

**Family-Focused Intervention Model:  
Application to Families Having Infants with  
Moderate and Severe Handicaps**

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### Abstract

A family-focused intervention model, based on Bailey et al. (1986) was adapted and utilized with 16 families having infants (birth to three years) with moderate or severe developmental disabilities. The intervention included the selection and development of appropriate instruments as well as a 20-week treatment program for the entire family unit. Individualized family service plans were developed and incorporated the collaborative efforts of parents and the interventionist. Multiple baselines across targeted, individualized, familial behaviors resulted in progressive skill attainment by each family member. As a result of intervention, predominantly positive interactions were exhibited between infants with handicaps and their family members. Data obtained from the family assessment tools revealed statistically significant relationships among the family variables. Qualitative analyses of parental and sibling statements and behaviors confirmed enhancement of their skill repertoire and the identification of specific events that impacted upon families. Evaluation of the effectiveness of the family-focused intervention model resulted in high levels of parental satisfaction, accelerated rates of progress by children with moderate or severe developmental disabilities, and acquisition of functional skills by families. Positive benefits of the model exceeded family gains acquired with previously implemented child-focused programs. Implications for future research are described.

### Résumé

Les familles de 16 enfants âgés de 0 à 3 ans ayant des handicaps moyens ou sévères furent l'objet d'un modèle d'intervention axé sur la famille tel qu'il fut décrit par Bailey et al. (1986). Chaque étape de l'intervention fut mis en place, ce qui mena à l'évaluation et à une intervention auprès de chacun des membres des familles, soient les enfants handicapés, leur parents, et leurs frères et soeurs. Des approches particulières furent formulées pour chaque famille par les parents et l'intervenante. Les évaluations de bases continues des comportements ciblés, individuels et familiaux donnèrent lieu à l'acquisition progressive d'habiletés par chaque membre des familles. Des interactions principalement positives résultant de l'intervention furent observées entre les enfants handicapés et les membres de leurs familles. Les données obtenues à l'aide des outils d'évaluation des familles indiquèrent des relations statistiquement significatives entre les variables reliées à la famille. Des analyses qualitatives des comportements et des paroles des parents et des frères et soeurs confirmèrent l'amélioration des répertoires d'habiletés des enfants handicapés, et permirent d'identifier des événements spécifiques qui eurent un impact sur la famille. L'évaluation de l'efficacité du modèle d'intervention axé sur la famille tel qu'il fut mis sur pied montra un haut degré de satisfaction chez les parents, des taux de progrès accélérés chez les enfants handicapés, et l'acquisition par les familles d'habiletés fonctionnelles. Les effets positifs de ce modèle dépassèrent les atouts des modèles axés sur les enfants tels qu'ils ont été utilisés auparavant. Les répercussions pour le domaine de la recherche sont décrites.

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## Table of Contents

Abstract.....	page i
Resume.....	page ii
Acknowledgments.....	page iii
Table of Contents.....	page v
List of Tables.....	page vii
List of Figures.....	page ix
Chapter 1, Introduction.....	page 1
Chapter 2, Review of the Literature.....	page 5
Selected Factors that Influence Family Well-Being.....	page 5
Family Systems Approach.....	page 5
Familial Stress, Resources, and Support.....	page 7
Interaction and Attachment Studies.....	page 11
Parental Factors That Influence Family Well-Being.....	page 20
Sibling Subsystem.....	page 24
Models of Intervention.....	page 33
Efficacy of Early Intervention.....	page 37
Chapter 3, Rationale.....	page 42
Chapter 4, Methodology.....	page 46
Subjects.....	page 46
Procedures.....	page 49
Chapter 5, Results.....	page 79
Chapter 6, Discussion.....	page 149
Program Implementation.....	page 151
Parental Behaviors.....	page 154
Sibling Behaviors.....	page 165

Methodological Considerations.....	page 171
Qualitative Analyses.....	page 173
Summary.....	page 175
Implications for Future Research.....	page 177
Concluding Remarks.....	page 182
Chapter 7, References.....	page 183
Appendix 1.....	page 209
Sibling Interaction Scale.....	page 210
Inventory of Siblings' Perspectives, Form A.....	page 213
Inventory of Siblings' Perspectives, Form B.....	page 215
Protocol for the Family-Focused Interview.....	page 217
Parent Satisfaction Scale.....	page 219
Appendix 2, Table 24, Strengths Exhibited by Parents during... the Assessments and the Family-Focused Interviews	page 220
Appendix 3, Table 25, Concerns of Parents Verbalized during... Intervention Sessions	page 222
Appendix 4, Table 26, Observations and Quotations Verbalized.. by Parents Concerning Parent-Infant Attachment	page 224
Appendix 5, Table 27, Parental Statements Regarding the..... Future Outlook of Their Children	page 227
Appendix 6, Table 28, Behaviors Displayed by Siblings of..... Children with Handicaps	page 228
Appendix 7, Table 29, Positive Comments Regarding..... Investigator's Behaviors	page 230
Appendix 8, Table 30, List of Activities Conducted for Case... Management	page 233
Appendix 9, Table 31, Results of the Parent Satisfaction..... Scale	page 234
Appendix 10, Table 32, Parental Statements Regarding the..... Family-Focused Intervention Model	page 235

## List of Tables

Table 1, Description of the Infants and Their Families.....	page 47
Table 2, Description of Services Received by the Children.....	page 50
Table 3, Summary of Tests Used to Assess Families' Needs.....	page 53
Table 4, Time Allocation for Each Step within the..... Family-Focused Intervention Model	page 54
Table 5, Critical Events Checklist.....	page 67
Table 6, Summary of Statistical Analyses.....	page 80
Table 7, Description of Assessment Results.....	page 81
Table 8, Summary of the Results on the Additional..... Assessments	page 84
Table 9, Results of the Home Observation for Measurement..... of the Environment	page 86
Table 10, Results of the Family Resource Scale.....	page 89
Table 11, Results of the Family Support Scale.....	page 93
Table 12, Results of the Child Expectation Scale.....	page 96
Table 13, Results of the Sibling Interaction Scale.....	page 99
Table 14, Results of the Inventory of Siblings' Perspectives.. Form A	page 105
Table 15, Results of the Inventory of Siblings' Perspectives.. Form B	page 108
Table 16, Results of the Parent Behavior Progression.....	page 111
Table 17, Results of the Teaching Skills Inventory.....	page 113
Table 18, Pearson Product Moment Correlations Among the..... Parent Variables	page 117
Table 19, Pearson Product Moment Correlations Among the..... Child Variables	page 118
Table 20, Pearson Product Moment Correlations Among the..... Parent and Child Variables	page 120
Table 21, Goals Targeted and Achieved by Families.....	page 121

Table 22, Composite of Critical Events Cited by Families.....	page 122
Table 23, Continua of Goal Attainment Scaling.....	page 129
Table 24, Strengths Exhibited by Parents During the..... Assessments and the Family-Focused Interviews	page 220
Table 25, Concerns of Parents Verbalized during..... Intervention Sessions	page 222
Table 26, Observations of and Quotations Verbalized by..... Parents Concerning Parent-Infant Attachment	page 224
Table 27, Parental Statements Regarding the Future..... Outlook of Their Children	page 227
Table 28, Behaviors Displayed by Siblings of Children with.... Handicaps	page 228
Table 29, Positive Comments Regarding Investigator's..... Behaviors	page 230
Table 30, List of Activities Conducted for Case Management....	page 233
Table 31, Results of the Parent Satisfaction Scale.....	page 234
Table 32, Parent Statements Regarding Family-Focused..... Intervention Model	page 235

## List of Figures

- Figure 1, Steps in the Family-Focused Intervention Model.....page 51
- Figure 2, Multiple Baseline of Sample Goals for Child 7 that...page 133  
Were Included in the Individualized Family Service Plan
- Figure 3, Multiple Baseline of Sample Goals for the Family....page 134  
of Child 7 that Were Included in the Individualized  
Family Service Plan
- Figure 4, Multiple Baseline of Randomly Selected Child and....page 136  
Family Goals for Child 1 that Were Included in the  
Individualized Family Service Plan
- Figure 5, Multiple Baseline of Random Child and Family Goals...page 137  
for Child 1, Which Were Included in the Individualized  
Family Service Plan
- Figure 6, Multiple Baseline of Random Child and Family Goals...page 138  
for Child 9, Which Were Included in the Individualized  
Family Service Plan
- Figure 7, Multiple Baseline of Random Child and Family Goals...page 139  
for Child 11, Which Were Included in the Individualized  
Family Service Plan
- Figure 8, Multiple Baseline of Random Child and Family Goals...page 140  
for Child 12, Which Were Included in the Individualized  
Service Plan
- Figure 9, Multiple Baseline of Random Child and Family Goals...page 141  
for Child 14, Which Were Included in the Individualized  
Family Service Plan
- Figure 10, Multiple Baseline of Random Child and Family.....page 142  
Goals for Child 16, Which Were Included in the  
Individualized Family Service Plan

## Chapter One

### INTRODUCTION TO THE STUDY

Individuals with severe disabilities often have a multiplicity of problems (Sailor, Gee, Goetz, & Graham, 1988). In populations with moderate and severe handicaps, impairments can include orthopedic, cognitive, serious medical and/or sensory deficits (Snell, 1987). The combination of these deficits are often unique, and may not be characteristic of other children with severe disabilities. Given the multitude of needs, the effects of a child's specific handicapping condition must be individually interpreted in order to determine an appropriate intervention for each family. Living with a child with handicaps can be a difficult task. Each family member's behaviors have an impact on the growth of the entire family, especially in families with children having moderate or severe handicaps. Techniques have been developed to facilitate the development and adaptation of each family member and as such, one cannot view the child in isolation. Intervention applied to the entire family is a vehicle toward promoting effective coping strategies, increasing self-esteem, cultivating positive interactions, and educating the child with handicaps. In essence, the well-being of the entire family is promoted.

The family unit most generally consists of parents and siblings as well as the handicapped child. The family's adaptation to the presence of a handicapped family member is demonstrated by individual reactions and the quality of the relationships achieved among all the family members. Within a family, its members often experience both positive and negative reactions to a child with handicaps. A family systems model can incorporate a multitude of concomitant factors that influence family

functioning.

The quality of family functioning is revealed by the transactions that occur among its members. Marital interactions can have a direct effect on spouse's behaviors, and an indirect effect on the parent-child and sibling-sibling relationship. Assessment and intervention to one portion of the family can have resounding effects on the rest of the family. The quality of relationships between family members may significantly differ.

A critical component within the family unit revolves around the parent-child relationship. The developmental progress achieved by children has been shown to be a function of the parents' emotional responsivity to the child and of their ability to provide a developmentally appropriate environment. While the ability to respond to the subtle and maladaptive behaviors of severely handicapped infants is difficult, parental understanding of their children's verbal and nonverbal cues is a prerequisite for appropriate interactions. The drive for parents and infants to understand each other's needs and desires is dependent upon the quality of their relationship. A central facet of this relationship is attachment, an emotional tie that forms the affective basis for their relationship.

There are, however, specific parent and child factors that impact on family functioning. The level of child responsiveness and the parents' resources and support system have a resounding influence on the family unit. Mutually satisfying interactions occurring in one familial component (e. g., parent-child) impacts on subsequent behaviors of all family members. When a family has a handicapped member, it is at risk



for developing unsatisfying relationships.

Similarly, siblings make their own individual contributions to the family well-being. The siblings' relationship also emerges over time and changes over the child's life span. Both the sibling and the child with handicaps bring their own needs, desires, and personality characteristics to this relationship. Their behaviors can be modified by direct parental input and the perceived benefits of the interaction.

Efforts have been devoted toward strengthening effective family relationships, especially in homes with a handicapped child. Intervention has focused upon the parent-child relationship. If one supports the family systems approach, intervention necessitates consideration of the relationships formed between the parent and child as well as all family members.

A variety of methodological approaches have been utilized in early childhood intervention. Researchers have evaluated the appropriateness of the methodologies used and the types of data collected. Limitations of previous early intervention efforts include a lack of detail and process information, which reduce generalizability of the methodological procedures.

Given the present knowledge concerning intervention strategies for infants with moderate and severe handicaps and their families, the overall objective of this study is to implement and evaluate the effectiveness of the family-focused intervention model, a conceptual framework for providing services to the entire family having infants with moderate and severe handicaps. While statistical and descriptive data may signal the efficacy of the family-focused intervention model, parental perspectives regarding implementation of the model will be used

to qualitatively assess its impact on family well-being.

Since intervention will be applied to family units, an opportunity to understand the relationships among all family members exists. The frequency and types of behaviors displayed by each member within the family unit will be assessed. Specific behaviors in the parent-child and sibling-sibling interactions will be analyzed.

Thus, the present study is designed to evaluate the applicability of the family-focused intervention model. Valuable clinical information for the early interventionist will be obtained concerning specific assessments of child functioning, family interaction patterns, and family resources as well as identification of appropriate interventions that can be applied to families having infants with moderate/severe handicaps. This research should provide rich qualitative data.

## Chapter Two

### REVIEW OF THE LITERATURE

An exploration of the family's coping and adaptive skills with handicapped infants is critical to understanding family functioning, child development, and effective intervention strategies. Relevant research will be described in terms of providing an overview of the transactional nature present across families. Using a family systems approach, interactions among the various components will be presented. Following the knowledge obtained from parental, child and sibling factors influencing family well-being, intervention efforts and evaluation of these treatments illustrate the extent of their potential success.

#### Selected Factors That Influence Family Well-Being

Family well-being can influence the quality of the interactions among the various members of the family unit, e. g., parent, child, and sibling. Specific factors that affect the quality of relationships obtained among family members will be reviewed.

#### Family Systems Approach.

A family systems approach represents a conceptual framework through which one can focus on the various subsystems within the family unit. This approach is important, because it emphasizes the reciprocal effects of each family member's behaviors on other members. These subsystems include marital (husband-wife), parental (parent-child), and sibling interactions.

Ascertaining the existing health of the family unit is determined by observing the interactions among the family members. Skrtic, Summers, Brotherson, and Turnbull (1984) and Turnbull, Summers, and Brotherson (1986) have presented a framework through which the family's interactions

within each of the subsystems can be formalized. Within this framework, each family member's personality and behaviors have been shown to affect the responses from and the relationships between the other family members. The central focus of this model includes the effects of each family member's interactions, coping behaviors, degree of closeness, and communication skills (Powell & Ogle, 1985; Silber, 1989; Turnbull, Summers, & Brotherson, 1986).

Influencing these family subsystems or interactions are the characteristics of the family, which include family functions, family structure, and the family life cycle (Skrtic et al., 1984). Family members may differentially seek assistance from family, friends, service agencies, etc. Family functions may be conceptualized as the degree of success of meeting the individual needs of each family member (Turnbull, Summers, & Brotherson, 1986). For children with severe handicaps, a potential drain on family resources and decreased time for employment opportunities may arise for all family members. Further, physical care, child-rearing, and household responsibilities are often assumed by siblings as well as parents. The siblings' performance of these added responsibilities may reflect an economic necessity, the excessive physical care required by a child with moderate and severe handicaps, and psychological stress reduction.

In addition to family functions, family structures are highly variable as they differ in membership (e. g., single parent), size, type, geographic location, ethnic or racial background, and religious beliefs. Simeonsson and McHale (1981) have reported that the religious beliefs of the family were a major influence on parental and sibling acceptance of a

handicapped child. The attitudes of the siblings could affect the level of parental acceptance of the child as well as the parents influencing the siblings' responses (Skrtic et al., 1984).

Lastly, the family life cycle was characterized by stress-related transitions to relatively level plateaus (Skrtic et al., 1984). The development of each individual has an impact on the growth of the entire family. When an event, such as the birth of a child with handicaps, occurs within a family, modification of the family's roles and expectations for one another could likely occur. This type of alternation could result in a modification of current patterns of family functioning (Fewell, 1986).

#### Summary of family systems approach.

The family systems approach was presented as a framework from which to view the transactional nature of the subsystems within the family unit. Thus, the family's ability to meet the needs of each family member, the structure of the family unit, and transitions to the subsequent changes in roles of each family member (family life cycle) results in individual family differences. When one considers the various subsystems within a family, significant stressful events could be managed differently.

#### Familial Stress, Resources, and Support

Family functioning, as defined by Fewell (1986) reflects the nature of the family's ability to cope with cultural, environmental, economic, and psychosocial stressors. Key familial factors that were found to influence the family's functioning revolved around needs, stress, and support. The family's ability to deal effectively with each of these factors affected the level of adaptation family members experienced in

their roles and interactions. Essentially, the level of stress was determined by whether a balance between family's resources and the demands they confronted was met; whereas the extent of support was assessed by the amount of available resources to meet the family's needs (Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986). To demonstrate effective coping a family member could have altered his/her personal needs in order to meet the requirements of the environment (Gath, 1978; Zeitlin & Williamson, 1988).

Stress may be conceived in the form of (a) emotional stress (e. g., anxiety, depression), (b) material or economic stress (e. g., additional expenses required on behalf of the handicapped member), and (c) physical stress (e. g., physical demands exerted in the care of an individual) (Fewell, 1986). Thus, the reaction of each family member to cope with the continuing stress is manifested as a result of the level of change in individual perceptions and needs.

Families possess two potential buffers, family resources and perceptions, that often reduce the level of stress. The family's social support and perceptions serve as significant indicators of a potential family crisis (Nihara, Meyers, & Mink, 1980). A family achieves a "goodness of fit" between personal needs and environmental demands when the environmental expectations meet the available abilities of the family (Zeitlin & Williamson, 1988).

Specific family resources, especially financial capabilities, were found to mitigate the level of stress (Wikler, 1986). Likewise, close relationships with extended family members, religious groups, etc. served as potential sources of support (Cohen, Agosta, Cohen, & Warren, 1989;

George, 1988; Waisbren, 1980).

Further, Dunst, Trivette and Cross (1986a) found varying types of support mediated differential child, parental, and family outcomes. For example, intrafamilial support accounted for the quality of family functioning and the level of opportunities experienced by the family; whereas extrafamilial support (e. g., day care) influenced parent-child interaction. Thus, the quality and interaction between different sources of support appeared to influence the varying subsystems within the family unit.

The perceptions of parents and children could be paramount for the interventionist to understand. Whether these perceptions were accurate or inaccurate, they could continue to influence the manner in which families responded to their children. An interesting question was if family stress was related to the child's handicaps or was present in families without handicapped children (Goldberg & Easterbrooks, 1984; Wikler, 1986). Frequently, families experienced stress when transitions within the family life cycle occurred, e. g., an adolescent with mental retardation leaves the public school system (Wikler, 1986). In addition, one must control for the confounding variable of the family's socioeconomic status when evaluating the level of familial stress.

In response to stressful events, the family's coping strategies influenced their reactions to stressful events (Turnbull, Summers, & Brotherson, 1986). Families were often found to exhibit internal coping strategies by avoiding direct confrontation with the crisis or by identifying aspects of the situation that were modifiable. External coping strategies involved the support received from extended family members, religious groups, and professional or community resources

(Turnbull, Summers, & Brotherson, 1986). Therefore, families could assume a passive stance or a proactive orientation toward dealing with the event.

In order to effect change within the family's coping strategies, consideration of the types of requests made of families must be carefully weighed against the available resources. Promoting change in one subsystem of the family unit could result in a ripple effect throughout the other subsystems (Berger & Foster, 1986). The amount of effort expended by each family member should be carefully monitored during intervention, in order to prevent dysfunction in the family unit.

Schneider and Gearhart (1988) utilized a family systems model in evaluating familial perceptions of living with handicapped children. Routine activities, family belief systems, and coping strategies were found to vary across families with or without handicapped children. Correspondingly, assessment of the family environment could be ascertained through application of Vygotsky's (1978) "zone of proximal development". Essentially, the "zone of proximal development" is the level of behavior a child can attain with the assistance from more capable and experienced family members, but is unable to perform independently. Parents and siblings can provide an environment that supports children's developmental progress and encourages children to approximate higher level skills through decreasing the amount of assistance provided. Further, the manner, in which families respond to their children with handicaps, can enable understanding of the transactional behaviors among the family members and how they nurture children's development (Rogoff, Malkin, & Gilbridge, 1984; Schneider &



Gearhart, 1988). As a result, naturalistic observation of families' response to stress, use of support systems, and interactions with one another would lead to more appropriate treatment program.

#### Summary of familial stress, resources, and support.

Familial adaptations to stressful events, such as birth of a handicapped family member, were found to interact with the levels of perceived support and resources, as well as familial evaluations of the these stressful events. Thus, the level of stress experienced by a family varied across the life cycle of the family unit (Minnes, 1988). Evaluation of the relationships among the subsystems were ascertained by naturalistic observation of their interactions. Central to the issue of the family's level of functioning is the quality of the relationships achieved by its members.

#### Interaction and Attachment Studies

Examination of the interactions between parents and their infants with handicaps involves accurate interpretation of each other's behavioral cues as well as the parents' ability to provide developmentally appropriate stimulation. The components of parent-infant interaction to be reviewed include infant behavioral characteristics, parental behaviors, and intervention efforts.

The infants' contribution to the interaction with the parent is manifested by the transactional behaviors of infants and their parents (Fox, 1985; McCollum & Stayton, 1985). Effective parenting is determined by accurate interpretation of infant needs, while infant responsiveness is portrayed by demonstration of behaviors that are easily understood by the parent (Goldberg, 1977; Wikler, 1986). Typically, nondisabled infants disseminate behavioral cues that are relatively easily

interpreted, resulting in adult feelings of efficacy (Goldberg, 1977).

Conversely, infants with handicaps were observed to have specific behaviors that were difficult for parents to interpret. More passive infant temperaments elicited fewer positive responses from their parents (Campbell, Leib, Vollman, & Gibson, 1989; Field, 1983; Hanson, 1984; Leifer & Lewis, 1983; Richard, 1986; Rothbart & Hanson, 1983; Stoneman, Brody, & Abbott, 1983). Similarly, increased response time to parental overtures and decreased levels of active infant behaviors were associated with fewer sustained parent-infant interactions (Brooks-Gunn & Lewis, 1984; Buckhalt, Rutherford, & Goldberg, 1978; Cicchetti & Sroufe, 1978; Dunst, Lesko, Holbert, Wilson, Sharpe, & Liles, 1987; Eheart, 1982; Gunn, Berry, & Andrews, 1979; Krakow & Kopp, 1983; Kubicek, 1982; Levy-Shiff, 1986; Mahoney, 1983; O'Sullivan, 1986; Richard, 1986; Spieker, 1986; Stevenson, Leavitt, & Silverberg, 1985; Tallman, 1965).

Previous efforts focused on encouraging parental and infant responsivity in families having handicapped infants. These parent-infant interaction studies revealed significant differences between parents with handicapped children versus parents of nondisabled children. The interactions between parents and their children with sensory, physical, or moderate to severe developmental disabilities consisted of less enjoyment and reciprocity, when compared to the parents of nondisabled children (Cicchetti & Sroufe, 1976, 1978; Gallagher, Beckman, & Cross, 1983; Kogan & Tyler, 1973; Wasserman & Allen, 1985; Wasserman, Shilansky, & Hahn, 1986; Yoder & Farran, 1986).

The frequency of sensitive responding by mothers and fathers was found to increase as a function of the children's enlarged repertoire of

communicative skills (Frey, Fewell, & Vadasy, 1989; Mahoney, Finger, & Powell, 1985; Wasserman et al., 1986). For those infants with severe handicaps and a limited range of behaviors, responsibility for initiating and maintaining parent-infant interactions were consistently assumed by parents (Mahoney, 1983; Yoder, 1986, 1987).

When compared to control groups, interactional behaviors exhibited by mothers toward their children with severe levels of mental and physical involvement included more directive and controlling behaviors to offset their children's decreased rate of responding (Buium, Rynders, & Turnure, 1974; Cardoso-Martin & Mervis, 1985; Hanzlik & Stevenson, 1976; Kogan & Tyler, 1973; Kogan, Tyler, & Turner, 1974; Kogan, Wimberger, & Bobbitt, 1969; Marshall, Hegrenes, & Goldstein, 1973; Mash & Terdel, 1973; Stoneman et al., 1983; Tannock, 1988; Wedell-Monig & Lumley, 1980). Bell's (1971) lower limiting control strategy could explain the frequency of maternal directives. In essence, the quality of infant behaviors did not coincide with maternal expectations; and in response, mothers attempted to elicit greater amounts of infant responses through prompts and directives.

While Mitchell (1987) and Seligman (1975) recommended moderate levels of stimulation, other researchers emphasized greater maternal contingent responding to their children (Mackey, 1978; Mahoney et al., 1985; Mahoney, Powell, & Finger, 1986). Conversely, Crawley and Spiker (1983) and Rodgers (1988) did not encourage a change in maternal directiveness, since these maternal behaviors were found to be positively related to accelerated parental sensitivity and higher cognitive functioning of handicapped children.

The effects of maternal directive behaviors may be best understood

on an individual basis, given that handicapped children present varying degrees of responsiveness and communication skills. When parental behaviors appear to be stifling active infant behaviors, reduction of parental intrusiveness may be encouraged; whereas for lower functioning children, maternal directiveness may be a natural, important adaptation to decreased functioning levels. Appropriate treatment regarding parental intrusiveness or sensitivity can be most accurately assessed and treated on an individual basis.

While most of the literature on parent-infant interaction focused on mothers, paternal behaviors received greater attention in recent years. Fathers were shown to display varying levels of child care and emotional involvement with their nondisabled and handicapped children (Bristol, Gallagher, & Schopler, 1988; Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Gallagher, Scharfman, & Bristol, 1984; Parke, 1986; Stoneman et al., 1983). More decisive research findings were reported with respect to the direct causal effects of fathers' level of adaptation and contingent behavior upon the developmental outcomes of their children with Down syndrome (Tallman, 1965). Fathers, when compared to mothers, were found to be more effective in obtaining handicapped children's compliance to requests and presenting more socially interactive games (McCollum, 1988).

Although paternal behaviors directly influenced children's behaviors, the level of fathers' adaptation indirectly influenced maternal coping behaviors and mother-infant interaction (Belsky, 1984; Bristol, 1984; Bristol & Gallagher, 1982; Bristol et al., 1988; Friedrich, 1979). Maternal attention reserved for fathers and infants'

siblings was found to indirectly influence sibling and paternal interactions with their handicapped children (Margalit, Leyser, & Avraham, 1989).

A further perspective of ascertaining the characteristics of parent-infant interaction with handicapped populations included determination of the quality of the parent-child relationship. The strength of the parent-child relationship has an impact on the entire family unit and serves as an effective basis from which parental feelings of efficacy and child progress arise. The extent of the bond (attachment) between parents and their nondisabled and handicapped children produces the enduring motivation to help them sustain effective family functioning throughout their lives, and make future affectional bonds with others (Bretherton, 1985). Attachment behavior may be defined as any form of behavior that results in the person attaining and maintaining physical proximity to a specific preferred individual (Ainsworth, 1967; Bowlby, 1973, 1978, 1980, 1982b; Cropley, Lester, & Pennington, 1976; Stayton, Ainsworth, & Main, 1973; Yarrow, 1967). Within the bonding paradigm, parents are viewed as the key agent in encouraging the infant's sense of security and his/her exploration of the environment from this secure base (Anderson, 1972; Bishof, 1975; Bowlby, 1982a; Bretherton, 1985; Bretherton & Ainsworth, 1974; Campos & Stenberg, 1981; Emde, 1983; Klinnert, Campos, Sorce, Emde, & Svejda, 1983; Main & Weston, 1982). Thus, the attachment system is formed in such a manner that feelings of security and actual conditions of safety are highly correlated (Bretherton, 1985).

Research on the assessment of attachment behaviors of parents and young children has predominantly focused on nonhandicapped populations.

From this body of literature, it was found that attachment formed in the neonatal period was not prognostic of later mother-infant attachment (Walker, 1980). However, studies conducted within the infants' first year of life proved to be predictive of later attachment (Bates, Maslin, & Frankel, 1985; Dontas, Maratos, Fafoutis, & Karangelis, 1985; Erickson, Sroufe, & Egeland, 1985; Hinde, 1982; Maccoby & Martin, 1983; Main, Kaplan, & Cassidy, 1985; Ricks, 1985).

The most frequent method of assessing attachment includes use of the Strange Situation paradigm (Ainsworth, Blehar, Waters, & Wall, 1978), an observational paradigm that evaluates infant responses with an unfamiliar adult in the presence and in the absence of the child's mother. The Strange Situation paradigm has been implemented with both nonhandicapped (Belsky, Rovine, & Taylor, 1984; Bretherton, Bates, Benigni, Camaioni, & Volterra, 1979; Egeland & Farber, 1984; Grossmann, Grossmann, Spranger, Suess, & Unzer, 1985; Miyake, Chen, & Campos, 1985; Sroufe, Schork, Motti, Lawroski, & LaFreniere, 1984; Waters & Deane, 1985) and high-risk populations (Bretherton & Waters, 1985; Egeland & Sroufe, 1981a, 1981b; Main & Weston, 1981, 1982).

With respect to infants with Down syndrome, application of the Strange Situation paradigm yielded similar behaviors as with nondisabled infants in terms of obtaining their mothers' attention (Cicchetti & Serafica, 1981; Serafica & Cicchetti, 1976). Infants with moderate developmental delays (e. g., Down syndrome) were observed to proceed through the same stages of attachment as nondisabled children, but at a slower rate, with increased response times, and with less separation anxiety (Blacher, 1984a; Blacher & Meyers, 1983; Cunningham, Reuler,

Blackwell, & Deck, 1981; Gunn, Berry, & Andrews, 1982).

In contrast, application and modification of the Strange Situation paradigm proved unsuccessful with infants with severe handicaps, since most of these children failed to demonstrate developmentally appropriate attachment behaviors (Blacher, 1984b; Blacher & Bromley, 1987; Stahlecker & Cohen, 1985). However, a wide range of responses were observed. Infants with severe handicaps exhibited behaviors ranging from neutral responses (e. g., nodding or glancing) to more demonstrative behaviors, such as smiling or crying. Thus, infants having severe handicaps did demonstrate less differentiated behaviors when compared to less impaired children, but they were able to elicit nurturing behaviors from their mothers.

