, teacher, friend, and leader (especially for younger siblings) (Cicirelli, 1995; McHale & Gamble, 1987).

The importance of understanding sibling relationships also arises from changes in contemporary family life. For example, there are fewer children born into families compared to years ago, making sibling relationships more interdependent and intense (Seligman & Darling, 1997). In addition, the rise in divorce and remarriage increases the disintegration of the family structure, and the rise in dual-worker families increases parental

stress and limits parental availability to children. These variables inevitably affect sibling relationships where siblings may rely on one another for more social and emotional support.

In short, sibling relationships are an important part of children's development. These relationships foster social and emotional strengths and weaknesses in individuals and provide early opportunities for learning roles and responsibilities and for sharing lifelong experiences. With changes in the contemporary family and the emergence of family systems theories, there has been greater interest in sibling relationships and their influence on children's adjustment (Cicirelli, 1995; Seligman & Darling, 1997).

Siblings of Children with Disabilities

In recent years, there has been particular interest in sibling relationships in families with a child with a disability (Hannah & Midlarsky, 1985; Lobato, Faust, & Spirito, 1988; McKeever, 1983). These sibling relationships are different than the relationship between children with typical development; they play an especially important part in children's development because of new experiences the disability brings to the relationship between siblings (Cicirelli, 1995). For example, it is sometimes difficult for non-disabled children to interact with a brother or sister with special needs because the disability may limit the child's communication skills, physical skills, and social skills necessary for work and play activities.

In addition, a child with a disability affects his/her entire family in many ways. The child's disability can be initially overwhelming for the family, and parents may experience emotions such as guilt, a sense of loss, overwhelming disbelief, disappointment, and depression (Seligman & Darling, 1997). Families might have to cope with social isolation, increased expenses, limited time for recreational and social activities, uncertainty of childcare needs, and extra demands on parenting (Fish, 1991; Wikler, 1981). The following quote from a mother raising a child with special needs suggests that there are overall affects on family functioning.

The stresses in a family with [a child with a disability] can be very unbearable most of the time. I have my children separated most of the time as their needs are so different...Nathan always sticks out in a crowd and as a family unit. There is an entire side of life we miss because of him. (Mother of 9-year-old boy with autism; Sgandurra, 1999).

For the non-disabled child, it may be difficult to live in a family facing many difficulties. These children may find themselves in unique and challenging roles and assuming more responsibilities (Coleby, 1995; McHale & Gamble, 1989). In addition, the sibling bond between the child(ren) with typical and atypical development might take on a special purpose and may

look unlike typical sibling relationships (Stoneman, Brody, Davis, Crapps, & Malone, 1991). The following quote is an example of such a sibling relationship:

The best part about having a brother/sister who has [a disability] is that I can teach people about [child's name]. In second grade, I brought [child's name] in, and people said "cool" or "this is fun" or "wow!" It felt really good and I still do! Although I wish [sister] was normal, I love her for who and what she is. (A 10-year-old girl with a sister with a disability; Sgandurra, 1999).

Siblings of children with developmental disabilities share a number of unique, challenging experiences which may be rewarding and also frustrating (Damiani, 1999; Hannah & Midlarsky, 1985; Seligman & Darling, 1997; Skrtic, Summers, Brotherson, & Turnbull, 1984). Perhaps the most difficult obstacle for siblings of children with disabilities is understanding the ramifications of the disability. Research suggests that young children tend to be unaware of their sibling's condition or do not fully comprehend it, being aware of only visible aspects such as speech and motor development (Lobato, 1990; Seligman & Darling, 1997). Siblings in early to middle childhood possess limited cognitive understanding and emotional maturity for coping with the nature, severity, or cause of a brother or sister's condition (Cicirelli, 1995). Yet siblings do have concerns – for the future, for their own health, for how they will explain the disability to neighbors and friends. Thus,

Thus, siblings of children with disabilities have serious worries that they may not openly and willingly express to their parents.

Often, siblings are faced with extra responsibilities in their families (Seligman, 1991). Siblings may assist their families with home and childcare responsibilities, and spend more time than other children babysitting, supervising, and/or providing daily bathing, dressing, and feeding care for their sibling with special needs (Damiani, 1997, McHale & Gamble, 1987), rather than participating in activities which are more unstructured and expressive, such as playing games together. Thus, siblings spend greater time with their brother or sister with special needs in “parenting” or “supervisor” roles, and less time as playmates or “enemies.”

Additionally, the relationship between the sibling and a child with a disability may be difficult (Kendall, 1999; Seligman & Darling, 1997). Siblings may perceive an “unequalness” in the relationship and feel that allowances and excuses accepted for mistakes by the special needs child are unfair. As a result, it may be difficult for siblings to resolve feelings of anger or resentment toward the special needs child given the disability, and thus siblings may harbor strong emotions instead of acting out or expressing their feelings. Siblings may either learn to retaliate or accommodate and avoid the child with a disability (Kendall, 1999).

Another difficulty for siblings is coping with strains which the disability places on aspects of family life, including the emotional, financial, and time

strains placed on parents who are trying to help the child with a disability (Seligman & Darling, 1997; Skrtic *et al.*, 1984; Vadasy *et al.*, 1984). Since counseling and treatment services may focus on helping parents cope and build relationships with the child with special needs, siblings may feel overlooked by parents and professionals. In addition, parents may have limited time and fewer financial resources available for their non-disabled children. Thus, siblings may feel forced to accept necessary sacrifices in order to help their families and brother or sister with special needs.

In summary, siblings of children with disabilities are coping with family and personal difficulties (Seligman & Darling, 1997). Compared to typical sibling relationships, they experience different roles with their siblings, share more responsibility in the home, have limited opportunities for expressive relationships with their siblings, and are coping with financial, emotional, and time strains that their parents are facing. Consequently, research has been interested in the adjustment of non-disabled sibling(s) of children with disabilities (Bagenholm & Gillberg, 1991; Cuskelly & Gunn, 1993; Dyson, Edgar, & Crnic, 1989; Mates, 1990; McHale & Gamble, 1989).

There is a substantial body of research that has explored whether living with a disabled brother or sister has an impact on the adjustment of the non-disabled sibling (Hannah & Midlarsky, 1985; Lobato, 1990). The research suggests that non-disabled siblings may be at risk for psychological maladjustment, such as increased anxiety, depression,

aggression, and social withdrawal (Hannah & Midlarsky, 1985; Seligman & Darling, 1997). On the other hand, the emotional and mental challenges resulting from living with a child with a disability may foster positive characteristics in non-disabled siblings (Lobato, 1990; Lobato, Miller, Barbour, et al., 1991) Thus, some siblings might develop increased empathy, tolerance, altruistic behavior, and enhanced self-concept (Hannah & Midlarsky, 1985). Consequently, living with a child with a disability may relate to both positive and negative adjustment of siblings.

Research findings on sibling adjustment has been inconsistent (Hannah & Midlarsky, 1985; Seligman & Darling, 1997). Studies do suggest that the presence of a special needs child alone does not predict the social-emotional adjustment of non-disabled siblings. Instead, there are static and dynamic variables that mediate the adjustment of siblings.

In the next chapter, there will be a review of research that assesses mediating variables and their relationship to siblings' adjustment. In addition, this chapter will review family systems theory, family resiliency, and literature exploring the effects which children with disabilities have on their families. There will be an emphasis on family process variables that relate to sibling adjustment.

The review of literature, though limited, will suggest that family process variables mediate the adjustment of siblings of children with disabilities (Dyson, 1996; Dyson, Edgar, & Crnic, 1996; Winick, 1996).

There is a need for further research that describes the relationship between family functioning and sibling adjustment. Thus, the present research will examine family processes mediating positive and negative social-emotional adjustment in siblings of children with developmental disabilities.

CHAPTER II

REVIEW OF THE LITERATURE

There are five main sections in this chapter. Section one is a review of research concerning the adjustment of siblings of children with disabilities. The literature is divided into three parts. The first part discusses research conducted on static variables, including children's gender, age, birth order, and severity of the disability, as well as family size and socioeconomic status, and their relationship to the adjustment of siblings. The second part is comprised of research conducted on process variables, including roles and responsibilities of the sibling and amount of social contacts. The third part discusses research conducted on family processes which relate to sibling adjustment, including communication, problem-solving, attitudes, and expectations.

The second section discusses the relationship between family functioning and sibling adjustment of children with brothers or sisters with developmental disabilities. This section describes research findings that suggest predictors of siblings' social-emotional adjustment. In addition, there is a discussion of how social-emotional adjustment has been measured in the research and study findings.

The third section explores family systems theory, a recent conceptualization for understanding sibling adjustment. There is a discussion of two family systems models: the Circumplex Model and the

Resiliency Model. Relevant research regarding the utility of such models in understanding sibling adjustment is explored.

The fourth section presents the rationale for the present investigation. The rationale is based on limitations of previous research and new conceptualizations of child development and family systems theory.

The fifth section lists five hypotheses that guided the present study.

Adjustment of Siblings of Children with Disabilities

Static Variables

Originally, research on siblings of children with disabilities examined static characteristics as possible mediating variables of siblings' adjustment. Static variables are characteristics of the children or families that are unchangeable, including gender, age, sibling birth order, and severity of disability, and characteristics that are likely to not change, such as family socioeconomic status. Because they are not changeable, static variables are not included as a focus of a treatment plan when counseling siblings and their families.

Research findings have suggested there is a relationship between siblings' gender, age, and birth order and their adjustment when there is a child with a disability in the family. Some studies report that younger brothers of children with disabilities are at greater risk for developing

behavior and/or emotional problems (Breslau, 1982; Vadasy *et al.*, 1984). Breslau (1982) suggested that there are differences in psychological adjustment for male compared to female siblings when birth order is considered. In comparison to a control group of siblings of children without disabilities, Breslau reported that younger males and those close in age to the child with a disability had greater psychological problems, unlike younger, female siblings who showed the greatest adjustment. Researchers suspect that younger boys whose parents are focused on the child with a disability will not receive the necessary behavior management essential to their development (Trachtenberg & Batshaw, 1997), which consequently will contribute to problems with interpersonal relations and aggression (Breslau, 1982).

Yet there are inconsistent findings regarding gender, age, and birth order and their affect on the adjustment of siblings (Hannah & Midlarsky, 1985). Research also suggests that older sisters are more like to experience psychosocial impairments (Vadasy *et al.*, 1984). It is believed that girls will take on extra childcare and household responsibilities (Coleby, 1995; Damini, 1999; Stoneman, Brody, Davis, Crapps, & Malone, 1991), which may overwhelm them and deny appropriate interpersonal growth. Other studies report greater maladjustment ratings in younger siblings whether boys or girls (Hannah & Midlarsky, 1985). One explanation is that younger siblings may be displaced from their family role as the most

dependent, immature child in the family and may be expected to assume greater childcare responsibility for the child with a disability (Breslau, 1982). Consequently, this role adjustment might place younger siblings at greater risk for anxiety, stress, and aggression.

In addition, research findings suggest that siblings of the same gender and closest in age to the child with a disability would most likely be at-risk for problems. Such children may be more likely to experience parental pressure to compensate for their siblings' deficiencies because they more likely resemble their siblings (Vadasy *et al.*, 1984), and because they will have limited opportunity for contact with peers (Coleby, 1995). For example, Dyson (1989) found that siblings with a larger age difference from the disabled child showed better adjustment than those siblings with a closer age gap. Overall, there have been inconsistent research results on siblings' gender, age, and birth order and the relationship to their adjustment.

Another static variable considered a possible mediator in sibling adjustment is the type and severity of a child's disability (Bagenholm & Gillberg, 1991; Knott, Lewis, & Williams, 1995). Hannah and Midlarsky (1985) suggest that a curvilinear relationship exists between sibling adjustment and severity of disability, such that disabled children with mild or severe conditions place their siblings at greater risk for maladjustment. For example, in homes of profoundly disabled children, siblings may take on

extra childcare responsibilities, and there may be strong parental pressure to achieve and be compliant. At the other extreme, non-disabled siblings of mildly disabled children may feel neglected and resentful; they may not believe their siblings are much different from themselves and thus feel their parents do not treat their children equally (Lobato, 1990).

Studies show that siblings of children with more severe disabilities interact in different ways than sibling dyads of children with less severe conditions. Knott *et al.* (1995) revealed that siblings of children with Down's Syndrome and Autism spend more time interacting as a caregiver and teacher than siblings of children with learning disabilities. Bagenholm and Gillberg (1991) reported communication deficits of parents to non-disabled siblings of children with autism and mental retardation. The majority of participating siblings of children with autism could not explain their brother or sister's disability. Siblings also revealed that there was limited opportunity within the family to discuss the child with a disability. These findings suggest that for siblings of children with more severe disabilities, siblings may assume more responsibility caring for their brothers and sisters, and families may experience greater difficulty sharing information with non-disabled children. Both variables may consequently affect the social-emotional adjustment of siblings.

Studies have also shown that family size may relate to adjustment of siblings such that siblings in larger families show better social competence

(Dyson, 1989; McHale, Sloan, & Simeonsson, 1986). When more children are present in the family, siblings can disperse among themselves the childcare responsibilities of the child with a disability, thus diminishing the burden of care for each sibling. Also, siblings have another normal functioning child with whom to share their fears and frustrations. Finally, in larger families, there are more children with needs to be met, causing the child with a disability to become less conspicuous and less of a focal point of concern, and consequently permitting the family system to appear more normal (Hannah & Midlarsky, 1985).

In addition, family socioeconomic status has been examined in relation to sibling adjustment (Dyson & Fewell, 1989; Hannah & Midlarsky, 1985; Vadasy *et al.*, 1984). In particular, middle class and upper-middle class families who hold career-oriented expectations for their children may view a disability as a "tragic loss". In contrast, research shows that lower-class families may view disabilities in terms of coping with a "reality crisis". Consequently, a family's social class mediates parental expectations that contribute to siblings' adjustment.

Summary. These findings suggest that static variables, including siblings' gender, age, and birth order, severity of disability, and family's socioeconomic status and size relate to the social and emotional adjustment of non-disabled siblings in families with a child with a disability.

These findings, however, have limited implications for interventions because the variables are not modifiable.

Dynamic Variables

Research on sibling adjustment has recently looked at the impact of dynamic variables on siblings' social-emotional functioning. Unlike the unchangeable quality of static variables, dynamic variables, including family roles, relationships, attitudes, and expectations, can be modified by family professionals who try to strengthen coping and functioning in families raising children with disabilities. Consequently, these variables have an overall impact on family functioning and adjustment. Research has begun to examine how these variables may affect the non-disabled sibling's psychosocial functioning (Hannah & Midlarsky, 1985; Vadasy *et al.*, 1984). Recent studies have examined social processes in families to understand sibling relationships between developmentally disabled and non-disabled children (Beavers *et al.*, 1986; Dyson *et al.*, 1993; McHale *et al.*, 1986).

Responsibility and adjustment. Early studies on sibling's adjustment measured the degree of home and childcare responsibilities which siblings of children with disabilities assume (Cuskelly & Gunn, 1993; Damiani, 1999). Some studies have examined the relationship of home and childcare responsibilities of non-disabled siblings to psychological well-being (McHale & Gamble, 1989, Stoneman & Brody, 1984). There are

inconsistent differences in household responsibilities between siblings of children with and without disabilities, and girl siblings in fact assumed greater household and childcare tasks regardless of whether a child with a disability was present in the family or not (Cuskelly & Gunn, 1993; Damiani, 1999). Nonetheless, family self-reports do express that household and childcare responsibilities are frustrating and fatiguing factors when raising a child with a disability. In addition, siblings' perceptions of burden of responsibility correlate with their perceptions of family management and coping (Weigner, 1999). According to the non-disabled siblings, a heightened sense of responsibility and limitation in family activities resulted in less favorable attitudes toward family functioning.

Reports show that while siblings of children with and without disabilities spend equal amounts of time engaged in sibling activities, the siblings of children with disabilities in fact spend greater time involved in caregiver activities with their siblings. In their study, Stoneman *et al.* (1991) assessed the family roles and responsibilities of younger siblings of children with mental retardation. They hypothesized that roles attributed to birth order positions would be reversed, such that younger, non-disabled siblings may experience social/emotional problems because they "untraditionally" assume responsibilities ascribed to older siblings. They interviewed mothers and siblings of children with MR regarding childcare responsibilities, household tasks, and peer contacts. Results suggested

that the younger siblings took on childcare roles typically expected of oldest children, although they did assume *fewer* household tasks than their cohorts with non-disabled, older siblings. However, non-disabled younger siblings were not restricted in social contacts and actually had frequent participation in social events. This finding is consistent with the work of Bagenholm and Gillberg (1991) that reports that siblings of children with mental retardation do not experience decreased contact with social groups despite extra involvement in home tasks. However, Stoneman et al. did not employ standardized outcome measures of siblings' psychological adjustment and did not attempt to look at family processes.

In another study, McHale and Gamble (1989) examined family processes (i.e., involvement with siblings, child-parent relationship, siblings' perception of parental favoritism, extra caregiving and household chores) that mediate the social and emotional adjustment of older siblings of children with mental retardation (MR). Using home interviews, self-rating scales of depression, social competence, and anxiety, in addition to parent rating scales, McHale and Gamble found that siblings did assume more childcare responsibilities (in both duration and frequency) compared to siblings in families without children with disabilities. Specifically, girl siblings recalled more involvement in household responsibilities compared to boys, while boy siblings reported equal amount of caregiving responsibilities as girl siblings of children without disabilities. In addition, their findings

showed positive correlations between the amount of childcare responsibilities and siblings' levels of anxiety.

In another study, Coleby (1995) examined siblings of children with severe multiple disabilities and found that siblings' burden of care correlated positively with their anxiety (i.e., according to parent and teacher ratings and self-reported measures). In addition, the siblings had restricted contact with friends, which suggests that increased childcare responsibility and restricted social contacts with peers combined predict increased anxiety in siblings of children with severe disabilities.

In summary, these results suggest that siblings of children with severe developmental disabilities do likely assume extra caregiving responsibilities, and can have reduced social contact with peers and increased household responsibility. These extra responsibilities to families and to siblings may correlate with negative social and emotional adjustment.

Parental attitudes, expectations, and communication and adjustment.

Recent research on siblings of children with disabilities examines family environment variables that may relate to sibling adjustment. Since families with a child with a disability may experience disruptions in typical family needs, roles, and relationships (Hannah & Midlarsky, 1985;

Trachtenberg & Batshaw, 1997), siblings may be affected due to differences in family routines.