Other observational techniques involved the collection of naturalistic data on attachment behavior (Odom & Shuster, 1986). Infants with severe handicaps were unable to initiate interactions with their parents, which was perceived to hamper future maternal bonding (Blacher & Meyers, 1983). It was found, however, that infants capable of eye contact and exhibiting a smile of recognition successfully formed attachments (Blacher & Meyers, 1983).

Infants with sensory, physical, and mental handicaps have been observed to exhibit delayed, aberrant, or subtle attachment behaviors toward their parents. The levels of children's communicative competence and parents' accurate interpretation of infants' nonverbal cues were seen as necessary prerequisites for development of attachment and maternal sensitivity (Als, Tronick, & Brazelton, 1980a, 1980b; Fraiberg, 1977; Greenberg & Marvin, 1979). Parents typically portrayed their handicapped child as having at least one disturbing behavior that impeded attachment

formation (McGuire & Meyers, 1971; Stone & Chesney, 1978).

Other researchers described the negative effects of children's delayed cognitive abilities and familial risk conditions (e. g., poverty, infant or maternal temperamental characteristics), which interfered with development of strong effective attachment behaviors and mutually satisfying, reciprocal interactions (Crittenden & Bonvillian, 1984; Schneider-Rosen, Braunwald, Carlson, & Cicchetti, 1985; Waters & Deane, 1985). Strong attachment behaviors and effective interactions with infants having severe handicaps were typically not obtained, unless intensive, early intervention was provided.

Intervention focusing on parent-infant attachment and interaction have been targeted for both mothers and fathers of infants with handicaps. The treatment methods included use of videotapes with immediate feedback, direct coaching, modeling, reinforcement of positive parental behaviors, assessment of parental teaching skills, and encouragement of infants' communicative behaviors (Booth, Mitchell, Barnard, & Spieker, 1989; Carney, 1983; Clark & Seifer, 1983; Hanzlik & Stevenson, 1986; Hopman, 1989; Kelly, 1982; Kogan & Tyler, 1973; Parke, 1986). During these types of interventions, parents were taught to interpret and respond contingently to their infants' cues and to enlarge their informal and formal support systems. After completing the infant program, parents, especially fathers, reported less depression and stress, increased child progress, and fewer family problems (Bristol & Gallagher, 1986; Parke, 1986; Vadasy, Fewell, Meyer, Schell, & Greenberg, 1984).

Similar intervention efforts were expended with the creation of the



Teaching Skills Inventory, an assessment of parents' teaching skills (Rosenberg, Robinson, & Beckman, 1984). Based on the data reported, the parents showed positive changes in their instructional skills within a four month period as a result of coaching and weekly-based instruction (Rosenberg et al., 1984; Rosenberg, Robinson, & Beckman, 1986).

Summary of interaction and attachment studies.

The research regarding parent-infant interaction and attachment patterns revealed significant differences between parents and their children with and without handicaps. The interactional behaviors included less contingent responding by parents and their children with blindness, deafness, moderate and severe mental handicaps, and orthopedic impairments. Parent-infant interaction patterns were negatively affected by infants' limited facial and vocal expression, decreased mental age, diminished activity levels, restricted behavioral repertoires, visibility of handicap, and lower communicative competence. When compared to control groups, parents of children with handicaps exhibited more directive and controlling behaviors in an attempt to accelerate their children's low rate of responding. The extent of the disrupting influence of the child's handicap appeared to be related primarily to the severity of the child's level of involvement and communication skills.

Effective parent-infant interaction was highly dependent upon the quality of infant, maternal, and paternal behaviors. Prerequisites for effective interactions consisted of parents' willingness to interpret subtle cues of infants with moderate and severe handicaps, clearly understand child behaviors, and nurture spousal support. When these parental and child behaviors were present, mutually satisfying interactions and effective attachment formation were obtained.

While the Strange Situation paradigm was used with handicapped infants, it appeared to be most applicable to children with moderate handicaps and was more limited for children with severe handicaps. Alternative methods of measuring attachment and interactional behaviors in more disabled populations need to be explored.

In general, the present research concerning attachment and interaction did not result in conclusive evidence regarding the long-term impact of fathers' involvement on the developmental outcomes of children with disabilities and the extent of paternal interest in being an integral part of intervention programs. Similarly, few studies emphasized the influence of early intervention program efforts on the behaviors of the entire family (Bristol & Gallagher, 1986; Sandler, Coren, & Thurman, 1983). Recently, there was a growing interest in specific parental behaviors that had an impact on family well-being.

#### Parental Factors That Influence Family Well-Being

Various factors affect the family's ability to function effectively and to establish mutually pleasurable relationships. Variables including the level of support, perceptions, and amount of parental stress have been shown to influence the quality of family functioning.

Still further, a combination of factors such as the family's subjective interpretation of the situation, family's belief system, available resources, family cohesion prior to the infant's birth, locus of control, quality of the home environment, etc. appeared to help predict which families would experience stress and anxiety (Bristol et al., 1988; Byrne & Cunningham, 1985; Friedrich et al., 1985; McCubbin & Patterson, 1983; Parke, 1986).

Stress experienced by parents and siblings was not necessarily viewed as an inevitable consequence of living with a mentally handicapped child. The stress of parenting a child with a disability was similar to the level of stress experienced by parents of children without handicaps (Bristol et al., 1988). The frequency of stress, as reported by single- and two-parent families having developmentally disabled children, resulted in no statistically differences, after one controlled for the levels of socioeconomic status and maternal education (Beckman, 1983; Bristol, 1985; Longo & Bond, 1984). Thus, one should not assume families may be experiencing accelerated levels of stress, because support from immediate family members could prevent or have a buffering effect on stress.

Interestingly, the severity and nature of the child's intellectual impairment was unrelated to reported levels of parental stress (Beckman, 1983; Bristol, 1987; Kazak, 1986). Instead, the level of physical impairment and behavior problems were seen as mediators of stress, regardless of the level of parental education, family income or ethnicity (Breslau, Staruch, & Mortimore, 1982). Other variables associated with higher levels of perceived stress related to the infant's level of responsiveness, temperament, and increased/unusual care-taking demands; resulting from excessive levels of physical involvement or inappropriate behaviors. Based on the child behaviors reported, an infant with severe physical and mental handicaps often added strain and tension within a family due to accelerated child care requirements.

Furthermore, both fathers' and mothers' satisfaction with the level of informal social support proved to be a salient factor in parental adjustment. Spousal support extended to mothers was positively related

to increased maternal parenting competence (Bristol, 1984; Bronfenbrenner, 1975; Cummings, 1976; Friedrich, Wiltner, & Cohen, 1985; Silber, 1989). Fewer familial coping problems were reported when adequate support and parent education were provided (Bristol, 1985; Dunst & Trivette, 1986a).

Comparative data indicated that fathers of preschool children with developmental delays reported less support on the reported measures, when compared to the mothers (Goldberg et al., 1986). The fathers' decreased levels of support could have been due to limited access to support personnel and professionals, and/or immediate family members could have extended greater maternal support as mothers often had increased child care responsibilities.

In reviewing the literature on parents of children with disabilities, conflicting results were apparent with respect to differential effects of support on mothers and fathers. Fathers of children with handicaps reported more marital difficulties, when contrasted to the fathers of nondisabled children (Bristol et al., 1988). With reference to the disabled children, the mediating factor for paternal adjustment was the amount of perceived spousal support; whereas for the mothers, it was dependent upon the amount of support received and the extent of perceived support (Friedrich, 1979; Parke, 1986).

Furthermore, Solomon (1979) extended the effects of stress presented by Byrne and Cunningham (1985) and Beckman (1983) by reporting stress to be a precipitating cause of abuse. Physical care of handicapped children, in general, taxed the families physically, emotionally and financially. As a result, the long-term physical care coupled with the

parents' initial reactions of anger, denial, and guilt increased the possibility of abuse (Solomon, 1979). Blacher (1984a), supporting Solomon's (1979) findings, reported that separation at birth and repeated hospitalizations could lead to the interference of the normal bonding process, parental abuse, and neglect of the child with severe handicaps. In general, handicapped children have a higher representation in abused populations (Frederich & Boriskin, 1976). Evaluation of studies involving handicapped children revealed, however, numerous methodological weaknesses and failed to support inevitable abuse/neglect of children with handicaps (Chandler & Lubeck, 1989; Dietrich, Starr, & Kaplan, 1980). As such, the presence of a handicapped child does not necessary place the family at-risk for child abuse or neglect.

Given the concerns indicated with the abuse literature, investigators have considered various methodological procedures in order to discern early intervention program's impact on perceived parental stress and behaviors (e. g., Dunst, 1986). Different forms of support can be viewed as mediating variables that affect parental attitudes, aspirations, expectations, and perceptions of child behavior. The more support provided, the less devastating a child's disability may possibly appear. Conceptually, one would evaluate the impact of social support while controlling for confounding and/or competing variables (e. g., age of enrollment into the program) (Dunst, 1986).

Statistical analysis in evaluating key variables affecting child progress could be conducted through stepwise or hierarchical multiple regression, given sufficient numbers of subjects were obtained (Bricker & Dow, 1980; Crnic et al., 1983; Dunst, 1986; Gunn et al., 1982; Marfo, 1984). Main and interactive effects of different sets of variables on

child progress could be obtained.

Summary of parent variables that influence family well-being.

Based on the studies involving parent characteristics, several themes arose. Parents, who experienced less intrafamilial support and greater stress, displayed less than optimal sensitivity and responsivity. As well, parents placed a greater emphasis on the level of their child's physical impairment and behavior problems as the primary cause of parental stress.

While Frodi (1981) and others cited that specific child characteristics or temperamental behaviors (e. g., piercing sounding cry) may precipitate parental abuse, numerous weaknesses in the literature failed to support the inevitable abuse/neglect of handicapped children. Lastly, measurement of the effects of support services extended to families was suggested as an alternative means from which the impact of various early intervention services could be assessed. While parental behaviors influenced the development of their relationships, interactions among siblings were also indicative of family well-being.

Sibling-Child Subsystem

A family systems approach emphasizes the interaction between all family systems. As such, one important subsystem was the sibling-handicapped child relationship. The transactional nature of their relationship results in each sibling influencing the behaviors of the others on a longitudinal basis (Crnic & Leconte, 1986).

The sibling subsystem has characteristics that are influenced by family interactions and are reflective of individual personalities. There are direct and indirect effects from family relationships on the

sibling subsystem. The quality of parental relationships and child-rearing practices with nondisabled and handicapped children has an indirect impact upon the sibling relationship; whereas siblings directly influence one another's behaviors (Brody & Stoneman, 1986; Dunn, 1988; Lawson & Ingleby, 1974; Rodger, 1985). For example, it has been found that the siblings' temperaments were related to the different types of conflicts that arose; while the family's emotional climate was influenced by the frequency and intensity of the conflicts between the children and the amount of parental attention (Brody, Stoneman, & Burke, 1987; Dunn, 1988). Belsky's (1981) approach, that events in one family subsystem (e. g., parent-child) impacts upon the other family subsystems (e. g., siblings), provides support for the transactional, interactional nature present in families. Thus, in any exploration of a family unit, one needs to examine the quality of relationships formed by siblings with all family members.

Specific characteristics associated with the adaptation by siblings to the presence of a child with handicaps have been examined. Previous research has focused upon children's ages, gender, family size, temperament, parental attitude, role assumption, and coping reactions. The focus of the research assumes a reciprocal, interactional model, whereby each child influences the other. In describing the adaptation of nondisabled children to a sibling with handicaps, coping responses have been found to be mediated by familial, psychological, and personality variables (Crnic & Leconte, 1986; Gallagher & Powell, 1989; Lobato, 1983; McHale et al., 1984; Powell & Ogle, 1985).

Graliker, Fishler, and Koch (1962) found that first-born and older siblings fared better by the later birth of a handicapped sibling,

whereas younger male siblings exhibited greater adjustment problems and assumed a more dominant role in the relationship (Breslau, 1982; Crnic & Leconte, 1986). Further, younger siblings close in chronological age did not experience the same amount of parental attention afforded to older children with handicaps (Simeonsson & Bailey, 1986). As well, the level of childhood competence influenced the perceived quality of the relationship by the siblings (Begun, 1989).

Similarly, older female siblings experienced greater adjustment problems, because they were frequently required to assume many of the child-rearing roles for handicapped children (Brody, Stoneman, & MacKinnon, 1982; Farber, 1960; Stoneman, Brody, Davis, & Crapps, 1988). Siblings of the same gender have been reported to be more adversely affected due to their close identification with their siblings with handicaps (Grossman, 1972; McHale, Sloan, & Simeonsson, 1984). Further, Pfouts (1976) has found that nondisabled brothers displayed ambivalence toward their brothers with mental retardation, while the handicapped siblings have been reported to be hostile toward their nondisabled brothers. Thus, differences among age and gender produced varying effects on siblings and demonstrated the interactional effects of siblings' behaviors (Baskett & Johnson, 1982; Brody & Stoneman, 1983, 1986; Lamb, 1978; Moore, 1969).

The research suggested that siblings from larger families adjusted better, since parental expectations were shared among the children (Stoneman et al., 1988; Taylor, 1980). Correspondingly, the children's temperaments and the family socioeconomic status (SES) resulted in differential effects (Gallagher & Powell, 1989). Children from low SES



homes assumed greater care-taking tasks, while middle class children exhibited greater concern with the stigma associated with having a handicapped sibling (Seligman, 1983).

A common theme throughout the studies was that the adaptation and attitudes of the children mirrored parental attitudes (Brody & Stoneman, 1986). It has been suggested that an indirect effect of parental attitudes occurs through the roles assigned and the demands placed upon siblings, e. g., teacher versus playmate (Brody & Stoneman, 1986). In a study exploring the outcomes of interactions between chronically ill children and their siblings, the quality of the marital relationship and maternal support system was related to the siblings' adjustment (Taylor, 1980). Therefore, positive relationships among all family members may be encouraged by including each family member within a treatment program.

Furthermore, determinants of siblings' adjustment were found to be a function of the severity of the handicapping condition, perceptions of the children's competence, and their interactional behaviors. A lack of conclusive evidence for determining typical behavioral reactions by siblings was partly due to the individualized nature and set of circumstances associated with the family's coping.

Siblings' decreased ability to cope with a child's severe handicapping condition originated from varying causes. For example, Skrtic et al. (1984) found that nondisabled siblings were more adversely affected when siblings had mild handicaps since they engaged in similar social activities. In contrast, children with severe handicaps rarely participated in the same social environments as their nondisabled siblings, and thus causing less negative sibling reactions.

Negative behaviors displayed by siblings included competition for

parental attention and resources, compensation for the handicapped child's limitations, confusion regarding parents' variability in coping, exclusion from the parent-disabled child dyad, demonstration of accelerated inappropriate behaviors, and being the recipient of bribes to compensate for diminished parental attention and time (Blackard & Barsh, 1982; Breslau, 1982; Chinitz, 1981; Crocker, 1983; Featherstone, 1980; Harder & Bowditch, 1982; McHale et al., 1984; Taylor, 1980; Tritt & Esses, 1988).

School-age children and adolescents frequently experienced difficulty in answering peer questions about their siblings' handicaps, embarrassment from people's stares, etc. (Skrtic et al., 1984). When siblings reached adulthood, Grossman (1972) found that they expressed fear about bearing a child with handicaps and/or guilt concerning the burden of care that rests with the parent. As the parents grew older, the shift of the responsibility for future care of the handicapped family member often remained with the sibling (Crocker, 1983; Powell & Ogle, 1985). Thus, the family life cycle included a gradual transition of responsibility from parents to their children (Turnbull et al., 1988).

Further, researchers investigated the impact of the normal sibling on the disabled child (e. g., Wellen & Brown, 1982). Siblings reported engaging in negative behaviors toward their disabled siblings, e. g., interrupting the handicapped child's responses, saying or performing cruel or angry acts and statements, etc. (Taylor, 1980; Wellen & Brown, 1982). Sibling reactions included poorer self-concepts, and anger over damage to personal belongings and restriction of family outings (Chinitz, 1981; Ferrari, 1984; Harvey & Greenway, 1984). When compared with

siblings without a handicapped sibling, they were reported to have negative emotions, which included accelerated anxiety, embarrassment, guilt, and anger concerning the handicapped child; conflictive relations with parents; and decreased amounts of interpersonal relationships (Breslau, Weitzman, & Messenger, 1981; Farber, 1963; Fowle, 1968; San Martino & Newman, 1974; Skrtic et al., 1984).

Gallagher and Powell (1989) found that siblings' adjustment problems increased as they became cognitively aware of the full extent of the effects associated with their siblings' handicapping conditions, regardless of child functioning levels. In contrast, Gath (1978) found that sibling adjustment problems, as reported by their parents, were found to exist prior to the birth of siblings with Down syndrome; and thus, not causally linked to the handicap. In review of the results from both studies, the siblings' adjustment was mediated by the children's perspectives, the functional behaviors of the handicapped child, and the severity of the handicapping condition.

While negative effects were reported (Skrtic et al., 1984), some research has yielded positive results. For example, siblings of children with mental retardation were shown to have large networks of friends (Caldwell & Guze, 1960; Cleveland & Miller, 1977; Stoneman et al., 1988), rather than the social isolation reported by Crnic and Leconte (1986).

Other studies considered the influence of the siblings with handicaps on the development and behaviors of nondisabled siblings. For instance, siblings expressed pleasure and a sense of pride resulting from their teaching efforts and their involvement in behavior modification programs (Schreibman, O'Neill, & Koegel, 1983). Yet, Crnic and Leconte

(1986) questioned whether siblings should assume these additional responsibilities. As well, siblings were rated as more supportive, kinder, and less hostile by their parents than siblings of nonhandicapped children (Chinitz, 1981; McHale & Gamble, 1989). Siblings also demonstrated positive, constructive reactions to the presence of a disabled sibling (e. g., an increased sense of competence and self-worth, functioning as behavior change agents, greater empathy, etc.) (Gallagher & Powell, 1989; Powell & Ogle, 1985). Dunn (1988), studying college students, found that they demonstrated higher levels of altruism, patience, and kindness when contrasted to families without handicapped children.

Although effective relationships between siblings may be difficult to establish and maintain, the incidence of relational problems is no more frequent than the control groups (Dunn, 1988). The effects of sibling relationships in families with handicapped children do not conform to a consistent pattern. The important conclusion is that siblings of children with handicaps may or may not have maladjustment. Their adaptations can range along a continuum of inadequate coping to satisfactory adjustment (Breslau et al., 1981; Simeonsson & Bailey, 1986).

Results of studies involving siblings generally have included derivation of arithmetic means for discrete behaviors. This statistical procedure does not permit illustration of the full range of extremely positive or negative behaviors (Simeonsson & Bailey, 1988). Without adequate discussion of all behaviors falling along a continuum, only typical behaviors are shared. Furthermore, many of the early studies

have not included direct observation of sibling interaction, nor comparison to nonhandicapped sibling dyads (Hannah & Midlarsky, 1985). In order to investigate siblings' adaptations to siblings with handicaps, the contexts must be considered, during which interactions are observed, and behaviors and attitudes fluctuate across various activities, e. g., play times, care-taking activities (e. g., feeding) (Brody & Stoneman, 1986; Crnic & Leconte, 1986; Lamb, 1978; Quilitch & Risley, 1973; Senapati & Hayes, 1988; Tritt & Esses, 1988). Many of the reported results revealed parental perspectives of sibling relationships for specific populations, rather than the siblings' viewpoints. Without use of comparison groups, it was not known whether sibling interactions involving handicapped and nondisabled children were typical of relationships shared by nonhandicapped children.

More importantly, Skrtic et al. (1984) have suggested that investigations should include observations of the entire family so a richer understanding of each family would be obtained. Interactions between family members may differ in one- and two-parent families (Bristol, Reichle, & Thomas, 1987; Fewell & Vadasy, 1986; Powell & Ogle, 1985). Thus, observations of the different behaviors displayed by siblings across contexts and times would be possible by investigating the transactional behaviors between family members.

Given the paucity of studies in which the entire family has been observed, Berger and Foster (1986) emphasized evaluation of treatment effects on individual family members and family subsystems. Siblings of children with handicaps have clearly expressed a consistent, recurrent need for information concerning handicapping conditions. Persistent questions raised by siblings involved requests for accurate information

on genetic implications, the nature and cause of the disability, and suggested responses to questions posed by peers (Crnic & Leconte, 1986; Powell & Ogle, 1985; Skrtic et al., 1984; Tritt & Esses, 1988). Other concerns centered upon parental expectations, personal feelings toward their siblings, and available community services for their handicapped siblings (Crnic & Leconte, 1986; Powell & Ogle, 1985).

In general, siblings appeared to be at-risk for social, behavioral, or emotional difficulties due to the continuing stress of living with a sibling with handicaps (Wikler, 1986). As with parents, adaptations varied throughout the siblings' lives. Thus, siblings must be considered as an integral part of the family unit whose needs and individual characteristics must be recognized. Rather than increasing the responsibility of teaching or care-taking, siblings should be provided with supports that strengthen their coping strategies (Crnic & Leconte, 1986; Powell & Ogle, 1985).

In conclusion, siblings exhibited a continuum of positive and negative reactions to the stresses associated with living with a handicapped family member (Turnbull, 1988; Turnbull, Blue-Banning, Behr, & Kerns, 1986). Future investigations should include exploration of effective coping behaviors and processes utilized by families (e. g., family strategies, integration into community activities, etc.). The knowledge gleaned from effective familial coping strategies may assist treatment efforts with other families.

#### Summary of the sibling subsystem.

Research on the effects of having a handicapped sibling produced both confusing and contradictory results. Siblings' adaptations to a

family member with handicaps varied as a result of child temperament, roles assumed, gender and age of siblings, parental coping, SES, and size of the family. The level of adjustment exhibited by nondisabled siblings was also influenced by the amount of integration of the handicapped child into similar environments, and siblings' appraisal of handicapped children's competencies.

Furthermore, siblings exhibited both positive and negative behaviors toward their brothers and sisters with handicaps. Sibling responses to a sibling with a disability significantly differed according to the contexts studied, families' life styles, and personality characteristics of each family member. The overwhelming request from siblings for information regarding the handicapping condition of their brothers and sisters has been well documented. Observation of sibling interaction was recommended as a means to understand the complexity of their responses.

It has been emphasized that the needs and concerns of siblings be incorporated into an intervention plan. No consistent pattern of sibling adjustment has been found as revealed by the variability in positive and negative behaviors across siblings of different ages, gender, and SES. Given the transactional nature of family subsystems, siblings are considered at-risk for developing adjustment problems and must be provided with support and intervention.

### Models of Intervention

A consistent effort to augment child competence and family well-being has been widely reported. A significant number of the previous intervention efforts have been directed toward young children from socially disadvantaged families. Providing services to these children was designed to interrupt the cycle of poor scholastic achievement

arising from poverty (Bereiter & Englemann, 1966; Bryant & Ramey, 1987; Field, Widmayer, Stringer, & Ignatoff, 1980; Heber & Garber, 1971; Lazar, Darlington, Murray, Royce, & Snipper, 1982; Ramey, Bryant, Sparling, & Wasik, 1985; Ramey, Stedman, Borders-Patterson, & Mengel, 1978; Schweinhart & Weikart, 1980; White, 1971).

In general, researchers have proposed two conceptual models of intervention to be used in home- and center-based settings, relationship-focused and family-focused intervention models. A relationship-focused approach refers to a model that emphasizes intervention in the parent-child subsystem. Essentially, a relationship-focused program encourages parent-infant reciprocity, parental competency, and problem-solving (Affleck, McGrade, McQueeney, & Allen, 1982a, 1982b).

Intervention using a relationship-focused model emphasizes the reciprocity inherent within parent-infant interactions; the creation of favorable condition for attachment, and of the foundation for successful parenting skills (Bromwich, 1976, 1978, 1979). When a professional uses this approach, assessment of parental feelings and behaviors results in the identification of specific parent goals. Through intervention, parents learn specific skills that will augment their child's competence as well as develop and reinforce mutually satisfying relationships.

Utilization of the relationship-focused model, as measured by the Parent Behavior Progression (PBP) (Bromwich, 1978), revealed that mothers, who received treatment using the relationship-focused model, displayed greater emotional and verbal responsivity to their infants, participated in more reciprocal activities, and appeared more involved with their children than the control group of parents and children with



high risk and handicapping conditions (Affleck et al., 1982a, 1982b). Similarly, parents continually improved the quality of their behaviors and provided home environments that were supportive of their children's development over a two year period (Allen, Affleck, McQueeney, & McGrade, 1982). The relationship-focused model provided a framework from which measurement of parent-child interactions served as guidelines for intervention.

An extension of the relationship-focused model is the development of the family-focused intervention model. Family-focused intervention emphasizes the parent-child relationship as well as relationships among the other family members (Bristol & Gallagher, 1982). The goals are to assist family members in (a) coping with the evolving needs of a child with a handicap, (b) comprehending the child's role as a family member and as an individual, (c) establishing and maintaining mutually pleasurable and developmentally appropriate parent-infant interactions, and (d) designing programs based on parental input (Bailey, Simeonsson, Winton, Huntington, Comfort, Isbell, O'Donnell, & Helm, 1986). The prior emphasis on the parent-child relationship is altered to include the entire family, in order to ensure the needs of all family members are balanced and child progress is acquired and maintained (Barrera & Rosenbaum, 1986; Darling, 1989; Dunst, Trivette, & Cross, 1986b; Flynn & McCollum, 1989; Mahoney, O'Sullivan, & Fors, 1989; Mahoney & Powell, 1988; Slater & Wikler, 1986).

Similarly, the family-focused intervention model considers the family's perspectives, competing needs, and relationships between various subsystems (Darling, 1989). Within this model, families are viewed as having the capability to make responsible decisions concerning their

children; and any digression from this capability is the result of insufficient opportunities to develop these decision-making skills (Cohen, Agosta, Cohen, & Warren, 1989). Professionals are regarded as facilitators of family change, resulting in parents deriving a sense of control over their life's circumstances. Proposed goals must reflect the cultural, religious, ethnic, and economic characteristics of each family. The importance of obtaining parental perspectives and approval of the proposed intervention goals is stressed, as professionals often overestimate the impact of the handicapping condition on family interaction patterns, the level of support needed, and parents' inability to utilize pertinent teaching techniques (Blackard & Barsh, 1982).

In summary, the family-focused model of intervention consists of observations of the family's interaction patterns, the development of hypotheses regarding family needs, and the implementation of techniques to facilitate family growth. Success of treatment is determined by the "goodness of fit concept", a match between the child, family, and environment (Bailey et al., 1986; Simeonsson, Bailey, Huntington, & Comfort, 1986). It is also suggested that goal attainment scaling could be used as a means to evaluate a matrix of individually determined goals (Bailey, Simeonsson, Isbell, Huntington, Comfort, & Helm, 1988; Calsyn & Davidson, 1978; Carr, 1979; Kiresuk & Sherman, 1968; Maher, 1983; Romney, 1976; Shuster, Fitzgerald, Shelton, Barber, & Desch, 1984; Simeonsson, Huntington, & Short, 1982; Woodward, Santa-Barbara, Levin, & Epstein, 1978). Thus, the impact of family-focused intervention should be evaluated through child progress, the interactions among the family members, and individual family goals.

Prior usage of relationship-focused models primarily involved families having infants with mild or moderate handicaps. The family-focused intervention model has not been implemented. Application of these models to families having children with severe handicaps would provide a holistic approach for facilitating change among the family members (Affleck et al., 1982a, 1982b; Bailey et al., 1986, Barrera & Rosenbaum, 1986; Bristol & Gallagher, 1982; Bromwich, 1978).

The success of any treatment is dependent upon whether the initial positive effects maintain themselves over a reasonable period. Realizing change in the entire family cycle increases the likelihood that positive change would be maintained in parenting skills, child competency, and sustained, pleasurable relationships throughout the family unit. Although these models have, in general, received limited interest, their applicability to families having a child with moderate/severe handicaps is warranted.

#### Summary of models of intervention.

Intervention emphasizing parent-infant interaction involved two approaches. The relationship-focused programs centered on reciprocity within the parent-infant interaction, competency in parenting and problem-solving. In contrast, the family-focused intervention model emphasized service to the entire family in order to assist families in coping with the evolving needs of a child with handicaps, recognizing the child's role as a family member and as an individual, and establishing mutually pleasurable relationships between family members.

#### Efficacy of Early Intervention

The research on the effectiveness of early intervention pointed to specific methodological weaknesses as well as recommendations for future

research. Of the studies presented in this review of the literature, 17 studies (28%) were critical reviews of research regarding attachment, parent-infant interaction and intervention. Throughout the examination of studies including children with handicaps and their parents, an additional 21% provided inadequate subject descriptions that prevented generalization within and across groups of comparable populations.

Similarly, previous reviews found design problems prevalent in the early childhood literature. Weaknesses such as inadequate delineation of criteria for the inclusion of different categories of children in the designs (Simeonsson, Cooper, & Scheiner, 1982), failure to randomly assign children to treatment and control groups (Ferry, 1981; Simeonsson, Cooper, & Scheiner, 1982), sample sizes (Ferry, 1981) and the absence of longitudinal follow-up data (Ferry, 1981) were reported.

Group research designs were not encouraged, because infants with a specific impairment (e. g., mental retardation) represent a heterogeneous group with varying parental characteristics, family interaction patterns, and requirements for community support services (Bailey & Simeonsson, 1986; Barna, Bidder, Gray, & Clements, 1980; Barrera, Routh, Parr, Johnson, Arendshort, Goolsby, & Schroeder, 1976; Mahoney, 1983; Marfo & Kysela, 1985). The heterogeneity of handicapped infant populations was markedly pointed out by Sandow, Clark, Cox, and Stewart (1981). In their study, they found that parents of infants with moderate handicaps were more concerned with cognitive and social developmental gains; whereas parents of infants with severe and profound handicaps viewed program success in terms of personal support and access to information regarding community resources (Sandow et al., 1981).

In response to the concerns associated with group designs, one could utilize specific time series, single subject designs, and replication of specific developmental phenomena across program participants (Kazdin, 1982; Kratochwill, 1978; Marfo & Kysela, 1985). Replication of a treatment program with its accompanying design could be applied across children/families and generalized across similar populations. For example, Kopp and Kaler (1989) recommended measurement of the adaptation made by families, and the growth in the handicapped infant's social-emotional and adaptive skills. In addition, group designs could be used for acquiring an overall measure of a program's applicability to a broader range of clients.

Many of the studies utilized the Bayley Scales of Infant Development (Bayley, 1969) as an index of progress for the handicapped samples. This assessment was standardized on a nonhandicapped population and its use with atypical populations was questioned. Concerns with normative tests involved their global orientation. Children with severe developmental disabilities may demonstrate minimal changes on the assessment. Essentially, these tools were shown to be insensitive to extremely small changes of behavior (Bricker, Carlson, & Schwartz, 1981). Assessment devices such as the Battelle Developmental Inventory, that are standardized, individually administered to nonhandicapped and handicapped persons were recommended (Mott, Fewell, Lewis, Meisels, Shonkoff, & Simeonsson, 1986).

Conversely, one should select measures that are consistent with the goals of the intervention (Dunst, 1986). For example, the relationship-focused intervention model emphasizes a mutually satisfying, reciprocal relationship between parent and child and as such the quality of the

parent-infant interactions should be assessed.

Other measures should concentrate on parental growth. For instance, Sandler, Coren and Thurman (1983) evaluated parental instructional competence as an index of program success. Investigation of the parent's role permitted one to determine the impact of parent training upon family interaction patterns, and parental attitude and knowledge (Marfo & Kysela, 1985; Sheehan, 1981). As mediators of eventual child developmental progress, parents as well as the entire family should be included in the intervention and measurement of program success (Bronfenbrenner, 1975).

Marfo and Kysela (1985) found that 90% of early childhood program considered the parents and the home environment as critical variables in intervention; yet only 10% of the studies collected process data (e. g., programmatic procedures were strictly followed). Two representative studies gathered process data which measured family progress and utilization of community services (Ludlow & Allen, 1979; Soboloff, 1981).

#### Summary of efficacy of early intervention.

The efficacy of previous intervention efforts revealed methodological measurement and assessment problems. Inadequate subject descriptions often limited the generalizability of the results.

Research recommendations encouraged the use of single subject designs with replication of treatment across families. Program models, such as family-focused intervention, appeared to be an attractive alternative to the standard curriculum model for families having children with moderate or severe handicaps. In this type of framework, measurement of family progress could be achieved through observational

data, self-report measures, tests standardized on handicapped populations, evaluation of the children's physical involvement, and inventories that assess specific programmatic goals. Statistical analyses of family variables could encompass the degree of change and the influence of each family member upon the level of child progress. It is with implementation and evaluation of the family-focused intervention model that sustained positive growth may be realized by families and their infants with moderate and severe disabilities.

### Chapter 3

#### Rationale

Infants with moderate and severe handicaps and their families present a multiplicity of needs in terms of support and resource requirements, behavioral competencies, and interaction patterns. Research investigating family functioning has suggested that the transactional nature of families results in each family member influencing the other (Silber, 1989). Infants' communicative competence can influence levels of parental responsivity and sensitivity, as well as affect parental ability to successfully interpret their children's behaviors (Goldberg, 1977). Furthermore, siblings have been considered at-risk for development of adjustment problems as a function of the continuing stress of living with a sibling with handicaps (Wikler, 1986). Based on the research, families having infants with moderate or severe handicaps do not present a typical repertoire of behaviors. Rather, they are characterized by unique qualities that need to be considered on an individual basis.

From the literature on efficacy of early intervention, many of the criticisms have focused on the use of group designs; whereby families, having children with a specific disability, were assumed to be alike (Bailey & Simeonsson, 1986). The lack of concern for the individuality of families has resulted in recommendations for single subject designs that acknowledge the heterogeneity of handicapped infant populations and their families (Marfo & Kysela, 1985).

As a result, a family systems theory is recognized as a framework, from which each family member's relationship influences the behaviors of the other members. Due to the individualized set of circumstances for



each family, a more holistic approach is required that assesses the needs of each family member. One recent, promising approach is the family-focused intervention model (Bailey et al., 1986). This model views the family relationships as a foundation from which mutual pleasure, appropriate interactional behaviors, increased child competencies, and understanding the child's role as an individual and a family member emerge. When professionals are able to facilitate changes in the entire family, there is an increased likelihood that positive behaviors and gains will endure, even after services have been terminated.

Further, the family-focused intervention model stresses flexibility and the analysis of the transactions between family members in order for individualized and varying needs to be identified and addressed. To date, explanation of the model has been presented (Bailey et al., 1986) and professional training for using the model has been reported (Bailey et al., 1988). Yet, there has been no investigation focusing on its implementation for families having infants with moderate and severe handicaps. Utilization of the family-focused intervention model emphasizes a type of research that is contextually bound, and lends itself to both qualitative and quantitative analyses.

Accordingly, evaluation of parent, sibling, and infant behaviors are necessary in order to substantiate progress and to determine the effectiveness of the family-focused intervention model. Measurement of change across family members should include assessment of interactional behaviors, resources, and attitudes. Acquisition of specific behaviors need to be determined by administration of appropriate assessments or goal attainment scaling. Goal attainment scaling has the advantage of

measuring idiosyncratic goals, whose constructs may not be readily available in traditional assessments. Although goal attainment scaling has been used in measuring child gains for specific developmental behaviors (e. g., Maher, 1983), application of this method has not occurred for analysis of behavior change across parents and siblings, nor in the context of family-focused intervention.

Thus, the overall objective of this study is to validate the family-focused intervention model with families and their infants with moderate and severe handicaps. In order to effectively evaluate the family-focused intervention model, the following subgoals will be investigated:

1. Ascertain the amount, type, and quality of behaviors displayed and reported by family members having infants with moderate or severe handicaps.
2. Determine the range of behaviors displayed by parents and their children by evaluating present child developmental functioning and neuromotor status, parental instructional behaviors, and sibling and parental attitudes.
3. Implement and assess the effectiveness of the intervention model through collection of a variety of data from family measures.
4. Determine the usefulness of the Parent Behavior Progression (Bromwich, 1978) for the evaluation of parent-infant bonding and interaction.
5. Determine which type of intervention techniques are most successful in augmenting parent, sibling, and child change through observational data and descriptive statistics.
6. Ascertain the potential usefulness of the Sibling Interaction Scale (Caro & Derevensky, 1989a) as an observational device designed to qualify the types of behaviors displayed by infants with handicaps and their siblings.
7. Determine the potential utility of the Parent Satisfaction Scale (Caro, 1989) and the Inventory of Siblings' Perspectives (Caro & Derevensky, 1989b) as a means to evaluate parental opinion regarding the intervention and the presence of any change in the siblings' attitudes toward their siblings with handicaps.

8. Describe the strategies families utilize as they cope with the current needs of the child with handicaps through the use of qualitative, descriptive, and quantitative data analyses.

The single subject design is chosen as preferable to a group design, since infants with moderate and severe handicaps represent heterogeneous populations. Each parent, infant and family possess their own unique characteristics, family interaction patterns, socioeconomic conditions, and need for community support services (Mahoney, 1983; Marfo & Kysela, 1985). As a result, the goals delineated for each family member will be assessed on an ongoing basis, e. g., level of parent-infant attachment, parental teaching skills, etc.

Furthermore, comparisons across families will occur by investigating the results on global measures, such as infant developmental assessments, parental expectations of child behavior, level of support, sibling interactional behaviors, and evaluation of the home environment. Lastly, an analysis of the objectives stressing unique behaviors through goal attainment scaling will occur. Similar family objectives implemented across families will be evaluated using a multiple baseline approach. When individual family objectives are different from the goal attainment continua of other families, progress will be reported on an individual basis.

Throughout the study, N refers to the sample number. In contrast,  $\bar{X}$  denotes the mean of the sample and S.D. is equivalent to the standard deviation.

## Chapter 4

### Methodology

The family-focused intervention model was designed to enhance effective family interactions and the skill repertoires of infants with handicaps. Documentation of programmatic goals was delineated within each family's individualized family service plan. A description of the families and procedures is provided in this chapter.

### Subjects

Sixteen families having infants with moderate or severe handicaps participated in the study (June-December, 1989). All infants possessed a chronological age that ranged from birth to three years and exhibited moderate or severe developmental delays. A prerequisite for participation in the study was that one parent or primary caregiver was willing to participate, was present for each intervention session, and was fluent in English.

Table 1 provides a detailed description of the infants and their families. The ages of the 11 boys and five girls ranged from two to 43 months ( $\bar{X}$  = 22.13 months, S.D. = 13.90 months). The majority of the children were white (69%), 18% were of mixed heritage, 6% were black, and 6% were hispanic. The children predominantly lived in middle class, intact families in the greater Montreal area and neighboring suburbs. Two single-parent families received public welfare assistance, and one family was high socioeconomic status (SES).

The parents' ages ranged from 23-40 years ( $\bar{X}$  = 31.45 years, S.D. = 4.79 years). As well, 90% of the siblings (12 boys and eight girls) were included in the assessment and intervention phases. The two siblings of child 3 were not included, because they lived in another country. Ages

Table 1

Description of the Infants and Their Families

Child No.	Child Characteristics				Family Characteristics				
	Age (mo.)	Race	Sex	Diagnosis	Estimated SES	Family Unit	Parents' Ages (years)	No. of Sibs	Age of Sibs (mo.)
1	2	W	Fe	DS, MHL	Middle	Intact	M= 27 F= 31	1	61
2	28	Mixed	Ma	Tuberous Sclerosis	Middle	Intact	M= 39 F= 35	1	60
3	29	W	Ma	CP, Spastic Quadriplegia	Lower	Single	M= 38 F= 40	2	120, 168
4	28	W	Ma	Suspected genetic defect	Middle	Intact	M= 35 F= 36	2	48, 74
5	2	Mixed	Ma	DS	Middle	Intact	M= 29 F= 30	0	
6	31	W	Ma	Prader-Willi	Middle	Intact	M= 32 F= 36	1	5
7	29	W	Fe	Tuberous Sclerosis	Middle	Intact	M= 24 F= 23	2	29, 11
8	36	W	Ma	Cortical atrophy, con. facial, mod HL	Middle	Intact	M= 27 F= 27	1	1
9	40	Mixed	Ma	DS	Lower	Single	M= 32	1	16
10	43	W	Ma	CP, Hemiplegia	Middle	Intact	M= 37 F= 37	2	65, 77
11	3	W	Fe	DS	Middle	Intact	M= 27 F= 36	1	32
12	10	W	Ma	DS	Middle	Intact	M= 28 F= 28	0	
13	31	W	Ma	Degenerative genetic disease, sev. visual	Middle	Intact	M= 32 F= 35	3	127, 161, 174
14	10	B	Fe	Hydrocephalus, epilepsy, hypotonia	Middle	Intact	M= 34 F= 34	2	65, 73
15	16	H	Ma	Undiag neuro	Middle	Intact	M= 26 F= 26	0	
16	25	W	Fe	MHL, Undiag neuro,	Upper	Intact	M= 26 F= 28	1	6

Note. B =Black, Child No. =Child number, CP =Cerebral Palsy, con. facial =congenital facial anomalies, DS =Down Syndrome, F =Father, Fe =Female, H =Hispanic, MHL =mild hearing loss, mod HL =moderate hearing loss, M =Mother, Ma =male, Mo. =month, SES =socioeconomic status, Sev. visual =severe visual deficit, Sibs =siblings, Undiag neuro =undiagnosed neurological deficit, W =white

of the siblings ranged from one to 174 months ( $\bar{X}$  = 68.7 months, S.D. = 15 months). The children typically had one older sibling ( $N$  = 8). Five of the children with handicaps had younger nonhandicapped siblings, whereas the remaining nondisabled children were older than their brothers and sisters with handicaps.

The primary diagnoses of the children's handicapping conditions included Down syndrome ( $N$  = 5), tuberous sclerosis ( $N$  = 2), undiagnosed neurological deficit ( $N$  = 2), cerebral palsy ( $N$  = 2), suspected genetic defect ( $N$  = 1), Prader-Willi syndrome ( $N$  = 1), cortical atrophy with congenital facial anomalies ( $N$  = 1), hydrocephaly with hypotonia ( $N$  = 1), and degenerative genetic disease ( $N$  = 1).

From the child assessments, the children displayed a wide range of functional levels. Children, who were considered age appropriate (child 1, 5, 11, 12), obtained age appropriate developmental levels. Child 5 demonstrated approximate age appropriate skills and was included within this group. All children in the age appropriate group have a diagnosis of Down syndrome and were considered at-risk for acquiring developmental delays. In contrast, child 4 exhibited a mild developmental delay and was felt to have mild handicaps.

Children functioning developmentally at one-half of their chronological age (child 2, 3, 6, 9, 10, 14) were classified as having moderate developmental delays, while the remaining group of children was judged as having severe handicaps, having developmental levels one-third to one-quarter of their chronological age (child 7, 8, 13, 15, 16). Furthermore, this latter group of children was diagnosed as having multiple handicaps.

The number of subjects was limited to sixteen families due to the

age of the children, traveling, meal and nap times, and length and duration of the intervention. All assessments and intervention had to be incorporated into family schedules.

All children had been previously referred to local infant programs. After the local infant personnel presented the purposes of this investigation to families, parents volunteered for participation in this study. Prior to the commencement of the study, 50% (N = 8) of the children had received at least six months of early intervention services, whereas the remaining children received educational or therapeutic services 2.5 months into the study (N = 6), or were solely served by the investigator (N = 2) (Table 2). The majority of children had received weekly home- or center-based services from an educator prior to the start of the study. The degree of training and expertise of these professionals differed widely, which was ascertained through discussions with each early interventionist.

### Procedures

Each family received a two-hour weekly home visit over a five month period. Services were provided at no cost to the families. Parent(s) and infant were present during the entire intervention session. Siblings were requested to attend monthly sessions. According to the steps delineated in the family-focused intervention model (Bailey et al., 1986), assessment and intervention proceeded in a systematic manner (Figure 1).

The purposes for each assessment device are outlined on Table 3 and discussed below. Assessment and intervention activities and their corresponding distribution of time are presented on Table 4. The strategies for each visit directly correspond to each step within the family-focused intervention model. The steps to be described, included

Table 2

Description of Services Received by the Children

Subject No.	Educator	PT	OT	Speech	Investigator
1	X*	X*			X
2		X	X	X	X
3			X*		X
4					X
5	X		X		X
6	X				X
7	X				X
8			X*		X
9	X*				X
10	X	X			X
11	X*				X
12	X	X			X
13					X
14	X				X
15		X*			X
16	X	X			X

Note. \* = services began mid-September

Educator = early childhood interventionist with 3 years post-secondary education within the Quebec system

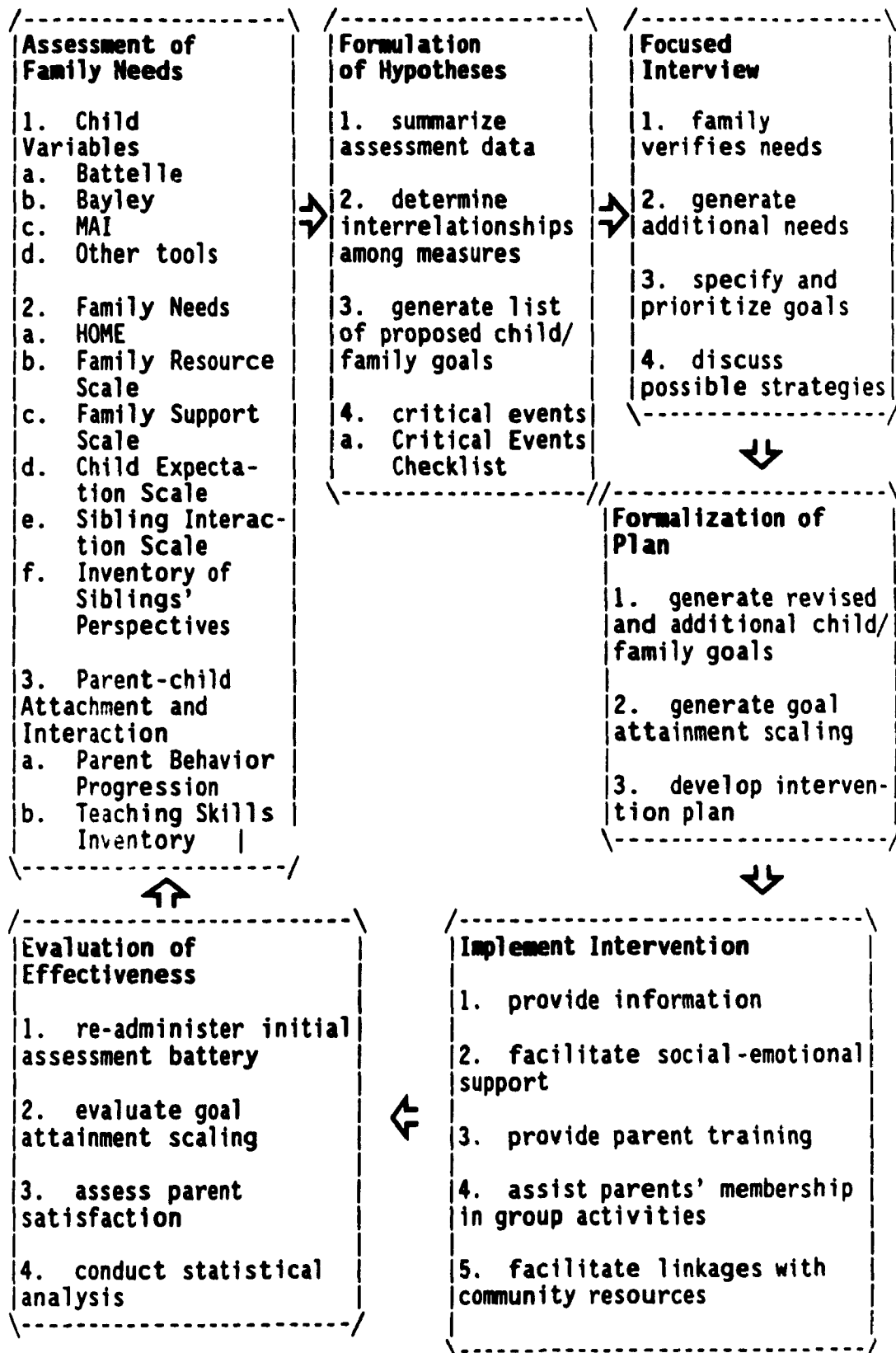
OT = Occupational Therapist

PT = Physical Therapist

Investigator = Home-based intervention provided by the researcher

Speech = Speech and Language Pathologist





**Figure 1.** Steps in the Family-Focused Intervention Model, (adapted from Bailey et al., 1986)

assessment (step one), formulation of hypotheses of family goals (step two), family-focused interview (step three), finalization of the plan (step four), intervention (step five), and evaluation of program effectiveness (step six).

### Step 1. Assessment of Families' Needs

Assessment of the children's developmental levels and neuromotor status, parent-infant interaction, and family needs represented the first step in the family-focused intervention model. The initial step involved the assessment of child, parent, and sibling behaviors in order to determine individual strengths and needs. Given the vast array of behaviors that could be evaluated, it was decided to restrict the numbers of measured behaviors. Through the use of standardized assessments, a composite profile of each family's behaviors was obtained. The assessment devices did indeed evaluate family functioning.

### CHILD VARIABLES.

1. Each infant was assessed with the Battelle Developmental Inventory (Newborg, Stock, Wnek, Guidubaldi, & Svinicki, 1984). The Battelle is a 341 item scale that measures children's (birth to eight years) responses in the personal/social, adaptive, motor, communication, and cognitive domains. It operationalizes specific behaviors, and provides scores for each area and a total score. Further, standard scores, percentile ranks, and age equivalents are provided.

The Battelle was standardized on a sample of 800 children stratified by race, sex, and geographical region. Test-retest reliability and inter-rater reliability ranged from .84 to .99 and .74 to 1.00, respectively. Internal consistency coefficients for all five domains

Table 3

Summary of Tests Used to Assess Families' Needs

<u>Title of Assessment</u>	<u>Purpose of Tool</u>
<b>Child Measures</b>	
Battelle Developmental Inventory	Overall developmental assessment of child
Bayley Scales of Infant Development (Mental Scale)	Cognitive/fine motor assessment
Movement Assessment of Infants (MAI)	Quality of infant's movements
Callier-Azusa Scale	Observational tool for children with deaf-blind and multiple handicaps
Educational Assessment of A Child With Little Or No Fine Skills	Developmental assessment for infants with physical involvement
<b>Parent/Family Measures</b>	
Home Observation for Measurement of the Environment (HOME)	Screening of home environment
Family Resource Scale	Adequacy of family's resources
Family Support Scale	Variety and extent of different sources of support
Child Expectation Scale	Parental perception of child's future capabilities
Parent Behavior Progression (PBP)	Parent-infant attachment and interaction
Teaching Skills Inventory	Parent's instructional skills
Inventory of Siblings' Perspectives	Sibling's attitudes toward the child with handicaps
Sibling Interaction Scale	Observation of the characteristics of the sibling relationship

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Table 4

Time Allocation for Each Step within the Family-Focused Intervention ModelVisit 1 (Step 1)

Child Assessment: Bayley (.5 hour)  
MAI (.5 hour)

Parent Assessment: Family Support Scale (.16 hour) (concurrent with  
child assessment)  
Family Resource Scale (.25 hour) (concurrent with  
child assessment)  
HOME (.50 hour)

Total Time= 1.91 hours

Visit 2 (Step 1)

Child Assessment: Battelle (.75 hour)

Parent-Infant Attachment: Parent Behavior Progression (.33 hour)  
(completed outside session)

Family: Child Expectation Scale (.16 hour) (concurrent with child  
testing)  
Teaching Skills Inventory (.33 hour) (completed outside  
session)  
Sibling Interaction Scale (.25 hour)

Total Time= 1.82 hours

Please note: Step 2 is performed outside the home visits

Visit 3 (Step 3)

Inventory of Sibling Perspectives (.16 hour)  
Family-focused Interview (1.84 hours)

Total Time= 2 hours

Visit 4 (Steps 4 and 5)

Agreement on Plan (.50 hour)  
Intervention (1.5 hour)

Total Time= 2 hours

**Visits 5-13 (Step 5)****Intervention****Monthly Observation of PBP (.33 hour)****Every 2 Months (Visits 6, 8, 10, 12)- Observation using Teaching Skills Inventory (.33 hour)****Total Time= 16 hours****Visit 14 (Final Session, Step 6)****Re-administration of Initial Battery of Tests****Child Assessments: Bayley (.50 hour)****MAI (.50 hour)****Battelle (.50 hour)****Family: Concurrent with the child assessments, completion of following tools:****Family Support Scale (.16 hour)****Family Resource Scale (.25 hour)****Inventory of Siblings' Perspectives (.16 hour)****During the session, the following scales will be administered:****HOME (.50 hour)****Sibling Interaction Scale (.25 hour)****Parent: Completion of Parent Satisfaction Scale (.16 hour) (Parental responses will be sought during administration of the child assessments)****Total Time= 2.98 hours**

were reported to be high (.89-.96) (McLean, McCormick, Bruder, & Burd, 1987). Correlational analyses between the mental and motor Scales of the Bayley Scales of Infant Development (Bayley, 1969), Vineland Social Maturity Scale (Doll, 1969), and various sub-sections of the Battelle ranged from .77 to .95 with most values in the .91 to .95 range.

Moderate correlations were obtained between the Bayley Mental Developmental Index and the various subscales of the Battelle and ranged from .41 to .63 (Boyd, Welge, Sexton, & Miller, 1989). Of significant interest was the high correlation of .89 between the Battelle cognitive

domain and the total age equivalent on the Bayley Mental Developmental Index (Boyd et al., 1989). In the group of infants (birth to 36 months) with identified handicapping conditions, the mean total score age equivalent was found to be significantly lower for the Battelle (7.93 months) when contrasted to the Bayley [9.08 months ( $t = 2.75$ ,  $p < .01$ )] (Boyd et al., 1989). These significantly lower scores could have been due to the re-standardization needed for the Bayley as the Bayley had not been standardized since 1969 (Campbell, Siegel, Parr, & Ramey, 1986). However, the differences between the mean age scores for the cognitive domain (Battelle) and the Mental Scale of the Bayley were found to be not significant, allowing adequate comparability.

2. The Mental Scale of the Bayley Scales of Infant Development (Bayley, 1969) consists of 163 items and measures responses in auditory-visual awareness, object manipulation, imitation, object constancy, social interaction, and expressive language. A mental developmental index and an overall age level are derived.

The standardization sample consisted of 1262 nonhandicapped children, stratified by sex, race, and parental education level. Split-half reliability coefficients were reported to be from .81 to .93 with a median of .88.

Since equivalent standard scores were not presented for functional levels below two months, an extrapolated standard score was determined by using the estimated Mental Developmental Index scores (Naglieri, 1981). Given that the Bayley Scales were not standardized on infants with developmental disabilities, some researchers questioned its validity for infants with handicaps, e. g., Fewell and Vadasy (1987). Other

researchers (Boyd et al., 1989; Shelton, 1989) described its wide acceptability and usefulness as an index of child progress in handicapped populations.

3. **The Movement Assessment of Infants (MAI)** (Chandler, Andrews, & Swanson, 1980) is a 65 item test that assesses the child's neuromotor status and evaluates the quality of the infant's movements, rather than the acquisition of normal developmental motor milestones. The MAI assesses muscle tone, autonomic reactions, primitive reflexes, and volitional movement. Based on the ratings of each behavior, a total is derived for each subscale and a total risk score is computed. The higher the risk score, the greater the indication of a motor handicap.

4. **The Callier-Azusa Scale** (Stillman, 1974) is an observational tool used to evaluate children (birth to nine years) with deafness, blindness, or multiple handicaps. It is especially comprehensive at the lower ranges of the scale and is predicated on the assumption that all children follow a "normal" developmental sequence.

The Callier-Azusa Scale consists of five areas: motor development, perceptual development, daily living skills, language development, and socialization. Based on observable behaviors, an age level for each subscale is obtained.

The major advantage of the Callier-Azusa Scale lies in its standardization sample (children from birth to nine years with multiple handicaps). The manual does not present any statistical data regarding its validation; and as such, one must consider it a teacher-made inventory designed to provide functional levels and programmatic suggestions.

5. **The Educational Assessment of A Child with Little Or No Fine**

**Motor Skills (Caro, 1980)** is a teacher-made inventory that attempts to minimize the fine motor bias found in many infant tools. The objectives, methods, and criteria are written in such a manner that one considers the physical abilities of children with orthopedic impairments as well as their non-verbal and verbal means of communication. Age levels in the cognitive, receptive language, expressive/gestural language, and personal/social areas are derived. The results provide valuable clinical information regarding the infant's behavioral repertoire of skills.

#### **FAMILY VARIABLES.**

Following the assessment of the children's skills, the parent(s) and sibling(s) behaviors and perceptions were evaluated in order to determine their strengths and needs. Given the transactional nature of interactions among family members, it was important to document baseline and post-treatment behaviors of each family member.

##### **Parent measures.**

1. **The Home Observation for Measurement of the Environment (HOME)** (Bradley & Caldwell, 1977), Form 1 (ages birth to three years), delineates the type of stimulation available in the child's home environment. Observations of specific behaviors, such as parental responsivity, acceptance of the child's behavior, organization of the environment, provision of appropriate play materials, parental involvement, and opportunities for varied stimulation are assessed. Individual subscale and total scores are obtained and placed on a continuum. The HOME has been administered to children of all functioning levels (Adams, Campbell, & Ramey, 1984) and has acceptable internal consistency reliability coefficients ranging from .44 to .89 (subscales)



and .89 (total score). Test-retest reliability is reported to be .27 to .77 for the subtests and .62 to .77 for the total score. Administrations of the HOME occurred during the first and last visits (Table 4).

In addition to observational assessments, parents were requested to complete three short checklists that assessed family resources, support, and expectations for their handicapped infants. When adequate personal and family resources were present, parental and family well-being, and investment in implementing prescribed treatments and in interacting with the targeted children were reported to occur (Dunst, Leet, & Trivette, 1988). Conversely, families with more frequently diminished personal and family resources were reported to have greater physical and emotional difficulties, and less time, energy and interest in implementing the treatment programs. The scales, that are included, are described below in numbers two through four.

2. The Family Resource Scale (Leet & Dunst, 1985) is a 30-item rating scale which measures the adequacy of a variety of resources; finances, food, intrafamilial support, informal support, child care, and availability of specialized child resources. Each item is rated on a Likert five point scale. Parents independently completed this scale during the second session. An index of the type of family needs is derived.

Statistical analyses of the Family Resource Scale included ranking of individual items, which yielded a correlation of .81 from the multiple ratings. Test-retest reliability of the hierarchical ranking was .70. When implemented with parents of young children at-risk or with handicaps, split-half reliability was .95. Dunst et al. (1988) reported that the Family Resource Scale accounted for 47% of the variance in

family well-being and 48% in commitment to intervention. Further, child characteristics (chronological age and developmental quotient) accounted for an additional 12% of the variance, but not in commitment to intervention (Dunst et al., 1988).

3. The Family Support Scale (Dunst, Jenkins, & Trivette, 1984) is an 18 item measure assessing the variety and extent of different sources of support. Each item is rated along a Likert five-point continuum ranging from "Not At All Helpful" to "Extremely Helpful". Based on parental responses, the differential sources of support include formal (familial), informal (friends), social groups, professionals, and professional groups (e. g., day care). A total support score is derived and provides a measure of the perceived overall helpfulness of the available support. Additional support requirements that may facilitate effective family integrity and functioning are ascertained.

Split-half reliability of the Family Support Scale was .75 (no inferential statistics were reported) and was corrected for length using the Spearman-Brown formula. Further, test-retest reliability for the total score, conducted one month apart, was .75, whereas after 18 months it was .41. The difference between the test-retest reliabilities most likely reflected the changing needs of the family, an expected occurrence.

In order to determine the level of the applied support each family initially received, analysis of its source, frequency, type, and satisfaction was conducted. Assessment of family resources, needs, and characteristics enabled the interventionist to identify family requirements, and to assess program effectiveness (Fewell, 1986). Thus,

a complete array of available coping strategies employed by parents and siblings were derived.