Research suggests that there is better adjustment among siblings when family members communicate their feelings openly and the disability condition is explained to non-affected children (Powell & Gallagher, 1993; Trachtenberg & Batshaw, 1997). It is necessary for parents to provide emotional support and to openly communicate with siblings in order for children to cope with their brother or sister's condition and the family's changing needs (Seligman & Darling, 1997). Some studies suggest that parents' lack of communication between themselves and with their children, whether due to limited knowledge or low perceived competence, can cause very young siblings to have misunderstanding about a child's condition. These misunderstandings may cause siblings to harbor beliefs that they may also acquire the disability or are responsible for their siblings' disabilities (Seligman & Darling, 1997).

Research has revealed that some siblings of children with disabilities do report limited communication in their families concerning their siblings with disabilities, and at times are not prepared to discuss their siblings with neighbors and friends (Bagenholm & Gillberg, 1991; Seligman & Darling, 1997). Lobato, Barbour, Hall, and Miller (1987) report that siblings of children with disabilities often were unable to explain their siblings' disabilities and did not provide accurate information about disabilities any

more than siblings of children without disabilities. In particular, Bagenholm and Gillberg (1991) report that 65% of siblings of children with mental retardation were unable to explain why their siblings were special.

However, these findings were not viewed in relation to measures on family communication styles or linked with outcomes in sibling adjustment.

In addition, adjustment of siblings of children with disabilities may also be affected by parental attitudes. Parental attitudes toward the child with a disability and the effects of parental attitude on family functioning may mediate differences in siblings' adjustment (Dyson & Fewell, 1989; Seligman, 1991; Vadasy *et al.*, 1984; Weigner, 1999). Some studies suggest that parental expectations put pressure on siblings to do well in order to compensate for the child with a disability (Hannah & Midlarsky, 1985). Specifically, siblings may believe that they must be well-behaved, attractive, socially accepted, and/or studious. In effect, they may feel pressure to fulfill expectations that are unattainable by the child with a disability.

Research suggests that attitudes of family members toward the child with a disability may relate to family functioning. Weigner (1999) measured mother and sibling's perceptions of the child with a disability (i.e., mental retardation) and their views regarding their families' functioning. Findings revealed that as attitudes toward the child became more positive, mothers and siblings reported more positive perceptions of their families' functioning.

Specifically, mothers and siblings felt that there were more positive communication and coping skills in the family. However, Weigner did not relate these findings to the social-emotional adjustment of siblings.

The attitudes which siblings harbor toward the child with a disability may also relate to their social-emotional adjustment. A study by McHale, Sloan, and Simeonsson (1986) examined sibling relationships between children with brothers and sisters with a disability to determine how attitudes and concerns impact on siblings' well-being. Findings suggested that a more positive sibling relationship is observed between children when the non-disabled sibling manifests less concern for the future (i.e., for his/her sibling with a disability and the role he/she will assume in caring for him/her), harbors fewer feelings of rejection (i.e., from family and peers), perceives more positive reactions by parents and peers to the child with a disability, and possesses less concern for parental favoritism. When attitudes toward favoritism, rejection, and future concerns of the child with a disability were less favorable, siblings shared a less positive relationship. In effect, problems between siblings may create psychosocial impairments for the non-disabled sibling.

In their research on sibling adjustment, McHale and Gamble (1989) found significant correlations between family process variables and siblings' psychosocial functioning. Their findings suggested that parents' expectations and communication style relate to parent-child interactions.

For example, siblings who experienced more frequent negative interactions with their mothers also reported more conflicts with the child with a disability, and conflicts between mothers and siblings correlated with lower self-esteem and higher ratings of depression and anxiety. Maternal negativity also related to siblings' self-worth, where siblings who reported lower general self-worth also experienced greater conflicts between themselves and their mothers. There were higher ratings of depression and anxiety for siblings reporting greater dissatisfaction with being treated differently from the exceptional child. Unfortunately fathers were not involved in this study, and future research might focus on fathers' responses to measures of family process variables in order to expand awareness of family relationships and siblings' social-emotional adjustment.

Finally, recent findings suggest that siblings' perceived parental treatment influences their adjustment (Kendall, 1999; Wolf, Fisman, Ellison, & Freeman, 1998). In a longitudinal study (Wolf *et al.*, 1998), siblings' social and emotional adjustment became more impaired when siblings perceived differential treatment from parents. Siblings of children with Down's Syndrome felt their brothers or sisters were preferred over them, and this perceived parental differential treatment correlated with internalized adjustment problems. Wolf *et al.* note that this finding is consistent with prior research associating parental favoritism and differential treatment with sibling's adjustment.

In summary, research on sibling adjustment has recently assessed the relationship between dynamic variables, specifically family process variables, and siblings' functioning. Findings suggest that family responsibility, parental attitudes and expectations, and family communication have an effect on siblings. However, these studies have provided limited information on the impact that these dynamic variables have on the social-emotional adjustment of non-disabled siblings.

The Social-Emotional Adjustment of Siblings

When investigators assess a siblings' adjustment, they must define this hypothetical construct and decide on observable and/or measurable aspects of adjustment. A number of different measures of adjustment have been used in studies, including parental reports of behavior problems and social competence (Dyson, 1989; Dyson, Edgar, & Crnic, 1989; McHale, Sloan, & Simeonsson, 1986), self-reports of depression and sibling interactions (McHale & Gamble, 1989), and teacher reports of school behavior and standardized tests of achievement (Mates, 1990). While there are several alternative adjustment measures, self-reports of self-concept and anxiety are of interest and are important indicators of social-emotional adjustment because research suggests they affect mood, learning, and social skill development (Wicks-Nelson & Israel, 1991).

Self-concept. Self-concept refers to ideas, feelings, and attitudes that collectively represent the way a child thinks about himself/herself (Hilgard, Atkinson, & Atkinson, 1979). When a child has a positive affect in response to the way she/he thinks of him/herself, positive self-esteem develops. Positive self-esteem provides internal support and confidence. This provides internal motivation to engage in challenging tasks, social situations, and academic work (Wicks-Nelson & Israel, 1991). Thus, self-concept impacts on one's self-esteem that ultimately gives internal strength to motivate toward school, social, and home experiences.

Consequently, many investigators have chosen to measure siblings' self-concept when assessing the social-emotional adjustment of siblings of children with disabilities. Research results of self-concept among siblings of children with and without disabilities have been inconsistent. Some research has suggested better ratings of self-concepts reported by siblings of children with disabilities compared to siblings of children without disabilities. In a study of siblings of autistic children, Berger (1980) reported siblings' ratings on a self-concept scale to be significantly higher compared to the normal population of children. Also, significant differences were not reported between the self-concepts of older and younger siblings. Interviews with these siblings suggested they did not feel significantly affected by their brothers or sisters.

Mates (1990) assessed the correlations of family and child static variables (i.e., gender and family size) with siblings' responses to a self-concept measure. As a group, older siblings of children with autism reported a mean self-concept score better than the population of children included in the norm sample, and this rating was not affected by gender or family size. However, siblings who participated in Mates's study were those of autistic children from a university-based special education program. This program provided family services that the researcher felt may have buffered problems in the families observed in comparison to other families living with a child with a developmental disability.

Dyson and Fewell (1989) assessed siblings of children with various developmental disabilities (i.e., mental retardation, autism, speech disorders, physical impairments) and overall found similar ratings of self-concept between these siblings and siblings of children without disabilities. However, Dyson (1989) found that siblings of children with mental retardation had higher self-concepts compared to siblings of children with milder disabilities (i.e., speech disorders, learning and behavior problems, and developmental delays).

In addition, Dyson (1996) assessed the self-concept of siblings of children with learning disabilities compared to a control group of siblings of children without learning disabilities. Dyson found that siblings in the disability group scored similarly on standardized measures of self-concept

compared to the control group [i.e., the Piers-Harris Children's Self-Concept Scale: The Way I Feel About Myself (CSCS; Piers, 1984)]. However, Dyson had assessed siblings of children with a milder disability.

Some research suggests that differences in the self-concept of siblings of children with disabilities are revealed when mediational variables are analyzed in regression models. Dyson, Edgar, and Crnic (1989) assessed psychological factors that mediate the self-concept of siblings of children with and without disabilities. Their results showed that family attributes, including parental stress and social support, and characteristics of the family social environment, including relationship (i.e., cohesiveness and expressiveness), personal growth, and system maintenance, significantly predict variances of self-concept for siblings of children with disabilities and not for siblings of non-disabled children. Dyson also revealed that parental stress and resources were the most significant predictors of self-concept of siblings.

In addition, the individual response analyses from Dyson (1996), Dyson (1989), and Dyson and Fewell (1989) revealed greater variability in self-concept of siblings of children with disabilities. In effect, although siblings of children with disabilities may appear on average as socially and emotionally adjusted as siblings of children without disabilities, the greater range in their adjustment suggests that there are differences in their adjustment not explained by a simple group comparison (Mates, 1990).

Thus, research that includes mediating variables may tease apart the varying levels of sibling adjustment by relating this outcome to varying levels of another variable. To this end, family characteristics may be those mediating variables that predict sibling adjustment, and aspects of family functioning may predict the self-concept of siblings.

Anxiety. Research studies have also examined siblings' anxiety as a measure of their social-emotional development. Anxiety is an important emotional factor because of its association with many problems in mental health, including depression, obsession-compulsion, and social phobias. For example, research suggests that children with high levels of anxiety are more likely to experience depression. In addition, lower levels of anxiety permit a healthy mood and affect necessary for a child to excel in social and academic situations (Wicks-Nelson & Israel, 1991).

Some studies have measured the anxiety of siblings and found correlations between higher anxiety and the presence of conflicts between mother-sibling dyads (McHale & Gamble, 1985) and the amount of home responsibilities (Coleby, 1995; McHale & Gamble, 1985). Although these findings suggest a link between family dynamics and siblings' anxiety, the research is limited.

In summary, in families with a child with a disability, non-disabled siblings' anxiety and self-concept have been shown to be affected. However, the mere presence of a child with a disability in the family does

not add predictability to the self-concept and anxiety of siblings since research findings have been inconsistent (Dyson, 1989).

Family Functioning and Children with Developmental Disabilities

Studies that identify mediating factors of sibling adjustment, such as family functioning, offer greater insight into sibling development. Families caring for a child with a developmental disability find that many aspects of family life may be different compared to families not raising a child with a disability. Parents may face financial, emotional, and social changes, and many reactions and adaptations by the family may follow (Fish, 1991; Trachtenberg & Batshaw, 1997). The life cycle of the family may arrest, and patterns of family roles may be altered (Blacher, 1983). While non-disabled children reach school age and gain greater independence, parents of children with developmental disabilities continue to care for a dependent child with limited, developmentally delayed skills. Initially, when families learn about the disability, members may experience a range of overwhelming feelings including shock, disbelief, a sense of loss, guilt, and depression (Seligman, 1991). Strong negative emotions and pessimistic attitudes could prevent families from finding necessary resources to cope with raising a developmentally disabled child.

In order to cope, parents learn to manage the time, energy, and emotional strains they encounter (Beavers, Hampson, Hulgus, & Beavers, 1986; Trachtenberg & Batshaw, 1997). Eventually, families may learn to

mobilize resources and social support while gaining a better understanding of their child's disability and opportunities to see progress in the child's development (Seligman, 1991). These factors, however, may directly and indirectly affect the development of non-disabled siblings through limited parental attention, increased responsibility to the family's needs, and/or decreases in child related activities (e.g., social contact with friends). Thus, there have been investigations into how the child with a disability has affected family functioning and relationships between family members.

In a recent investigation, Costigan, Floyd, Harter, and McClintock (1997) observed entire families in problem-solving scenarios to assess the influence of raising a child with mental retardation on family dynamics. Researchers observed intra-familial interactions of 165 families with children with mental retardation and 52 families in a comparison group. Overall, findings suggested that siblings of children with mental retardation were not less involved in family discussion nor did they exhibit greater negative behavior in comparison to siblings of children without disabilities. However, among siblings who were 6 to 12 years of age, both boys and girls demonstrated lesser degrees of active problem solving in their family interactions compared to girl siblings in the comparison group. These siblings also displayed the greatest number of negative behaviors compared to all sibling age groups.

Costigan *et al.* (1997) suggest that during middle childhood, siblings of children with developmental disabilities experience a crisis event in their development. Siblings, especially those who are younger, surpass the abilities of their brother or sister with a disability while concurrently gaining greater awareness of the definitiveness of the disability and its impact upon their brother or sister's overall development. Siblings in middle childhood may also demonstrate more difficulties because of their concrete operational stage of cognitive development. In this stage, children are concerned with fairness in family rules, and subsequently may disagree with rules that give special treatment to their brother or sister with special needs. Similarly, siblings also may prematurely assume childcare tasks for the child with a disability, and consequently siblings feel resentment toward their families because they must unwillingly take on more responsibility. Costigan *et al.* suggest this resentment may cause a withdrawal in problem-solving behaviors and manifestation of negative behaviors observed among children 6 to 12 years old.

Costigan *et al.* (1997) also observed differences in the role of parents with and without children with disabilities during problem solving interactions. They reported that during family interactions, mothers and fathers were more directive during problem-solving exchanges than parents of children without disabilities. However, Costigan *et al.* did not consider

the adjustment of sibling's within the context of these family process interactions.

Additional research has uncovered significant family dynamics when there is a child with a developmental disability in the family. In their study on coping in families with MR children, Beavers *et al.* (1986) showed that well adjusted families demonstrated good family cohesion and appeared to place blame outside the family. To this end, researchers believe that by establishing a scapegoat (i.e., pediatricians, neighbors), family stress was permitted and relieved through sources that did not undermine family togetherness and bonding. In contrast, dysfunctional families show boundary problems; they focused excessively on the disabled child's needs and used this child as a target during unresolved conflicts. Further, these families were less flexible, supportive, and respectful to individual family members compared to better functioning families. Dysfunctional families in Beavers *et al.*'s study also exhibited less equality in parenting tasks between the spouses, such that one parent took on more parenting responsibility. In summary, well functioning families of children with mental retardation demonstrated healthy adaptation characterized by good conflict resolution, and good agreement in the perception of family and individual responsibility, suggesting that these well functioning families can balance individual and group actions and feelings.

Research also suggests that the quality of relationships within families of children with developmental disabilities relates to sibling relationships. McHale *et al.* (1986) found that mothers of developmentally disabled children rated greater variability in the quality of the sibling relationship (i.e., positive to negative) when compared to sibling relationships between non-disabled children. McHale *et al.* identified family qualities that related to positive and negative sibling relationships, including parental favoritism, coping ability, and concerns for the child with a disability's future. Specifically, siblings who reported greater understanding of the disabling condition and more positive reactions to the child with a disability from parents and peers had mothers who were more likely to report a positive relationship between siblings. On the contrary, a negative relationship between siblings was more likely when three family variables were reported by non-disabled siblings: worrying about the disabled child's future, feeling parental favoritism, and feeling rejected by the child with a disability. These findings suggest that effective communication and adaptability toward the disability were related to a healthier relationship between siblings.

Another investigation suggests that the family environment within families of children with developmental disabilities relates to sibling adjustment. Dyson *et al.* (1989) explored psychological factors in the family system which predict adjustment in siblings of children with

developmental disabilities compared to siblings of children without disabilities. Dyson *et al.* asked parents to rate the family's psychological environment on measures of parental stress, social support, family relationship, personal growth, and systems maintenance. Concomitantly, parental responses (i.e., 87% maternal, 9% maternal and parental, 4% only paternal) on children's social competence and behavior, and children's self-reported self-concept, were analyzed in the context of the family environment.

Analyses revealed that there were different psychological predictors of adjustment for siblings with and without a child with a disability in the family. Specifically, among siblings of children with a developmental disability, 18% of the variance in their self-concept was related to the combination of family psychological attributes (i.e., parental stress, social support, family relationship, personal growth, and systems maintenance), and the single best predictor of self-concept was parental stress. Thus, when there was a child with a disability in the family, higher parent stress was associated with non-disabled children reporting lower self-concepts. However, in families with non-disabled children, the family relationship (measured as family cohesiveness, expressiveness, and conflict) more significantly related to self-concept in the children. In families with a child with a disability, family relationship was a predictor of behavior problems for siblings, such that fewer problems were reported when parents rated their

families as supportive and open with their feelings. In addition, in siblings of children with disabilities, their social competence was related to the family's emphasis on personal growth, that is, one's striving toward the development of independence in moral-religious beliefs and cultural-recreational activities. This supports findings of Dyson (1996) who showed that well-balanced families with LD children emphasized personal growth. Among families with non-disabled children, however, Dyson *et al.* found that familial social support was the most significant predictor of social competence in siblings.

Thus, Dyson *et al.* showed that families raising developmentally disabled children possess a combination of psychological factors (i.e., personal growth/relationship, seeking personal support, coping with stress) that significantly accounted for variance in sibling adjustment ratings (i.e., self-concept, behavior problems, social competence). Further, the researchers suggested that these prediction models differed compared to a group of siblings of children without developmental disabilities.

In summary, the above studies highlight family dynamics that differentiate families of children with developmental disabilities from those of families with non-disabled children. Further, this research also suggests the impact of raising a child with a developmental disability on family processes including problem-solving capabilities, family cohesiveness, sibling relationships, and suggests how the family environment relates to

the adjustment of non-disabled siblings. Research which further explores these variables and which invites more fathers to participate will expand the field's understanding of how family system variables relate to adjustment in non-disabled siblings.

Family Systems Theories

In the field of family therapy, systems or strategic theories conceptualize the family as an open system capable of change in the roles, routines, goals, and structure that define the family in order to maintain typical or optimal family functioning (Minuchin, 1974). Its principles are derived from General Systems Theory which is a "...scientific paradigm applied to physical systems and extended to biological and social systems as well." (Paget, 1987, p. 429). Normal family functioning is viewed as a "process" or interactive transactional patterns which emerge over time and are determined by organizational rules (Walsh, 1993).

Minuchin (1974) applies several principles in the definition of a systems theory of family functioning. First, the family unit is considered an organized whole with interdependent subsystems or units. The family is a collection of its members as well as the reciprocal processes that occur between parent-parent, parent-child, and child-child. According to systems models, family patterns emerge over time and influence family members'

behavior individually and wholly. This view emphasizes understanding the context of the individual within the whole family unit (Paget, 1987).