4. The Child Expectation Scale (Dunst & Trivette, 1986) is constructed to assess parental perceptions of the future capabilities of preschool children with handicaps. It is an eight item rating scale that measures parental perspectives of the children's capabilities in academic, financial, community, and social independence spheres. Parents indicate their perceptions along five possible responses. For example, in answer to "Where do you think your child will live as a teenager?", the parents can circle any one of the five possible responses: "(1) in an institution, (2) in a group home, (3) in a residential school full time, (4) in a residential school/go home on weekends and holidays, and (5) with his/her own family."

Reliability and validity were conducted with 137 parents of preschool children with mental retardation, physical impairments, and developmental delays. The alpha coefficient computed for the eight items was .89 and for the total scale score was .94 (no inferential statistics were reported). Further, split-half reliability yielded a coefficient of .95. The stability coefficient for the total score was  $r = .96$  and for the individual items was  $r = .85$ . Parental responses on the Child Expectation Scale were obtained during the second and final sessions.

#### Sibling measures.

In order to develop a more holistic and appropriate intervention plan for families, assessments of the siblings' perceptions and behaviors were conducted. These assessments included:

1. The Sibling Interaction Scale (Caro & Derevensky, 1989a) is a twelve item observational scale that assesses specific sibling behaviors

and the handicapped infant's (birth to three years) responses (Appendix 1). Specific observable behaviors are examined (e. g., body position, language, feedback), which focus on the sibling as well as the infant (e. g., level of response, role assumed), yielding a composite profile of sibling interaction.

The Sibling Interaction Scale is not a standardized tool, but rather, an observational device upon which discrete behaviors are recorded. A range of observable behaviors within each item are compared across multiple sessions.

This scale was administered during a ten minute unstructured play time session. Naturalistic observation of unstructured play was conducted during the second and final home visits in order to identify specific sibling behaviors (Table 4).

Based on the results, specific behaviors were targeted for each sibling. Interpretation of the results was provided to the parents, while the extent of feedback to the sibling was dependent upon his/her developmental level. Preschool children received praise as well as suggestions regarding how to make interactions more pleasurable with their handicapped siblings. Similarly, feedback was provided to school-age children with specific suggestions and explanations being given.

2. The Inventory of Siblings' Perspectives Forms A and B (Caro & Derevensky, 1989b) (Appendix 1) evaluated children's reactions to their siblings with handicaps. This self-report inventory contains ten items assessing siblings' roles and self-concept, parental availability, behaviors learned from siblings, and the siblings' perceptions of the family's community involvement. As such, it enables exploration of

sibling perceptions concerning their siblings with handicaps and how the family functions.

On the school age version (Form A), the child selects the most applicable items or writes responses into the blank spaces. Children, who are able to read, complete this form independently. On the preschool version, Form B, the child marks the respective "face" after each questions is read by the investigator. A continuum of sad to happy faces represents the potential responses. Feedback regarding each profile is given to the siblings incorporating an individualized summary format.

Upon identification of sibling needs, specific strategies were implemented. For example, if the sibling had informational needs, pertinent material or discussion was provided. Similarly, if the sibling indicated insufficient parental time, presentation of the sibling's perspectives was expressed in order to develop parental awareness. Through problem-solving, observation, and additional resources or support, parents were more able to successfully address the siblings' needs. The combination of the Sibling Interaction Scale and the Inventory of Siblings' Perspectives provided observational and individual data.

#### Parent-infant interaction.

Assessment of parent-infant attachment and interaction comprised an important component within the evaluation process. Parental baseline behaviors concomitant with infants' developmental needs provided the impetus for the specific intervention program (Bristol & Gallagher, 1982; Howard, 1989; Mahoney et al., 1983).

1. The Parent Behavior Progression (PBP) (Bromwich, 1978) is an observational tool that sensitizes the professional to the emergence of

discrete, individual parenting behaviors. The scale is predicated on the assumption that mutually satisfying parent-child interactions, sensitivity, and responsivity result in an optimally stimulating environment for the child.

The PBP is divided into six levels and two forms. Levels one through three comprise the affective basis or the existence of parent-infant attachment. In contrast, levels four through six constitute a delineation of parental behaviors thought to actively provide experiences, which promote the child's developmental growth. Form One is designed for parents of infants with developmental levels of birth up to nine months, whereas Form Two is used with parents of infants functioning within the nine to 36 month age range.

The sequence of the levels within each form serves as a point of reference for specific parental behaviors. This scale, however, does not form a rigid hierarchy that must be strictly followed. Rather, specific parent behaviors are prioritized by professionals in order of importance. Using the PBP, professionals assist parents in balancing the needs of family members.

Included within the manual are case studies with recommendations for intervention. Unfortunately, no statistical analyses (e. g., reliability and validity) were performed. Affleck et al. (1982a, 1982b) and Allen et al. (1982) in validation studies found that HOME and PBP scores were significantly correlated at successive age ranges.

Administration of the PBP occurred during the second home visit and thereafter monthly, in order to ascertain the changing parental needs and subsequent objectives for parenting effectiveness. While the PBP

evaluates the quality of the parent-child interaction and attachment, it does not evaluate the extent to which a parent displays a specific skill.

2. The Teaching Skills Inventory (Version III) (TSI) (Rosenberg & Robinson, 1985) is an observational assessment that is conducted within the context of the home and measures such behaviors as interaction, sensitivity to the child's interests, basic instructional skills, feedback, and child responses. Each of the 14 items is accompanied by a behavioral description, an example, and a list of possible responses.

The content of the TSI assumes that (a) a developmental match between the child's current functional levels and the expectations should be present and, (b) parental responsiveness to the child's interests are continuously available. Similarly, active responding, appropriate feedback, and parental input must be developmentally appropriate. Scores range from one to seven for each item, with six being considered adequate parental performance.

Internal consistency was found to be .96 (no inferential statistics were reported) (Rosenberg et al., 1984). Inter-rater reliability for individual items varied from .83 to .89, with an average of .88 (Rosenberg & Robinson, 1985). Initial evaluation of the parents' teaching skills occurred during the second session and subsequently, every two months (Table 4). New parental skills were targeted after each observational session.

### Step 2. Generating Initial Hypotheses

Within this step, the professional summarized the assessment data and compared the behaviors of each family member on the respective assessments (see Figure 1). Consistency of parental and child behaviors was identified. When discrepant profiles were derived from the various

assessments, consideration of test procedures and the underlying constructs were reviewed, in order to determine test bias, or the presence of any interfering environmental events (e. g., the child displaying an absence seizure).

Within this step, the interventionist completed the Critical Events Checklist, Table 5 (Bailey et al., 1986), which delineated eight stressful emotional and developmental events for families. If a stressful event was present, the professional planned specific interventions in order to reduce its impact, e. g., increasing the amount of the family's resources, providing information, discussion, etc.

A list of potential child and family goals were subsequently formulated. Parental goals in the areas of attachment, interaction, teaching, resources, and support system were established. Family goals emphasized interaction between nondisabled and handicapped siblings, support, and sharing of information.

Curricular objectives for infants were ascertained from the Carolina Curriculum for Handicapped Infants and Infants At Risk (Johnson-Martin, Jens, & Attermeier, 1986). Individualized objectives were formulated in the following areas: sensory abilities, cognitive development, communication, social skills, self-care, fine motor and gross motor. In order to utilize this curriculum, the assessment log and developmental progress chart were completed.

### Step 3. Focused Interview

The family-focused interview comprised the third step (Figure 1). During this interview, the professional explored parental understanding, concerns and goals with respect to the family and the infant with



Table 5

Critical Events Checklist

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**Non-developmental Events**

- |   |     |    |
|---|-----|----|
| 1. Has family learned of diagnosis within last six months?  | Yes | No |
| 2. Does handicapped child have a younger sibling who is at the point where s/he is matching or beginning to exceed the handicapped child's abilities? | Yes | No |
| 3. Is the family anticipating a program transition (e. g., child will enter a developmental center) within the next six months?                       | Yes | No |
| 4. Is the child expecting a medical operation within the next six months?   | Yes | No |

**Developmental Events**

- |  |     |    |
|--|-----|----|
| 1. Has the child just reached or is s/he about to reach the age at which most children walk and is not walking?                                    | Yes | No |
| 2. Has the child just reached or is about to reach the age at which most children begin to feed themselves independently, and is not self-feeding? | Yes | No |
| 3. Has the child just reached or is about to reach the age at which most children talk and is not talking?   | Yes | No |
| 4. Has the child just reached or is about to reach the age at which most children are toilet-trained (bladder control), and is not toilet-trained? | Yes | No |

Bailey, Simeonsson, Winton, Huntington, Comfort, Isbell, O'Donnell, & Helm (1986)

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handicaps (see Protocol for the Family-Focused Interview, Appendix 1).

The primary purpose of this interview was to explore the variety of parental perceptions and responses to parenting young children with handicaps. Their stories relayed specific themes as they recounted

salient episodes in their lives. The organization of their thoughts allowed the investigator to understand the significant events that had an impact upon their lives (Mishler, 1979).

In keeping with the premise of family-focused intervention, identification of the family's cultural values and belief system enabled the suggested parental roles and responsibilities to match the family's value system (Bristol & Gallagher, 1986; Farber & Lewis, 1975; Winton & Turnbull, 1981).

Based on the family's responses on the Family Support Scale, Family Resource Scale, Child Expectation Scale, and Inventory of Siblings' Perspectives, salient issues for the family were identified. From the PBP, TSI, and Sibling Interaction Scale, naturalistic observation of the quality and frequency of parental, sibling, and infant behaviors were obtained. The importance of these data as mediating variables were incorporated into the treatment plan. Using data from the self-report measures and observations, important additional issues were delineated for discussion during the interview. These issues were formulated into questions to be answered and a list of goals to be prioritized. Exploration of these potential avenues for intervention occurred during the third visit.

Pertinent topics to be included were parental and familial coping style, constituents of parental and familial stressful events, as well as the extent of and need for support, information, and education. Critical events that influenced the family's daily living patterns, parental priorities for intervention, parental expectations for their child(ren), characteristics of the home environment, personal attributes of the

family members, and existing environmental or financial problems were also included (McGonigel & Garland, 1988). An occurrence labeled as stressful for a particular family may not constitute a stressful event for another (Bailey & Simeonsson, 1984), and as such, a more individualized program was warranted.

In order to reduce the intrusiveness of the assessment process and the family-focused interview, families were requested to provide pertinent information concerning their prioritized needs, rather than being requested to share extraneous, personal information. All parents were assured of confidentiality (Gallagher, 1989).

The four phases of the family-focused interview included introduction, inventory, summary and priority, and closure (Bailey & Winton, 1988). In order to promote an environment conducive to parents sharing their feelings, the professional used open-ended questions, non-jargon phraseology, effective listening, and avoided giving advice or analysis. Consensus concerning the family's needs, goals, and priorities was derived during the summary and priority phase as the professional and parents discussed parental statements.

The final phase, closure, included the proposed objectives being summarized and the parents being given opportunities to provide additional comments about their feelings or concerns. The importance of this phase was demonstrated by Bailey et al. (1988) in that 25 percent of the final goals were changed to include more specificity.

Each family-focused interview was recorded (audio) and transcribed in order to ensure a comprehensive picture of each family. The context of the parental statements and the overall home environment were considered in interpreting these data (Mishler, 1979). A close reading

of all parental responses and subsequent coding of the patterns revealed recurrent themes (Miles & Huberman, 1984). Previous use of this qualitative research method ascertained parental attitudes toward enrollment in an early intervention program and social interaction among handicapped and nonhandicapped preschool children (Calhoun, Calhoun, & Rose, 1989; Salisbury, Britzman, & Kang, 1989).

The combination of anecdotal notes and the audiotapes helped to ensure accurate interpretation of parental statements and provided a means of "revisiting the data" (Erikson & Wilson, 1982). A consideration of the interactions between parents, siblings, and handicapped children in the context of the interview and assessment sessions suggested reactions, concerns, and cultural beliefs for each family. The comparison of parental responses on the self-report measures (e. g., Child Expectation Scale) and during the interviews permitted the identification of central themes and consistencies in responses.

During this step, parents were also provided with the results from the developmental assessments. Discussion of the children's strengths and weaknesses were described in detail along with information concerning children's functional age levels. The proposed goals were verified and prioritized by the parents. Subsequently, additional objectives were jointly developed, ranked, and possible strategies were defined.

Parental opinions were considered valid pieces of information and constituted the focus of the third step. Bailey and Simeonsson (1984) and Calhoun and Rose (1988) emphasized the importance of gathering such information regarding child and family characteristics, and suggested obtaining parental input regarding the format of the proposed program.

#### **Step 4. Formalization of a Plan**

The finalization of the plan stemmed from the collaborative efforts of parents and professionals. Goals delineated by families took precedence over those recommended by the professional. It was reasoned that goals, which did not fit the family's value system or life style, would be inconsistently implemented or not emphasized (Bailey & Simeonsson, 1984). More importantly, these families perceived the need for immediate intervention for specific family problems. Any proposed plan had to include the family's requested level of involvement with respect to time demands, life style, and value system. If treatment was applied to the family's priorities, potential increases in their skill acquisition could be realized, and a trusting relationship with the interventionist could be established.

Additional goals perceived as less important, were initiated after an effective therapeutic relationship had been established. While reference to the Carolina Curriculum for Handicapped Infants and Infants At Risk assisted in designing specific infant goals and associated treatment activities, parent and family goals incorporated family needs.

As suggested by Turnbull (1988), skills that were required across the life-span of the family were emphasized (e. g., providing adequate food, health, shelter; problem-solving, advocacy, displaying sustained effort, balancing family members' needs, etc.). These skills were developed and evaluated on an ongoing, individual basis.

The combination of assessment data and the parental priorities formed the basis for the proposed treatment. In addition to the inclusion of functional/developmental infant goals, specific family objectives were derived from the assessment data.

Goal attainment scaling provided an avenue in which to explore the hierarchy of possible outcomes for idiosyncratic goals (Maher, 1983). A measurable scale was operationalized with its accompanying behavioral descriptions of possible outcomes. The measurable behaviors formed a continuum ranging from most unfavorable to most favorable outcome. The procedures outlined by Bailey & Simeonsson (1988), Kiresuk and Sherman (1968), Maher (1983), Shuster et al. (1984), and Simeonsson et al. (1982b) were followed and included delineation of specific behaviors and program evaluation.

Case management occurred by mobilizing the necessary resources or services to meet the family's needs. An empowerment and enablement perspective (Dunst & Trivette, 1988) was assumed, in which the family identified its own needs and strengths, and actively approached the specific resources and support according to its desires. A professional, serving in the capacity as a case manager, encouraged the family's capabilities as they learned to negotiate the service delivery system. A proactive approach was promoted, whereby the family's strengths were further developed, their responsibility for their actions was assumed, and their development of making informed decisions was encouraged concerning both short- and long-term goals (Bailey, 1989; Dunst & Trivette, 1988; Dunst, Trivette, & Cross, 1986b). Further, intervention consisted of direct treatment in increasing progress in the following areas: children's competencies, parenting skills, and sibling-infant interactions.

#### Step 5. Implementation of Intervention

In applying intervention to families, a proactive approach was

assumed, which strengthened the family unit (Kaiser & Hemmeter, 1989). The major components of intervention using the family systems approach included assisting families in fulfilling their needs, aspirations, and roles; enhancing family functioning; and assisting in acquiring adequate social support and resources (Deal, Dunst, & Trivette, 1989; Turnbull & Turnbull, 1986). Components were not mutually exclusive and were balanced in order to maintain effective family functioning. The family unit was viewed within the context from which their competencies were acquired.

The major goals of the intervention phase were to increase child competence, parenting skills, parent-infant attachment, family interaction, parental instructional behaviors, and to establish or elaborate the family's support system and resources. While ambitious plans were easily developed, they would have served little purpose in promoting rapport or positive change.

Realistic goals that considered the family's life style were implemented within the context of daily activities. Various demands (e. g., time, finances, intrusiveness, and disruption of family activities) were taken into consideration. Within this context, the child with handicaps represented a central, but not an exclusive, component of the intervention.

The intervention plan was written in a manner that considered the strengths of the family unit, the child's present functional levels, family-identified needs, specific actions assumed by the family and the interventionist, and the evaluation procedures. In selecting the types of interventions, alternative strategies were presented to the parents enabling them to select their preferred option. In delineating short-

and long-term skills, the suggested techniques were flexible, functional, and viable.

Although each family had its unique needs, several themes were encouraged for all families. First, sibling and parental feelings of efficacy were emphasized by increasing their ability to interpret the infants' cues. Parents and siblings were instructed in how to recognize the infants' behavioral changes in requests and temperament (Goldberg, 1977). This aim included teaching infants to respond appropriately to parental and sibling cues and signals.

Given the importance of attachment, instructional strategies included encouragement, modeling, and discussion concerning parental interpretation of their infants' bonding behaviors. It was through these efforts that the establishment of a loving, caring relationship remained a priority of treatment. Another focus was to increase parental sensitivity, contingent responsiveness to the infants' communicative cues, and reinforcement of active infant behavior (Bell, 1971; Mahoney et al., 1985, 1986; Yoder, 1986).

Similarly, parents were encouraged to capitalize on environmental events as opportunities for learning. Incidental teaching often provided the foci of the children's interests. For example, the playing of a cassette tape recorder could serve as an opportunity during which a young child learned to operate the machine independently. Incidental teaching encouraged reciprocal play between infants and their family members and the infants' ability to control play activities with others (Dunst et al., 1987).

Parents were taught specific instructional strategies that enhanced



their teaching effectiveness. Effective parental teaching techniques included providing corrective and positive feedback, task analysis, use of adapted materials, and selecting developmentally appropriate tasks. Reference to the ongoing data from the TSI provided appropriate target behaviors.

The importance of establishing parental instructional skills was predicated on several findings. First, parents with greater teaching skills were apt to provide more appropriate teaching and were more committed to providing appropriate stimulation (Bristol & Gallagher, 1982). Similarly, parents, who displayed instructional competence, extended these skills to other family members, e. g., infants' siblings. Marfo and Kysela (1985) reported that parents with instructional competence produced positive changes in family interaction patterns, attitudes, and knowledge. Thus, the entire family could benefit from the parents' increased skills.

Parental behaviors such as observation, problem-solving, discussion and experimentation were emphasized in order to assist parents in identifying the precipitating causes of events, possible outcomes, and appropriate responses (Bromwich, 1978; Calhoun & Rose, 1988). Through this type of exploration parents could generalize these skills, as well as increase their perceptions of confidence as effective change agents.

In addition to demonstration of effective parenting skills, the interventionist was an empathetic listener and provided positive reinforcement and encouragement to parents as they shared their concerns and aspirations for their children. It was from these informal exchanges that parents often received support. This was substantiated by parental statements verbalized during intervention. In general, the

interventionist served as a support and a resource, and assisted the parents in establishing their own informal support networks.

Throughout the intervention, daily anecdotal notes were written immediately following each home visit. Observation, recording, and interpretation of the families' behaviors suggested the influences of their cultural beliefs upon the activities presented, skills learned, roles assumed, and parental standards for behavior (Jacob, 1982). Qualitative analyses of these observations provided identification of similarities across families, irrespective of their cultural backgrounds.

The importance of assuming a family systems model stemmed from the fact that intervention applied to one member of the system affects the targeted person as well as the entire family (Bronfenbrenner, 1975). The repercussions of any intervention plan involved the accumulated effects of the goals on the child and the family as a whole.

#### Step 6. Evaluation of Effectiveness

The final step of the family-focused intervention model (Figure 1) concerned evaluating the effects of the treatment plan. The initial assessment battery was re-administered through a post-test paradigm and included the Battelle Developmental Inventory, Bayley Scales of Infant Development (Mental Scale), and Movement Assessment of Infants. Those infants who required other appropriate assessments (e. g., use of Callier-Azusa Scale) were reassessed at this stage.

Further, the parents completed the self-report measures, which encompassed the Child Expectation Scale, Family Resource Scale, and the Family Support Scale. As well, observational tools that assess parent-infant interaction and attachment (PBP), the home environment (HOME), and

parental instructional competence (TSI) were conducted during the last two sessions. The Sibling Interaction Scale was also administered during the final home visit.

Specific outcomes that represent change in family functioning included: increased perceived level of support, higher sibling satisfaction, improved sibling-sibling and parent-child interactions, improved quality of the home environment, independent utilization of community services, pursuit of personal or recreational goals, and increased acceptance of the characteristics associated with the child's disability (Bailey & Simeonsson, 1986). These individually determined goals were measured by goal attainment scaling, in which the achieved level of performance was recorded.

Parental satisfaction was measured both in terms of the various facets of the program and of whether the intervention program met the families' expectations (Parent Satisfaction Scale, Appendix 1). Sibling responses were elicited on the self-report measure (Inventory of Siblings' Perspectives) and the observational measure (Sibling Interaction Scale).

Analyses of the results from each assessment involved the calculation of descriptive statistics (Hays, 1981). A single subject analysis with multiple baselines were used to evaluate the progress of each family on all individualized goals. Further, qualitative analyses of sibling and parental statements and behaviors were conducted. Qualitative analyses involved the observation and interpretation of the behaviors and the contexts in which these behaviors were observed. Within all anecdotal and observational data, each sentence was read and the construct associated with the behavior was noted in the margin.

Central themes were then developed from the aforementioned constructs, thus comprising an array of related behaviors. Coding of the behaviors proceeded in this manner for all qualitative analyses. The use of qualitative analyses added to the extent of information obtained from the quantitative data (Jacob, 1982).

In sum, family-focused intervention addressed the major requirements for effective treatment of families with a handicapped infant. This model possessed the means to consider the developmental and functional needs of infants, parental acquisition of parenting and instructional skills, parent-infant attachment and interaction, characteristics of the home environment, and the perceptions and transactions between family members. Implementation of the purposes of the family-focused intervention model encouraged the identification of individual family strengths and needs and the formulation of appropriate treatment plans.

## Chapter Five

### Results

The family-focused home-based intervention model was implemented for 16 families on a weekly basis over a five month period. Based on the research that explored the efficacy of early intervention, a major emphasis was placed on analyzing the child, parental, and sibling behaviors. Due to the heterogeneity of handicapped infant populations, it was expected that the families would differ with regards to their needs for instruction, resources, and community support services (Mahoney, 1983; Marfo & Kysela, 1985). The model was designed to accommodate for these individual differences. Therefore, data were analyzed using a single subject design.

As well, multiple baseline procedures across individual tests and behaviors were conducted for infants, siblings, and parents. In order to determine the rate of progress for each behavior, periodic probes (re-assessments) were conducted to ascertain the effectiveness of treatment. Data regarding the children's, siblings' and the parents' performances were compared to the number of intervention sessions along the X-axis. In that manner, one ascertained whether the treatment techniques were successful in producing changes in the targeted behaviors within specific time intervals. The evaluation of treatment techniques was an important distinction from previous studies, since few studies examined process data (Marfo & Kysela, 1985).

Data analyses included derivation of the mean, range, and standard deviation for the family measures (Table 6). The frequency of observable behaviors was described for each item on the Inventory of Siblings' Perspectives and the Sibling Interaction Scale.

Table 6

Summary of Statistical Analyses


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<u>Procedure</u>	<u>Rationale</u>
Pre-post-test of all instruments	Ascertain child and parent progress
Descriptive Statistics	Ascertain the central tendency and the extent of dispersion of the scores for each variable
Pearson Product Moment Correlation	Determine any relationship among the variables

---

The quantitative and descriptive data are presented according to the steps outlined in the family-focused intervention model (Figure 1). For comparison purposes, pretest and post-test data will be delineated for the infant, parental, and sibling scales within Step 1. The progress obtained on the goals attainment scaling and parental evaluation of the program's effectiveness are presented in Step 4 and Step 6, respectively. While the initial data on child 13 and his family were presented, post-test data were not collected due to the child's death after 2.5 months of home-based services. As a result, family intervention evaluations excluded this family.

Step 1Child Variables

Each child was administered the Bayley Scales of Infant Development (Mental Scale), Battelle Developmental Inventory, and the Movement Assessment of Infants during the pretest and post-test sessions (Table 7). Given that nine of the children were older than 30 months at either

Table 7

Description of Assessment Results

Child No.	CA (mo.)	Bayley MDI	Age Level (mo.)	Battelle Developmental Inventory P/S	Adap	Motor	Comm	Cog	Total	MAI Risk Score	
1	Pre	2.5	84	1.5-2	2	1	2	2	2	1	39
	Post	8	135	9.5	8	8	6	8	7	8	3
*2	Pre	28	<28	9.5	8	10	9	8	10	10	8
	Post	31	N/A	13-13.5	14	15	15	18	14.5	16	4
*3	Pre	29	<28	11	5	10	5	9	16	8	26
	Post	33	N/A	16.5	10	15	9	12	18	12	15
4	Pre	28	56	19	15	15	19	14	17	17	3
	Post	33	N/A	26.5	21	23	29	18	26	23	0
5	Pre	2	91	1.5-2	0	0	2	1	1	0	28
	Post	6.5	88	6	6	5	4	5	6	5	13
*6	Pre	31	N/A	12.5-13	8	13	14	12	14.5	12	13
	Post	36	N/A	18-18.5	10	16	16	14	19.5	15	3
**7	Pre	29	<28	7.5	7	8	7	5	7	7	46
	Post	34	N/A	12	9	11	10	12	13	11	14
**8	Pre	36	N/A	9	8	13	8	10	12	10	32
	Post	41.5	N/A	11.5	11	16	11	12	14.5	13	8
*9	Pre	40	N/A	22	17	23	23	18	18	20	4
	Post	45	N/A	29	23	24	32	22	27	25	0
*10	Pre	43	N/A	19-19.5	14	17	23	18	17	18	21
	Post	48	N/A	26.5	17	20	26	18	24	21	12
11	Pre	3	86	2.5-3	1	2	2	1	3	2.5	10
	Post	8	140	10	7	7	6	8	12	8	0
12	Pre	10	71	9	6	9	7	10	12	8	16
	Post	14	97	14	8	13	10	14	12	11	4
**13	Pre	31	N/A	1	0	0	0	1-2	0	0	70
	Post	Deceased									
*14	Pre	10	<28	4.5	2	3	2	4	3	2.5	68
	Post	14	35	9	6	5	4	8	10	6	64
**15	Pre	16	<28	4.5-5	5	4	2	5	7	4	69
	Post	20	<28	5.5-6	7	6	3	7	8	6	59
**16	Pre	25	<28	5	1	5	4	6	2	4	50
	Post	30	<28	6.5	6	7	4	6	6	6	26

Note. Child 13 died, resulting in no post-test being conducted. Adap = Adaptive, CA = Chronological Age, Child No. = Child number, Cog = Cognition, Comm = Communication, MDI = Mental Developmental Index, Mo. = Month, N/A = Not Applicable, Pre = Pretest, Post = Post-test, P/S = Personal/Social, \* = moderate developmental delay, \*\* = severe developmental delay.

pretest or post-test, comparisons were performed by analyzing obtained age equivalent scores. During the pretest, the children obtained a mean age level of 9.33 months on the Bayley (S.D. = 6.53 months); whereas at post-test (approximately 4.5 months later), they demonstrated an overall average of 14.33 months (S.D. = 7.65 months). Thus, as a group, increases in their mental age levels were equivalent to performances expected for nondisabled children. Inspection of individual performances revealed 10 of the children exhibited accelerated progress (Table 7). Child 5 and 7 approximated normal progression; while child 8, 15, and 16 made minimal gains on the Bayley, but slightly increased their rate of progress. While t-test procedures (Blalock, 1979) of pre- and post-test scores failed to yield significant results, they nevertheless were clinically important, because the children demonstrated increased rates of progress.

On the Battelle Developmental Inventory, the children exhibited similar results ( $\bar{X}$  = 8.27 months, S.D. = 6.29 months) on the pretest. Post-test administration of the Battelle indicated that as a group the children achieved a mean of 12.47 months (S.D. = 6.39), resulting in a gain of 4.2 months in a five month period. Examination of the individual total Battelle scores revealed, as with the Bayley Scales that five of the children (child 1, 2, 4, 6, 11) displayed accelerated rates of performance above the expected normal progression. One child (child 9) exhibited normal progression, while the remaining children exhibited significantly delayed rates of progress (gains of two to four months). As found with the Bayley, t-test analyses failed to reach statistical significance ( $t = 1.93$ ,  $p < .06$ ).



Based on the results from the Bayley and the Battelle, only four children (child 1, 5, 11, 12) were found to be functioning age appropriately or approximately age appropriate on the post-tests. Each of these four children had Down syndrome and were considered to be at-risk for severe developmental delays. Given that these children were functioning at or above their chronological ages, they exhibited important increases in their functional levels. The remainder of the children had functional levels ranging from one-half to one-quarter of their chronological ages. Although these 11 children had significantly lower functional levels on the post-test, the extent of their developmental delays was lessened due to their demonstration of rapid skill acquisition.

Inter-rater reliability was conducted across the Bayley and the Battelle for 6% of the subjects ( $N = 1$ ). Comparison of the test procedures, child responses, Mental Developmental Index, and age levels revealed 100% agreement. While further inter-rater reliability may have been warranted, the 100% agreement and lack of funding precluded any further checks.

On the Movement Assessment of Infants (MAI), the quality of the children's motor abilities was evaluated. A decrease in a score denoted improved performance and less risk. On the pretest, the MAI risk scores ranged from three to 69 (maximum = 70,  $\bar{X} = 28.87$ ,  $S.D. = 21.65$ ); yet on the post-test, the scores ranged from 0 to 64 ( $\bar{X} = 15.00$ ,  $S.D. = 20.22$ ) (Table 7). All children lowered their initial risk scores (decreases ranging from 3-36) and improved the quality of their motor movements.

Additional assessments were administered to four children with increased levels of levels of physical impairments and/or sensory

impairments (Table 8). On the Educational Assessment of a Child with Little Or No Fine Motor Skills, pretest data indicated that the development for child 14 and 15 consisted of gains of one month for every two chronological months. On the post-test, child 14 and 15 displayed a gain of approximately 3.5 months over the 5 month period. In contrast, less positive results were exhibited on the Callier-Azusa Scale. Two children (child 14 and 16) gained approximately two months over the course of intervention. Although this did not approximate a similar level of progress as the other children, their rates of performance

Table 8

Summary of the Results on the Additional Assessments

Child No.	Educational Assessment of A Child with Little Or No Fine Motor Skills				Callier-Azusa Scale				
	Cog	Recep- tive (months)	Expres- sive	P/S	Motor	Percep	Daily Living guage (months)	Lan- guage	Social
13 Pre		N/A			B-1	3	B	3	3
Post *									
14 Pre	4.5-5	4	5	5.5	2.5	4.5	4	5.5	6
Post	8.5	8.5	8	9	6	6.5	4	7.5	9
15 Pre	6.5	6	5	6			N/A		
Post	9.5	9.5	9	8.5					
16 Pre		N/A			5	5.5	8	5.5	6
Post					6.5	7	8	6.5	7.5

Note. \*Child 13 died, resulting in no post-test being conducted.  
 B = Birth, Child No. = Child Number, Cog = Cognitive,  
 Daily Living = Daily Living Skills, Expressive = Expressive Language  
 Perceptual = Perceptual Development, P/S = Personal/Social,  
 Receptive = Receptive Language

increased beyond the previously demonstrated rate.

In general, it appears that the children's performances constituted accelerated or normal functional gains; certainly, their rates of progress increased over time. In addition, all children improved their motor abilities and decreased their risk scores.

#### Parent Variables

In order to describe the parental needs, evaluation of the home environment and the parents' perspectives regarding resources, supports, and expectations of children were gathered. On the Home Observation for Measurement of the Environment (HOME) (Bradley & Caldwell, 1977), the parents (15 mothers, one father) initially exhibited low to moderate rates of responsivity (factor one), with medium to high levels on the post-test (Table 9). Typically, these parents obtained moderate levels of performance for avoidance of punishment (factor two), organization of the environment (factor three), and opportunities for variety in the daily routine (factor six) on the pretest. A majority of the parents consistently achieved the highest ratings on the post-test for these same factors, suggesting an improvement in organizational and interaction skills.

On the provision of appropriate infant equipment and toys (factor five), parents received low (N = 1), medium (N = 8) and high ratings (N = 7) on the pretest. All parents received the highest rating on factor four on the post-test. Although these parents volunteered for the study, no prior knowledge about their level of skill acquisition was ascertained previous to the commencement of the study. More importantly, parental involvement with their children (factor five) was initially high on the pretest and remained high on the post-test, resulting in the conclusion

Table 9

**Results of the Home Observation for Measurement of the Environment****N = 16**

Factors	Frequency of Ratings				
	Low	Medium	High		
I. Emotional and Verbal Responsivity of Mother					
Pretest	6	8	2		
Post-Test	0	2	13		
II. Avoidance of Restriction and Punishment					
Pretest	0	10	6		
Post-Test	0	3	12		
III. Organization of the Environment					
Pretest	1	10	5		
Post-Test	0	3	12		
IV. Provision of Appropriate Play Materials					
Pretest	1	8	7		
Post-Test	0	0	15		
V. Maternal Involvement with the Child					
Pretest	2	2	12		
Post-Test	0	0	15		
VI. Opportunities for Variety in Daily Routine					
Pretest	3	9	4		
Post-Test	0	2	13		
VII. Total Score					
Pretest	0	10	6	Mean	Range
Post-test	0	1	14	35.53	25-41
				42.60	38-46

**Note.** There was no post-test completed on the home environment of child 13, due to his death.

that these parents were responsive to their children.

Similar progress was evident in the parents' total scores. On the pretest, parents typically achieved low to medium ratings ( $\bar{X} = 35.53$ , S.D. = 4.19), as opposed to high levels on the post-test ( $\bar{X} = 42.67$ , S.D. = 1.84). While there were initially lower scores on the pretest, there were no low scores on the post-test. Instead, parental scores approximated the upper levels of the HOME. The t-test of pre- and post-test scores resulted in statistical significance ( $t = 6.04$ ,  $p < .01$ ) substantiating progress in providing a nurturing home environment. Thus, significant progress was obtained for all parents as they achieved higher ratings after treatment.

Parental ability to provide suitable home environments was found to vary according to the children's functional levels. On the pretest, parents of children having severely delayed or age approximate developmental levels received medium ratings for each of the factors, whereas the parents of children functioning with moderate developmental delays had predominantly high ratings. It may well be that children with moderate handicaps encouraged greater responsivity from their parents after exhibited developmental progress, when compared with the other children. On the post-test, the highest ratings were achieved for all parents. In general, appropriate stimulation with accompanying materials or activities substantially increased across all parents.

Parental evaluation of familial resources and supports were ascertained on the Family Resource Scale and the Family Support Scale during the second home visit. On the Family Resource Scale, parents rated 30 different resources along a continuum from "does not apply" to "almost always adequate." Fifteen mothers and one father typically rated

the basic necessities (e. g., food, housing, plumbing, money for necessities, etc.) as "almost always adequate" on the pretest and post-test (Table 10). Similar results were obtained for employment opportunities, public assistance, furniture, access to a telephone, dental care, transportation, child care, and financial ability to purchase equipment. As such, families perceived having an adequate supply of basic necessities.

In contrast, there was a high degree of variability concerning parents' ability to have time for solitude, to socialize, and to remain in good physical condition. In general, parental responses were varied on both the pre- and post-tests. No patterns of responses could be attributed to the severity of the child's disability. While variability continued to be present on the post-test, a positive trend toward a perception of greater adequacy was reported by the parents.

Other concerns involved having sufficient financial resources for baby-sitting, entertainment, savings, and travel or vacations were generally consistent across testing sessions and were distributed from "seldom" to "almost always adequate" for all families. From the parents' perspectives, adequate levels of basic necessities were present across all SES levels, whereas time for socialization was typically rated lower for middle and low SES families than for families in the upper class. While no statistical significance was obtained, changes in parental ratings indicated improvement from a clinical perspective in the extent of available financial resources. Also, increased amounts of time for family activities were reported.

Table 10

Results of the Family Resource Scale

N = 16 (15 mothers and 1 father)		Frequency of Responses					
Resources	N/A	1	2	3	4	5	
1. Food for 2 meals a day							
Pretest	0	0	0	0	0	16	
Post-test	1	0	0	0	2	12	
2. House or apartment							
Pretest	0	0	0	1	0	15	
Post-test	0	0	0	0	3	12	
3. Money to buy necessities							
Pretest	0	0	0	0	5	11	
Post-test	0	0	0	0	5	10	
4. Enough clothes							
Pretest	0	0	0	0	2	14	
Post-test	0	0	0	0	4	11	
5. Heat for house or apartment							
Pretest	0	0	0	0	0	16	
Post-test	0	0	0	0	2	13	
6. Indoor plumbing							
Pretest	0	0	0	0	2	14	
Post-test	0	0	0	0	3	12	
7. Money to pay bills							
Pretest	0	0	0	3	2	11	
Post-test	0	0	0	2	4	9	
8. Good job							
Pretest	2	0	0	1	3	10	
Post-test	2	0	0	1	3	9	
9. Medical care							
Pretest	0	0	0	1	2	13	
Post-test	0	0	0	0	1	14	
10. Public assistance							
Pretest	3	1	0	1	3	8	
Post-test	3	0	0	1	0	11	
11. Dependable transportation							
Pretest	1	2	1	0	3	9	
Post-test	1	1	0	2	3	8	

	N/A	1	2	3	4	5
12. Time to get enough sleep/rest						
Pretest	0	1	2	4	5	4
Post-test	0	0	2	6	6	1
13. Furniture for home						
Pretest	0	0	0	0	2	14
Post-test	0	0	0	0	9	6
14. Time to be by self						
Pretest	0	4	4	4	3	1
Post-test	0	0	3	7	4	1
15. Time for family to be together						
Pretest	1	0	2	2	5	6
Post-test	1	0	1	4	6	3
16. Time to be with children						
Pretest	0	0	1	4	4	7
Post-test	0	0	0	3	8	4
17. Time to be with spouse or close friend						
Pretest	0	2	1	6	2	5
Post-test	1	0	3	3	7	1
18. Telephone						
Pretest	0	0	0	0	1	15
Post-test	0	0	0	0	3	12
19. Babysitting						
Pretest	1	0	3	3	4	5
Post-test	2	0	1	3	6	3
20. Child care/day care						
Pretest	6	1	0	1	2	6
Post-test	5	0	1	2	3	4
21. Money to buy special equipment for child						
Pretest	2	1	1	3	2	7
Post-test	1	0	1	1	6	6
22. Dental care						
Pretest	1	0	0	1	4	10
Post-test	0	1	0	0	5	9
23. Someone to talk to						
Pretest	0	1	0	4	4	7
Post-test	1	0	2	3	6	3



	N/A	1	2	3	4	5
24. Time to socialize						
Pretest	0	1	1	9	2	3
Post-test	0	1	6	2	6	0
25. Time to keep in shape						
Pretest	1	3	1	5	2	4
Post-test	0	0	4	4	5	2
26. Toys for children						
Pretest	0	0	0	2	7	7
Post-test	0	0	0	1	7	7
27. Money to buy things for self						
Pretest	0	0	2	2	8	4
Post-test	0	0	1	5	6	3
28. Money for family entertainment						
Pretest	1	0	1	4	6	4
Post-test	1	0	0	6	5	3
29. Money to save						
Pretest	1	4	2	5	3	1
Post-test	1	3	4	4	1	2
30. Travel/vacation						
Pretest	1	3	3	4	2	3
Post-test	4	0	7	1	1	2

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Note. Child 13 died, which resulted in no post-test evaluation by his parents. The number of parents completing the scale for the post-test totaled 15.

A further perspective was obtained by the parents' completion of the Family Support Scale (Table 11). On this measure, parents evaluated the amount of perceived helpfulness of various types of support (ranging from "not available" to "extremely helpful"). Immediate family members tended to be considered as "sometimes" to "extremely helpful" on the pretest and post-test. On the post-test, there were small increases in the perceived level of support from immediate family members. A high degree of variability was evident in their evaluations of relatives with physical

proximity and degree of availability affecting parental impressions. As a result, immediate family members were considered to be more helpful when they lived in the same town, as opposed to living at great distances from their families.

Parents did not typically avail themselves of any community groups (e. g., parent groups, social clubs, religious organizations). Many considered these sources of support not applicable and verbalized disinterest in these community groups. Similarly, these parents failed to seek support from other parents, co-workers, and day care centers anytime during the study.

The perceived support extended by physicians, professionals, and agencies, as well as early intervention programs was similarly extremely variable with little change during the five month period. Therapists and educators were considered slightly more helpful than physicians and professional agencies. No consistent trends for SES or child functional levels were apparent.

Computation of informal, formal, and total support scores was performed on the Family Support Scale. Informal support included relatives, friends, parents having children with handicaps, co-workers, and community groups, whereas professional groups comprised the more formal support network. The total support score represented the combined formal and informal support scores. On the pretest, informal support was utilized more frequently ( $\bar{X} = 13.2$ , S.D. = 4.35, maximum = 24) than formal supports ( $\bar{X} = 8.73$ , S.D. = 4.92, maximum = 20). While the preference for informal support remained after treatment, increases in both the informal and formal support scores were evident ( $\bar{X} = 15.13$ , S.D. = 4.69, maximum = 25;  $\bar{X} = 10.47$ , S.D. = 4.52, maximum = 20;

Table 11

Results of the Family Support Scale

Number of Mothers completing the form: 15

Number of Fathers completing the form: 1

Item	Frequency of Responses					
	N/A	0	1	2	3	4
1. My parents						
Pretest	3	0	2	3	2	6
Post-test	2	0	1	3	4	5
2. My spouse's parents						
Pretest	2	1	5	2	3	3
Post-test	4	1	2	2	2	4
3. My relatives						
Pretest	5	0	7	2	0	2
Post-test	3	1	3	5	3	0
4. My spouse's relatives						
Pretest	6	1	3	5	0	1
Post-test	4	2	3	3	2	1
5. Husband or wife						
Pretest	1	0	1	1	6	7
Post-test	1	0	0	6	3	5
6. My friends						
Pretest	6	1	3	4	0	2
Post-test	2	1	6	4	2	0
7. My spouse's friends						
Pretest	8	1	2	5	0	0
Post-test	5	2	4	4	0	0
8. My own children						
Pretest	7	1	2	4	2	0
Post-test	8	0	2	1	2	2
9. Other parents						
Pretest	12	0	2	2	0	0
Post-test	7	0	5	3	0	0
10. Co-workers						
Pretest	13	0	1	2	0	0
Post-test	12	0	1	2	0	0
11. Parent groups						
Pretest	16	0	0	0	0	0
Post-test	12	1	1	1	0	0

	N/A	0	1	2	3	4
12. Social groups/clubs						
Pretest	16	0	0	0	0	0
Post-test	13	0	1	0	1	0
13. Church						
Pretest	15	1	0	0	0	0
Post-test	12	0	2	1	0	0
14. My family or child's physician						
Pretest	0	3	4	2	2	5
Post-test	1	2	2	5	2	3
15. Professional helpers						
Pretest	1	0	0	5	5	5
Post-test	0	0	2	2	5	6
16. Professional agencies						
Pretest	8	1	0	2	2	3
Post-test	3	1	2	4	0	5
17. School/day care						
Pretest	15	0	0	0	0	1
Post-test	11	0	1	1	1	1
18. Early intervention program						
Pretest	5	0	0	1	5	5
Post-test	0	0	3	1	4	7
	Range		Mean		S.D.	
Informal Support Score						
Pretest	8-24		13.13		4.35	
Post-test	9-25		15.30		4.69	
Formal Support Scale						
Pretest	2-20		8.73		4.92	
Post-test	2-20		10.47		4.52	
Total Support Score						
Pretest	14-32		22.00		5.87	
Post-test	13-39		25.60		7.36	

Note. Parents of child 13 did not complete the post-test due to his death.

respectively). Comparison of highest scores obtained on pretest and post-test evaluations revealed an increase of one point for the formal

support score and no change for the informal support score. In general, there was little change in the range of both informal and formal support scores.

On the Child Expectation Scale, parental perceptions regarding their children's future capabilities revealed projected school placements ranging from self-contained special education programs to completion of grades seven through twelve (Table 12). The parents of two children with very severe developmental delays envisioned special education programs for their children, a realistic prediction. Similarly, parental responses regarding their children's future financial independence were varied. Parents of children with moderate and severe handicaps envisioned their children would attain moderate to high levels of financial independence, a highly unrealistic outlook. Parents of children with age appropriate levels predicted their children would attain close to total self-sufficiency, a more realistic approach.

Parents perceived that their children would require varying degrees of assistance in their decision-making skills and self-care skills. Likewise, all parents predicted that their children would participate in community activities to a certain extent and develop friendships with family acquaintances and/or children within the immediate neighborhood. Although parental responses varied, they remained consistently within the mid-range of potential responses. For parents of children with age appropriate skills, parental responses were realistic; whereas for parents of children with moderate and severe handicaps, the forecasted levels were highly questionable.

On a more positive note, parents routinely indicated that their children would live at home throughout their adolescent years. A greater

Table 12

**Results of the Child Expectation Scale****N = 17 (14 mothers and 3 fathers)**

Expectation	Frequency of Responses				
	1	2	3	4	5
1. School					
Pretest	1	5	4	6	2
Post-test	0	5	3	6	2
2. Financial Independence					
Pretest	1	5	3	5	3
Post-test	2	3	4	4	3
3. Physical Care for Self					
Pretest	1	1	5	8	2
Post-test	1	0	5	7	3
4. Plan/Manage Own Affairs					
Pretest	2	0	10	4	2
Post-test	1	0	6	8	1
5. Active in Community					
Pretest	2	2	9	4	0
Post-test	2	1	5	6	2
6. Social Relationships					
Pretest	0	2	3	11	1
Post-test	0	2	3	8	3
7. Residential Location during Adolescent Years					
Pretest	0	0	0	2	15
Post-test	0	1	0	0	15
8. Residential Location during Adulthood					
Pretest	0	5	5	3	6
Post-test	0	5	3	2	6

**Note.** Both father and mother of child 1 completed this scale resulting in a total of 17 parents completing this scale during the pretest. The mother of child 13 did not completed the post-test, because her son died prior to the completion of the study, resulting in 16 parents completing the post-test.

The fathers of children 11, 15 and 16 completed the form during the pretest and the post-test.

School= Level of anticipated school placement

Financial Independence= Level of financial independence as an adult

Physical Care= Extent of physical care required as an adult

Plan/Manage Own Affairs= Ability to make decisions as an adult

Active in Community= Participation in church or community activities

Social Relationships= Types of relationships formed, e. g., friends, marriage

Residential Location= Living arrangements as a teen-ager and as an adult

range of responses was given to the child's perceived residential placement at adulthood. Some parents ( $N = 5$ ) envisioned child dependence upon family members, others thought their children would live independently in their own apartments ( $N = 6$ ), and the remaining parents ( $N = 5$ ) projected group home placement. For one-third of the families, parental perspectives were considered unrealistically low (given their children's mild or moderate delays) or unrealistically high (given their children's severe developmental delays). The appropriateness of parental perspectives was determined by considering the children's present rate of progress and the advances made in community residential placements. For the remaining families, realistic outlooks were assumed. In comparison to maternal expectations, fathers consistently indicated lower projected achievement levels for their children, on all items, irrespective of children's abilities.

In conclusion, most parents perceived their children acquiring some level of independence in conjunction with varying degrees of reliance upon others. Parents, who envisioned inappropriately low or high ratings, became slightly more realistic, as indicated by their responses on the post-test. Their more reasonable perspectives could have been due to the information supplied about community alternatives and their observation of their child's rate of progress. Total independence or dependence comprised the least frequency of responses.

### Siblings

As previously suggested, siblings' attitudes and behaviors have been shown to influence the extent of family well-being. Two observational scales were devised in order to explore the role of siblings. During unstructured play sessions, siblings were found to initially maintain momentary, close physical proximity to their siblings with handicaps

(Table 13) on the Sibling Interaction Scale. After intervention, the nondisabled siblings generally increased their involvement by offering toys or initiating games with their handicapped siblings. Similarly, they improved their ability to incorporate language that was understandable to their siblings with handicaps. In contrast, accurate interpretation of the handicapped siblings' behaviors was varied. Throughout intervention, they consistently demonstrated enjoyment while interacting with their siblings. Mutually pleasurable interactions were exhibited by all nondisabled siblings, and were not associated with the child's functional level or disability.

Over time, the siblings exhibited some relinquishing of control concerning which toys or activities were selected. Although the siblings typically chose activities according to their own desires, some were able to intersperse the preferred activities of handicapped children with their own, and/or to permit them to select the type of play. Similar improvements were found in the nondisabled siblings' rise of positive feedback to children with handicaps. The children responded to their nondisabled brothers and sisters by consistently showing active involvement in games. This involvement promoted increased levels of responsivity in nondisabled siblings. There was no trend for gender and chronological age of siblings.

Various roles were assumed by the siblings and the children in their play. Initially, siblings acted as teachers or providers of stimulation. A significant shift in the roles was observed during the intervention program. While siblings continued to teach, manage, or provide stimulation, they also encouraged their brothers and sisters to function as equal playmates during the various activities. In response to the



Table 13

Results of the Sibling Interaction Scale


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N (siblings) = 16    N (children) = 12
Age of Siblings = 1-72 months ( $\bar{X}$  = 41.5 months)

	<u>Frequency of Behaviors</u>					
1. Sibling Body Position	1	2	3	4	5	
Pretest	2	4	2	7	1	
Post-test	0	3	5	7	0	
2. Language	1	2	3	4	5	
Pretest	3	4	2	5	2	
Post-test	0	5	1	5	4	
3. Intensity of Involvement	1	2	3	4		
Pretest	2	4	3	7		
Post-test	0	1	7	7		
4. Extent of Pleasure Demonstrated by Sibling	1	2	3	4	5	
Pretest	3	2	2	5	4	
Post-test	2	0	2	7	4	
5. Sibling's Choice of activities	1	2	3	4	5	
Pretest	8	5	3	0	0	
Post-test	4	1	5	4	1	
6. Attempts to Engage Child	1	2	3	4		
Pretest	5	5	6	0		
Post-test	3	6	6	0		
7. Accuracy of Reading Child's Behavioral Cues	1	2	3	4	5	6
Pretest	6	2	2	2	4	0
Post-test	2	0	6	1	6	0
8. Level of Response by Child	1	2	3	4	5	6
Pretest	1	4	7	0	4	0
Post-test	0	2	2	1	10	0
9. Feedback Provided by Sibling	1	2	3	4	5	
Pretest	5	2	3	5	1	
Post-test	1	0	4	6	4	

<b>10. Role assumed by Sibling</b>	<b>Pretest</b>	<b>Post-test</b>
teacher	7	4
learner	0	0
manager	4	3
manatee	0	0
helper	1	1
helped	0	0
equal playmate	1	7
provider of stimulation	5	5
no role assumed	5	2

<b>11. Role assumed by child</b>	<b>Pretest</b>	<b>Post-test</b>
teacher	1	0
learner	9	3
manager	0	0
manatee	0	0
helper	0	0
helped	0	0
equal playmate	2	4
provider of stimulation	0	0
no role assumed	3	8

**12. Other behaviors observed by sibling and child:**

**Pretest**

1a = Older female sibling shifted the child's position frequently, which eventually annoyed the child.

2a = Older male sibling offered toys to the child, but he became impatient. He frequently wanted the child to do what he desired and rarely considered the child's point of view.

3a and 3b = These older male siblings live in another country.

4a and 4b = The child was included in their activities and these two siblings smiled whenever the child demonstrated a skill to criterion.

6a = This is a young infant. Her actions were a source of stimulation to the child, but the child was involved in his own actions. Little interaction occurred between them.

7a = Due to the sibling's physical abilities far exceeding the child's motor skills, the child steers clear of the sibling. Sensitivity to the child's needs was expected at least occasionally, given her age.

7b = This sibling is a young infant and was more interested in obtaining her mother's attention. Consistent watching of the child was observed by the sibling.

8a = Sibling is a one month old and her behavior was commensurate with her age.

9a = Mutual enjoyment in the interactions between the child and the sibling existed. Frequent eye contact, vocalizations, imitations of each other's actions, and giving toys to the child were evident by the sibling.

10a = Older male sibling displayed laughter when the child purposefully did the opposite of the behavior requested by the parent.

10b = Older male sibling verbalized consistently negative comments, which revolved around how the child could not perform more mature behavior.

11a = Given her age, it was understandable that the sibling could not gauge the intensity of her stimulation to her younger sister.

13c = Older female sibling verbalized, "He's not a baby, so he doesn't use a pacifier", which indicated her knowledge of age appropriate behavior. The sibling spontaneously provided affection and appropriate stimulation, and stated what activities the child enjoys.

14a = Older female sibling provided appropriate stimulation to the child using the available materials, spontaneously spoke to her, and spontaneously provided affection. Occasionally, the objects were presented too close to the child's eyes.

14b = Older male sibling has a mental handicap. He competed for his mother's attention, while the child laughed at and continually watched her brother's actions.

16a = Younger male sibling is a young infant. Sibling did approach the child. Given the child's decreased level of attentiveness, sibling received little feedback/reaction from the child. His behavior was commensurate with his age.

No siblings for children 5, 12, and 15.

#### Post-test

1a = Older female sibling exhibited delight at the child's attempts to crawl and to respond to her requests.

2a = Older male sibling wanted the child to demonstrate behaviors commensurate with his abilities. When the child did not perform the skills up to the sibling's expectations, the grabbing of toys from the child occurred.

4a = Older male sibling alternated between roles as he attempted to maintain the child's engagement in play. The sibling exhibited sensitivity and affection by responding accurately to the child's nonverbal cues.

4b = The older male sibling laughed heartily when the child performed a humorous act. They both engaged with toys of mutual interest.

6a - The younger female sibling exhibited consistent eye contact toward the child. In contrast, the child was observed to exhibit fleeting glances toward his sibling.

7a - The twin female sibling was observed to display obvious pleasure as she spontaneously made overtures toward the child.

7b - The younger female sibling spontaneously offered a dropped pacifier, bottle, and toys to the child on three occasions. Her offers were momentary.

8a - The sibling is a younger female infant. She was observed to vocalize, consistently watch the child, and respond positively to his overtures.

9a - The younger male sibling displayed pleasure as the child and he engaged in water play, cars, and building with blocks.

10a - Older male sibling was observed to direct the child's behaviors in terms of complying with his wishes during unstructured play.

10b - Older male sibling was observed to tell the child to sign for more instead of whining. He consistently observed the child's responses to stimulation and encouraged him to join in the activities with 10a and him.

11a - The older female sibling enthusiastically presented toys to the child. She was observed to dart in and out of the room in order to play with the child.

14a - Older female sibling was warm, affectionate, and enthusiastic in her interaction with the child. Objects were presented at the appropriate distance. Sibling spontaneously encouraged targeted skills from having observed previous intervention sessions.

14b - The older male sibling looked at and vocalized to the child. He was unable to interpret his behaviors in relation to the child's interests due to his significant mental deficit.

16a - Younger male sibling spontaneously approached and vocalized to the child.

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Note. The post-test for child 13 was not conducted due to the death of her younger sibling.

siblings' behaviors, the handicapped children with age appropriate or moderate delays reacted by assuming the active roles of learner, and equal playmate by sharing control of the activities. Children with severe handicaps consistently displayed no identifiable interactive role

with their nondisabled siblings and thus, behaved as passive recipients of their siblings' actions. Due to their diminished levels of awareness and responsivity, children with severe handicaps did not actively interact with their siblings. Given that all children with severe handicaps and three of the children with moderate delays assumed no interactive role, the responsibility for initiating and maintaining these interactions remained with the nondisabled siblings.

Additional spontaneous sibling behaviors observed during the pretest included both positive (e. g., mutual enjoyment, affection, etc.) and negative acts (e. g., impatience, verbalization of negative comments, etc.). Conversely, a shift to consistently more positive behaviors were noted during the intervention and post-test sessions. Siblings exhibited greater pleasure, increased eye contact, initiation of parallel play with toys, and enthusiastic delivery of social games during the post-test. Two brothers (child 10a and 10b) changed their initial stance from predominantly negative behaviors to more prosocial behaviors of managing their handicapped brother's oppositional behavior. One older male sibling (child 2a) continued to perform negative actions toward his disabled brother due to his continuing difficulty in sharing parental attention and in understanding his brother's perspectives.

As a result of being included within the intervention program, more sustained, mutually pleasurable interactions occurred between siblings. Although the nondisabled siblings increased the frequency of their positive behaviors, the responsivity levels of the handicapped children continued to influence the quality of sibling interactions.

Further insight into siblings' behaviors was acquired through the

Inventory of Siblings' Perspectives. On the School Age version (Form A), only three children (ages eight to 14 years) completed the form, which precluded formal statistical analyses. Rather, descriptive information indicated that the older siblings' behaviors included playing, teaching, watching, helping, or baby-sitting their siblings with handicaps (Table 14). The amount of time their parents spent with them ranged from "not enough" to "great".

When in the presence of the handicapped children, siblings indicated both feelings of happiness and pity (e. g., "I feel very bad for him."). Positive outcomes were reported on the pretest and post-test with respect to the siblings' self-concepts, e. g., "Makes me feel good." In contrast, an older brother and sister perceived they were required to assume additional responsibilities in order to augment the quality of the home environment (e. g., baby-sitting).

In general, siblings initially indicated insufficient leisure time as opposed to sufficient time on the post-test. With respect to family involvement in community events, siblings expressed that infrequent opportunities existed for family activities on both assessments.

The siblings thought that they possessed some understanding of the children's handicapping conditions but did not fully comprehend the effects of these disabilities on the pretest and post-test. The study of the results led to the conclusion that there was no effect for the chronological age of the siblings. As a group, they were evenly divided as to whether they would like to join peer support groups. Further, the siblings indicated that they acquired feelings of patience and accepted additional responsibilities, when asked what emotions or behaviors they learned from their disabled siblings.

Table 14

Results of the Inventory of Siblings' Perspectives

(Form A, School-Age Version)

N = 3

## 1. Activities with sibling with handicaps

	frequency	
	Pretest	Post-test
play with	13a, 14a	10a, 14a
feed		
teach		10a
watch the actions of	13a	14a
change diapers		
help with		10a
baby-sit	13b	

2. Time Mother spends	1	2	3	4
Pretest	1	1	1	0
Post-test	0	1	1	0

3. Time Father spends	1	2	3	4
Pretest	1	1	0	1
Post-test	0	2	0	0

## 4. Presence

## Pretest

(13a) "Very bad for him." (13b) "Happy." (14a) "Happy."

## Post-test

(10a) "Happy." (14a) "Happy."

## 5. Self-concept after birth of sibling with handicaps:

## Pretest

(13a) "Supposed to help things go alot smooth around the house because my parents are having a hard enough time as it is." (13b) "Like an older brother." (14a) "Makes me feel good, feel like a grown-up, helpful a little to her."

## Post-test

(10a) "That things have changed very well." (14a) "Her baby-sitter."

6. Time for Leisure	1	2	3
Pretest	1	2	0
Post-test	0	0	2

7. Family Leisure Time	1	2	3	4
Pretest	1	1	1	0
Post-test	2	0	0	0

8. Extent of Information Regarding Sibling's Handicap	1	2	3
Pretest	1	2	0
Post-test	0	2	0

9. Sibling with handicaps learned from sibling:

**Pretest**

(13a) No response. (13b) "Nothing." (14a) "Make her laugh, play."

**Post-test**

(10a) "To talk a little." (14a) "Play."

10. Sibling learned from sibling with handicaps:

**Pretest**

(13a) "Try to be nice and have alot of patience." (13b) "Take alot of responsibilities." (14a) "Treat her different."

**Post-test**

(10a) "That you have to be patient with a baby in the house." (14a) "Take care of her."

11. Desire to meet peers with siblings with handicaps:

	<b>Pretest Frequency</b>	<b>Post-test Frequency</b>
Yes	1	
No	1	1
Maybe	1	1

---

**Note.** 10a refers to eldest male sibling of child 10.

13a refers to eldest male sibling of child 13.

13b refers to older male sibling of child 13.

14a refers to oldest female sibling of child 14.

Post-test data for the older male siblings of child 13 were not collected due to subject 13's death.