Another principle of systems theory applied to families is the circularity, as opposed to linearity, of family patterns (Walsh, 1993; Paget, 1987). Circularity of transaction patterns suggests that family problems are multifaceted, and one shouldn't view problems as having a direct cause. Instead, the *cycle* of interactions between family members maintains the problem (see Figure 1). For example, a father's concerns may upset a mother who causes the child to become upset and behave symptomatically, further causing concern in the mother. This example shows that each behavior has a prior cause and also contributes to a later event. In order to adjust the family's problems, interventions need to change the *reciprocal patterns* within the family unit (Carlson, 1987).

Family System

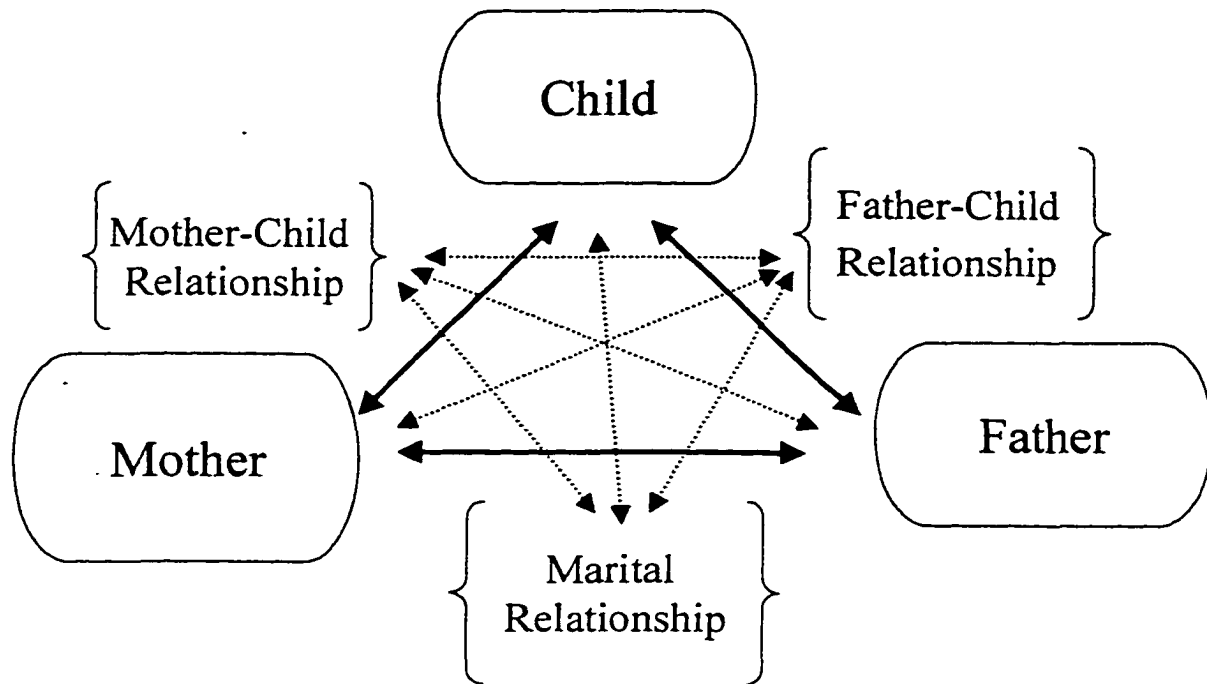


Figure 1: Interactions in the Family System

In addition, family systems theories acknowledge a need for homeostasis in order to maintain family patterns (Paget, 1987). Because families strive to maintain homeostasis, any behavior that is beyond the range of reoccurring family patterns will be “challenged” or controlled by other family members. For example, a child may develop a serious health

condition, following which major family changes in routine and activities may occur. Families may respond with rigidity (i.e. interactions which prevent change) or adaptability (i.e., interactions which permit change). The family's response is one that attempts to reestablish homeostasis, although there may be dysfunctional or functional family processes that result from this.

The inevitability of change is another principle of family systems models (Paget, 1987). As family members experience emotional and physical maturity, so to does the family life cycle. These periods of change in the family life cycle create new challenges for the family members. Change is a necessary aspect of family life, and accommodating change is possible by re-establishing family patterns, reorganizing rules and routines, and mobilizing resources within and outside the family. Family systems theory proposes that change is met most effectively when every member of the family participates in re-establishing family patterns.

Finally, family systems theories define a family unit as one comprised of various subsystems (Paget, 1987). Examples of subsystems include the parental subsystem, sibling subsystem, and gender subsystem. These subsystems are separated by boundaries that are established by rules and routines. Family subsystems are necessary for organization and for maintenance of roles and rules. Yet rules and routines change in all

families as the family life cycle progresses, and in dysfunctional families, one may see ambiguous boundaries established between subsystems.

In summary, the family systems models suggest that events occurring within families affect individual member's social-emotional and behavioral adjustment through transactional patterns established among family members within and across subsystems (Carlson, 1987). Minuchin (1983) proposes that all families face problems, and one should not conceive of dysfunctional families as possessing problems but rather consider how the family reacts to maturational and environmental changes.

There are several different family systems including structural and strategic/systemic, which share conceptualizations of the family as *changing* social systems requiring frequent reorganization (Walsh, 1993). Structural family therapy (Walsh, 1993; Minuchin 1974) places importance on the organization of the family in understanding functioning. The family is considered a frequently transforming open system that develops over time and adapts to changes so that the *whole* family maintains continuity and individual family members further their psychosocial growth. Systemic family theory, however, emphasizes the *actions* among family members as suggesting a family's cohesion, adaptability and communication style which characterize the family's functioning (Walsh, 1993).

Circumplex Model of Marital and Family Systems.

In the Circumplex Model of Marital and Family Systems, Olson (1993) identifies three dimensions along which family functioning is measured: cohesion, adaptability (flexibility), and communication. Cohesion is the emotional bonding that is seen between self and the family, the extent of family involvement, the nature of the marital and parent-child relationships, approach to decision-making, and the amount of individual versus group interest (see Appendix A). The Circumplex Model posits that healthy family functioning is within a midrange level of cohesion; to be both independent yet connected is ideal family cohesion (Olson, 1993). In contrast, families that are disengaged or enmeshed, the two extremes of cohesion, are at-risk for problems. A disengaged family has extreme emotional separateness, very low involvement or interaction between its members, and maintains separate activities and interests. Families with extreme enmeshment, on the other hand, show intense emotional closeness and loyalty that are placed before personal needs, and the family members find themselves too dependent and reactive to one another. There is limited separateness, very high family involvement, and family decisions are made based on the needs of the entire group. In the enmeshed family, together dominates, there is high affective responsiveness by family members toward each other, and subsystem boundaries are unclear. In families raising a child with a developmental

disability, an extreme cohesiveness or enmeshment may be seen in order for the family to cope with the child's special needs. Thus, there may be poor boundaries between self and the family in response to meet the needs of the disabled child (Beavers *et al.*, 1986). At the other extreme, families with a child with a developmental disability may show disengagement. For example, the child's special needs may limit family togetherness and emotional closeness if parents take on separate responsibilities for caring for the child.

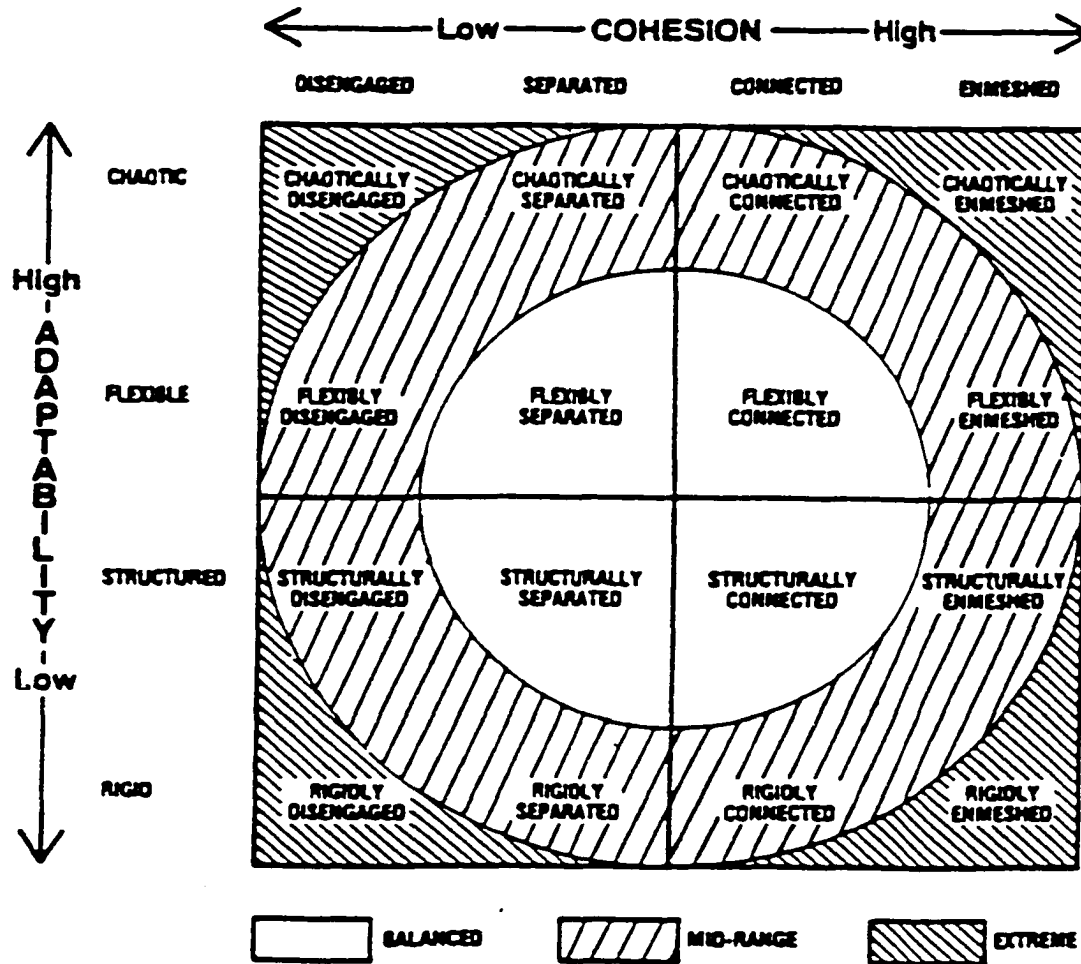
The second dimension in the family system is adaptability or flexibility. This refers to the family's capability to adapt its structure and rules in response to both expected developmental changes (e.g. children growing older) and unexpected changes (e.g., birth of a child with a disability) in the family's life cycle. This is measured by assessing the family's negotiation style, relationship roles, relationship rules, and leadership style (e.g., democratic, authoritarian) (see Appendix B). Similar to the cohesion domain, families which demonstrate balance between structure and flexibility will experience healthier functioning; families which find themselves extremely structured (rigid) or too flexible (chaotic) will have more difficulty dealing with change (Olson *et al.*, 1983; see figure 2).

In a flexible/adaptive family system, rules are allowed to change to accommodate children's development and the family's changing needs (Olson *et al.*, 1983). In a family raising a child with a severe disability,

however, rules and roles might not be as flexible over time compared to “typical” families because the child with a disability may never pass a certain developmental level. For example, the child with a disability may continually need supervision, forcing the family to remain within the “young children” stage of the family life cycle despite the developmental changes seen in

typical developing siblings. If rules and roles are very rigid, inflexible family functioning may affect sibling’s adjustment. For example, the family may require very specific childcare responsibilities without opportunities for negotiation by the sibling, which in turn limits the sibling’s time for social contact and pursuing personal interests. In addition, a lack of negotiation may foster frustration and resentment in the sibling.

Figure 2. The Circumplex Model of Marital and Family Systems



Olson, D.H. (1993). Circumplex Model of Marital and Family Systems: Assessing family functioning. In F. Walsh (Ed.), Normal family processes. New York, NY: Guildford Press.

Some research findings suggest that family adaptability relates to sibling adjustment. Dyson *et al.* (1989) suggest that families showing flexibility in decision-making and role relationships demonstrated better functioning, and that parental stress and overall negative family environment related to greater social and behavioral problems in siblings. Beavers *et al.* (1986) reported that well-adjusted families raising a child with a developmental disability had their children without a disability taking a larger part in family problem-solving than was observed in dysfunctional families.

The final dimension in the Circumplex Model of Marital and Family System Theory is communication. This dimension represents the many communicative qualities that collectively represent the family's ability to discuss ideas and feelings with one another and facilitate family rules and routines (Olson *et al.*, 1983; see Appendix C). This includes the family's listening and speaking skills, respect and regard during conversation, self-disclosure of self and relationships, and clarity and continuity of conversations (i.e., not interrupting or changing subjects). This dimension is considered a facilitating factor because a family with good communication reestablishes balance in cohesion and adaptability more successfully than families that lack good communication.

For families raising a child with a disability, communication may be difficult. For example, research has shown that some siblings of children

with developmental disabilities felt they could only talk about their brother or sister to someone outside their immediate family, and were not always able to explain the disability of their siblings (Bagenholm & Gillberg, 1991; Lobato, Barbour, Hall, & Miller, 1987).

In summary, the Circumplex Model acknowledges that change in response to stress and life events is more accessible when a family's system is one characterized by a moderate degree of cohesion and adaptability (Olson *et al.*, 1983). When a family is faced with raising a child with a disability, this is considered a "second-order change" in the family life cycle that forces a "change in the system itself." During this period, a family may appropriately react by moving into extreme levels of cohesion and adaptability, becoming too rigid and enmeshed, or too chaotic and disengaged. Yet families inherently strive to maintain homeostatic functioning, and thus those families who can restore healthy functioning more easily, as facilitated by the quality of communication and their cohesion and adaptability, will find it easier to adjust to their new family situation.

Family Systems and Sibling Adjustment

Research studies have applied family systems theories in assessing the relationship between family functioning and the social-emotional adjustment of siblings of children with disabilities. Dyson (1996) assessed sibling adjustment (i.e., self-concept) and parental stress and family

functioning in families with a learning disabled child. The study included 19 parent-sibling pairs, and participating children were between the ages of 7 and 14. Families responded to questionnaires on parenting stress, the family environment, and siblings' self-concept. Mothers (84%) completed most of the questionnaires; fathers and both parents completed 5% and 10% of questionnaires, respectively.

Dyson obtained correlations between family measures and siblings' self-concepts and compared these findings to a comparison sample of families with non-learning disabled children. Findings revealed greater parental stress in families raising children with learning disabilities compared to families without disabilities. Parents in families with a learning disabled child reported feeling guilty about spending more time with the learning disabled child than their other children, having difficulty handling their children's deficiencies, and being overwhelmed with family strains including reduced family time and financial resources.

Findings from Dyson (1996) also showed similar levels of family relationships and maintenance of a "balanced" family system between families with and without children with a disability, although parents of children with learning disabilities reported greater personal growth in their families. In summary, these findings suggest that families with a child with a learning disability may possess positive family relationships that

demonstrate “balanced” levels of cohesion and flexibility such that rules and routines facilitate family functioning.

Dyson’s (1996) results also showed similar ratings of self-concept between siblings of children with and without learning disabilities, where both groups scored in the positive range of self-concept. Thus, sibling outcome measures suggest similar self-concepts between siblings of children with and without learning disabilities. However, these were siblings of children with milder disabilities. Since family role and routines are often more stressed with more severe disabilities (Coleby, 1995; McHale & Gamble, 1989; Stoneman *et al.*, 1991), more research with other disability populations on similar variables is needed to understand the relationship between family functioning and sibling adjustment.

Another study by McHale *et al.* (1986) investigated siblings’ perceptions of the disability on family and sibling relationships through interviews and self-reports with the non-disabled child. Ninety children ages 6 to 15 were either siblings of children with mental retardation, autism, or typical development. Siblings were asked open-ended questions concerning their attitudes toward the child with a disability, their perceptions of the child’s role in his/her family, and the extent to which the child with disability affects his/her relationship with peers. In addition, mothers completed a rating scale on the non-disabled child’s behavior toward

his/her sibling, including statements measuring the sibling's acceptance, hostility, support, and embarrassment toward the child with a disability.

Findings from McHale *et al.* (1986) showed large variance in the responses of siblings of children with disabilities, ranging from extremely positive to negative reports about sibling relationships. McHale *et al.* revealed that siblings and mothers described positive relationships between siblings when the siblings' worries about the child's future, resentment toward perceived parental favoritism, and feelings of rejection toward the child with the disability were minimal. A positive relationship was also observed when siblings perceived positive acceptance of the disability by parents and when siblings felt better able to cope with their brother or sister's condition. In addition, there was a more positive relationship reported between siblings in those families with greater religious involvement.

Overall, McHale *et al.*'s (1986) findings suggest a relationship between communication and adaptability by the family toward the disability and family functioning. Specifically, when siblings' revealed good perceptions of their families' responses to the disability and when their sibling relationship reflected good cohesion, adaptability, and communication, the sibling relationship was more positive. A positive sibling relationship and attitude toward one's family is essential to the functioning of the sibling subsystem and its impact on the entire family

system. However, this study did not explore the relationship between family adaptability and communication processes and siblings' social-emotional adjustment.

Finally, in an unpublished doctoral dissertation, Winick (1996) applied a systems model of family functioning in her assessment of sibling adjustment (i.e., competence and behavior). In 39 families, the child with a disability showed a severity ranging from mild to severe and multiple disabilities. Parents', including mothers and fathers, completed the Family Adaptability and Cohesion Scale II (Olson, 1982) measuring family cohesion and adaptability, and mothers, fathers, and adolescent siblings each completed the Family Satisfaction Scale (Olson & Wilson, 1982) which assesses satisfaction with one's family. To assess sibling behavior and competence, parents completed the Child Behavior Checklist (CBC) (Achenbach, 1991) and siblings completed the Youth Self Report of the CBC.

Winick's (1996) findings revealed that family adaptability and cohesion were not significantly related to siblings' competence. However, Winick did report a negative relationship between adaptability and cohesion and siblings' behavior, with siblings of more adaptive and cohesive families exhibiting fewer behavior problems. Regression analyses revealed that the best predictors for behavior problems were family adaptability and the siblings' gender, with boys from less adaptive families exhibiting greater

behavioral difficulties. However, the lack of a comparison group weakens the assumption that a disability condition in the family places siblings at-risk for maladjustment since boys from normal families which are chaotic or rigidly structured might also show similar patterns of behavior problems. Also, Winick was interested in assessing behavior problems of siblings and did not measure siblings' self-reports of self-concept and anxiety.