Sibling 10a was given both forms of this scale in order to have a pretest and post-test on the initial form (Form B) and to acknowledge his increasing maturity to respond on the school-age form (Form A).



The three school-age siblings (ages eight to 14 years) reported additional responsibilities, a lack of time with their parents, and ambivalence regarding meeting other children with handicapped siblings. Positive outcomes were expressed in terms of learning from and interacting with siblings with handicaps. Since only three siblings were able to complete Form A, because of their age, these results are considered to be speculative and exploratory in nature.

Consistent with obtaining the older siblings' perspectives, preschool-aged siblings (N = 8) (ages three to five years) completed Form B of the Inventory of Siblings' Perspectives. Using a continuum of happy to sad faces, these young children marked the corresponding face for each question. Children with severe handicaps either did not have siblings or their nondisabled siblings were too young (e. g., six months) to understand the measure. The results included siblings of children with age appropriate to moderately delayed functional levels. Typically, the siblings expressed happiness playing with their handicapped brothers and sisters during both assessments (Table 15).

In addition, highly similar pretest and post-test responses became evident concerning the perceived amount of parental time available for siblings and the extent of community activities. With respect to their understanding of the children's handicapping conditions, siblings indicated increasingly greater comprehension, after the five months of intervention.

Table 15

**Results of the Inventory of Siblings' Perspectives****(Form B, Preschool Version)**

<b>N = 8</b>		<b>Frequency of Responses</b>			
<b>Feeling</b>		<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>1. Presence</b>	<b>Pretest</b>	<b>6</b>	<b>1</b>	<b>0</b>	<b>1</b>
	<b>Post-test</b>	<b>7</b>	<b>0</b>	<b>0</b>	<b>0</b>
<b>2. Play with</b>	<b>Pretest</b>	<b>4</b>	<b>3</b>	<b>0</b>	<b>1</b>
	<b>Post-test</b>	<b>6</b>	<b>1</b>	<b>0</b>	<b>0</b>
<b>3. Alone</b>	<b>Pretest</b>	<b>2</b>	<b>2</b>	<b>3</b>	<b>1</b>
	<b>Post-test</b>	<b>2</b>	<b>1</b>	<b>3</b>	<b>1</b>
<b>4. Time mother spends</b>	<b>Pretest</b>	<b>4</b>	<b>3</b>	<b>1</b>	<b>0</b>
	<b>Post-test</b>	<b>6</b>	<b>1</b>	<b>0</b>	<b>0</b>
<b>5. Time father spends</b>	<b>Pretest</b>	<b>4</b>	<b>3</b>	<b>0</b>	<b>1</b>
	<b>Post-test</b>	<b>6</b>	<b>1</b>	<b>0</b>	<b>0</b>
<b>6. Family outings</b>	<b>Pretest</b>	<b>6</b>	<b>1</b>	<b>1</b>	<b>0</b>
	<b>Post-test</b>	<b>6</b>	<b>1</b>	<b>0</b>	<b>0</b>
<b>7. Information regarding handicap</b>	<b>Pretest</b>	<b>3</b>	<b>2</b>	<b>3</b>	<b>0</b>
	<b>Post-test</b>	<b>4</b>	<b>2</b>	<b>1</b>	<b>0</b>

**8. Learned from sibling with handicaps:****Pretest**

(1a) "Nothing, I can't tell." (2a) "No." (4a) "Nothing." (4b) "Kicking balls." (10a) "That he doesn't understand too well." (10b) "It's hard to remember." (11a) No response. (13c) "Just play with him."

**Post-test**

(1a) "To shake my head, because (child's name) taught me." (4a) "To be a good brother." (4b) "Nothing." (10a) "Patience." (10b) "A lot of things. I learned when he wants to play with me, bother me, play rough with me, play dumb with me." (11a) "She is handicapped, very special, a little slow, have to be gentle, and needs help."

### 9. Sibling with handicaps learned from sibling:

#### Pretest

(1a) "Everything I want to tell her, bicycle, most things mommy does, patty cake, kicking, only one who can ride one bicycle." (2a) "I forget." (4a) "To say 'go' and to say 'ee'." (4b) "Kick balls." (10a) "To talk a little." (10b) "Yad Gimal (Hebrew letter) he says it." (11a) "Toilet, to be gentle, still a baby." (13c) "Talk, he goes yes, moves his hands when I sing."

#### Post-test

(1a) "To nod, bang, drop toys." (2a) "Pretend karate/wrestling." (4a) "How to say words." (4b) "How to walk up stairs." (10a) "To talk a little." (10b) "Not to play rough, not to throw usually, to play good; not to put his foot, his hand, and nose in his cake; not to cough on his cake. When (child's name) stands on the chair, I get him off." (11a) "To laugh, to take kleenex, to smile."

Note. 1a refers to older female sibling of child 1.

2a refers to older male sibling of child 2.

4a refers to oldest male sibling of child 4.

4b refers to older male sibling of child 4.

10a refers to oldest male sibling of child 10.

10b refers to older male sibling of child 10.

11a refers to older female sibling of child 11.

13c refers to older female sibling of child 13.

13c was not given the post-test due to the death of her sibling.

1= happy

2= okay

3= sad

4= angry

Similarly, siblings described a greater number of behaviors they learned from their siblings with handicaps on the post-test. Initially, responses were negative or indicative that their siblings had developmental delays. After intervention, the responses seemed to reflect the handicapped children's increased behavioral repertoire and more realistic expectations of the children's capabilities. These young siblings were actively involved in teaching their handicapped siblings motor, verbal, and social skills, as well as compliance to simple requests (e. g., not throw toys).

In summary, the attitudes of the preschool siblings were typically positive concerning enjoyment of being with the handicapped children, their parents, and the frequency of family outings during both assessment sessions. During the intervention, the siblings appeared to have acquired more positive behaviors and increased their teaching skills.

#### Parent-Child Attachment and Interaction

The final component in the evaluation of family needs concerned an analysis of parent-child attachment and interaction. The quality of attachment and interaction between parents and their children as well as parental instructional skills were assessed over successive time intervals. Evaluation of parent-infant attachment and interaction was conducted four times during the study utilizing the Parent Behavior Progression.

From a potential total of 54 observable behaviors, parents ( $N = 8$ ) (Form 1) displayed a mean of 38 attachment and interactional behaviors ( $S.D. = 5.97$ ) on the pretest (Table 16). Over successive assessments, parents as a group increased their behavioral repertoires to the point at which they exhibited all the behaviors on the profile. As a result, parental test scores reached the ceiling of the test. Through the evaluation of individual responses, no differences were found among parents of children with different handicaps and those from different SES levels.

With the inspection of individual parental behaviors, parents ( $N = 8$ ), having children functioning above nine months (Form 2), demonstrated positive increases over time (Table 16), independent of their children's disabilities. On the pretest, these eight mothers displayed in excess of

Table 16

Results of the Parent Behavior Progression

		Form 1			
N= 8 (7 mothers, 1 father)					
Total Score (Maximum = 54)	Pretest	Month 2	Month 3	Post-test	
Range	29-46	47-54	52-54	54.00	
Mean	38.00	51.86	53.57	54.00	
S.D.	5.97	2.34	.79	0.00	

Note. The mother of child 13 was not evaluated after Month 2 due to her son's death.

N = 8 mothers	Form 2			
	Pretest	Month 2	Month 3	Post-test
Total Score (Maximum = 70)				
Range	27-58	50-70	45-70	46-70
Mean	45.63	64.50	63.00	64.63
S.D.	9.93	6.80	9.10	8.31

Note. S.D. = Standard Deviation

50% of the specified behaviors ( $\bar{X}$  = 45.63, S.D. = 9.93, maximum = 70) on the protocol. At month two, a substantial increase was found over the initial rating ( $\bar{X}$  = 64.50, S.D. = 6.80). During the subsequent months and the post-test, one mother's lack of improvement appeared to appreciably reduce the group score (see pages 156-157). During Month 3, parents obtained a mean of 63.00 (S.D. = 9.10), with similar increases on the post-test ( $\bar{X}$  = 64.63, S.D. = 8.31). When one excludes the extremely low scores of mother 10 on the post-test, the final scores ranged from 60

to 69 (maximum = 70). While most parents displayed definite increases in their attachment and interactional behaviors over the five month period, the findings were not statistically significant, yet were clinically important. Increments in these behaviors indicated the acquisition of a strong bond with their children and the ability to promote mature child behaviors in all developmental domains.

In addition to the behaviors observed on the Parent Behavior Progression, parental instructional competence was identified through repeated administrations of the Teaching Skills Inventory (TSI). This instrument reflected the parents' ability to respond contingently to their children as well as match their expectations to their children's skill repertoire. The TSI was administered during the pretest, month three (mid-point) and post-test (Table 17).

While the goal of initiating activities was to be shared equally among parents and their children, the parents typically chose which activities their children were to experience on the pretest. Over time, there was a gradual trend for all parents becoming less directive during play times with their children. Similarly, parental behaviors resulted in an increased sensitivity to their children's non-verbal behavior over the five month period.

Parental educational levels and previous employment experiences resulted in varying levels of parental sensitivity. Parents (parent 1, 2, 4, 5, 6, 16) having undergraduate or graduate degrees exhibited sensitivity levels slightly above the group norm, independent of the child's functional level. Conversely, parents with limited work experience and no college degree (parent 7, 8, 13) exhibited decreased

Table 17

Results of the Teaching Skills Inventory

Ratings	1	2	3	4	5	6	7
	Frequency of Behaviors						
I. Structure							
1. Adult Initiated Versus Child Initiated Activities							
Pretest	8	1	2	3	1	1	0
Mid-point	1	3	3	4	3	1	0
Post-Test	0	5	4	5	1	0	0
II. Adult Sensitivity to Child							
Pretest	0	0	1	1	0	4	10
Mid-point	0	0	0	0	2	1	12
Post-Test	0	0	0	0	1	2	12
III. Instructional Skills							
1. Clarity of Activity Objectives to the Rater							
Pretest	0	0	0	0	2	7	7
Mid-point	0	0	0	0	0	3	12
Post-Test	0	0	0	0	0	3	12
2. Developmental Appropriateness of the Activities							
Pretest	0	0	0	1	1	4	10
Mid-point	0	0	0	0	1	2	12
Post-Test	0	0	0	0	0	1	14
3. Appropriateness of Verbal Instruction							
Pretest	0	0	0	0	2	6	8
Mid-point	0	0	0	0	0	4	11
Post-Test	0	0	0	0	0	1	14
4. Appropriateness of Non-Verbal Instruction							
Pretest	0	0	0	1	0	4	11
Mid-point	0	0	0	0	1	1	13
Post-Test	0	0	0	0	0	1	14

Ratings	1	2	3	4	5	6	7
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### 5. Adjustment of the Complexity of the Activities

Pretest	0	0	0	1	3	6	6
Mid-point	0	0	0	0	1	5	9
Post-test	0	0	0	0	0	2	13

### IV. Feedback

#### 1. Description

	Mostly Verbal	Mostly Non-Verbal	Both
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Pretest	15	0	1
Mid-point	14	0	1
Post-Test	5	2	8

2. Count of Positive Feedback	Range	Mean	S.D.
Pretest	0-7	2.80	1.97
Mid-point	2-10	6.40	2.80
Post-Test	4-12	7.80	2.34

3. Count of Verbal Corrective Feedback	Range	Mean	S.D.
Pretest	0-8	2.33	2.53
Mid-point	0-5	2.53	1.60
Post-Test	1-6	3.13	1.46

4. Appropriateness of Feedback	1	2	3	4	5	6	7
Pretest	1	0	1	2	3	7	2
Mid-point	0	0	0	1	0	7	7
Post-test	0	0	0	0	0	3	12

### V. Child Responses

1. Count of Activities	Range	Mean	S.D.
Pretest	2-4	2.93	0.59
Mid-point	2-6	3.80	1.08
Post-test	3-7	4.40	0.99

2. Frequency of Criterion Responses	Range	Mean	S.D.
Pretest	0-100%	50.20%	31.83
Mid-point	20-100%	70.00%	19.74
Post-Test	75-97%	83.47%	7.95

3. Child Participation	1	2	3	4	5	6	7
Pretest	0	4	1	0	2	4	5
Mid-point	0	0	0	1	2	2	10
Post-Test	0	0	0	0	0	4	11

**Note.** N = 16, The mother of child 13 was only given the pretest of this tool due to her son's death.

levels of sensitivity to their children with severe handicaps. While some of the parents of children with severe handicaps demonstrated



diminished sensitivity, others displayed high levels of sensitivity. Parents of children with moderately delayed or age appropriate skill levels exhibited consistently high levels of sensitivity.

Likewise, parental instructional skills reached the ceiling for each item on both assessment sessions. Positive parental behaviors included presenting developmentally appropriate activities with clear objectives, modifying tasks according to the child's capabilities, using non-verbal and verbal modes of instruction, and providing appropriate feedback. Statistical analysis confirmed that increases in parents' teaching skills were significant ( $t = 4.71$ ,  $p < .01$ ).

Throughout intervention, parents altered their initial high rates of verbal feedback to include a more desired mix of verbal and non-verbal feedback on the post-test. On the post-test, the frequency of both positive and corrective feedback increased with no effect for SES and parental educational level.

In response to parental requests, the children initially exhibited the targeted behaviors 50.2% (S.D. = 31.83) of the time. In contrast, they increased the rate of their correct responses to 83.47% (S.D. = 7.95) on the post-test. In addition, children participated more frequently in the activities on the post-test. These positive results were a function of the children's expanded skill repertoire and their increased participation ( $t = 3.93$ ,  $p < .01$ ;  $t = 4.94$ ,  $p < .01$ , respectively). In conclusion, parents became less directive, their instructional behaviors were broadened, and child participation increased.

Coupled with the results on the individual assessments, comparison among the parent and child variables was performed on the family scales. The siblings' responses on the Sibling Interaction Scale and the

Inventory of Siblings' Perspectives (Forms A and B) were not included in any statistical analysis. The results from these two assessments were descriptive in nature and were analyzed according to the interactional behaviors observed across all siblings.

Other analyses of data included the determination of inter-correlation matrices among the child and parent variables. The Pearson product-moment correlations were obtained in order to investigate whether the correlations obtained matched theoretical expectations.

Researchers, such as Beckman (1983) and McCollum and Stayton (1985), suggested that levels of family resources and support systems influenced the extent of attachment, parental sensitivity, parental instructional competence, and appropriate stimulation provided to children. Further, Bronfenbrenner (1975) emphasized that the quality of the home environment resulted in varying parental abilities to provide developmentally appropriate stimulation. In order to measure the viability of their claims, parent scores on the Family Resource Scale and Family Support Scale were correlated with scores obtained on the Child Expectation Scale, PBP, HOME, and TSI (Table 18).

Correlations between pretest and post-test scores on the Family Support Scale and the Parent Behavior Progression (PBP) with the HOME were in the low to moderate range (Table 18). It could be concluded that the quality of the parent-infant interactions and levels of perceived support were only moderately associated with the quality of the home environment and could reflect a possible narrow range of parental behaviors.

The pretest scores on the Family Resource Scale were significantly

Table 18

Pearson Product Moment Correlations Among the Parent Variables

	HOME1	HOME2	FRS1	FRS2	FSS1	FSS2	CES1	CES2
HOME1	1.00	.67**	-.12	.25	.37	.20	-.23	-.25
HOME2		1.00	-.05	.41	.65**	.34	-.14	-.06
FRS1			1.00	.71**	-.02	.15	-.25	-.32
FRS2				1.00	.44	.46	-.19	-.26
FSS1					1.00	.78**	-.10	-.03
FSS2						1.00	-.04	-.09
CES1							1.00	.93**
CES2								1.00

	PBP1	PBP2	PBP3	PBP4	TSI1	TSI2	TSI3
HOME1	.23	.20	.00	.07	.26	.18	-.01
HOME2	.52*	.38	.37	.40	.02	.07	.09
FRS1	.22	.11	.11	.10	.21	.18	.62**
FRS2	.44	.26	.22	.24	.10	.25	.46
FSS1	.44	.33	.34	.33	-.05	-.01	-.10
FSS2	.43	.32	.33	.31	-.05	-.02	.13
CES1	.15	-.01	-.10	-.10	.36	.32	.11
CES2	.10	.00	-.01	-.07	.34	.34	.05
PBP1	1.00	.76**	.70**	.72**	.32	.27	.52**
PBP2		1.00	.94**	.96**	.35	.41	.48
PBP3			1.00	.98**	.14	.30	.45
PBP4				1.00	.12	.25	.42
TSI1					1.00	.70**	.51
TSI2						1.00	.60*
TSI3							1.00

Note. N = 15. \* = significant at .05 level, \*\* = significant at .01 level, HOME1 and HOME2 = Home Observation for Measurement of the Environment, FRS1 and FRS2 = Family Resource Scale at pretest and post-test, FSS1 and FSS2 = Family Support Scale at pretest and post-test, CES1 and CES2 = Child Expectation Scale at pretest and post-test; PBP1, PBP2, PBP3, and PBP4 = Parent Behavior Progression at pretest, month 2, month 3, and post-test, respectively; TSI1, TSI2, and TSI3 = Teaching Skills Inventory at pretest, mid-point, and post-test, respectively.

related to post-test results on the Teaching Skills Inventory (TSI)

( $r = .62$ ,  $p < .01$ ), thereby indicating initial level of resources were

related to parental instructional competence. The pretest ratings on the

PBP were associated with post-test ratings on the TSI ( $r = .52, p < .05$ ), suggesting a positive relationship concerning the quality of parent-infant interactions and the amount of parental instructional competence.

In addition, the Pearson product moment correlation procedure was used with the child variables in order to determine if there was a strong relationship between the scores of the two tests. If a strong positive correlation was obtained, it would indicate that the functional levels of the children were similar on both assessments. Post-test Bayley scores were significantly correlated with the post-test scores on the Battelle ( $r = .96, p < .01$ ) (Table 19). Thus, administration of either tool indicated they measured comparable cognitive, fine motor, and social skills.

Table 19

Pearson Product Moment Correlations Among the Child Variables

	BSID1	BSID2	BDI1	BDI2
BSID1	1.00	.97**	.99**	.96**
BSID2		1.00	.95**	.96**
BDI1			1.00	.97**
BDI2				1.00

Note. N = 15, \* = significant at .05 level, \*\* = significant at .01 level, BSID1 and BSID2 = Bayley Scales of Infant Development (Mental Scale) at pretest and post-test, BDI1 and BDI2 = Battelle Developmental Inventory during pretest and post-test.

Researchers, such as Dunst (1986), hypothesized that the quality of parental interactional behaviors and the home environment influenced the

extent of skill acquisition demonstrated by children with handicaps. In order to investigate the viability of this claim, calculation of the Pearson product moment correlation for the parent and child variables was conducted (Table 20). No significant correlations were obtained. The correlations were in the low to moderate range and included the absolute values of .01 to .51. The limited sample size precluded any regression analyses. In sum, significant correlations were obtained for pretest and post-test administrations of the child scales, while parental scores were significantly related to one another for some of the parent scales.

### Step 2

Within Step Two, formulation of hypotheses and goals was performed based on individual family data. All proposed goals involved functional behaviors, included measurable criteria, and represented developmental increases in each domain. Family goals consisted of increasing the quality of family interactional behaviors. An average of 53 child goals and 11 family goals constituted each family plan (Table 21). Post-test analyses of child and family goals revealed that children achieved 79.80% (S.D. = 12.77) of the targeted goals; whereas the families acquired 98.67% (S.D. = 5.16) of their objectives (Table 21). The results suggested that each family unit typically learned 64 new behaviors within the five month period. Clinically significant levels of goal accomplishment were clearly related to the children's increased rates of progress as demonstrated on the developmental assessments. The identification and treatment of parent, child, and sibling needs resulted in clinically significant skill acquisition for all family members.

Another component within Step Two was completion of the Critical Events Checklist (Appendix 1). On this inventory, the investigator

Table 20

Pearson Product Moment Correlations Among the Child and Parent Variables

	BSID1	BSID2	BDI1	BDI2
HOME1	.39	.38	.44	.44
HOME2	.22	.23	.26	.33
FRS1	-.13	-.08	-.16	-.17
FRS2	-.05	-.05	-.01	-.02
FSS1	.30	.26	.32	.34
FSS2	.15	.12	.17	.22
CES1	.10	.20	.10	.21
CES2	.10	.20	.11	.20
PBP1	.14	.12	.16	.22
PBP2	.42	.38	.44	.47
PBP3	.22	.18	.23	.28
PBP4	.32	.27	.34	.37
TSI1	.47	.51	.43	.45
TSI2	.26	.32	.30	.37
TSI3	-.05	.05	-.09	.03

**Note.** N = 15, \* = significant at .05 level, \*\* = significant at .01 level. BDI1 and BDI2 = Battelle Developmental Inventory at pretest and post-test, BSID1 and BSID2 = Bayley Scales of Infant Development (Mental Scale) at pretest and post-test, CES1 and CES2 = Child Expectation Scale at pretest and post-test, FRS1 and FRS2 = Family Resource Scale at pretest and post-test, FSS1 and FSS2 = Family Support Scale at pretest and post-test, HOME1 and HOME2 = Home Observation for Measurement of the Environment at pretest and post-test, PBP1, PBP2, PBP3, PBP4 = Parent Behavior Progression at pretest, month 2, month 3, and post-test, respectively; TSI1, TSI2, and TSI3 = Teaching Skills Inventory at pretest, mid-point, and post-test, respectively;

indicated that three families had been informed of their children's diagnoses within the past six months, had a younger child possessing skills that exceeded those of the handicapped child ( $N = 3$ ), and expected a transition to a new special education program ( $N = 1$ ) (Table 22). These nondevelopmental events were consistently present for children with severe handicaps, whose younger siblings (as young as six months) were surpassing the handicapped child in the areas of gross motor and social skills.

Table 21

Goals Targeted and Achieved by Families

	Number of Targeted Goals		Number of Goals Achieved		Percentage of Goals Achieved	
	( $\bar{X}$ )	S.D.	( $\bar{X}$ )	S.D.	( $\bar{X}$ )	S.D.
Child	53.93	16.04	43.07	15.71	79.80%	12.77
Family	11.93	2.67	11.80	2.81	98.67%	5.16

In conclusion, the children in the present study and their families demonstrated substantial amounts of skill acquisition. Clinical observation and use of the Critical Events Checklist revealed that families experienced considerable stress when their children with handicaps displayed skills significantly below their age norms, were responding to recent diagnoses, or reacting to their other children's capabilities.

Table 22

Composite of Critical Events Cited by Families

N = 16			
	Frequency		Age Range of Children Described in "Yes" Column (months)
	Yes	No	
Non-developmental Events			
1. Diagnosis	3	13	2-3
2. Younger Sibling	3	13	25-31
3. Program Transition	1	15	28
4. Medical Operation	0	16	
Developmental Events			
1. Not Walking	6	10	16-36
2. Not Self-feeding	6	10	28-31
3. Not Talking	9	7	28-43
4. Not Toilet-trained	7	9	28-43

Step 3

As part of this interview phase (third home visit), parents responded to questions on the Protocol for the Family-Focused Interview (Appendix 1), verified the appropriateness of each family plan, prioritized the mutually agreed-upon goals, and discussed possible strategies. The family-focused interviews consumed a total of 35.08 hours across the 16 families, with a mean of 2.19 hours per family. Both parents were present during six of the interviews, while the remaining interviews were completed with nine mothers and one father.

In addition to the protocol questions, clarification of parental responses on the Child Expectation Scale, Family Resource Scale, and Family Support Scale was sought. The interpretation of these family-focused interviews occurred by reading all entries, and then identifying the recurrent themes or salient issues across the families. These repetitive themes formed patterns of familial behaviors (Miles &



Huberman, 1984). Families displaying similar needs, behaviors, or requests were clustered into individual patterns. All 16 interviews were taped, transcribed, and analyzed for specific clusters.

### Question 1

Within Question 1, parents were requested to describe what life is like with their children with handicaps. From the parental responses, varying degrees of adjustment to living with handicapped children were evident. Frequently cited attributes included busy, demanding, depressing, etc. and were associated with the extent of a structured schedule in the home, rather than being related to the level of child functioning, employment status of the parents, and SES level of the family. Seven parents focused upon the uncertainty associated with their children's diagnoses (e. g., seizures) and manifestations of their diseases (e. g., loss of skills). Successful parental coping was exemplified by parental desires to maintain close proximity to their children and to balance the needs of all family members.

### Question 2

The strongest emotions displayed by parents occurred when parents were asked how they learned of their children's diagnoses. Parental concerns involved coping with the doctors' negative predictions and the manner in which the diagnoses were given. Furthermore, the lack of informed medical personnel and consideration of parental perspectives continued to be troublesome to parents, resulting in the need for additional information and appreciation of parental viewpoints.

### Question 3

This question involved requesting parents to describe a stressful

event and the actions they utilized to obtain its resolution. Parental stress focused upon financial concerns, children's handicapping conditions, and family members' coping behaviors. For all families, resolution of stressful events was derived from familial support. In addition, seven parents utilized rational problem-solving techniques, while four other families assumed a negative reactive approach to resolving crisis situations. There was no effect for the family's SES or child functional levels.

#### Question 4

In terms of the support systems available to families, relatives were overwhelmingly cited as the major source of family support. Twelve families described the importance of the children's grandparents and aunts. Professionals and parents' friends were occasionally considered helpful (N = 6). As one parent remarked, "They (friends) listen and it's fine, but they forget about it. They don't know what it's like living with children who have problems." Other parents disliked having to be "over-aggressive and assertive in order to obtain educational services." Furthermore, persons to assist with child care or parent workshops were positively valued by parents. For those families with insufficient child care opportunities, diminished familial finances or the lack of qualified child care personnel were cited as causes for the poor ratings. Similarly, governmental and private agencies were not considered supportive, since they frequently delayed payment for reimbursement of prosthetic devices and pharmaceutical bills.

#### Question 5

Parental request for additional services (question 5) involved therapy for their children (e. g., physical therapy), child care, and

assistance with governmental financial agencies. When the possibility of enrollment in a parent group was presented, all 16 families refused, a clinically significant finding. Parents were reluctant to share their problems with strangers.

#### Question 6

A wide array of positive and negative effects were verbalized by parents when asked, " Could you tell me some of the things that your child has taught you? What have you learned about yourself?" This question directly required parental reflection about the positive and negative outcomes of parenting a child with developmental disabilities. Positive feelings and skills included increasing patience, becoming more creative, developing maturity, acquiring inner strength, increasing their self-concept; and learning how to interpret accurately their children's non-verbal cues and to teach their children. Two parents became grateful for having other children, who were healthy. Another parent learned to lower her expectations of child progress in order to confront the reality of her child's significant developmental delay. Parents learned predominantly positive behaviors or emotions in response to parenting children with varying levels of developmental delay.

#### Question 7

Present and future expectations held by parents for the siblings of their handicapped children were explored in this question. Present parental concerns focused upon siblings' patience, tolerance, and love toward the handicapped children (N = 5). Six parents also verbalized specific actions they desired their children to exhibit, e. g., include the children in the siblings' activities. Other parents focused upon the

literature concerning the negative repercussions for siblings living with handicapped children.

Expectations of future siblings' behaviors varied. Three families expected their nonhandicapped children to assist their siblings with severe handicaps. Most parents failed to verbalize their expectations for future behaviors by their healthy children. They perceived that their nonhandicapped children had a right to their own lives and any interaction with the handicapped siblings should occur spontaneously.

#### Question 8

Parents were asked about their present and future goals for their handicapped children. In terms of present goals, 12 out of the 16 families verbalized realistic, functional behaviors in all developmental areas. These behaviors were included in the family plans and all children demonstrated progress toward acquisition of these parent selected goals. Future goals involved children learning to become independent and integrated within the community (N = 13). One parent was asked to explain why she had low expectations for her child's future abilities and living arrangement. She attributed her expectations to her child's developmental delay. All parents verbalized at least one functional behavior to be acquired by their child.

#### Question 9

The parents' level of desired involvement in the proposed intervention plan was requested. Ten parents reported varying levels of daily time commitment to the proposed goals, which ranged from five minutes to four hours. Four other parents expressed they would perform as much intervention as possible, given other family concerns. Two parents explained how the goals or intervention should be integrated

throughout the daily activities, a desired attitude.

#### Question 10

This question concerned ascertaining whether any medical tests or surgeries were pending. If parents indicated specific medical procedures were scheduled, prior planning for support services and information could be provided. Although no surgeries were scheduled, eight families indicated that medical examinations were to occur within the year (e. g., electroencephalogram). For these families, an explanation of the types of information obtained and the procedures associated with the tests was given.

#### Goals and Strategies

The final purposes of the family-focused interview were to review and prioritize the proposed child and family goals, and discuss possible intervention strategies. Each goal and its corresponding methods were presented to the parents for their approval. Parents indicated that equal emphasis should be placed on all developmental areas and the family goals during the weekly sessions.

Once a review of the child assessment results occurred, parents agreed to the 863 (total) proposed child goals and the 195 proposed family goals. Only two parents requested that three family goals be omitted from their individualized plans. These goals focused upon family finances and opportunities for adult socialization. On the whole, a high rate of approval was derived for the individualized family service plans. One plausible explanation for this high level of approval was that involvement in the process encouraged parents to become more committed to the plan and to reflect on the needs of all family members. Given the

diversity of needs addressed for all family members, all parents considered the family assessment results to be realistic and the plans to be immediately useful.

#### Step 4

The individualized family service plans were finalized within step four. These plans included goals specifying child, parent, and sibling behaviors. As well, the case management activities conducted by the investigator were included in each plan.

Goal attainment scaling continua were developed for specific individual behaviors. Progress on each of these goals was ascertained by comparing pretest and post-test levels for six parents, four siblings, and one child (Table 23). Parent goals focused on maternal enjoyment, sensitivity to child's interests, implementation of behavioral limits, ability to problem solve and verbalize feelings, and reduction of intrusive social games. Each continuum had a range of possible outcomes which could be acquired by the end of the five month period. Each outcome was assigned a numerical value ranging from pretest level (-2), to expected outcome (0), to best expected outcome (+2). All skills were based on functional behaviors. The results indicated that each of the parents surpassed the projected outcomes and displayed skills at the upper levels of the continua.