In summary, there is some research to suggest that family functioning mediates the adjustment of siblings through processes that impact their self-concept and emotional affect (Dyson, 1996; Winick, 1996). However, the research is limited. More studies that assess process variables would substantiate the relationship between family systemic functioning and adjustment of siblings of children with developmental disabilities.

Model of Family Resiliency

The concept of resiliency is traditionally viewed as an ability within an individual that enables one to withstand and heal from crisis situations (Walsh, 1996). In the literature on family resilience, Walsh (1996) posits that within a systems perspective, family resilience is relational, meaning that a family's ability to cope with difficult challenges may rest on the family's transactional processes. Over time, these qualities may impact both family and individual adjustment to stress during crises.

Family resiliency is characterized by several important events in family functioning (Walsh, 1996). First, families with good resiliency demonstrate emotional bonding. Strong familial cohesion fosters shared beliefs that facilitate changes in transactional patterns to face new situations resulting from the crisis. Second, good adaptability is essential in family resiliency because families facing crises can change the family's routines, values, and needs, and long-term adaptation is a necessary coping strategy. Third, family resiliency includes open communication and problem-solving skills in order to negotiate adaptation and cohesion. A strong belief system is an important quality in family resiliency because this affects family members' perceptions and attitudes toward crisis events. Finally, the presence of financial, social, and logistical community resources and a family's ability to mobilize access and use of these resources also suggests family resiliency.

The Resiliency Model of Family Adjustment and Adaptation and Sibling Adjustment

Drawing upon the concept of family resiliency, The Resiliency Model of Family Adjustment and Adaptation (McCubbin & McCubbin, 1993) emphasizes the family's in "action" responses to crisis situations, and describes the processes in a family's efforts to utilize resources and manage demands when a crisis event enters the family (see Figure 3).

This model is derived from Hill's ABC-X model of family functioning to crisis events (Saddler, Hillman, & Benjamins, 1993). McCubbin & McCubbin delineate four domains in which the family system functions: 1: interpersonal relationships; 2: development, well-being, and spirituality; 3: communication relationships and nature; and 4: structure and functioning. These aspects of the family compose its strengths and weaknesses for managing stress. In addition, the model also emphasizes adaptation: a family's capability to change and access environmental and community resources to re-establish balance and family harmony that existed prior to the crisis event.

The Resiliency Model proposes that families cope with crises on two levels: the family internally handles the problem (i.e. between family members), and the family externally copes with the problem (i.e. relationship to the social environment). The model hypothesizes that families that demonstrate both levels of coping will show "bonadjustment" or functioning more effectively. Further, the model conceptualizes that there are two kinds of resources accessible to families in crisis situations: the family's use of social support and the family's approach to problem-solving (McCubbin & McCubbin, 1996).

Families with a child with a disability must manage internal and external problems in order to cope. Internally, this includes restructuring roles, relationships, rules, routines, activities, and other aspects of family

life which are disrupted. A functional approach to problem-solving would also facilitate internal family coping. Externally, families may seek community resources for support, and ask family and neighbors for help. A family demonstrating good use of social support would be considered by the resiliency model as showing good external coping (McCubbin & McCubbin, 1996).

To this end, families that demonstrate good resiliency would be expected to facilitate siblings' social-emotional adjustment. Unfortunately, there is very little research on family resiliency and sibling adjustment. In a recent study, Nixon & Cummings (1999) showed that family coping is related to non-disabled, elementary school-aged siblings' emotional reactivity to social conflicts in the family of a child with a disability (e.g., marital and sibling conflicts). Two groups of siblings, those with and those without a child with a disability in their families, expressed their emotional distress (mad, sad, worried), their cognitions, and their coping strategy (involved coping or avoidance) to everyday family conflicts. Responses revealed that children with disabled siblings responded with more negative emotional reactivity (greater emotional distress), more negative cognitions (e.g., assuming responsibility for others' problems), and more active coping strategies compared to children with non-disabled siblings. Group differences were more pronounced for less intense social conflicts, suggesting a lower threshold for emotional reactivity, negative cognitions,

and involved coping among siblings of children with disabilities. According to maternal reports on the Child Behavior Checklist (Achenbach, 1991), siblings of children with disabilities had greater externalizing problems (especially boys) and showed lower social competence, and this finding was related to greater involved coping. Nixon and Cummings suggest that siblings of children with disabilities face higher levels of stress in their families and are more emotionally reactive though less able to cope.

In summary, there is research suggesting that family coping relates to sibling adjustment. Yet, it remains to be shown how coping relates to family cohesion and adaptability when families are raising children with disabilities. It would be expected that families that function within the balanced range of cohesion and adaptability on the Circumplex Model would have higher ratings on measures of coping capabilities. Families caring for children with severe disabilities, such as cognitive/neurological impairments, find themselves not only managing expected family life cycle stressors but also extra demands imposed on them due to the child's special needs (Fish, 1991; Wikler, 1981). Thus, in order to understand family functioning in these families, one would have to assess both family systems functioning and the family's resiliency and coping capabilities, including the use of internal and external family resources (Dyson, *et al.*, 1989).

Research Rationale

The literature presented leads to several conclusions regarding sibling adjustment in families with children with developmental disabilities. First, families with children with developmental disabilities find themselves going through many stages of emotions and changes in expectations and are facing new stressors, including financial, childcare, and social integration (Fish, 1991, Seligman & Darling, 1997). For the family to cope with these new stressors, changes in roles, responsibilities, and family organization are often necessary.

The mediational processes that impact family functioning include the family's cohesion, adaptability, and communication styles. Critically, this conceptualization of family systems suggests that to facilitate family functioning in the event of a significant family stressor (e.g., a disabled child), these factors act as buffers which promote resilience and coping (Beavers et al., 1986; Costigan *et al.*, 1997; Walsh, 1996). In the literature on family resilience, Walsh (1996) posits that within a systems perspective, family resilience is relational, meaning that a family's ability to cope with difficult challenges, such as raising a developmentally delayed child, may rest on the family's "...cohesion, flexibility, open communication, problem-solving, and affirming belief system" (p.273). Thus, based on this theoretical framework, it is important to examine differences in family functioning between families with and without a child with a disability.

Compared to families without a child with a disability, a larger percent of families of children with special needs may show family functioning in extreme ranges, such as disengaged or enmeshed, because these families may be coping with more stressors than other families.

Second, a review of the literature suggests that there has been little research assessing family process variables when one child has a disability (Dyson, 1996; Margalit, Raviv, & Ankonina, 1992; Morrison & Zetlin, 1992, Winick, 1996). In one study, for example, Morrison and Zetlin (1992) assessed families with children with learning disabilities and measured their cohesion, adaptability, and communication in relation to problem behaviors for learning disabled adolescents. Their results showed that families with adolescents with learning disabilities revealed more rigid adaptability and low cohesion and communication compared to families with non-learning disabled adolescents. Morrison and Zetlin were assessing families of children with milder disabilities, however, and did not include the impact on siblings in their research.

Third, the literature has identified differences in family processes between healthy and less functional families when a child has a development disability (Beavers et al., 1986). In dysfunctional families, members provide less support, flexibility, and respect for one another's needs. The family's concerns may focus excessively on the child with special needs at the expense of the needs of siblings and parents,

however, Beavers et al. (1986) did not assess whether these processes might also predict sibling's adjustment.

Although research findings suggest that siblings of children with special needs may be at-risk for emotional and social maladjustment (Hannah & Midlarsky, 1985; Seligman & Darling, 1997), and/or may experience psychosocial benefits (McHale & Gamble, 1987), few research studies have explored family processes as mediating factors in the adjustment of siblings. Yet preliminary research suggests that families with a developmentally disabled child who demonstrate healthy family functioning also include well-adjusted, non-disabled children. Based on the Circumplex Model of Marital and Family Systems Theory (Olson, 1981), families exhibiting balanced cohesion and flexibility would be raising better adjusted non-disabled siblings. This finding is expected because these families are better able to adapt their family system to meet a family member's needs and to pull together cohesively in support of individuals' needs. Conversely, families functioning within extreme ranges of cohesion and flexibility (i.e., maladjusted levels) would not put forth efforts to change adaptively and, therefore, would have more difficulty coping with the disabled child. This in turn may have a negative impact on the non-disabled siblings' social-emotional adjustment.

There has not been sufficient research assessing the connection between a family's adaptability, cohesion, communication, and

coping/resiliency capability and siblings' social-emotional adjustment (i.e., anxiety and self-esteem). Therefore, the purpose of this study was to assess family functioning in relationship to adjustment in siblings with disabled brothers or sisters. Specifically, this study assessed family functioning (i.e., cohesion, adaptability, communication and coping/resiliency) in relation to adjustment measures of siblings of children with developmental disabilities (i.e., self-concept and anxiety) in order to determine whether family processes relate to positive and negative adjustment in siblings. This study expanded the research by determining if (1) families with children with developmental disabilities have different adaptability, cohesion, communication, and resiliency compared to families without disabled children, (2) family cohesion, adaptability, and communication relates to family resiliency in families with and without children with disabilities, and (3) family functioning and coping predicts non-disabled siblings' perceived self-concept and anxiety. Thus, this study examined whether family functioning mediates positive and negative adjustment of siblings of children with developmental disabilities. In addition, it examined whether there was greater variability in family cohesion, adaptability, communication, resiliency skills, and sibling adjustment observed for children with disabled siblings as compared to siblings in families without children with disabilities.

Therefore, the purpose of this study was to assess family functioning in relationship to adjustment in siblings of children with developmental disabilities. Based on the literature, several hypotheses were proposed:

- Hypothesis 1: Families of children with developmental disabilities will have less favorable levels of adaptability, cohesiveness, and problem-solving communication compared to families with children without developmental disabilities;
- Hypothesis 2: Families of children with developmental disabilities will have poorer coping skills compared to families without children with developmental disabilities;
- Hypothesis 3: For both groups of families, cohesion, adaptability, and communication will positively correlate with family coping skills;
- Hypothesis 4: Siblings of children with developmental disabilities will have lower self-reported self-concept and higher self-reported anxiety compared to siblings of non-disabled children;
- Hypothesis 5: Family functioning as measured by family adaptability, cohesion, problem-solving communication, and coping will better predict the self-concept and anxiety of siblings of children with developmental disabilities compared to siblings of children without disabilities.

Chapter III

Method

Participants. Two groups of families participated in this study: 28 families raising a child with a developmental disability (Disability group) and 28 families with children who are non-disabled (Non-Disability group). In each family, a mother, father, and one non-disabled sibling participated. Participating siblings were those children in the families who completed questionnaires on anxiety and self-concept. Non-participating siblings were those children in the family who did not complete questionnaires. Non-participating siblings included children with and without developmental disabilities. The participating siblings ranged in age from 8 to 14. This age group was selected because the literature suggests that during middle childhood, siblings of children with developmental disabilities experience many difficulties (Costigan *et al.*, 1987). Participating siblings in the Disability group were brothers and sisters of children with developmental disabilities, and participating siblings in the Non-Disability group were brothers and sisters of children without disabilities or who had typical development. All participating families were intact, two-parent families (living together).

In order for families with a developmentally disabled child to qualify in the Disability group, parents were asked to provide a brief description and the name of their child's disability. All non-participating siblings with

developmental disabilities were attending special education programs designed to serve children with developmental delays and/or physical impairments. Table 1 provides the types of developmental disabilities seen in the non-participating siblings. Parents provided these diagnoses on the family background questionnaire.

Table 1. Developmental Disabilities of Non-Participating Siblings in Disability Group

<u>Developmental Disability</u>	<u>N</u>
Autism	7
Down's Syndrome/Mental Retardation	8
Cerebral Palsy	4
Pervasive Developmental Disorder	3
Cornelia DeLange	1
Mentally Delayed	1
Mild Cerebral Palsy/Autism	1
Deaf, Blind, & Mute	1
Developmental Disability	1

* One family did not provide a written description of child's disability.

To participate in the Non-disability group, no children in these families had social, emotional, or intellectual impairments and none were receiving mental health services in either the community or school. Families were excluded from the Non-Disability group if any of their children were receiving therapy, special education, or counseling, or if any child had previously received these services.

Families in the Disability group were invited to participate using several different resources. Approximately 100 letters were sent home to families through their children's special education program or family support

groups. Four families received parent letters through the United Cerebral Palsy in the New York City. Some families (N=12) responded to parent letters from sibling support groups offered through the New York City division of the Association for the Help of Retarded Children (see Appendix D). Enclosed in the parent letter was a participant card to be returned if families wanted to take part in the study. The participant card asked for some background information on the family (e.g., type of disability, number and ages of children in the family, and an address and phone number). Once the investigator received these cards through the mail, families were subsequently contacted over the phone and asked several questions regarding their families in order to determine whether they met the Disability group criteria.

Another set of families learned about the study after reading an announcement (see Appendix E). One announcement was placed in the parent newsletter of the SPAN organization (a New Jersey based agency for families of children with special needs), and 5 families responded and eventually participated. Another set of families received an announcement from the Blue Feather schools of the Association for the Help of Retarded Children, a New York City based special education program serving children with developmental disabilities. The announcement included a phone number, address, and e-mail address by which families could contact the investigator. Once parents expressed an interest in

participating, the researcher determined whether the family met the research criteria. These families were also contacted over the phone and asked about their child's disability and their children's ages. Over 100 hundred families received information about the study through AHRC's Blue Feather Programs, and 9 families volunteered to participate.

Non-Disability families were invited to participate through a community agency and local education programs. Some families learned about the study from attending a family fair held at the Bronx, NY chapter of the YMCA. The principal investigator gave potential families information regarding the purpose of the study and the selection criterion (e.g., two-parent households with multiple children where one child is between 8 to 14). These families were told the purpose of the study was to compare families with and without children with special needs. Families were offered a \$15 stipend for participating. Participation was voluntary and all families were informed that they could withdraw from the study at any time. Those parents who were interested and who met the family qualifications were encouraged to provide their name, address, and phone numbers, and research packets were subsequently mailed to their homes. A total of 30 families initially volunteered at the family fair, half of whom later withdrew from the study.

Another set of families in the Non-Disability group volunteered to participate after reading about the study from announcements posted at

local school programs in the Westchester area (see Appendix F). Similar to the Disability group, families contacted the principal investigator via mail, phone, or email, and were asked several questions about their families (e.g., ages and number of children). Once these families met the Non-Disability group criteria, a research packet was then mailed to their home.

Table 2 presents the different educational and family programs through which the participating families were recruited.

Table 2. Agencies/Special Education Programs Represented by Families

Agency/Program	N
Disability Group	(N=20)*
United Cerebral Palsy	4
Association for the Help of Retarded Children - sibling support group	12
Association for the Help of Retarded Children – Blue Feather educational programs	9
SPAN (parent agency)	5
Non-Disability Group	(N=34)**
YMCA Bronx Chapter	15
Other Educational/Community Programs	19

* Two families were removed from final sample because fathers refused to participate. **Six families were removed from the final sample because they did not meet group criteria for participation.

Prior to soliciting families for the study, approval was obtained from the cooperating community agencies and parent organizations. Once the questionnaires were completed and returned to the investigator, each family received a thank you letter with a \$15 stipend check enclosed. In addition, all families were told that they would received the results from the completed study.

Instruments. Families completed six questionnaires, including a family background questionnaire, family functioning measures, and sibling adjustment measures.

Family Background Questionnaire. A family background questionnaire was designed by the investigator to measure family income, parent education and occupation, family composition, and severity of disability as perceived by the responding parent (see Appendix G). Two open-ended questions asked parents to describe household and childcare responsibilities assumed by the participating sibling. Families in the Non-disability group completed a different background questionnaire that omitted statements regarding disabilities (see Appendix H).

Family Functioning Measures

Mothers and fathers each completed the following scales measuring family functioning.

Family Adaptability and Cohesion Environment Scale- II (FACES-II, Olson, 1982, see Appendix I). The FACES-II scale asks family members to respond to 30 statements about general family actions and attitudes in the day to day routines of families. Individuals respond on a Likert scale from 1 (almost never) to 5 (almost always). The FACES-II has two subscales: 14 statements relating to the family's adaptability and 16 statements regarding the family's cohesiveness. The four family cohesiveness categories are: very connected, connected, separated, or disengaged, while the four family

adaptability categories are: very flexible, flexible, structured, or rigid. The raw scores for cohesion and adaptability are derived by summing the responses for some questions and subtracting the sum for reversed scored items. Although the FACES-II provides scaled scores, the total raw scores for both Cohesion and Adaptability scales were used as independent variables in the regression analysis because these scores offered a larger range.

The FACES-II has been shown to be a psychometrically sound assessment tool. Cronbach Alpha reliability scores for internal consistency are .87 for the Cohesion subscale and .78 for the Adaptability subscale; the total scale has an alpha reliability of .90. Test-retest reliability estimates for a retest delay of 4 to 5 weeks reveal .83 for questions within the Cohesion subscale and .80 for the Adaptability subscale. Concurrent validity ratings also support the use of FACES-II as an assessment tool. When compared with another instrument measuring constructs similar to family cohesion and adaptability, a .93 correlation was found for the Cohesion subscale and .79 for Adaptability, with $p < .01$ for both. In the statistical analysis of this study, the raw scores for family cohesion and adaptability were utilized.

Family Crisis Oriented Personal Scales (F-COPES, McCubbin, Olson, & Larsen, 1981, see Appendix J). The F-COPES is a 30 item Likert scale designed to assess family problem solving and strategies used during difficult family situations. The scale measures family resources (i.e., its use

of social supports and approach to problem solving), pile-up of stressors, and its interpretation or perception of the situational crisis event.

Respondents are asked to rate items by marking one of five choices (from strongly agree to strongly disagree) to statements about possible actions and attitudes of the family in response to problems or difficulties (e.g., seeking advice from relatives, showing that we are strong).

There are five subscales in the F-COPES. Nine items on the "Acquiring Social Support" subscale tap the family's actions to actively seek familial and community support. Eight items composing the "Reframing" subscale assess the family's actions to reconceptualize a stressor so that it appears more manageable to the family. The four items of the "Seeking Spiritual Support" subscale assess the use of spiritual support by the family. "Mobilizing Family to Acquire and Accept Help" has 4 items examining the family's initiative to gain access to community resources, and to accept help from extra-familial sources. Finally, the "Passive Appraisal" subscale has 4 items that measure the family's acceptance of a stressor event with minimal reactivity.

Test developers have found adequate psychometric properties for the F-COPES. Test-retest reliability scores are as follows: acquiring social support (.78), reframing (.61), seeking spiritual support (.95), mobilizing family to acquire and accept help (.75), and passive appraisal (.75). The test-retest reliability for all 30 items is .81. Two samples were employed to

obtain internal consistency reliability. In a sample of 1338 respondents, internal consistency reliability using Cronbach's Alpha is .86 for the total scale. Individual subscales ranging from .64 (passive appraisal) to .84 (acquiring social support). Validity data using factor analyses via varimax rotation provided good support for the five factor subscales. Thus, analysis was performed using the F-COPES total scale score and the five-subscale scores.

Family Problem-Solving Communications (FPSC, see Appendix K) (McCubbin, McCubbin, & Thompson, 1988). This 10 item, four-point Likert scale assesses family communication style during problem solving situations. Respondents are instructed to determine to what extent the statements describe their family during problems or conflicts, and responses are from false, mostly false, mostly true, to true. Two subscales comprise the FPSC: Affirming Communication and Incendiary Communication (5 items per scale). When obtaining a total FPSC score, more positive scores represent higher affirming communication, negative scores represent greater incendiary communication, and scores around zero represent equal amounts of affirming and incendiary communication.

Reliability and validity data are available for the FPSC and indicate that the scale possesses good psychometric properties. Specifically, overall alpha reliability is .89, and .78 for the Incendiary Communication subscale and .86 for the Affirming Communication subscale. Overall test-

retest reliability is .86. Concurrent validity for the FPSC was confirmed through large scale studies correlating outcomes on the FPSC with other measures of family functioning; Affirming Communication correlated positively with family cohesion, family hardiness, and self-actualization and negatively with family system distress (McCubbin & Thompson, 1989). Analysis was performed using the FPSC total raw score and subscale scores.

Consent from test developers for permission to use the above family measures was obtained (see Appendixes L & M).

Sibling Adjustment Measures

Siblings completed two scales to assess their social-emotional adjustment.

The Piers-Harris Children's Self-Concept Scale (CSCS, Piers & Harris, 1983, see Appendix N). The CSCS contains 80 statements about a child's perception of his/her behavior, intellectual and school status, physical appearance and attributes, anxiety, popularity, and happiness and satisfaction. Respondents indicate whether they agree or disagree for each statement, and individual subscales are rated based on the summation of these responses. Ratings are converted into percentiles that compare the respondent to the normed sample.

Studies have shown the Piers-Harris scale to be psychometrically sound for both temporal stability and internal consistency (Epstein, 1985).

The manual provides age and gender norms that allow test administrators to compare children's self-concept to those children similar in gender and age. Test-retest reliabilities for the subscales range from .42 to .96, with a mean reliability of .73 for the entire scale. In addition, internal consistency coefficients for the entire scale range from .88 to .93. Validity studies show moderate relationships between this scale and other measures of personality and behavior. Although standardized norms have not been updated since the 1960's, continued research supports the scale's use (Epstein, 1985). Analysis for this study used the Total Self-Concept scaled score.

Reynolds' Children's Manifest Anxiety Scale (RCMAS) (Reynolds & Richmond, 1985, see Appendix O). This 37 item self-report scale asks children to either agree or disagree with statements about what they think and feel (e.g., "I never get angry", "I am nervous"). The total score is a measure of the child's self-reported anxiety. In addition to a Total Anxiety score, the respondent obtains a score in four subareas: Physiological Anxiety, Worry/Oversensitivity, Social Concerns/Concentration, and a Lie index (i.e., the extent of one's social desirability.)

The RCMAS has been used extensively in clinical practice and research because of its ease in use and good psychometric properties. The RCMAS provides norms for ages, gender, and race (White and African American), which enables professionals to compare anxiety to a

representative sample of children. The manual suggests that reliability coefficients (internal consistency) range from .42 (black females age 6) to .87 (black males ages 12 and 15). The majority of alpha coefficients (31 of 48) fall above .80, and caution should be exercised for those groups which fall below this number (Gresham, 1989). The stability coefficient for Total Anxiety ranges from .98 for a three-week interval to .68 for a nine-month test-retest interval. Gresham reports that good internal consistency of the Total Anxiety score permits individual interpretation, though subscales show reliability too low for separate interpretation. Based on this review, analysis for this study used RCMAS's total scaled score. In addition, reviews suggest the test has a standardization sample that appears to be a good representation of the U.S. population.

Procedure. After meeting the research criteria for Disability or Non-Disability groups, families were mailed a participant packet to their home. The packet included parental and youth consent forms, a family background questionnaire, 2 sets of family functioning measures (i.e., FACES-II, F-COPES, and FPSC), sibling outcome measures (i.e., CSCS and RCMAS), and instructions on completing the packet (see Appendix Q). Either parent completed the family background questionnaire. Each parent separately complete a set of family functioning measures, and participating siblings completed the RCMAS and the CSCS. Each family member was instructed to seal their questionnaires in separate envelopes and asked not

to discuss their answers with others. This procedure was intended to insure honest responses without the influence of another family member.

Families returned these mailers once all questionnaires were completed and consent forms were read and signed. Parents returned the consent forms and the family background questionnaire in one envelope, and the family functioning and sibling adjustment questionnaires were mailed separately in another envelope. This procedure was implemented in order to keep the participants' identity separate from their responses to family and sibling measures and ensure confidentiality to all families. Forty-four Disability families were mailed a participant packet from which 30 families eventually returned the completed questionnaires (68% response rate).

In the Non-Disability group, the procedure for completing and returning participant packets was similar to the procedures used with the Disability group, however, families were told that a child between the ages of 8 and 13 completes the child self-report questionnaires, and not a non-disabled sibling (see Appendix Q). A total of 67 families were mailed a participant packet, from which 34 families eventually returned the completed questionnaires (50% response rate).

Scoring Procedures. The total raw score for mothers' and fathers' responses were calculated on FACES-II for cohesion and adaptability. The parents' responses were averaged together to obtain a family cohesion and

adaptability rating for the statistical analyses. Similarly, mothers' and fathers' family coping skills scores were averaged together to obtain a family coping skill total used in the statistical analyses. Mothers' and fathers' problem-solving communication scores were obtained by adding together scores on the incendiary communication subscale and subtracting this from the affirming communication total. Parents' subscale and total scale scores were averaged together to obtain family problem-solving communication total score and family incendiary and affirming communication subscales.

Chapter IV

Results

Descriptive Analysis

The family background questionnaire provided information on family composition and demographic variables. Group differences on these variables were examined using t -tests and chi-square statistics. Twenty-eight of the original 30 families in the Disability group were used in the analyses. Two families were excluded because the fathers refused to participate. In the Non-Disability group, a total of 35 families completed questionnaire packets, however, only 28 families were included in the analyses. Seven families were excluded because they did not meet the Non-disability group criteria. Six of the families had children with speech/language impairments, learning disabilities, or attention deficit disorder, and one family had only a single child.

Age of Participants

The participating siblings in both groups ranged from ages 8 to 14 years. As shown in Table 3, there were similarities in the ages of corresponding family members between the two groups. T -test revealed no significant differences between groups for the age of mothers ($t(54) = -.38$, $p = .71$), fathers ($t(54) = -.03$, $p = .98$), and participating siblings ($t(54) = -1.55$, $p = .13$) (negative scores suggest higher mean ages in Disability group).

Table 3. Ages of Mothers, Fathers, and Participating Siblings in Disability & Non-Disability groups.

Family Members	Disability Group (28)			Non-Disability Group (28)		
	Mean	SD	Range	Mean	SD	Range
Participating Sibling	11.2	1.6	8 - 14	10.5	2.0	8 - 14
Mother	40.1	6.3	29 - 57	39.5	5.7	28 - 50
Father	41.7	5.7	31 - 54	41.6	8.3	20 - 58

Table 4 provides the ages of non-participating siblings in the Non-Disability group and the ages of children with developmental disabilities in the Disability group. Since siblings in the Non-Disability group did not have a child with a disability in the family, the target non-participating sibling in the Non-Disability group was the child closest in age to the participating sibling. t -tests revealed that non-participating siblings in Disability and Non-Disability groups have similar mean ages.

Table 4. Ages of Non-Participating Siblings

	Disability Group (N=28)			Non-Disability Group (N=28)		
	Mean	SD	Range	Mean	SD	Range
Non-participating child	10.21	4.8	3 - 20	10.00	4.9	3-20
t -test	$t(54) = -.17, p=.87.$					

The mean age difference for sibling dyads in the Disability group was 1.0 ($SD=4.8$), which is not significantly different from mean age difference for sibling dyads in the Non-Disability group ($M=.46$, $SD =4.6$; ($t(54) =.43$, $p=.67$).

Child Variables: Gender, Birth Order, and Family Size

Table 5 shows the gender for participating siblings by group. A Chi-square analysis showed no significant difference in the proportion of male versus female children who participated in each group.

Table 5. Gender for Participating Siblings

Gender	Disability Group	Non-Disability Group	Total <u>N</u>
Female	16	13	29
Male	12	15	27
chi-square	$\chi^2 (1, N=56) = .64, p=.42.$		

Among non-participating siblings, there was a larger percentage of females in the Non-Disability group (64%) versus the Disability group (44%), but the proportions of gender by group were not significantly different (see Table 6).

Table 6. Gender of Non-Participating Siblings

Gender of Non-Participating Sibling	Disability Group	Non-Disability Group	Total <u>N</u>
Female	12	18	30
Male	16	9	25
chi-square	$\chi^2 (1, N=55) 3.14, p=.08$		

Also, there was no significant difference between groups for the proportion of same-sex and different-sex sibling pairs who were older and younger (see Table 7). Overall, there were similar proportions of younger and older

participating siblings who were either the same or opposite gender from the non-participating sibling.

Table 7. Birth Order and Gender of Participating Sibling as Compared to Non-Participating Sibling

Birth Order and Gender for Participating Sibling	Disability Group	Non-Disability Group	Total <u>N</u>
Younger, same sex	4	4	8
Younger, opposite sex	7	6	13
Older, same sex	8	6	14
Younger, opposite sex	9	11	20
chi-square	$\chi^2 (3, N=55) = .55, p=.91$		

Families also provided information regarding the size of their families. Chi-square analysis showed similar proportions of families with two, three, four, and more than four children between Disability and Non-Disability groups. Most families in both groups were had two children, and few families had more than three children (see Table 8).

Table 8. Total Number of Children in the Family

Total N of Children in Family	Group Status		Total <u>N</u>
	Disability	Non-Disability	
Two Children	15	13	28
Three Children	8	11	19
Four Children	3	2	5
More Than Four	1	2	3
chi-square	$\chi^2 (3, N=55) = 1.13, p=.8.$		

Finally, preliminary analysis was performed on the participating siblings' birth order. Listed in Table 9 are the frequencies of different birth order positions described by the participating families.

Table 9. Birth Order of Participating Sibling

Birth Order	Disability Group	Non-Disability Group	Total <u>N</u>
Youngest of Two	5	6	11
Youngest of Three	2	6	8
Oldest of Two	9	7	16
Oldest of Three	4	6	10
Middle of Three	4	0	4
Oldest of More Than Three	3	2	5
Other	1	1	2
chi-square	$\chi^2 (6, N=54) = 6.94, p = .33$		

A majority of the participating siblings were either the youngest or oldest in a two-child family, and few siblings were the middle child or the oldest child in large families. Chi –square analysis performed on the proportions of birth order positions between groups was insignificant, thus suggesting similar proportions of oldest and youngest siblings in two, three and four children size families.

Household Responsibilities

Parents were asked to describe the different types of household responsibilities assumed by the participating sibling. The number of household responsibilities listed by the parents were added together. All responsibilities listed which referred to the sibling caring for his/her own room and possessions were counted as one household responsibility (e.g., making bed, putting clothes away, keeping room neat, putting toys away). All other responsibilities were counted separately (e.g., helps set the table, cleans the dishes, takes out garbage, walks/feeds family pet). Table 10

lists the number of household responsibilities assumed by siblings in the Disability and Non-Disability groups.

Table 10. Number of Household Responsibilities Assumed by Participating Siblings in Disability and Non-Disability Groups.

	Disability (n=28)		Non-Disability (n=28)	
	Mean	SD	Mean	SD
# of Household Responsibilities	2.41	1.8	2.50	1.1
t-test	$t(54) = .23, p = .82.$			

Results suggest that siblings in the Disability and Non-Disability groups assume similar amounts of household responsibilities, and most siblings on average assumed two to three chores in their homes.

Demographic Variables: Education Level, Income, and Ethnicity

Analyses were performed on education level, income, religious affiliation, and ethnicity of families. Parents who completed junior through high school education were included in the secondary education group. Parents who completed some college through a bachelor's degree were included in the college education group. Finally, parents who reportedly completed master's degrees, law degrees, medical degrees, and doctoral degrees were included in the professional education group. Table 11 provides a frequency count and chi-square statistics for parents' highest level of education achieved.

Table 11. Highest Level of Education Attained for Mothers and Fathers

Education Level	Mothers		Fathers	
	Disability	Non-Disability	Disability	Non-Disability
Secondary Education	6	9	8	9
College Education	7	4	6	5
Professional Education	12	18	14	13
	$\chi^2 (2, N=56) = 2.62, p=.27$		$\chi^2 (2, N=55) = .17, p=.92$	

Chi-squares showed there were similar proportions of mothers and fathers between groups who attained a secondary education, a college education, and a professional education. Parents in both groups attained education levels ranging from secondary level to professional degrees.

Further, there were similar proportions of ethnicity identified by families (see Table 12). In both groups, a majority of participating families identified themselves as White Caucasian, and the remaining families were identified as Black/African American and Hispanic. Two families (one in each group) identified themselves as mixed ethnicity where one parent was Hispanic and the other was White Caucasian. These families were entered into the data set as Hispanic. Five families in the Disability group and 1 in the Non-Disability group did not identify their ethnicity.

Table 12. Ethnicity Identified by Disability & Non-Disability Families

Ethnicity	Disability Group	Non-Disability	Total
White Caucasian	15	18	33
Black/African American	4	4	8
Hispanic	4	5	9
Total	23	27	50
chi-square	$\chi^2 (2, N=50) 1.45, p=.70.$		

Families provided their religious affiliations, and frequency counts show similar proportions of religions between groups. Separate chi-square analyses were performed for mothers' and fathers' religious affiliation due to marital differences on this variable. Table 13 provides the religious affiliations identified by mothers and fathers and chi-square statistics. The proportions of the different religious affiliations represented by mothers and fathers were similar between Disability and Non-Disability families. In both groups the largest proportion of religion represented was Roman Catholicism. A smaller number of families identified themselves as Non-Catholic Christian (e.g., Baptist, Protestant, Episcopal), Jewish, and Greek Orthodox.

Table 13. Religious Affiliation for Mothers and Fathers by Group Status

Religious Affiliation	Mothers			Fathers		
	D*	ND**	Total	D	ND	Total
Non-Catholic Christian	5	6	11	5	6	11
Jewish	4	2	6	4	3	7
Greek Orthodox	2	-	2	2	-	2
Roman Catholic	10	18	28	10	17	27
Other	2	-	2	2	-	2
Unknown	5	2	7	5	2	7
Total	23	26	49	23	26	49
chi-square	$\chi^2 (5, N=49) = 6.89, p=.14$			$\chi^2 (5, N=49) = 5.89, p=.21$		

*D=Disability group; **ND=Non-Disability group.

Five fathers and mothers in the Disability group and 2 fathers and mothers in the Non-Disability group did not identify their religious affiliations.

Finally, there was no significant difference between groups for the proportions of income level. Of the 51 families who provided their annual income level, a majority of these families earned an annual income of \$50,000 to over \$100,000, while a smaller proportion of families fell in lower income ranges. Five families in the disability group did not provide their family income (see Table 14).

Table 14. Income level for Disability and Non-Disability Families

Yearly Income Level	Disability Group (23)	Non-Disability Group (28)	Total
Under \$30,000	1	2	3
\$30,000 – 49,999	1	5	6
\$50,000 – 74,999	9	7	16
\$75,000 – 99,999	6	5	11
\$100,000 Plus	6	9	15
chi-square	$\chi^2(4, N=51) = 3.48, p=.48$		

Summary. Descriptive analyses revealed that families in the Disability and Non-Disability groups were similar on many family background variables. Groups showed similarity on child variables, including the age, gender, and birth order of participating and non-participating siblings, and siblings had similar household responsibilities. In addition, there were similarities on demographic variables, such as parent education level, religion, ethnicity, and income level. The majority of families in both groups were white Caucasian with two to three children and with middle to high income levels.

Hypothesis Testing

Statistical analysis for testing the hypotheses included ANOVAs, correlations, and regressions. Table 15 provides the means and standard deviations of mothers' and fathers' responses on FACES-II, F-COPES, and FPSC. T-tests were performed between mothers' and fathers' total scores on the cohesion and adaptability subdomains of the FACES inventory, for parents' total F-COPES score, and for parents' total FPSC score. Results showed similar ratings between mothers and fathers on these measures (see Table 16). Based on these results, average ratings for mothers' and fathers' scores on family cohesion, adaptability, problem-solving communication, and coping skills were used in the analyses for hypothesis testing.

Table 15. Means and Standard Deviations of Mother's and Father's Responses on FACES-II, F-COPES, and FPSC by Group Status.

	Disability Group			Non-Disability Group		
	Mean	SD	Range	Mean	SD	Range
Cohesion						
Mother	65.1	7.5	49-76	65.8	7.9	40-78
Father	64.9	9.1	41-78	63.7	9.6	37-79
Adaptability						
Mother	47.8	6.6	32-57	47.3	6.6	35-39
Father	48.3	7.0	33-62	46.5	5.4	36-60
Family Problem-Solving Communication (FPSC)						
Mother	7.6	4.	-2-15	7.3	4.5	-4-15
Father	7.0	5.8	-5-15	7.1	5.2	-3-15
F-COPES						
Mother	109.4	11.6	86-134	102.6	14.1	58-126
Father	103.6	16.7	64-140	97.4	13.9	59-122

Cohesion scores: 71-80=very connected, 60-70=connected, 51-59=separated, and 15-50=disengaged. Adaptability scores: 55-70=very flexible, 46-54=flexible, 40-45=structured, and 15-39=rigid. Higher scores indicate more balanced cohesiveness and flexibility. For FPSC, higher scores indicate better problem-solving communication. Higher F-Copes scores indicate better family coping skills.

Table 16. T-tests Between Mothers' and Fathers' Scores on Family Measures.