As well, specific sibling behaviors were addressed and included learning to gauge the intensity of stimulation presented to their siblings with handicaps (N = 2), and to assume realistic outlooks about their handicapped siblings (N = 2). From the initial pretest levels (-2), the nondisabled siblings made significant progress. They were able to respond to the children's behavioral cues in order to ascertain the

Table 23

Continua of Goal Attainment Scaling(6) Maternal Enjoyment of the Child

- \*+2 Exhibits sheer enjoyment at observing child
- \*+1 Smiles, provides physical contact and verbalization to child
  - 0 Stays within 3 feet of child for 5 minutes and states 2 positive comments
- 1 Verbalizes one neutral statement regarding child and remains in the same room
- 2 Shows no pleasure in being with child

(3) Maternal Implementation of Behavioral Limits to the Child

- \*+2 Implements behavioral limits 90% of the time
- +1 Implements behavioral limits 50% of the time
  - 0 Implements behavioral limits 35% of the time
- 1 Implements behavioral limits occasionally
- 2 Does not implement behavioral limits

(7) Maternal Insensitivity to Child's Interests

- \*+2 Is sensitive 90% of the time to the child's interests
- +1 Is sensitive 50% of the time to the child's interests
  - 0 Occasionally (25% of the time) to the child's interests
- 1 Is insensitive to the child's interests 90% of the time
- 2 Is insensitive to the child's interests 100% of the time

(10) Maternal Inability to Problem-Solve

- \*+2 Gathers information before acting, exploring and pursuing one of the possibilities
- +1 Gathers information with no exploration of alternatives
  - 0 Relies on others to perform problem-solving, but listens to alternatives being suggested
- 1 States prior planning would be helpful, but is still overwhelmed
- 2 Is reactive to problems and verbalizes being overwhelmed by events with little visible coping

(11) Maternal Inability to Verbalize Feelings

- \*+2 States feelings in presence of professional and spouse
- +1 States feelings openly to professional when spouse is not present
  - 0 States one comment that involves an emotionally laden feeling to the professional
- 1 States comments that do not reveal any personal feelings
- 2 Looks to spouse to state her feelings 90% of the time

(14) Reduction of Mother's Intrusive Social Games to the Child

- \*+2 Presents a wide array of social games that do not incorporate intrusiveness
- +1 Presents social games with minimal use of intrusive (facial) games (25% of the time)
  - 0 Presents intrusive facial/social games 50% of the time
- 1 Presents intrusive facial/social games 75% of the time
- 2 Presents intrusive facial games 100% of the time

(1) (14) Siblings Gauge Intensity of the Stimulation Presented

- \*+2 Alters intensity of stimulation 90% of the time
- +1 Alters intensity of stimulation 75% of the time
- 0 Alters intensity of stimulation 50% of the time
- 1 Alters intensity of stimulation 25% of the time
- 2 Does not alter intensity of stimulation according to the infants' responses

(2) (10) Siblings Assume Realistic Outlook about the Children

- \*+2 Remarks about child's successes and present needs
- +1 States 1 positive comment and looks astonished when child achieves a targeted skill
- 0 States 1 neutral comment
- 1 States negative comments
- 2 States negative comments and exhibits hurtful acts

(7) Child's Rejection of Play with Her Siblings

- +2 Looks at, smiles and vocalizes to siblings
- \*+1 Looks at and vocalizes to siblings
- 0 Looks but does not withdraw from contact with siblings
- 1 Withdraws momentarily, but then looks at siblings
- 2 Withdraws from any contact presented by siblings

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Note. (number) = subject number, - = pretest level, \* = post-test level

type of stimulation needed. Similarly, the siblings became more realistic about the children's strengths and needs, which resulted in more pleasurable interactions among the children. The last continuum involved a handicapped child's consistent withdrawal when her siblings initiated interaction. On the post-test, she was able to interact positively with her twin and younger siblings.

Meaningful progress was realized by eight families on the goal attainment scaling continua. Further, the individualized family service plans were finalized and given to the families and local infant programs. Also, significant progress was realized by eight families on the goal attainment scaling continua, a positive finding.

Step 5

In step five, weekly home-based intervention (sessions of two hour



duration) were implemented for all families. During the initial intervention session, each parent was provided with a list of strengths they displayed during the family-focused interview and assessment sessions. All parental strengths were read and similarities among the parental behaviors were determined. Clusters of parental behaviors were identified and categorized as follows: family relationship, parenting, acceptance of their children with handicaps, teaching, and personality characteristics (Table 24, Appendix 2). A total of 41 different parent behaviors were observed across the 16 families, noting the multitude of needs addressed.

During weekly sessions, approximately 12 goals per family were emphasized and jointly determined by the parents and the professional. Parents selected two to four goals from the list of the 12 weekly goals to stress over the week.

Strategies for encouraging the functional behaviors included systematic instruction (Snell & Zirpoli, 1987), which incorporated distributed trial learning, positive reinforcement, system of least intrusive prompts, time delay, shaping, differential reinforcement of incompatible behaviors, and functional analysis of behavior. In order to ensure consistency across all professionals working with the family, the family plan was given to each professional, copies of weekly goals with the accompanying methods and responses were shared, and observations of each other's techniques were conducted for each family. For two families, the investigator was the sole service provider.

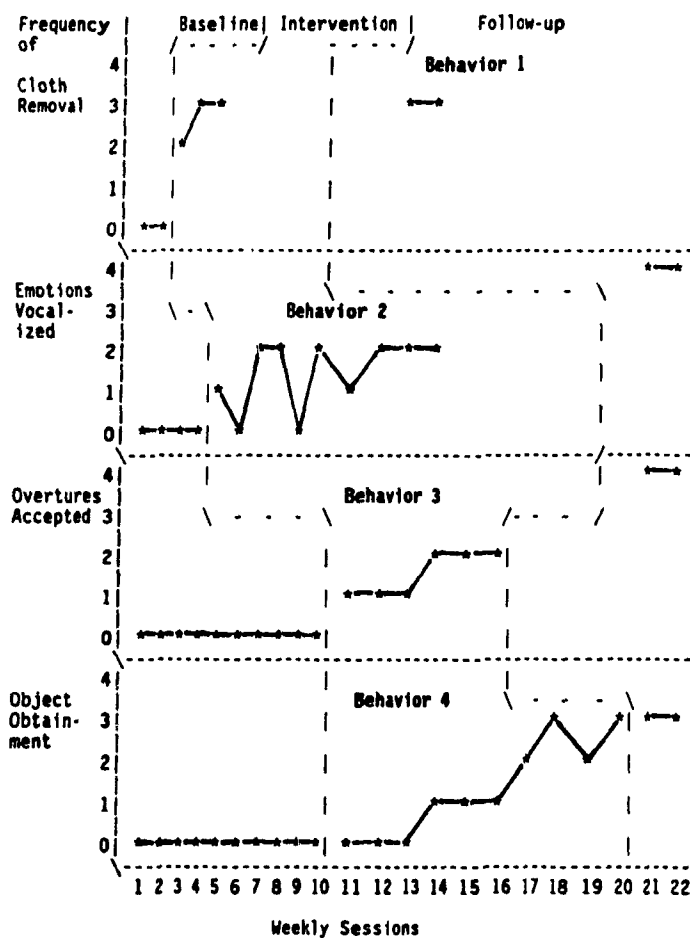
Weekly progress on each family plan was monitored through multiple baseline procedures. Intervention was applied to the first behavior and continued until the criterion was met. Treatment of the second behavior

commenced, once stable intervention data were derived for the first behavior. Intervention to subsequent behaviors began after progress was demonstrated on the previous behaviors. Use of multiple baseline designs permitted the examination of progress across several goals on a simultaneous basis. For goals about to receive intervention, baseline behaviors were monitored. Therefore, one could compare "treated" behaviors and those about to receive treatment during the same time frame (Kazdin, 1982). From the initial stability of the behaviors during baseline, the magnitude and rapidity of change during intervention provided convincing evidence that the treatment was responsible for the behavioral changes.

Application of multiple baselines in this investigation proceeded in a manner that gave priority to parent-infant interactional behaviors (parent behaviors observed on the PBP), followed by emphasis on parents' instructional competence (as measured by the TSI). Child and sibling behaviors were selected based on observations of their interactions and the intervention priorities of the parents.

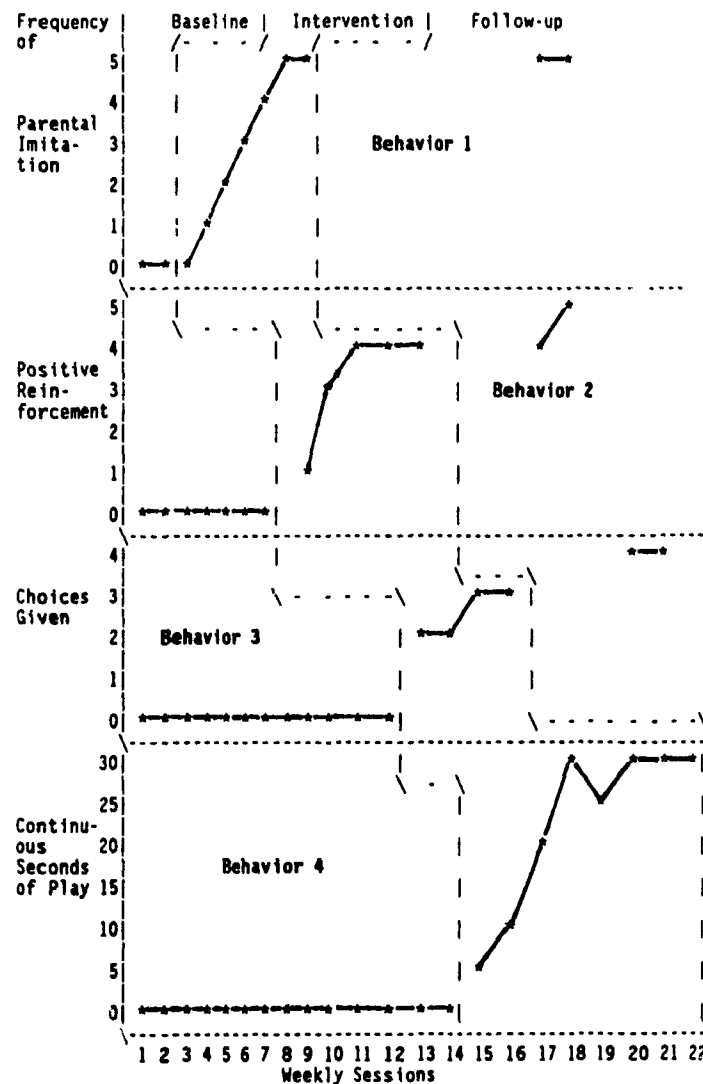
Throughout the study, multiple baselines were conducted across specific behaviors for each family unit. Using family 7 as an example, the types of child and family goals emphasized are presented in Figures 2 and 3.

Consistent progress was displayed by child 7, as she acquired the sample behavioral objectives in the cognitive, expressive language and social areas (Figure 2). Since her level of functioning was severely diminished, significant progress was revealed by her accomplishment of the specified behaviors. Any decrease in her weekly performance was related to changes in her anticonvulsant medication. Even more rapid skill acquisition was exhibited by her family members (Figure 3). Review



**Figure 2.** Multiple Baseline of Sample Goals for Child 7 that Were Included in the Individualized Family Service Plan

**Note.** Behavior 1= The child will remove a cloth from her face within five seconds, two out of three times for two consecutive sessions; once a game of peek-a-boo has been initiated.  
 Behavior 2= The child will be observed to vocalize a specific sound for each of three emotions during two consecutive sessions.  
 Behavior 3= The child will accept two overtures from her siblings within five seconds, by looking or smiling at her siblings, and not withdrawing from their touch; for three consecutive sessions.  
 Behavior 4= The child will obtain an object placed beyond her reach by using one object in order to obtain the desired toy; within ten seconds, two times per session, for three consecutive sessions.



**Figure 3.** Multiple Baseline of Sample Goals for the Family of Child 7 that Were Included in the Individualized Family Service Plan

**Note.** Behavior 1= The child's mother and father will imitate child 7's sounds within three seconds, four times per day for three consecutive days.

Behavior 2= The parents of child 7 will provide positive verbal reinforcement to the child in response to observing appropriate behaviors; four times per day for three consecutive days.

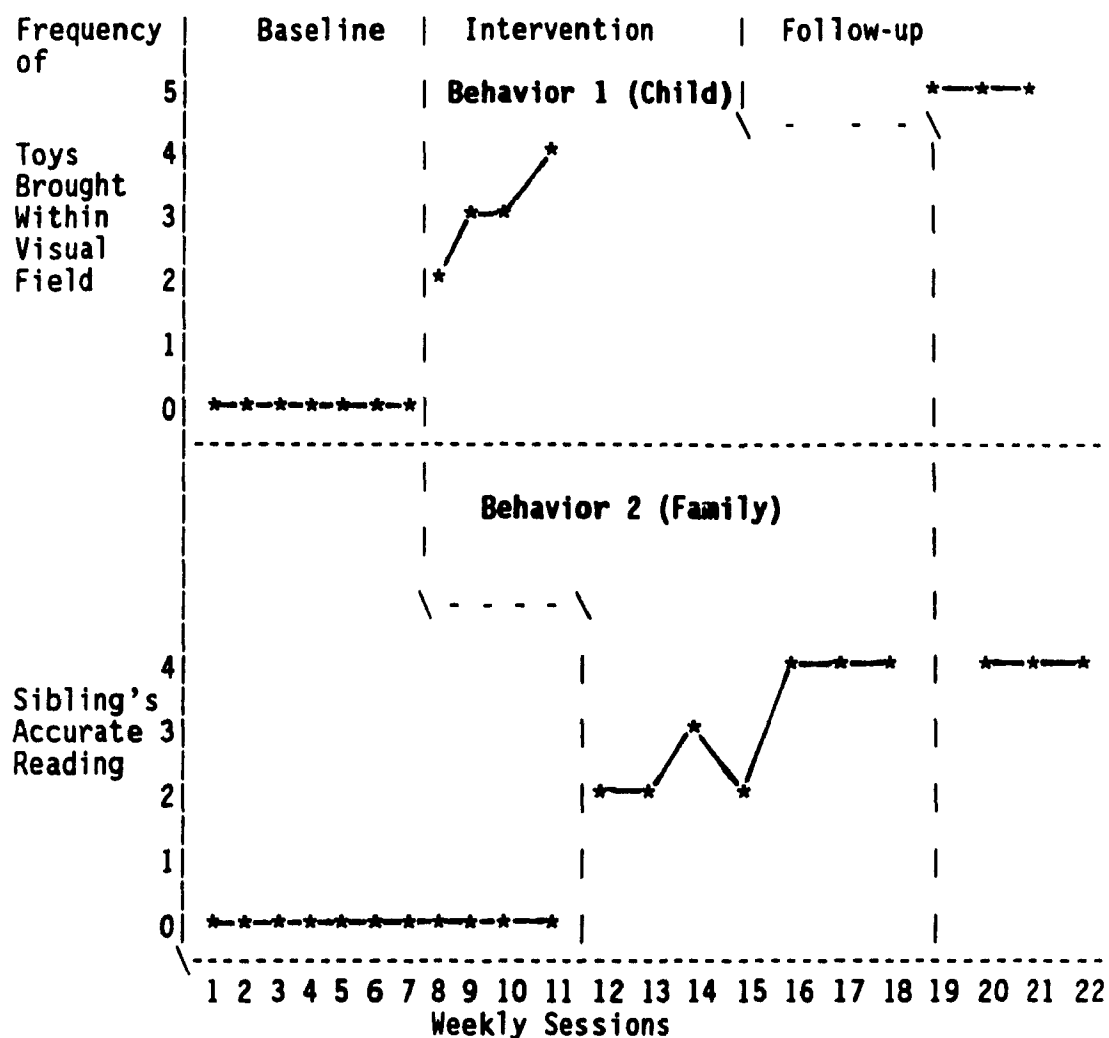
Behavior 3= The mother of child 7 will give the child at least two opportunities per day to chose preferred activities or food items for three consecutive sessions.

Behavior 4= Child 7 and her sisters will exhibit parallel play for 30 continuous seconds for three consecutive sessions.

of the behavioral objectives demonstrated that the mother learned to imitate her child's sounds, to provide positive reinforcement, and to permit child choices. As well, her siblings learned to exhibit parallel play within eight sessions.

Using a table of random numbers, individual families were initially selected, then the respective child goals, and finally the family goals were chosen. These goals are presented in Figures 4-10. In order to provide an illustration, seven families, seven child goals, and seven family goals were randomly selected. On Figure 4, child 1, with age appropriate skills, visually inspected toys; and her older sister learned to accurately interpret the child's behavioral cues. Similarly, child 1 demonstrated differential responses to varying tones of voice, while her parents planned future goals for her (Figure 5). On Figure 6, child 9 (who has moderate handicaps) exhibited acquisition of object permanence skills and his mother provided a language-rich environment. Further, child 11 learned to vocalize for the attention of a family member (Figure 7). Her acquisition of this goal helped her to maintain age appropriate skills. Meanwhile, her parents discussed alternatives for child care and determined the most appropriate choice for them (Figure 7).

Child 12 exhibited acquisition of object permanence at the expected age level as his parents learned to become sensitive to his tolerance for stimulation (Figure 8). Child 14, who has a severe level of physical involvement and moderate handicaps, learned to reach toward an object (Figure 9). Her parents displayed increased involvement with her by reporting activities enjoyed by all family members (Figure 9). Given child 16's low level of responsiveness, the goal was to have her respond

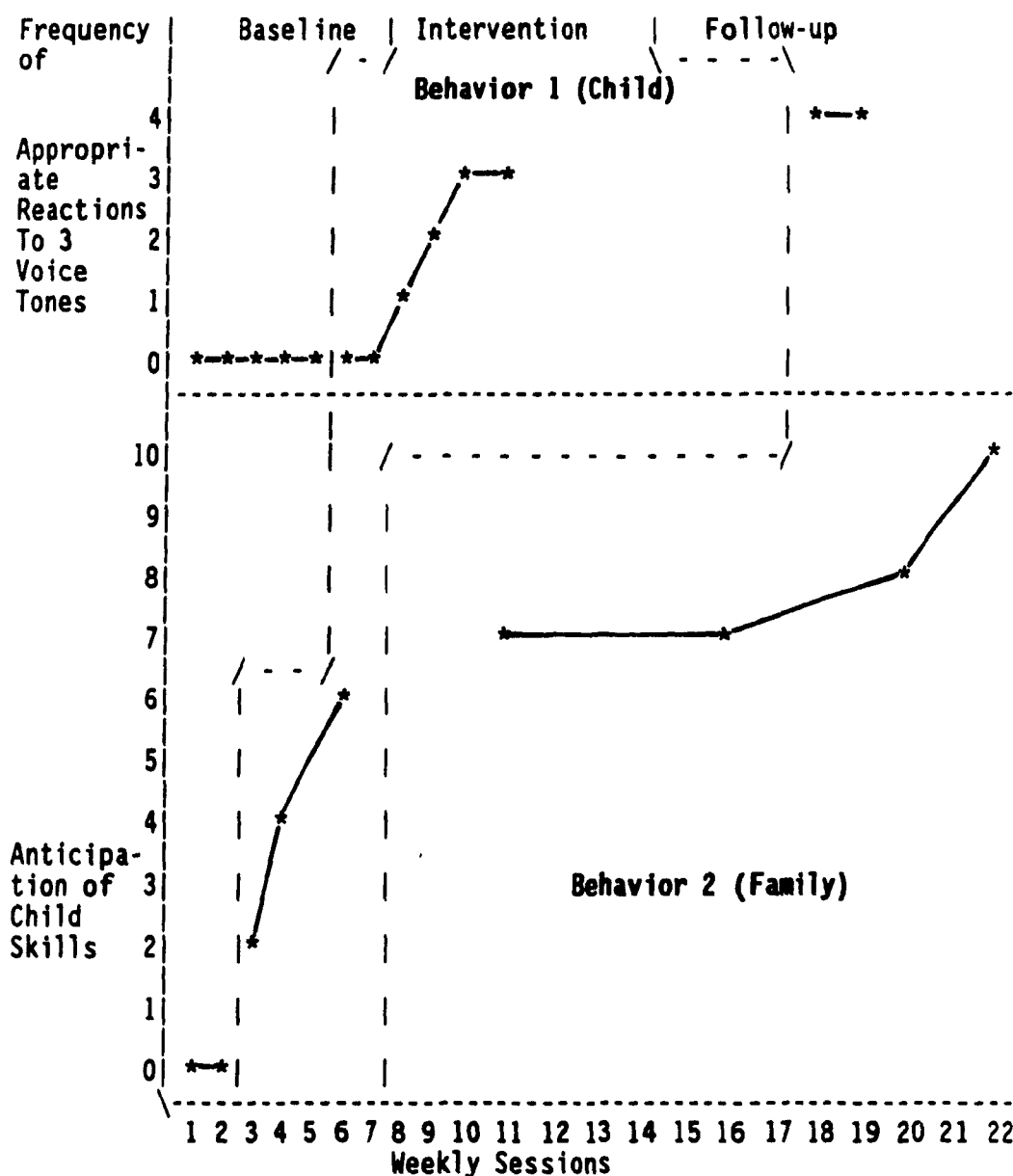


**Figure 4.** Multiple Baseline of Randomly Selected Child and Family Goals for Child 1 Included in the Individualized Family Service Plan

**Note.** Behavior 1= Child 1 will bring a toy into her visual field or turn toward it, when it is placed in her hand; three out of five times on three separate days.

Behavior 2= The sibling of child 1 will learn how to tell when child 1 is ready to play and when she (child 1) has had enough play time; three out of four times on three consecutive days.

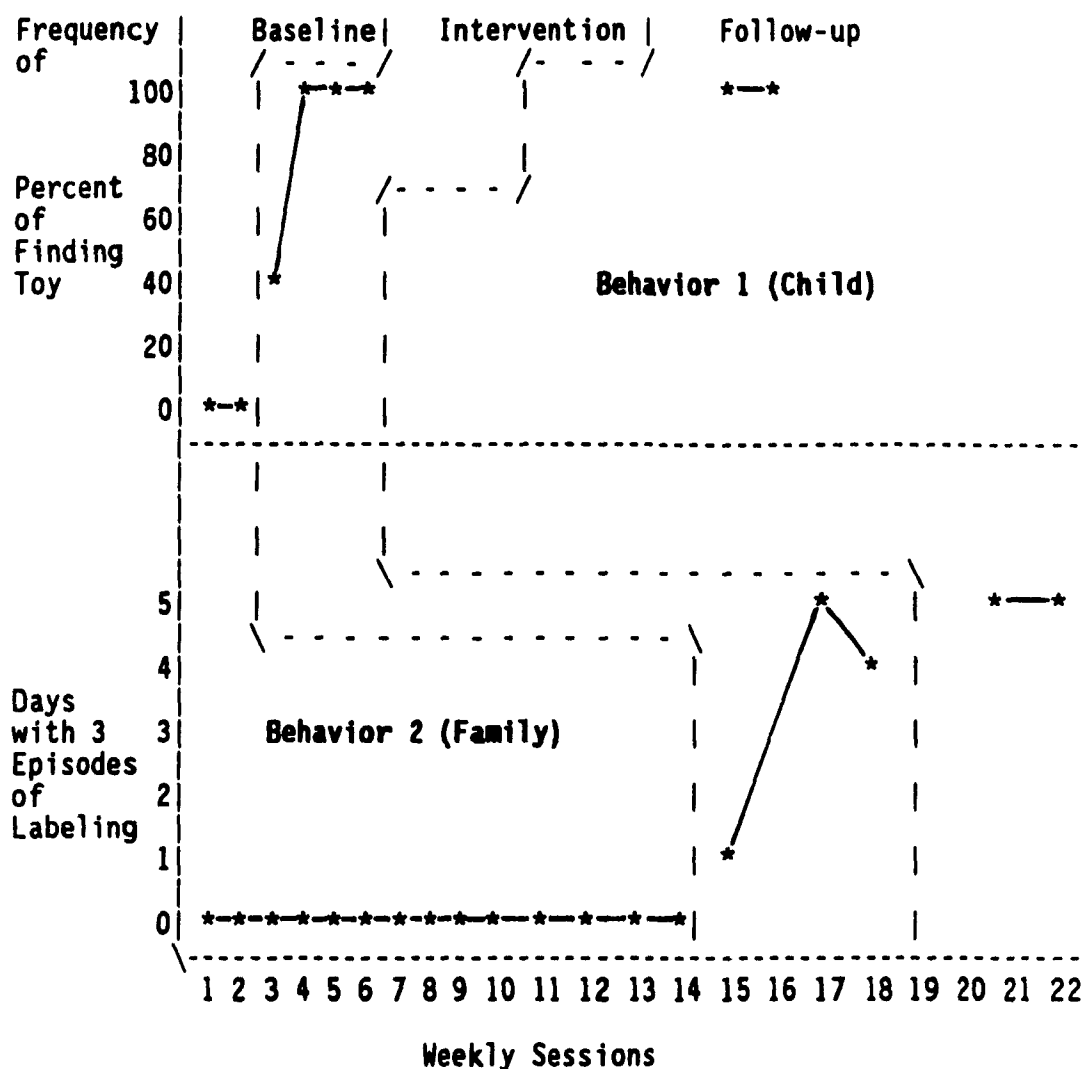
to social games. Although child 16 exhibited brief periods of attention, she became more responsive to social games (Figure 10). In order to maximize her learning, her parents learned to prepare for the play periods and to provide stimulation (Figure 10).



**Figure 5.** Multiple Baseline of Random Child and Family Goals for Child 1, Which Were Included in the Individualized Family Service Plan

**Note.** Behavior 1= Child 1 will show appropriate responses to each of three different tones of voice by exhibiting a different reaction for each of three verbalized or vocalized emotions; 2 times for each voice tone on two separate days.

Behavior 2= The parents of child 1 will anticipate child 1's next steps in her development by planning challenging activities for her on a monthly basis (criterion = three episodes per session for three sessions).

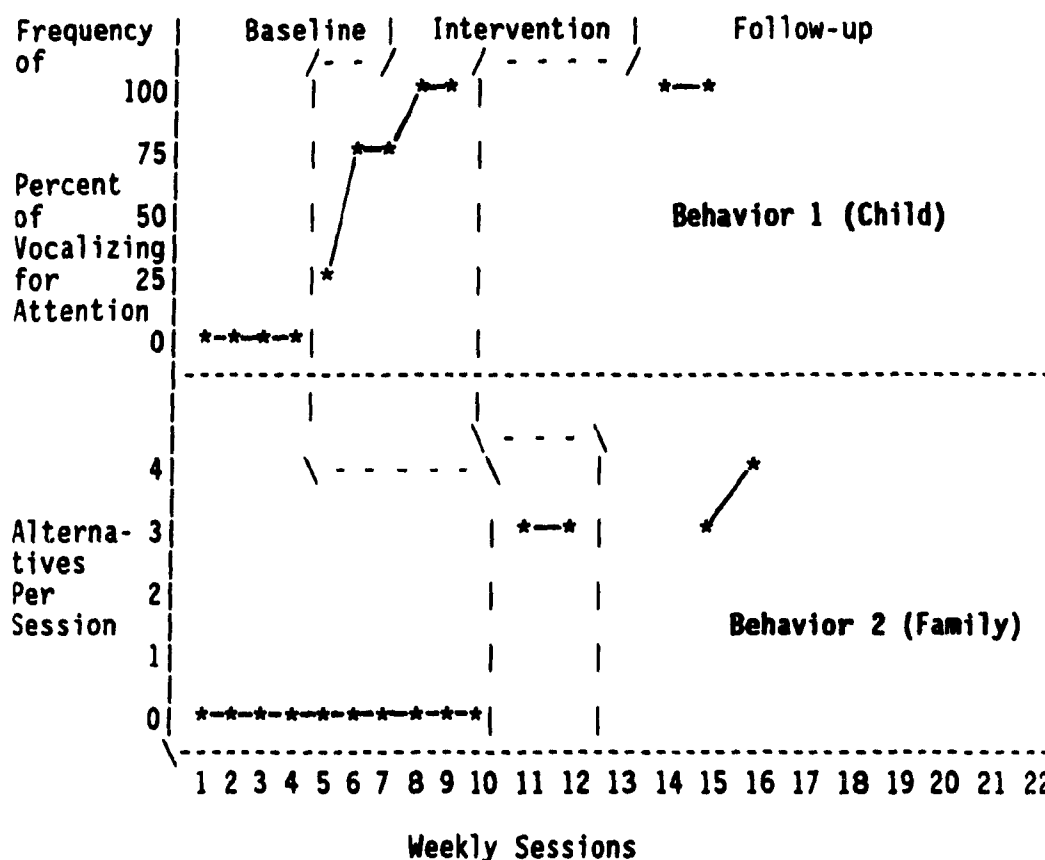


**Figure 6.** Multiple Baseline of Random Child and Family Goals for Child 9, Which Were Included in the Individualized Family Service Plan

**Note.** Behavior 1= Child 9 will look at the correct place to find a toy after he has seen it successively placed under three covers 80% of the time on three separate days.

Behavior 2= While doing the household tasks, the mother of child 9 will tell her child what she is doing, in order to continue increasing his understanding; three times per day, four times per week.