Family Variable	Disability Group	Non-Disability Group
	t-Test*	t-Test
Cohesion	.15	1.47
Adaptability	-.28	.60
Coping	1.42	1.81
Problem-Solving Communication	1.06	.17
Affirming Communication	.43	.89
Incendiary Communication	-.95	.62

* None of the t-tests were significant. Negative T scores indicate higher ratings by Mothers.

- **Hypothesis 1: Families of children with developmental disabilities will have less favorable levels of adaptability, cohesiveness, and problem-solving communication compared to families with children without developmental disabilities.**

One-way ANOVAs compared parents' ratings for family cohesion, adaptability, and problem-solving communication by group status. Table 17 provides information on parents' mean ratings on these variables for Disability and Non-Disability groups. A one-way ANOVA comparing cohesiveness as the dependent variable by group status was not statistically significant [$F(1, 54) = .02, p = .887$]. Adaptability and family problem-solving ratings were also not significantly different between groups [$F(1, 54) = .64 (p = .427)$ and $F(1, 54) = .12 (p = .730)$, respectively].

Table 17. Mean Parent Rating on Family Systems Variables by Group Status

Group (N)	Mean	SD	Range
Cohesion Ratings			
Disability (28)	65.0	7.0	50-75
Non-Disability (28)	64.7	7.9	38.5-77.5
Adaptability Ratings			
Disability (28)	48.0	5.5	35-57.5
Non-Disability (28)	46.9	5.1	38.5-57
FPSC Ratings			
Disability (28)	7.7	5.2	-3.5-17
Non-Disability (28)	7.3	4.3	-3.5- 14.5

Cohesion scores: 71-80=very connected, 60-70=connected, 51-59=separated, and 15-50=disengaged. Adaptability scores: 55-70=very flexible, 46-54=flexible, 40-45=structured, and 15-39=rigid. Higher scores reflected more balanced cohesiveness and flexible. For FPSC, higher scores reflect better problem-solving communication.

Hypothesis 1 was not supported. Families raising children with developmental disabilities showed similar levels of cohesiveness, adaptability, and problem-solving communication compared to families raising children without disabilities.

- **Hypothesis 2: Families of children with developmental disabilities will have less coping skills compared to families without children with developmental disabilities.**

To investigate differences in family coping skills, an ANOVA was performed examining family coping skills (i.e., parents' responses to the F-COPES scale) by group status. Table 18 presents parents' mean ratings for the Total F-COPES scale score.

Table 18. Mean Parent Rating on Total Family Coping Skills by Group Status

Group (<u>N</u>)	Mean	<u>SD</u>	Range
Disability (28)	106.5	9.2	91.5 – 123.0
Non-Disability (28)	100.0	11.7	75.5 – 121.0

Higher scores reflect better coping skills.

There was a significant difference between groups on family coping skills ratings. Parents of children with disabilities reported significantly higher coping skills compared to parents of children with typical development, $F(1, 54) = 5.31, p = .03$. To further explore why this difference was observed, additional ANOVAs were performed on F-COPES subscales. Results reveal that the effect of group was statistically

significant for two of the subscales: Acquiring Social Support and Mobilizing Family Support (see Table 19). Parents in the Disability group rated themselves higher on both factors compared to parents in the Non-Disability group.

Table 19. Means Parent Ratings on Subscales on the F-COPES

F-Copes Subscale	Disability Group (28)		Non-Disability Group (28)	
	Mean	SD	Mean	SD
Acquiring Social Support ¹	28.0	2.9	24.8	6.2
Reframing	32.4	4.1	32.2	4.2
Seeking Spiritual Support	12.8	3.9	13.2	4.1
Mobilizing Family Support ²	14.5	1.8	11.5	3.1
Passive Appraisal	16.0	2.0	15.9	2.4

¹ $F(1, 50) = 5.82, p < .02$; ² $F(1, 51) = 18.9, p < .00$.

Hypothesis two was not supported based on these findings. Families with children with developmental disabilities rated themselves as showing more coping skills compared to families not raising children with disabilities.

- **Hypothesis 3: For both groups of families, cohesion, adaptability, and problem-solving communication will positively correlate with family coping skills.**

Parents' ratings on family cohesion, adaptability, and problem-solving communication were correlated with family coping skills within each group. These correlations are listed in Table 20. Z -tests were performed between the independent r 's in the Disability and Non-Disability groups, and results suggested that these correlations were not significantly different.

For Disability families, a positive correlation was observed between family cohesion and family coping skills and between family problem-solving communication and family coping skills. In addition, coping skills correlated positively with affirming communication and correlated negatively with incendiary communication. There was no correlation between adaptability and coping skills ratings. For Non-Disability families, a positive correlation was observed between family adaptability and family coping skills.

Based on these findings hypothesis three was partially supported for families in the Disability group and for families in the Non-Disability group.

Table 20. Correlations and Z -scores Between Family Cohesion, Adaptability, and Problem-Solving Communication and Coping Skills for Disability and Non-Disability Groups

Family Systemic Variables	Family Coping Skills: F-COPES Total Score		Z - test
	Disability Group	Non-Disability Group	
Cohesion	.37**	.15	.85
Adaptability	.26	.42*	-.65
Problem-Solving Communication	.43*	.24	.77
Affirming Communication	.47*	.26	.87
Incendiary Communication	-.49**	-.13	1.45

* Significant at 0.05 level (2 tailed); ** Significant at 0.01 level (2 tailed).

- **Hypothesis 4: Siblings of children with developmental disabilities will have lower self-reported self-concept and higher self-reported anxiety compared to siblings of non-disabled children.**

Siblings' total scaled scores on the Piers-Harris Children's Self-Concept Scale and the Revised Children's Manifest Anxiety Scale were used in the analyses. Mean ratings and F -test scores on siblings' reported anxiety and self-concept by group status are provided in Table 21. A one-way ANOVA was performed for each of the dependent variables. The effect of group was not statistically significant for siblings' anxiety and self-concept.

Table 21. Mean Ratings of Siblings' Self-Reported Anxiety and Self-Concept

Group (N)	Self-Concept			Anxiety		
	Mean	SD	Range	Mean	SD	Range
Disability (28)	57.9	9.1	42-79	43.9	9.8	27-66
Non-Disability (28)	62.1	10.0	43-81	42.0	12.6	18-73
F -test	$F(1, 54) = 2.62, p = .11$			$F(1, 54) = .392, p = .53$		

Higher self-concept scores represent better self-concept; higher scores on anxiety represent more anxiety.

Further, it was suspected that sibling adjustment is mediated by the amount of household responsibilities assumed. However, there was no correlation seen between siblings' self-concept and household responsibilities ($r = .04, p = .83$) and anxiety and household responsibilities ($r = -.12, p = .56$). Based on these results, hypothesis four was not supported. Thus, siblings of children with developmental disabilities reported similar anxiety and self-concept compared to siblings of non-disabled children.

- **Hypothesis 5: Family functioning as measured by family adaptability, cohesion, problem-solving communication, and coping will better predict the self-concept and anxiety of siblings of children with developmental disabilities compared to siblings of children without disabilities.**

Regression analyses were performed using family systemic and coping variables as predictors of self-concept and anxiety. Also, interactions between group status and family cohesion, adaptability, coping, and problem-solving communication were entered as possible predictors. A backward method was employed in all analyses, and a 0,1 coding scheme was used where 0 represented membership in the Non-Disability group and 1 represented membership in the Disability group.

Findings showed family problem-solving communication and group status significantly predicted siblings' self-concept (see Table 22). As family problem solving increased, the predicted self-concept increased equally for siblings in both groups. However, siblings of children with typical development are expected to have higher self-concept ratings relative to siblings of children with developmental disabilities.

Regression analysis showed siblings' anxiety was significantly predicted by family problem-solving communication (see table 23). As family problem solving increased, siblings' anxiety scores decreased equally for siblings of children with and without developmental disabilities.

Based on these results, hypothesis five was not supported, as family problem-solving communication equally predicted siblings' anxiety and self-concept in both groups.

Table 22. Summary of Regression Analyses for Predicting Siblings' Self- Concept

Predictor Variable	b-weight	Beta	t-value	p-value
<u>Variables in Model</u>				
(constant)	57.02	2.54	22.43	.00
Family Problem-Solving Communication	.70	.26	2.69	.01
Group Status	-4.45	2.43	-1.83	.07
Mult. $R=.40$, $F(2, 53) = 5.08$, $p=.01$				
<u>Excluded Variables</u>				
		Beta In	t-value	p-value
Family Cohesion		-.04	-.21	.83
Family Adaptability		.01	.03	.98
Family Coping Skills		-.01	-.09	.93
Interaction of Cohesion & Group Status		.26	.25	.80
Interaction of Adaptability & Group Status		.28	.28	.78
Interaction of Coping Skills & Group Status		1.34	1.20	.24
Interaction of Problem-Solving Communication & Group Status		-.21	-.71	.48

Table 23. Summary of Regression Analyses for Predicting Siblings' Anxiety

Predictor Variable	b-weight	Beta	t-value	p-value
<u>Variables in Model</u>				
(constant)	48.13	2.74	17.60	.00
Family Problem-Solving Communication	-.69	.31	-2.24	.03
Mult. $R=.29$, $F(1, 54) = 5.00$, $p=.03$				
<u>Excluded Variables</u>				
		Beta In	t-value	p-value
Group Status		.10	.76	.45
Family Cohesion		-.03	-.15	.88
Family Adaptability		-.06	-.31	.76
Family Coping Skills		-.02	-.14	.89
Interaction of Cohesion & Group Status		.11	.81	.42
Interaction of Adaptability & Group Status		.11	.80	.43
Interaction of Coping Skills & Group Status		.08	.61	.54
Interaction of Problem- Solving Communication & Group Status		.22	1.40	.17

Exploratory Analyses: Disability Severity as Predictor Variable

Though not included in the hypotheses, information on severity of the disability was explored as a predictor of siblings' adjustment. Three questions on the family background questionnaire asked Disability families to rate the severity of their child's needs based on limitations in self-care and physical mobility, as well as the intensity of childcare needs (see Table 24). The average of these responses was calculated to obtain a total disability severity score.

Table 24. Mean Ratings for Disability Severity Questions

Severity Rating Question (N):	Mean	SD.
How limiting is your child's disability on his/her physical activities*? (28)	2.14	1.24
How limiting is your child's disability on his/her self-care skills? (28)	2.71	1.21
What amount of caretaking responsibility is required for your child with a disability? (28)	3.82	1.12
Total severity score for disability (average of three questions) (28)	2.89	.99

* (1=None, 2=Somewhat, 3=Fair Amount, 4=A large Amount)

A regression analysis was used to investigate whether disability severity predicted siblings' self-concept and anxiety. Results showed that family cohesion and total severity of the disability were significant predictors of siblings' self-concept (see Table 25). Specifically, as the family cohesion increases and the severity of the disability increases, it is predicted that siblings' self-concept will increase. When the disability severity is constant, a one-point increase in family cohesion increases siblings' self-concept by $\frac{1}{2}$ a

point on the Piers-Harris Children's Self-Concept Scale. When interaction terms were entered into the regression analysis (i.e., the interactions between family systems variables and disability severity), the results were not stronger than the main effect model.

Table 25. Summary of Regression Analysis for Disability Group: Main Effect Model for Predicting Self-Concept

Predictor Variables	b-weight	Beta	t-value	p-value
<u>Variables in Model</u>				
(constant)	6.94		.64	.53
Family Cohesion	.59	.45	2.64	.01
Disability Severity	4.44	.48	2.81	.01
<u>Excluded Variables</u>				
Family Adaptability		.11	.38	.11
Family Coping Skills		.1.42	1.42	.25
Family Problem-Solving Communication		.42	.42	.10

Mult. $R = .57$, $F(2, 25) = 5.90$, $p < .01$.

In addition, a regression analysis was also performed to investigate the relationship between family functioning and severity of disability on siblings' anxiety. Table 26 shows the results from this analysis. An interaction model provided the most significant prediction of siblings' anxiety. Results showed that three variables significantly predicted siblings' anxiety: the interaction between family coping skills and disability severity, the interaction between family cohesion and disability severity, and family

cohesion. When the disability severity is constant, an increase in family cohesion and family coping skills predicted a decrease in siblings' anxiety. The rate of change in siblings' anxiety scores is a function of the interaction between the severity of the disability with family cohesiveness and coping skills. Additional regression analyses revealed that family functioning significantly predicted siblings' adjustment when mediated by disability.

Table 26. Summary of Regression Analysis for Disability Group:
Interaction Model for Predicting Anxiety

Predictor Variable in Model	b-weight	Beta	t-value	p-value
(constant)	107.6			
Family Cohesion	-.83	-.59	-2.54	.02
Interaction of Family Cohesion and Disability Severity	.23	1.41	2.06	.05
Interaction of Family Coping and Disability Severity	-.17	-1.87	-2.71	.01
<u>Excluded Variables</u>				
Total Disability		-.17	-.98	.34
Family Coping Skills		.34	.92	.37
Family Problem-Solving Communication		.14	.56	.58
Family Adaptability		-.14	-.52	.61
Interaction of Adaptability and Disability Severity		-.66	-.73	.47
Interaction of Family Problem-Solving Communication and Disability Severity		.28	1.01	.33

Mult. $R = .61$, $F(3, 24) = 4.77$, $p < .01$.

Chapter V

Discussion

Interpretation of Findings.

This investigation assesses the family functioning and social-emotional adjustment of the siblings of children with developmental disabilities. Families of a child with a disability in this sample show similar levels of cohesiveness, adaptability, and problem-solving communication compared to families having no disabled children.

Family cohesiveness in both Disability and Non-Disability families ranges from functional to extreme, with both groups falling within the disengaged to very connected range. Thus, both types of families show similar degrees of emotional bonding between members. Although Beavers *et al.* (1986) suspected that extreme enmeshment would be necessary in order to meet family needs in families raising children with mental retardation, families in the present study are characterized by a connected level of cohesiveness that was similar to families without disabled children.

Family adaptability in both groups ranges from rigid (too structured) to very flexible or even chaotic, representing the functional to the extreme. Thus, both types of families are similarly flexible in their family structures, rules, and routines when confronted by both expected and unexpected family events and problems. Although the "stressor" of a child with a disability was present for Disability families, overall, these families function

similarly to Non-Disability families. The present study extends the findings of Dyson (1996), showing similar levels of adaptability between these two types of families, though the present study extends this finding to families of children with developmental disabilities (as opposed to learning disabilities).

Findings also suggest similar problem-solving communication for families with and without children with developmental disabilities.

Specifically, both types of families have similar proportions of affirming and incendiary communication. 'Affirming communication' is the calming component that facilitates support and caring, while 'incendiary communication' refers to communication that exacerbates a situation by increasing tensions in family members (e.g., yelling and screaming). Thus, both types of families show problem-solving communication that ranges from slightly more incendiary (i.e., more negative communication that is detrimental to the family's overall well being) to high levels of affirming (i.e., healthy family communication that nurtures and supports).

This similarity in problem-solving communication possibly explains why Disability and Non-Disability families show similar cohesiveness and adaptability. 'Family problem-solving communication' enables families to recognize and resolve family conflicts (McCubbin *et al.* 1996). Effective problem-solving communication facilitates better cohesiveness and adaptability because family members express concern for one another and describe specific behaviors that need to change, and parents are explicit

about rules and boundaries. This finding is consistent with the Circumplex Model of Marital and Family Systems (Olson *et al.* 1983) because the model suggests that communication both directly and indirectly impacts on a family's emotional ties and structure.

The present findings also suggest that two-parent disability families use more coping skills when compared with two-parent Non-Disability families. This disparity is largely due to differences in acquiring social support (external coping) and mobilizing family support (both internal and external coping). 'Acquiring social support' refers to the seeking out of emotional support (e.g., sharing problems with family) and accepting assistance with daily living responsibilities (e.g. sharing dinners, accepting favors from neighbors). Families of children with developmental disabilities report higher usage of these coping mechanisms when compared with families of children with typical development. 'Mobilizing family support' refers to the family's ability to gain insight and informational support from professionals or friends and family in similar situations. The following questions comprise the 'mobilizing family support' scale:

- *"Seeking information and advice from persons in other families who have faced the same or similar problems";*
- *"Seeking assistance from community agencies and programs designed to help families in our situations";*
- *"Seeking information and advice from the family doctor";*
- *"Seeking professional counseling and help for family difficulties"* (McCubbin & McCubbin, 1996).

Thus, families of children with developmental disabilities access family and community resources more than families without children with disabilities. This may be because families of disabled children more regularly face overwhelming situations that require outside assistance. Also, the educational program for the child with a disability may encourage parents to seek outside support from friends and neighbors, and individuals outside the family may empathize with the family's stress and offer their support. These families may confront more frequently difficulties and therefore must utilize healthy coping skills to remain an effective family unit.

Parents who are effective at solving family conflicts may be more likely to remain together when there is a child with a developmental disability in the family. In this way, parents reduce the likelihood of placing blame and anger on one another and thereby prevent the marriage from disintegrating. (It may also be that the present sample possesses better coping skills than single-parent Disability families, something that remains to be proven).

Further, family coping skills correlate positively with family cohesion and problem-solving communication for families raising children with developmental disabilities. Therefore, cohesiveness and problem-solving communication facilitate family coping skills, a finding consistent with The Resiliency Model of Family Adjustment and Adaptation (McCubbin &

McCubbin, 1993). Families that can discuss problems in a caring and supportive manner, with respect for one another's feelings, are better able to access resources necessary for effective coping. Effective problem-solving communication enables families to collaboratively decide how they will manage problems. Family members are able to clearly communicate ideas and interests that best serve the family without allowing personal issues to obstruct the best interest of the family. These members are then motivated to solve problems in order to help alleviate one another's stress. Furthermore, by seeking professional and community support, families also indirectly strengthen the family bond. As families agree to seek support in order to help the family and the child with special needs, they help to establish family cohesiveness.

Families of children with developmental disabilities, however, show no relationship between their adaptability and coping skills. A family's 'adaptability' represents the covert and overt rules and routines that structure the family unit internally, such as redefining roles to support family needs. Although they show more coping skills, this does not seem to be related to greater adaptability because they are making changes outside the family. Thus, family adaptability may be tangentially related to family coping behavior in families with children with developmental disabilities.

By contrast, families of children with typical development show positive correlations between family adaptability and family coping skills.

This finding suggests that families without disabled children cope with family crises most effectively through adjusting overt and covert rules, routines, and boundaries among family subsystems (e.g., parental unit). In general, these families focus on managing problems internally, unlike families of children with disabilities who tend to address their problems both internally and externally.

Furthermore, findings suggest that, during middle childhood, siblings of children with developmental disabilities have similar self-concept and anxiety compared to siblings of children with typical development. Other studies have also shown that siblings of children with disabilities do not differ on measures of social-emotional adjustment when compared to siblings of children without disabilities (Dyson, 1996; Dyson *et al.*, 1989). However, these studies involved siblings of children who were less impaired (Dyson, 1996) than those in this study. Therefore, the present study extends these findings to siblings of children with more severe disabilities and to siblings of middle-childhood age.

Past studies have also suggested that siblings of children with disabilities assume greater household responsibilities that may relate to their social-emotional development (Coleby, 1995; McHale & Gamble, 1985). The present study, however, does not support this assumption. Instead, siblings of children with and without developmental disabilities assumed similar amounts of household responsibilities, and the amount of

household responsibilities does not associate with siblings' self-concept or anxiety.

Finally, findings from the present research suggest that family problem-solving communication predicts anxiety in siblings of children with and without developmental disabilities. The two types of families show similar problem-solving communication skills. Although families of children with disabilities encounter daily stress, the present findings suggest that families of typically developing children also confront daily stressors that require effective problem-solving communication in order to maintain lower levels of family stress. In a family with strong problem-solving communication, each member has an opportunity to express his or her frustrations and to have his or her feelings validated. Also, the family does not allow problems to remain unresolved. Further, parents model communication skills to their children, enabling them to effectively express feelings and needs in conflict situations both inside and outside the family. These factors predict anxiety in children regardless of whether there is a child with a disability present in the family. Thus, effective family problem solving alleviates stress in children at the same level for both types of families.

In addition, family problem solving communication and group status both predict siblings' self-concept. As the two groups of families demonstrate equally effective problem-solving communication, siblings of

children with developmental disabilities will have lower self-concept relative to siblings of children with typical development. Some family problems may continue no matter how strong the family's problem-solving communication skills because the child with a disability can never be "cured". Therefore, non-disabled siblings may develop a belief that some problems are beyond their control, and subsequently, feel socially ineffective.

In their work on family conflict, Nixon and Cummings (1999) found that siblings of children with disabilities assumed more responsibility for other's problems in response to everyday conflicts compared to siblings of children without disabilities. These differences were more pronounced when the conflicts were mild, suggesting that siblings of children with disabilities more frequently assume personal responsibility for family problems. They may feel disappointed with themselves for being unable to help their brothers or sisters, or their families, as effectively as they would like. Thus, siblings of children with disabilities may feel less competent and more disappointed in themselves, and these factors may contribute to lower self-concepts.

Disability Severity. In families with children with developmental disabilities, the severity of the disability helps significantly predict siblings' adjustment. Specifically, the family cohesion and disability severity predicted siblings' self-concept. Further, family cohesion, the interaction of

family cohesion and disability severity, and the interaction of family coping skills and disability severity predicted siblings' anxiety. As the severity of the disability results in greater developmental delays, families that are more cohesive have non-disabled siblings' with greater self-esteem and less anxiety. This may be due to a strong support system that helps the family cope with stress associated with the child's extensive needs. Inversely, a cohesive family with greater coping skills may be more capable in managing severe disabilities because they are able to work together and because they access external resources for support. For example, fathers may be more involved with household and childcare needs and/or may be more emotionally supportive toward their spouses, and this may alleviate maternal stress. Family cohesiveness and external family coping, therefore, may facilitate parent-child relationships through alleviating parental stress, and these relationships have been shown to impact on siblings' self-esteem (McHale & Gamble, 1989).

Family cohesiveness and coping skills may also relate to siblings' self-esteem and anxiety if parents are conscientious about discussing the disability and how it is affecting their family. Specifically, if siblings are being teased at school because of their brothers and sisters, a cohesive family will respond supportively to this teasing by exploring siblings feelings and helping siblings decide on how to manage social stigma. As a result,

the non-disabled siblings may feel better about themselves and their families and internalize their worries less.

Summary. Overall, families with children with developmental disabilities are similar in family cohesiveness, adaptability, and problem-solving communication compared to families of children with typical development. Although Disability families practice greater coping skills, this does not significantly predict non-disabled siblings' adjustment. Instead, family problem-solving communication predicts self-concept and anxiety for siblings in both groups of families. Furthermore, at an equal level of effective problem-solving communication, siblings of children with developmental disabilities will show lower self-concepts, perhaps due to the fact that siblings of children with special needs are frustrated by inevitable family problems and by not being able to help their disabled brothers and sisters. In turn, this may cause them to possess lower self-concepts. Finally, the severity of the disability proves to be the strongest predictor of non-disabled siblings' adjustment.

Implications.

The present investigation helps expand the research findings on the social-emotional adjustment of siblings of children with disabilities and offers practical information on working with families raising children with developmental disabilities and with typical development. In fact, many of

the participating families expressed a strong interest in obtaining the results from this study. They had a genuine concern for their non-disabled children and were excited to be part of the project because it focused on the children they felt were generally overlooked. Many parents spoke about their non-disabled child's efforts to help his/her siblings and families. The families overwhelmingly agreed that non-disabled children share special sibling relationships with their brothers and sisters, and at times witness difficult family situations that may affect how these children feel about themselves.

Findings suggest the importance of family counseling that teaches families how to develop affirming problem-solving communication skills. These skills may facilitate the family's ability to develop balanced cohesiveness and adaptability and help families utilize effective coping skills. Establishing a balanced family system is especially essential for families with severely impaired children since cohesiveness and adaptability interact with the severity level of the disability to impact on siblings' adjustment.

These findings also imply that siblings would benefit from access to programs that support the development of their social/emotional needs. Specifically, there are sibling programs that are designed to help siblings of children with disabilities appreciate their unique family experiences and also learn how other children in similar situations feel about themselves. These

findings suggest that such programs also teach siblings ways to have positive experiences with their brothers and sisters so that they may feel successful. Such programs for siblings will need to focus on ways to build self-concept since the present findings suggest these children are at risk for developing lower self-concept.

In sum, the current findings suggest that family problem-solving communication relates to the social/emotional adjustment of siblings of children with developmental disabilities. This finding shows the importance of psychologists, social workers, and family support personnel to provide information and emotional support services for families and non-disabled siblings of children with developmental disabilities.

Strengths and Limitations

The present study furthers the literature on the social-emotional adjustment of siblings of children with disabilities by improving upon the methodology. First, unlike earlier studies, there is a comparison group of families raising children with typical development. The comparison group helps determine how prediction models of siblings' social/emotional adjustment may differ when there is a child with a disability present in the family.

Another strength in the present investigation is the inclusion of fathers. Most previous studies only included the mothers' responses on family variables. Fathers' responses help to strengthen the findings

because there are now two respondents on the family system, which provides a more complete picture of family functioning and coping processes. Since fathers were not traditionally included, the present findings offer new information about the father's role in family functioning.

Finally, the selection of siblings of children with developmental disabilities strengthens the present investigation, since some of the previous research on this population included a larger distribution of disabilities or milder disabilities (e.g., learning disabilities). The present findings extend the research to siblings of children with more severe limitations in functioning.

There are also limitations in the present study that need to be addressed. First, the quasi-experimental design prevents any assumptions of true causality in the prediction model. This undermines the findings and, at best, suggests a relationship in the variables.

In addition, the present study used a mail survey that included voluntary participation by families. This reduced the chances that less functional families would be included in the data analysis due to subject selection bias. For example, families with less cohesiveness and poorer communication skills may not have been communicating well enough to express an interest in participating in the study. Thus, the present study may have ultimately included families with more balanced systemic functioning compared to the total population of families.

In addition, limitations in subject selection may vary across groups. Many of the participating families in the disability group were internally motivated to participate because they were concerned for their non-disabled children. However, families in the non-disability group likely had less motivation to participate because the study did not focus on their issues. Since the level of motivation may have differed between groups, this may have affected the sample selection across groups. Thus, the disability group may have an over-representation of higher functioning families compared to the overall population of families raising children with disabilities. The sample of non-disabilities families, however, may be a more accurate representation of the population of these families.

An additional limitation of the present study is that only one informant provided an assessment of the siblings' adjustment. Since only self-reported inventories of anxiety and self-concept were included, it is questionable how accurate these self-appraisals are. An additional informant (e.g., mother's responses on children's self-esteem) might have validated siblings' adjustment.

Finally, there were no medical records to verify the disability condition for families in the disability group. Without verifying the disability, the results of this study solely depended on whether parents provided accurate information on their children's developmental condition.

Summary. There are several significant strengths and limitations of the present study. Strengths of the current investigation include the use of a comparison group, the participation of fathers, and the selection of a specific classification, developmental disability. These factors add support for the findings. Limitations include the lack of an experimental design, the inherent weaknesses of mail surveys, a subject selection bias, and the lack of multiple informants on siblings' adjustment. Future research should address these limitations and seek to correct these weaknesses.

Future Directions

The present investigation suggests that family problem-solving communication establishes an environment that facilitates effective functioning of family cohesion and adaptability in families with a child with a disability and families of children with typical development. Both the **Circumplex Model of Marital and Family Systems** and the **Resiliency Model of Family Adjustment and Adaptability** emphasize the function of communication, and specifically, problem-solving communication, in *empowering* families to change and gain resources. Based on these findings, future research might therefore assess family communication patterns and their impact on families raising children with developmental disabilities as compared to families raising children with typical development. For example, future research might consider measuring

receptive communication styles such as to what extent family members demonstrate high functioning receptive communication skills that help them understand each other's communication messages.

In addition, future studies may include other measures of siblings' adjustment, such as measuring siblings' ability to cope with family stress. Since the present investigation merely measured parents' perceptions of the family's resiliency, additional research may explore how siblings' perceive their coping skills and how these relate to other measures of their social-emotional adjustment. Parental reports of children's behavior and social competency may also be included as additional measures of siblings' adjustment. Future studies may wish to include parental report measures such as the Child Behavior Checklist (Achenbach, 1991).

The present sample includes two-parent families of children with developmental disabilities, and these families show better coping skills when compared with two-parent families of children with typical development. Future studies should include single-parent families compared with two-parent families to further assess how coping skills relate to siblings' social-emotional adjustment. In addition, it would be interesting to investigate the differences in family systemic functioning and coping skills between families of children with developmental disabilities and families of children with chronic illness, such as cancer, and how these differences relate to siblings' adjustment.

Finally, the present findings suggest that cohesion and adaptability of disability families are significant predictors of siblings' adjustment when information on the severity of the disability is available. Although the present study aimed to decrease the range in disability severity, this factor proved to be a significant predictor of siblings' adjustment. Future research may wish to include families raising children with wider ranges of severity in their disabilities, including extremely mild to extremely limiting conditions, in order to further explore the relationship between limitations of the disability and family functioning. Future research may also compare the family stress of childcare between Disability and Non-Disability families in order to determine whether this variable significantly predicts siblings' adjustment.

Conclusion.

This study was designed to investigate the relationship between family system processes and coping skills, and anxiety and self-concept of siblings of children with and without developmental disabilities. Results show that family problem-solving communication significantly predicts siblings' anxiety and self-concept in families with and without children with developmental disabilities. Also, siblings of children with disabilities show lower levels of self-concept relative to siblings of children with typical development as predicted by the family's problem-solving skills. Furthermore, family cohesiveness and adaptability predicts siblings' self-

concept as a function of the limitations in self-care skills for the disabled child.

In sum, family communication provides similar predictability of siblings' adjustment among families with and without a child with a developmental disability. Family interventions that support the development of affirming communication skills are beneficial to siblings' social-emotional development.

APPENDIX A: Family Cohesion

Couple/Family Score	Disengaged		Separated		Connected		Enmeshed	
	1	2	3	4	5	6	7	8
EMOTIONAL BONDING	Extreme emotional separateness. Lack of family loyalty.		Emotional separateness. Limited closeness. Occasional family loyalty.		Emotional closeness. Some separateness. Loyalty to family expected.		Extreme emotional closeness. Little separateness. Loyalty to family demanded.	
FAMILY INVOLVEMENT	Very low involvement or interaction. Infrequent affective responsiveness.		Involvement acceptable. Personal distance preferred. Some affective responsiveness.		Involvement emphasized. Personal distance allowed. Affective interactions encouraged and preferred.		Very high involvement. Fusion, over-dependency. High affective responsiveness and control.	
MARITAL RELATIONSHIP	High emotional separateness. Limited closeness.		Emotional separateness. Some closeness.		Emotional closeness. Some separateness.		Extreme closeness, fusion. Limited separateness.	
PARENT-CHILD RELATIONSHIP	Rigid generational boundaries. Low p/c closeness.		Clear generational boundaries. Some p/c closeness.		Clear generational boundaries. High p/c closeness.		Lack of generational boundaries. Excessive p/c closeness.	
INTERNAL BOUNDARIES	SEPARATENESS dominates.		MORE separateness than togetherness.		MORE togetherness than separateness.		TOGETHERNESS dominates.	
TIME (Physical & Emotional)	Time apart maximized. Rarely time together.		Time alone important. Some time together.		Time together important. Time alone permitted.		Time together maximized. Little time alone permitted.	
SPACE (Physical & Emotional)	Separate space needed and preferred.		Separate space preferred. Sharing of family space.		Sharing family space. Private space respected.		Little private space permitted.	
DECISION-MAKING	Individual decision-making. (Oppositional)		Individual decision-making, but joint possible.		Joint decisions preferred.		Decisions subject to wishes of entire group.	
EXTERNAL BOUNDARIES	Mainly focused outside the family.		More focused outside than inside family.		More focused inside than outside family.		Mainly focused inside the family.	
FRIENDS	Individual friends seen alone.		Individual friendships seldom shared with family.		Individual friendships shared with family.		Family friends preferred. Limited individual friends.	
INTERESTS	Separate interests.		Separate interests.		Some joint interests.		Joint interests mandated.	
ACTIVITIES	Mainly separate activities.		More separate than shared activities.		More shared than individual activities.		Separate activities seen as disloyal.	
Global Cohesion Rating (1-8)	Very Low		Low to Moderate		Moderate to High		Very High	

Olson, D.H. (1993). Circumplex Model of Marital and Family Systems: Assessing family functioning. In F. Walsh (Ed.), *Normal family processes*. New York, NY: Guilford Press.

APPENDIX B: Family Flexibility

Couple/Family Score	Rigid		Structured		Flexible		Chaotic	
	1	2	3	4	5	6	7	8
LEADERSHIP (Control)	Authoritarian leadership. Parent(s) highly controlling		Primarily authoritarian but some equalitarian leadership.		Equalitarian leadership with fluid changes.		Limited and/or erratic leadership. Parental control unsuccessful. Rebuffed.	
DISCIPLINE (For families only)	Autocratic "law & order." Strict, rigid consequences. Not lenient.		Somewhat democratic. Predictable consequences. Seldom lenient.		Usually democratic. Negotiated consequences. Somewhat lenient.		Laissez-faire and ineffective. Inconsistent consequences. Very lenient.	
NEGOTIATION	Limited negotiations Decisions imposed by parents.		Structured negotiations. Decisions made by parents.		Flexible negotiations. Agreed upon decisions.		Endless negotiations. Impulsive decisions.	
ROLES	Limited repertoire. Strictly defined roles. Unchanging routines.		Roles stable, but may be shared.		Role sharing and making. Fluid changes of roles.		Lack of role clarity. Role shifts and role reversals. Few routines.	
RULES	Unchanging rules. Rules strictly enforced.		Few rule changes. Rules firmly enforced.		Some rule changes. Rules flexibly enforced.		Frequent rule changes. Rules inconsistently enforced.	
Global Cohesion Rating (1-8)	Very Low		Low to Moderate		Moderate to High		Very High	

Note: The global rating is based on your overall evaluation, not a sum score of the sub-scale.

Olson, D.H. (1993) *Circumplex Model of Marital and Family Systems: Assessing family functioning*. In F. Walsh (Ed.), *Normal family processes*. New York, NY: Guilford Press.

APPENDIX C: Family Communication

Low ← ————— Facilitating ————— → High

Couple/Family Score	1	2	3	4	5	6
LISTENER'S SKILLS Empathy Attentive listening	Seldom evident Seldom evident		Sometimes evident Sometimes evident		Often evident Often evident	
SPEAKER'S SKILLS Speaking for self Speaking for others* <i>*Note reverse scoring</i>	Seldom evident Often evident		Sometimes evident Sometimes evident		Often evident Seldom evident	
SELF-DISCLOSURE	Infrequent discussion of self, feelings and relationships.		Some discussion of self, feelings and relationships.		Open discussion of self, feelings and relationships.	
CLARITY	Inconsistent and/or unclear verbal messages. Frequent incongruences between verbal and non-verbal messages.		Some degree of clarity, but not consistent across time or across all members. Some incongruent messages.		Verbal messages very clear. Generally congruent messages.	
CONTINUITY/TRACKING	Little continuity of content. Irrelevant/distracting non-verbals and asides frequently occur. Frequent/inappropriate topic changes.		Some continuity, but not consistent across time or across all members. Some irrelevant/distracting non-verbals and asides. Topic changes not consistently appropriate.		Members consistently tracking. Few irrelevant/distracting non-verbals and asides. Facilitative non-verbals. Appropriate topic changes.	
RESPECT AND REGARD	Lack of respect for feelings or message of other(s). Possibly overtly disrespectful or belittling attitude.		Somewhat respectful of others, but not consistent across time or across all members. Some incongruent messages		Consistently appears respectful of other's feelings and messages.	
Global Family Communication Rating (1-6)						

Olson, D.H. (1993). Circumplex Model of Marital and Family Systems: Assessing family functioning. In F. Walsh (Ed.), *Normal family processes*. New York, NY: Guilford Press.

Note: The global rating is based on your overall evaluation, not a sum score of the subscale.

Randall D. Martin, Ph.D.
[REDACTED]

AHRC
200 Park Avenue South
3rd Floor
New York, NY 10003
212.780 2592
Fax. 212.777 3918

4/22/99

Dear Parent(s)/Guardian(s)/Caretaker(s):

I am writing to you to tell you about an important research project for families with a child with a developmental disability. AHRC has given Ms. Carolyn Sgandurra, a Ph.D. candidate at City University of New York, permission to invite you to participate in her study. The study involves nondisabled children in the family and their parents/caretakers. This study will help us better understand family experiences, and the nondisabled children's thoughts about themselves. You will be able to receive the results of the study if you participate. We believe that additional information about siblings and families will be useful to helping professionals in giving you and your families the highest level of service.

I strongly encourage you to participate in this study.

Sincerely,



Randall Martin, Ph.D.
Sibling Services Manager



United Cerebral Palsy
of New York City

Family Support Services
120 East 23rd Street
New York, NY
10010-4519

tel 212 979 9700
fax 212 260 7469

www.ucpnyc.org

May 8, 2000

Dear Parent(s):

I am writing to you to tell you about an important research project for families with a child with a developmental disability.

United Cerebral Palsy of New York City, Inc., has given Ms. Carolyn Sgandurra, a Ph.D. candidate at the Graduate Center of the City University of New York, permission to invite you to participate in her study. The study involves siblings of children with developmental disabilities and their parents. This study will help us better understand family experiences, and siblings' thoughts and feelings about themselves.

Ms. Sgandurra is offering a stipend and the results of the study if you participate. We believe the additional information about siblings and families will be useful to helping professionals in giving you and your family the highest level of services.

Sincerely,

A handwritten signature in black ink, appearing to read "Amy Bittinger".

Amy Bittinger, MPH
Director - Family Support Services Department

AB:pas

Understanding Disabilities. Creating Opportunities.

Families Needed

Earn \$15

Families are invited to participate in a research project. Participation is by mail and takes about 20 minutes of each family member's time. Families will receive \$15 for their participation. This is a study about families and brothers and sisters of children with developmental disabilities. Families must be two-parent with a non-disabled sibling between the ages of 8 - 13. Parents will each complete several short questionnaires about their families, and siblings will complete two questionnaires about themselves.

Individual responses are confidential. This study is intended to develop guidelines for families in which there is a child with a disability. If your family is interested or for further information, call: Ms. Carolyn Sgandurra at (212) 861-6981 or write to Ms Sgandurra at: Gracie Station P.O. Box 1595 New York, NY 10028
E-mail Family_project2@yahoo.com



Families Needed

Earn \$15

Families are invited to participate in a research project. Participation is by mail and takes about 20 minutes of each family member's time. Families will receive \$15 for their participation. This is a study about Families with children. Families must be two-parent and have at least two children. One child, either boy or girl between the ages of 8 - 13, will complete two questionnaires about him or herself. The mother and father will each complete several short questionnaires about the family.

Individual responses are confidential. This study is intended to develop guidelines for families raising children. If your family is interested or for further information, please call: Ms. Carolyn Sgandurra at (212) 861-6981 or write Ms. Sgandurra at: Gracie Station P.O. Box 1595 New York, NY 10028 E-mail Family_project2@yahoo.com



Family Background Questionnaire:

1. This questionnaire was filled out by Mom/Dad (circle one)

2. Please answer these questions about **Mother**:

Age _____

Highest Education Level _____

Occupation _____

3. Please answer these questions about **Father**:

Age _____

Highest Education Level _____

Occupation _____

4. Please answer these questions about the **child who has a disability**:

Age _____

Gender _____

Name/ description of disability _____

a. How limiting is your child's disability on his/her physical activities? (Please circle one)

1	2	3	4	5
Mild	Somewhat Moderate	Moderate	Severe	Extremely
Severe Limitations				
Limitations				

b. How limiting is your child's disability on his/her self-care skills? (Please circle one)

1	2	3	4	5
Mild	Somewhat Moderate	Moderate	Severe	Extremely
Severe Limitations				
Limitations				

c. What amount of caretaking responsibility is required for your child with a disability?

1	2	3	4	5
A Little	Less than	Moderate	A Large	Considerable

5. Please answer these questions about the **participating sibling**:

Age _____

Gender _____

What is the birth order position of the participating sibling? (e.g., oldest of three, youngest of three, second born) _____

a. Please describe the type of household responsibilities your child has around the home: _____

b. Please describe the type of responsibilities your child has for his/her sibling with a disability: _____

6. Total number of children in your family _____

What are the **ages and gender** of your other children? _____

7. Please answer the following questions:

Religious Affiliation _____

Ethnic Background _____

Yearly Income Level: (check one)

Under \$ 30, 000 _____

\$ 30 - 49,999 _____

\$50 - 74,999 _____

\$75 - 99,999 _____

\$100,000 plus _____

Family Background Questionnaire

1. This questionnaire was filled out by Mom/Dad (circle one)

2. Please answer these questions about **Mother**:

Age _____

Highest Education Level _____

Occupation _____

3. Please answer these questions about **Father**:

Age _____

Highest Education Level _____

Occupation _____

4. Please answer these questions about the **participating child**:

Age _____

Gender _____

What is the birth order position of the participating child? (e.g., youngest of three, oldest of two) _____

a. Please describe the type of household responsibilities your child has around the home

b. Please describe the type of childcare and helping responsibilities this child has for his/her sibling(s), if applicable (for example, babysitting, helping with homework).

5. Total number of children in your family _____

What are the ages and gender of your other children? _____

6. Do any of your children attend special education? Yes / No (please circle one)
Do any of your children receive therapy /special instruction of any kind? Yes / No
Do any of your children have serious medical or physical conditions? Yes / No

If you answered yes to any of the above, please explain: _____

If you answered yes to any of the above, what is this child's age and gender: _____

7. Please answer the following questions :

Religious Affiliation _____

Ethnic Background _____

Yearly Income Level: (check one)

Under \$ 30, 000 _____

\$ 30 - 49,999 _____

\$50 - 74,999 _____

\$75 - 99,999 _____

\$100,000 plus _____

Appendix I : Family Adaptability and Cohesion Scale
(FACES-II)

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



Family Stress, Coping and Health Project
School of Human Ecology
1300 Linden Drive
University of Wisconsin-Madison
Madison, WI 53706

F-COPES

FAMILY CRISIS ORIENTED PERSONAL SCALES

Hamilton L. McCubbin David H. Olson Andrea S. Larsen

Purpose

The Family Crisis Oriented Personal Evaluation Scales is designed to record problem-solving attitudes and behaviors which families develop to respond to problems or difficulties.

Directions

First, read the list of "Response Choices" one at a time.

Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you strongly agree; if the statement does not describe your response at all, then circle the number 1 indicating that you strongly disagree; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

Please circle a number (1, 2, 3, 4, or 5) to match your response to each statement. Thank you

<i>When we face problems or difficulties in our family, we respond by:</i>	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
1. Sharing our difficulties with relatives	1	2	3	4	5
2. Seeking encouragement and support from friends	1	2	3	4	5
3. Knowing we have the power to solve major problems	1	2	3	4	5
4. Seeking information and advice from persons in other families who have faced the same or similar problems	1	2	3	4	5
5. Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6. Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
7. Knowing that we have the strength within our own family to solve our problems	1	2	3	4	5
8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	1	2	3	4	5

<i>When we face problems or difficulties in our family, we respond by:</i>	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
9. Seeking information and advice from the family doctor	1	2	3	4	5
10. Asking neighbors for favors and assistance	1	2	3	4	5
11. Facing the problems "head-on" and trying to get solution right away	1	2	3	4	5
12. Watching television	1	2	3	4	5
13. Showing that we are strong	1	2	3	4	5
14. Attending church services	1	2	3	4	5
15. Accepting stressful events as a fact of life	1	2	3	4	5
16. Sharing concerns with close friends	1	2	3	4	5
17. Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18. Exercising with friends to stay fit and reduce tension	1	2	3	4	5
19. Accepting that difficulties occur unexpectedly	1	2	3	4	5
20. Doing things with relatives (get-togethers, dinners, etc.)	1	2	3	4	5
21. Seeking professional counseling and help for family difficulties	1	2	3	4	5
22. Believing we can handle our own problems	1	2	3	4	5
23. Participating in church activities	1	2	3	4	5
24. Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25. Asking relatives how they feel about problems we face	1	2	3	4	5
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27. Seeking advice from a minister	1	2	3	4	5
28. Believing if we wait long enough, the problem will go away	1	2	3	4	5
29. Sharing problems with neighbors	1	2	3	4	5
30. Having faith in God	1	2	3	4	5



Family Stress, Coping and Health Project
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FPSC
FAMILY PROBLEM SOLVING COMMUNICATIONS
Marilyn A. McCubbin Hamilton I. McCubbin Anne I. Thompson

<i>When our family struggles with problems or conflicts which upset us, I would describe my family in the following way:</i>	False	Mostly False	Mostly True	True
1. We yell and scream at each other.	0	1	2	3
2. We are respectful of each others' feelings.	0	1	2	3
3. We talk things through till we reach a solution.	0	1	2	3
4. We work hard to be sure family members were not hurt, emotionally or physically.	0	1	2	3
5. We walk away from conflicts without much satisfaction.	0	1	2	3
6. We share with each other how much we care for one another.	0	1	2	3
7. We make matters more difficult by fighting and bring up old matters.	0	1	2	3
8. We take the time to hear what each other has to say or feel.	0	1	2	3
9. We work to be calm and talk things through.	0	1	2	3
10. We get upset, but we try to end our conflicts on a positive note.	0	1	2	3

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

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

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

Sincerely,

David H. Olson
David H. Olson, Ph.D.

AWARE	PREPARE	PREPARE-MC	ENRICH	MATE
	Growing Together	Coping & Stress Profile		

Dear Ms. Sgandurra,

This letter is to confirm that you are a registered user of the F-COPES Family-Crisis Oriented Personal Evaluation Scale, and the FPSC Family Problem Solving Communication instruments. As a registered user, you have permission to make photocopies of the instruments, administer them, and present a copy in your final publication, such as a thesis, dissertation or journal article. This permission does not extend to revenue generating publications such as books. If you require this type of permission, please contact the project office. Permission is granted to you as an individual and is not transferable to a colleague or student.

If permission is required at a later date for additional instruments or for the same instruments but for a different project, please photocopy and send another abstract form, and this written permission will be sent at no additional charge as well.

If we could be of any further assistance to you please let us know.

Sincerely,

Hamilton I. McCubbin
Director

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- | | | |
|--|-----|----|
| 1. My classmates make fun of me | yes | no |
| 2. I am a happy person | yes | no |
| 3. It is hard for me to make friends | yes | no |
| 4. I am often sad | yes | no |
| 5. I am smart | yes | no |
| 6. I am shy | yes | no |
| 7. I get nervous when the teacher calls on me | yes | no |
| 8. My looks bother me | yes | no |
| 9. When I grow up, I will be an important person | yes | no |
| 10. I get worried when we have tests in school | yes | no |
| 11. I am unpopular | yes | no |
| 12. I am well behaved in school | yes | no |
| 13. It is usually my fault when something goes wrong | yes | no |
| 14. I cause trouble to my family | yes | no |
| 15. I am strong | yes | no |
| 16. I have good ideas | yes | no |
| 17. I am an important member of my family | yes | no |
| 18. I usually want my own way | yes | no |
| 19. I am good at making things with my hands | yes | no |
| 20. I give up easily | yes | no |
| 21. I am good in my school work | yes | no |
| 22. I do many bad things | yes | no |
| 23. I can draw well | yes | no |
| 24. I am good in music | yes | no |
| 25. I behave badly at home | yes | no |
| 26. I am slow in finishing my school work | yes | no |
| 27. I am an important member of my class | yes | no |
| 28. I am nervous | yes | no |
| 29. I have pretty eyes | yes | no |
| 30. I can give a good report in front of the class | yes | no |
| 31. In school I am a dreamer | yes | no |
| 32. I pick on my brother(s) and sister(s) | yes | no |
| 33. My friends like my ideas | yes | no |
| 34. I often get into trouble | yes | no |
| 35. I am obedient at home | yes | no |
| 36. I am lucky | yes | no |
| 37. I worry a lot | yes | no |
| 38. My parents expect too much of me | yes | no |
| 39. I like being the way I am | yes | no |
| 40. I feel left out of things | yes | no |

THE WAY I FEEL ABOUT MYSELF

THE PIERS-HARRIS CHILDREN'S SELF-CONCEPT SCALE

Ellen V. Piers, Ph.D. and Dale B. Harris, Ph.D.

Client's Name: _____

Today's Date: _____

Age: _____

Sex: (circle one) Girl Boy

Grade: _____

School: _____

Teacher's Name (optional): _____

Directions

Here is a set of statements that tell how some people feel about themselves. Read each statement and decide whether or not it describes the way you feel about yourself. If it is *true* or *mostly true* for you, circle the word "yes" next to the statement. If it is *false* or *mostly false* for you, circle the word "no." Answer every question, even if some are hard to decide. Do not circle both "yes" and "no" for the same statement. If you want to change your answer, cross it out with an X, and circle your new answer.

Remember that there are no right or wrong answers. Only you can tell us how you feel about yourself, so we hope you will mark the way you really feel inside.

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41. I have nice hair	yes	no
42. I often volunteer in school	yes	no
43. I wish I were different	yes	no
44. I sleep well at night	yes	no
45. I hate school	yes	no
46. I am among the last to be chosen for games	yes	no
47. I am sick a lot	yes	no
48. I am often mean to other people	yes	no
49. My classmates in school think I have good ideas	yes	no
50. I am unhappy	yes	no
51. I have many friends	yes	no
52. I am cheerful	yes	no
53. I am dumb about most things	yes	no
54. I am good-looking	yes	no
55. I have lots of pep	yes	no
56. I get into a lot of fights	yes	no
57. I am popular with boys	yes	no
58. People pick on me	yes	no
59. My family is disappointed in me	yes	no
60. I have a pleasant face	yes	no
61. When I try to make something, everything seems to go wrong	yes	no
62. I am picked on at home	yes	no
63. I am a leader in games and sports	yes	no
64. I am clumsy	yes	no
65. In games and sports, I watch instead of play	yes	no
66. I forget what I learn	yes	no
67. I am easy to get along with	yes	no
68. I lose my temper easily	yes	no
69. I am popular with girls	yes	no
70. I am a good reader	yes	no
71. I would rather work alone than with a group	yes	no
72. I like my brother (sister)	yes	no
73. I have a good figure	yes	no
74. I am often afraid	yes	no
75. I am always dropping or breaking things	yes	no
76. I can be trusted	yes	no
77. I am different from other people	yes	no
78. I think bad thoughts	yes	no
79. I cry easily	yes	no

Appendix O : Revised Children's Manifest Anxiety Scale
(RCMAS)

"WHAT I THINK AND FEEL"

Circle one answer for each sentence.

Yes	No	1. I have trouble making up my mind.
Yes	No	2. I get nervous when things do not go the right way for me.
Yes	No	3. Others seem to do things easier than I can.
Yes	No	4. I like everyone I know.
Yes	No	5. Often I have trouble getting my breath.
Yes	No	6. I worry a lot of the time.
Yes	No	7. I am afraid of a lot of things.
Yes	No	8. I am always kind.
Yes	No	9. I get mad easily.
Yes	No	10. I worry about what my parents will say to me.
Yes	No	11. I feel that others do not like the way I do things.
Yes	No	12. I always have good manners.
Yes	No	13. It is hard for me to get to sleep at night.
Yes	No	14. I worry about what other people think about me.
Yes	No	15. I feel alone even when there are people with me.
Yes	No	16. I am always good.
Yes	No	17. Often I feel sick in my stomach.
Yes	No	18. My feelings get hurt easily.
Yes	No	19. My hands feel sweaty.
Yes	No	20. I am always nice to everyone.
Yes	No	21. I am tired a lot.
Yes	No	22. I worry about what is going to happen.
Yes	No	23. Other people are happier than I.
Yes	No	24. I tell the truth every single time.
Yes	No	25. I have bad dreams.
Yes	No	26. My feelings get hurt easily when I am fussed at.
Yes	No	27. I feel someone will tell me I do things the wrong way.
Yes	No	28. I never get angry.
Yes	No	29. I wake up scared some of the time.
Yes	No	30. I worry when I go to bed at night.
Yes	No	31. It is hard for me to keep my mind on my schoolwork.
Yes	No	32. I never say things I shouldn't.
Yes	No	33. I wiggle in my seat a lot.
Yes	No	34. I am nervous.
Yes	No	35. A lot of people are against me.
Yes	No	36. I never lie.
Yes	No	37. I often worry about something bad happening to me.

Appendix P: Instructions for Disability Group

Instructions

Parents should not discuss their answers with one another while completing the questionnaires. You may discuss the items afterwards, but do not compare responses or be concerned if there is a lack of agreement.

Mothers

1. Mom independently completes the following scales:
 - Family Adaptability and Cohesion Scale II (FACES II)
 - Family Crisis Oriented Personal Evaluation Scale (F-COPES)
 - Family Problem Solving Communication (FPSC) Index.
2. Mom places the completed scales in the envelope marked MOTHER.

Fathers

1. Dad independently completes the following scales:
 - Family Adaptability and Cohesion Scale II (FACES II)
 - Family Crisis Oriented Personal Evaluation Scale (F-COPES)
 - Family Problem Solving Communication (FPSC) Index.
2. Dad places the completed scales in the envelope marked FATHER.

Sibling:

1. A non-disabled sibling who is 8 to 13 years old completes two questionnaires:
 - "The Way I Feel About Myself"
 - "What I Think and Feel"
2. These are placed in the envelope marked SIBLING.

Be sure to **seal the envelopes** marked MOTHER, FATHER, and SIBLING and place these into the large, brown envelope with return address and postage. **Please mail back all forms within 2 weeks.**

If you have any questions or concerns, please call Carolyn Sgandurra at (212) 861-6981. Your time and interest is greatly appreciated.

Appendix Q: Instructions for Non-Disability Group

Instructions

Parents should not discuss their answers with one another while completing the questionnaires. You may discuss the items afterwards, but do not compare responses or be concerned if there is a lack of agreement.

Mothers

1. Mom independently completes the following scales:
 - Family Adaptability and Cohesion Scale II (FACES II)
 - Family Crisis Oriented Personal Evaluation Scale (F-COPES)
 - Family Problem Solving Communication (FPSC) Index.
2. Mom places the completed scales in the envelope marked MOTHER.

Fathers

1. Dad independently completes the following scales:
 - Family Adaptability and Cohesion Scale II (FACES II)
 - Family Crisis Oriented Personal Evaluation Scale (F-COPES)
 - Family Problem Solving Communication (FPSC) Index.
2. Dad places the completed scales in the envelope marked FATHER.

Child:

1. One child who is 8 to 13 years old completes two questionnaires:
 - "The Way I Feel About Myself"
 - "What I Think and Feel"
2. These are placed in the envelope marked CHILD.

Be sure to **seal the envelopes** marked MOTHER, FATHER, and CHILD and place these into the large, brown envelope with return address and postage. **Please mail back all forms within 2 weeks.**

If you have any questions or concerns, please call Carolyn Sgandurra at (212) 861-6981. Your time and interest is greatly appreciated.

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