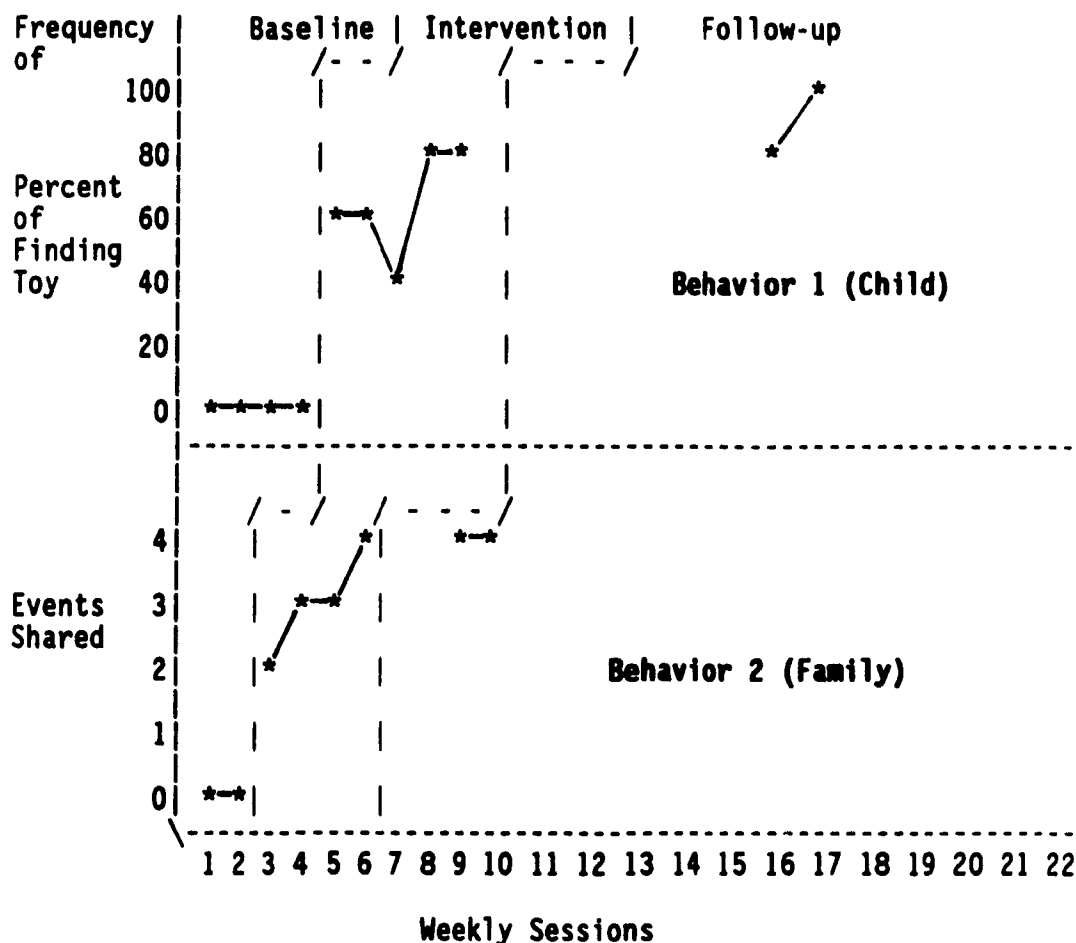




**Figure 7.** Multiple Baseline of Random Child and Family Goals for Child 11, Which Were Included in the Individualized Family Service Plan

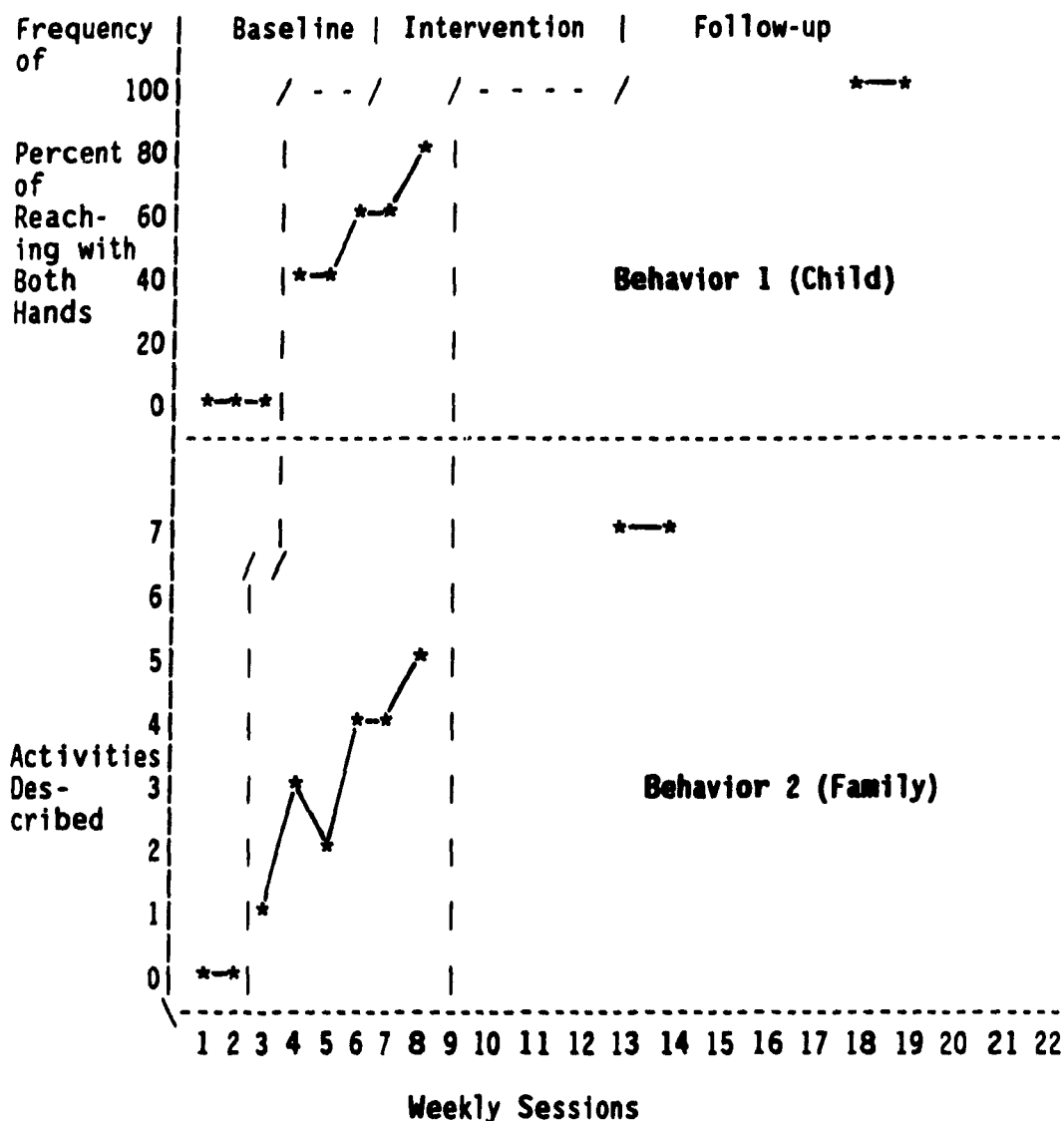
**Note.** Behavior 1= Once child 11 has received attention from one of her family members and then no longer has the exclusive attention of that person, she will vocalize sounds (no crying sounds) within ten seconds after the attention has been withdrawn; 75% of the time on three different days.

Behavior 2= The interventionist and the parents of child 11 will brainstorm ways so they (the parents) can obtain more time for themselves and friends, and to have baby-sitting opportunities; three alternatives that meet parents' approval.



**Figure 8.** Multiple Baseline of Random Child and Family Goals for Child 12, Which Were Included in the Individualized Family Service Plan

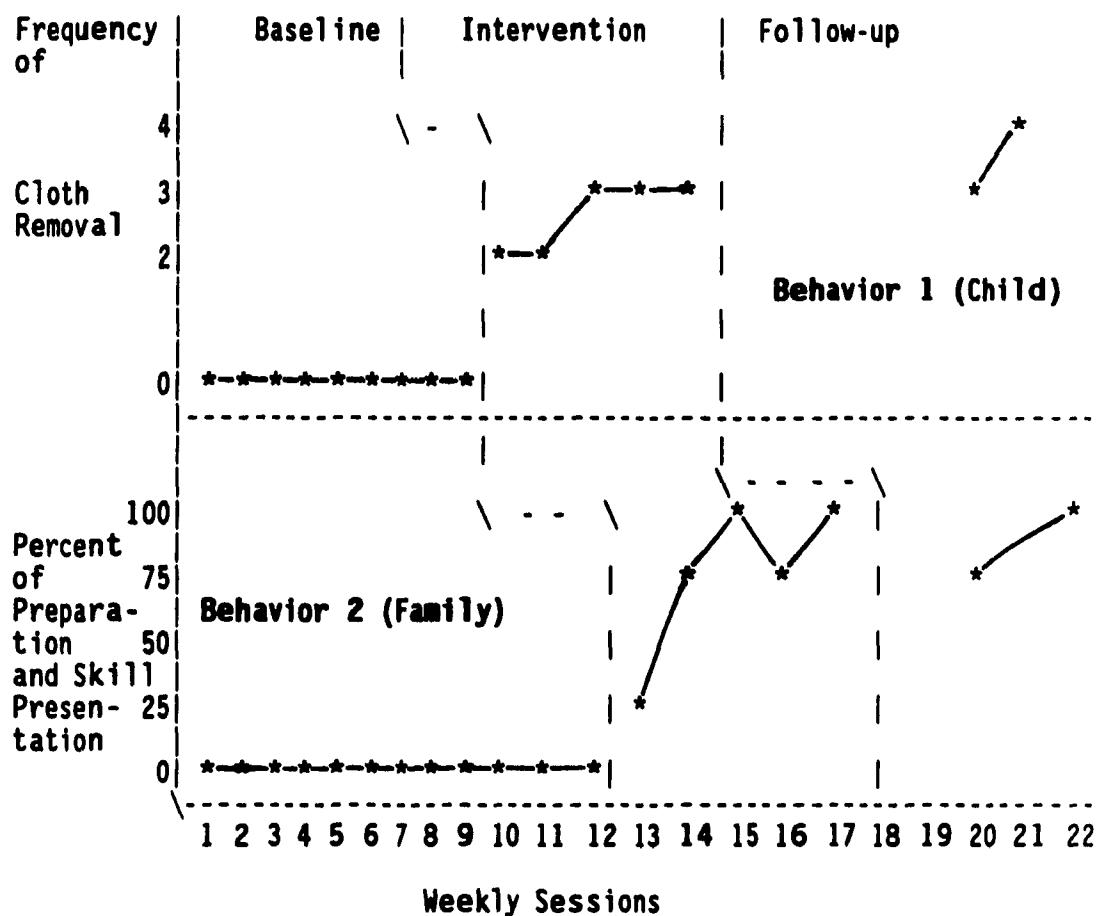
**Note.** Behavior 1= Child 12 will find a toy within five seconds under one of three covers without any errors, upon seeing it moved from place to place; 80% of the time.  
 Behavior 2= The parents of child 12 will adapt the amount and the intensity of stimulation to the amount that their child can handle by sharing with the interventionist, his reactions to new people, noises, and situations; three events on a weekly basis for three weeks.



**Figure 9.** Multiple Baseline of Random Child and Family Goals for Child 14, Which Were Included in the Individualized Family Service Plan

**Note.** Behavior 1= Child 14 will raise or reach with both of her hands on a spontaneous basis toward an object held at her chest level; with her hands partially open, within ten seconds, 60% of the time.

Behavior 2= The parents of child 14 will describe activities that they enjoyed doing with their child and that their child enjoyed; description of three activities on a weekly basis for three weeks.



**Figure 10.** Multiple Baseline of Random Child and Family Goals for Child 16, Which Were Included in the Individualized Family Service Plan

**Note.** Behavior 1= Child 16 will completely removed a cloth placed over the adult's face in a peek-a-boo games; three consecutive times on three different days.

Behavior 2= While teaching Child 16 a new skill, her parents will have the toys ready in advance and present the skill four times in succession, lasting a total of five minutes; everyday, 75% of the time (Criterion = preparation and four presentations for five minutes, 75% of the time).

The multiple baseline procedures reflected rapid acquisition and maintenance of targeted child, parent, and sibling behaviors (Figures 2-10). Additional behavioral goals, emphasized for the entire sample, resulted in progressive acquisition of functional behaviors, a most significant finding. Thus, the effectiveness of the intervention was further exemplified by continuous achievement of new skills and was reflected in these randomly selected multiple baseline figures.

Whenever siblings were present in their homes, they were actively encouraged to join the sessions. Typically, siblings of all ages partook in the various activities for at least 20 minutes of each session during the summer, late afternoon, and evening sessions. Consistent with the requirements of enrollment in the study, parents were present for each entire session.

Qualitative analyses were conducted in order to determine characteristics of family functioning and parental priorities for family goals. During intervention, daily anecdotal notes concerning family behaviors, questions and/or concerns were noted immediately following each home visit. Upon conclusion of the study, these notes were analyzed in order to determine major clusters of familial behaviors. Based on the analyses of the data, the following salient family issues were derived: parental concerns (Table 25, Appendix 3), parent-infant attachment (Table 26, Appendix 4), future parental expectations for their children with handicaps (Table 27, Appendix 5), sibling behaviors (Table 28, Appendix 6), positive comments regarding the investigator (Table 29, Appendix 7), and case management activities (Table 30, Appendix 8).

The concerns of parents reflected in their statements were the needs

associated with the health and development of their families (Table 25, Appendix 3). They indicated the desire to work with well qualified professionals, who should consider the parents' perspectives. Parental concerns included availability of provincial services, early intervention services, professionals, parental teaching skills, children's bodily functions and behaviors, familial characteristics, and children's future abilities.

Although parents experienced ongoing stress from parenting children with handicaps, they displayed positive affectionate behaviors which were consistent with their statements (Table 26, Appendix 4). Demonstration of these positive behaviors occurred during social games or conversations with the investigator. Thus, positive parent-infant attachment behaviors were observed across different contexts, and involved both mothers and fathers.

During conversations with the investigator, parents verbalized their continued concerns regarding to their child's abilities (Table 27, Appendix 5). Parents expressed optimism and the desire to acquire a more realistic appraisal of their child's future abilities. These discussions arose during the intervention sessions.

The negative behaviors of siblings observed during the first two home visits stressed the importance of including siblings in the intervention program. These behaviors included decreased appraisal of the children's capabilities (N = 2), diminished understanding of the children's present abilities (N = 1), and difficulty with sharing parental attention with their handicapped brothers and sisters (N = 2) (Table 28).

However, an increase in positive social behaviors occurred during

intervention sessions (Table 28, Appendix 6). Improved sibling behaviors resulted from social reinforcement (N = 2), participation in the sessions (N = 5), and modeling of developmentally appropriate games (N = 2). Thus, the inclusion of siblings within the intervention sessions apparently promoted more positive interactional behaviors.

Social-emotional support and parent education were provided during the intervention sessions. Parents and siblings verbalized statements about the investigator's role during the intervention sessions (see Table 29, Appendix 7). Siblings typically verbalized pleasure as they enthusiastically joined the intervention sessions.

Furthermore, positive parental statements focused upon assessment results (N = 2), the thoroughness of the plan (N = 3), structure of the sessions (N = 8), methodological approach (N = 3), and the investigator's support (N = 4). In addition, specific personality characteristics of the investigator were mentioned as helpful, e. g., warmth. One father remarked that "It's amazing how much someone's day to day work can bring hope and improve the quality of life of a family like ours." From parental statements, the perceived provision of support, information, and parent education resulted in their acquiring positive perceptions about the purposes and implementation of the family-focused intervention model. These positive statements were consistent with previous findings. The delivery of the home-based services resulted in positive comments throughout the intervention sessions.

Although the intervention sessions were home-based, parents encouraged the investigator to attend family events, in order to derive a more thorough understanding of the family and to express their sincere

appreciation. For example, one family requested the investigator attend a day trip to observe parent-child and parent-parent interactions, while another family urged the investigator to be present at the christening of the younger child. Anecdotal notes were taken and family behaviors were extracted from the ongoing notes. From these additional visits, parents were observed to provide social-emotional support for each other. The children were observed to display independence as they amused themselves, as well as seek out their parents' attention in socially acceptable ways.

Other activities by the investigator included case management. Upon parental request or the investigator's suggestions, parents were provided with names of additional personnel and services, as well as inter-agency coordination (Table 30, Appendix 8). Assistance was given for organizing the home environment, developing coping responses, and learning specialized educational techniques. While the activities varied significantly, 94% of the parents requested specific instruction on the determination of future goals for their children. Acquiring this knowledge enabled parents to assume a larger degree of advocacy, self-reliance, and self-confidence. All case management activities were implemented in an attempt to improve the current quality of life for families and to provide support for their future needs.

#### Step 6

The final step in the family-focused intervention model included the evaluation of program effectiveness. In step one, post-test administration of parent, child and sibling scales were described. The results on the goal attainment scaling were given in step four.

Additional evaluations included obtaining parental opinions about the quality of the program and each facet of the family-focused



intervention model. To obtain objective appraisal of the intervention model, the parents were requested to rate the quality of their parenting skills, instructional competence, and family relationships, as well as the investigator's skills on the Parent Satisfaction Scale. The majority of their responses consisted of the highest ratings for each item (Table 31, Appendix 9).

Variability across parents occurred concerning the quality of their familial relationships ( $\bar{X} = 2.47$ , S.D. = 1.18, maximum = 4.0). Parents indicated their familial relationships continued to be good ( $N = 4$ ), or improved due to intervention ( $N = 11$ ). In general, parents gave the highest ratings concerning the quality of the parent education and the intervention sessions.

In addition, parents were asked to contrast how this approach differed from previous early intervention efforts. Those families, who had not experienced the services of another early interventionist, were requested to describe their thoughts concerning each facet of the program. Direct quotations were recorded in the investigator's notes during the interviews with the parents (Table 32, Appendix 10). From qualitative analyses of these comments, recurrent themes emerged.

Parents expressed key characteristics associated with the model. Their comments were conceptually organized under the following headings: program approach, program planning, program implementation, resources, case management, family relationship, family goals, parent education, parental attitude, characteristics of the investigator, and similarities with other current services. Positive attributes included thoroughness, organization, global orientation, and consideration of the entire family.

Another central theme was the development and/or reinforcement of parental self-sufficiency. Self-sufficiency lessened parental dependence upon professionals and enabled parents to select appropriate goals for their children, advocate for specific services, utilize community networks, enhance parenting and teaching skills, and assume an objective appraisal of children's needs and abilities.

Parents denoted specific traits they valued with respect to the interventionist, e. g., commitment, experience, etc. In comparing other intervention models, two families concluded that there were similarities among child-focused programs and the family-focused intervention model. These similarities involved comparable short-term goals and intervention strategies. Given that each family plan was distributed to the respective professionals, it was not unusual for duplication of goals and methods to occur.

Clinically and/or statistically significant progress was revealed by families in terms of their individual behaviors and interactions with one another. Not only did scores on family measures increase, but the parents also reported growth in all their family members. The combination of qualitative and quantitative data analyses provided the data necessary to formulate the descriptive profiles of family functioning and at the same time, it supported the effectiveness of the family-focused intervention model.

## Chapter Six

### Discussion

The family-focused intervention model was implemented for 16 families having infants (2-43 months) with moderate and severe handicaps. Throughout the family-focused interview and intervention, parental preferences were gathered and helped shape the type of program provided. More importantly, satisfying and nurturing relationships were reinforced and these, in turn, facilitated the children's developmental progress.

The results suggested that most of these infants approximated near normal rates of progress over the five month period of intervention. This was an unusual outcome, as children with moderate or severe handicaps were expected to gain one month in their skill levels for every two to three months of increased chronological age. Instead, these infants progressed at faster rates, which seemed to suggest the appropriateness of the family-focused intervention model.

These handicapped infants demonstrated the acquisition of functional skills, which would serve as a basis for future independence. Gains in the cognitive area, as measured by the Bayley Scales of Infant Development and the Battelle Developmental Inventory, demonstrated that these children increased their short-term memory, problem-solving abilities, and imitation skills. In the motor area, children improved the quality of their movements (MAI scores) and acquired developmental milestones as measured by the Battelle. Similarly, their repertoire of appropriate interactional behaviors was expanded as a result of greater infant communicative competence, infant responsiveness to social overtures, and accurate family interpretation of their behavioral cues. There was less dependence on family members for self-help skills, since

the children acquired varying amounts of feeding, dressing, and toileting skills (as measured by the Battelle).

Essentially, these infants with handicaps learned many necessary, practical skills, which are utilized throughout their daily activities. The potentiality for regression of these attained child behaviors is reduced, since these behaviors are being reinforced during daily activities, such as at play, meal, and bed times. Furthermore, each goal on the individualized family service plan is a hierarchical elaboration of a previously learned skill. The successive acquisition of more mature child behaviors has been realized through parental reinforcement of specific skills across several developmental domains, e. g., imitation of actions, words, and social gestures.

Similarly, their parents and siblings increased the frequency and the quality of their interactional behaviors to levels at which familial satisfaction was obtained. These more frequent positive interactions among family members were directly related to the handicapped children's increased behavioral repertoires. Since the infants with handicaps became more responsive, parents and siblings received immediate feedback regarding their actions. Thus, a natural feedback system was formed in which the transactional nature of families was recognized and greater sensitivity by each family member was encouraged.

These positive behaviors pointed to the proactive perspective associated with the family-focused intervention model (Kaiser & Hemmeter, 1989). Assistance to families included promoting fulfillment of their needs, aspirations, and roles. Achievement of targeted goals was manifested by positive changes in each family member, in that each family

member assumed personal responsibility for the behavioral change. In turn, the interventionist supplied information, support, suggestions, and materials that promoted these changes.

Parents and siblings acquired 98.67% of the targeted goals; whereas the children with handicaps learned 79.80% of the intervention goals (Table 21). Given the numbers of goals designed for all families, a significant increase in positive behaviors was acquired by family members. The families obtained skills that were functional, utilized across environments and individuals, and increased the frequency of pleasurable interactions among the family members.

#### Program Implementation

The formulation of the family plan occurred through collaborative efforts between parents and investigator, resulting in the identification of functional and appropriate child behaviors which coincided with the values and existing demands of each family. Parents, within the family-focused interview, requested varying levels of involvement in their children's program, regardless of child functional levels. Given that parental priorities for family goals and preferences for level of involvement were incorporated within the intervention, mothers and fathers may have become more interested in the program, resulting in their facilitating their children's skills acquisition (Bailey, 1987).

The importance of ascertaining parental perspectives regarding intervention was underscored by the various ethnic and religious backgrounds of the families. According to specific ethnic (e. g., Indian) or religious groups (e. g., Orthodox Judaism), strict gender roles existed. Mothers' and fathers' responsibilities for child-rearing and teaching differed, and then value systems had to be considered in

developing the family plan. For example, one family of southern European descent unrealistically wanted early toilet training (at one year) of their child with handicaps. Instead of immediate rejection of the parents' goals, information and viewpoints from the parents and the investigator were shared, resulting in greater parental sensitivity to the physical and intellectual capacities of their child. Thus, support for parental perspectives encouraged their receptivity to alternative viewpoints while simultaneously remaining in control of the intervention.

Parents were encouraged to choose the number of goals they wished to emphasize each week. The investigator consistently recommended that the goals be integrated into the context of daily family activities. Generally, a range of two to four goals were targeted by parents. There was considerable progress on these goals by each family member.

During the weekly intervention sessions, the professional targeted approximately eight child goals and four family goals. The parents and the investigator cooperatively presented the goals to their child. It was interesting to note that the families were not overwhelmed by the number of goals, since each was task analyzed (divided into hierarchical steps) and related to other goals within the same or other developmental domains, e. g., imitation of actions and vocal play.

The methods used for the children's skill acquisition were derived from two sources, the Carolina Curriculum for Handicapped Infants and Infants At Risk (Johnson-Martin et al., 1986) and the principles of systematic instruction (Snell & Zirpoli, 1987). Using techniques such as time delay, facilitated gradual skill acquisition by the children.

In terms of family goals, the procedures were developed by the

investigator, following the principles of Bromwich (1978). As such, mutually pleasurable interactions among family members were encouraged through the use of problem-solving, discussion, modeling, empathetic listening, and encouragement. Siblings learned how to interpret the children's cues, which games were pleasurable to the children, and specific techniques to increase the probability of effective interactions. Parents acquired specific teaching procedures, behavior modification strategies, handling and positioning techniques, and understanding of functionality, integration, and available resources. The purposes underlying the parent goals included advocacy, establishment of strong parent-infant attachment, and accurate interpretation of their children's behavioral cues. They also included parental ability to anticipate their children's developmental, social, and emotional needs, and to persevere with their priorities for intervention.

Based on anecdotal data, skill acquisition among the families was partially a result of the model's emphasis on the collaborative approach between the families and the investigator and the use of various intervention techniques. Collaboration entailed discussions about treatment of various child problems. In deciding the appropriate actions to perform, experimentation with different techniques was found to be successful, given that prior professional suggestions had not eliminated specific child behaviors. For example, suggested methods from therapists, that failed, were altered in order to reduce torticollis and nagging behavior by two children. Similarly, encouragement from the investigator promoted parental advocacy. Parents learned to take the initiative in contacting agencies for additional services and potential school placements.

Further, the parents appreciated the individualized plans. From these plans, they were able to determine which future skills needed to be acquired and those goals that had been achieved by the families. Other professionals working with the families (e. g., physical therapist) emphasized the same goals and the complimentary methods. Since all the professionals used the same procedures, it could be hypothesized that parents gained familiarity with the methods and exhibited faster skill acquisition with the additional professional input.

Within the family-focused intervention model, goal attainment continua were devised (Table 23). Specific maternal, sibling, and child behaviors were targeted. Since these individual behaviors (e. g., maternal insensitivity to the child's interests) were not included on the assessment tools, measurement of progress was performed by comparing pre- and post-test levels. Analysis of progress, as suggested by Kiresuk and Sherman (1968), involved t-test analysis by weighting the various goals for a specific person. Within this study, the goals on the continua comprised various functional behaviors across families, rather than within family units. As a result, these goals had equal importance for each family and could not be weighted. In order to assess progress, comparison of pre-treatment and post-test levels was conducted. All subjects exceeded the expected level (labeled 0) and displayed behaviors at the upper end of each behavioral continuum.

#### Parental Behaviors

Similarly, parents achieved the highest ratings on the HOME, suggesting that the reinforcement and modeling of appropriate parenting behaviors resulted in contingent responding, the provision of pertinent



materials, and a safe learning environment. These positive effects were especially evident for parents of children with severe handicaps or age appropriate behaviors. These parents increased their behaviors to the upper levels of each area on the post-test. Parents of children with moderate handicaps maintained their high scores on the HOME. While significant progress was realized by subgroups of the sample, intervention applied to parenting behaviors resulted in improvement across all families.

Moderately high positive correlations between scores on the PBP and the HOME suggested that effective parent-infant interactions were significantly related to the establishment of a nurturing and responsive home environment. The data supported the previous results of Affleck et al. (1982a, 1982b).

As well, parents emphasized the importance of their affective relationship with their children as a necessary component of promoting child competence. In their statements regarding attachment during the intervention sessions, parents predominantly linked the strengths of their bond with their children's skill acquisition. It would follow that stronger attachments were potentially associated with higher levels of child progress. While this hypothesis was confirmed for most of the subjects, children with very low functioning levels (e. g., functioning one-quarter of their chronological ages) failed to demonstrate significant gains. This lack of substantial child progress may have reflected the extent of child impairments (Macpherson & Butterworth, 1988). In order to determine the quality of the parent-child relationships, one needs to look at the level of attachment as well as the amount or type of parental effort necessary to increase children's

abilities.

One of the aims within the family-focused intervention model was the development of a mutually pleasurable, rewarding relationship between parents and their children with handicaps. The formulation of a satisfying relationship was a necessary skill required across the life-span of the family (Turnbull, 1988). Measurement of parent-child relationships was conducted through repeated administrations of the PBP. In comparison to the initial scores, the parents (14 mothers, one father) achieved 85% of all the behaviors listed on the two forms (Form A, Form B). Parents displayed between 54 and 70 attachment and interactional behaviors on the post-test, resulting in increased sensitivity and responsivity to their children's basic needs and development. The ability to develop effective attachments was realized by all parents of children included in this study. The items on the PBP proved to be sensitive to individual parental behaviors. Furthermore, these families exhibited differences in cultural orientation, value systems, and child developmental levels, which were considered by the PBP and attested to its usefulness.

This positive parental growth resulted in the conclusion that the parents clearly increased their enjoyment of their children and, as a result facilitated their general development. For two parents, the mothers of child 6 and 10, positive relationships were primarily targeted. With respect to child 6, a goal attainment scaling continuum was devised. Through the use of modeling, discussion, and brainstorming, the mother attained the level at which her positive statements were consistent with her body language. This was illustrated by smiling,

spontaneous affection (e. g., kissing), and enthusiastic positive reinforcement to her child.

The mother of child 10 viewed life events "beyond her control." She was frequently overwhelmed by typical life events (e. g., child's ear infection). Further, she provided an unstructured home life for her spouse and children. Due to her perceived, continual upheaval, her ability to exhibit appropriate behavior and reserve appropriate time for her children was extremely variable. This mother's ineffective coping strategies resulted in her dependence on professionals for making simple decisions.

For this mother, initial practice in problem-solving and assumption of responsibility focused upon realistic concrete problems. After the parent identified the problem and its potential solutions and implemented the most desirable course of action, the need to make major decisions (e. g., transition to a public school placement) was then addressed. After exploring the parent's desires, a timeline of activities was devised in which each person's responsibility was clearly delineated. Based upon maternal behaviors, gradual acquisition of problem-solving skills was accomplished. On the goal attainment scaling, this mother reached the highest level of the scale, which encompassed gathering information before acting, and exploring and pursuing the most desirable solutions.

The behaviors of this mother, as well as the other parents, suggested a relationship between level of attachment and parental desire to promote child skill acquisition. This relationship was confirmed by the significant positive correlation between scores on the PBP and the scores on the Teaching Skills Inventory. In fact, Rodgers (1988) found

that levels of maternal responsiveness were associated with the extent of handicapped children's skill acquisition at three years. The existence of strong attachment behaviors certainly facilitated the children's developmental gains.

In addition, the high levels obtained on the PBP were clinically significant, given that researchers, such as Blacher (1984a), stated that strong parent-infant attachments were often difficult to achieve. The subjects in this study demonstrated increased amounts of attachment and interactional behaviors, and as such may have comprised an unusual sample of parents. All families volunteered for this study and may have been more motivated to respond to intervention efforts. Future investigations could determine whether attachment levels vary as a function of parental motivation, child functional levels, and/or improve as a result of intervention. For the present sample, parents increased the quality of their attachment and interactional behaviors as a result of sufficient resources, supports, explanations, positive reinforcement and modeling.

Parental knowledge clearly increased as a result of the intervention sessions. This knowledge was demonstrated by high scores on the Teaching Skills Inventory. Enhancing parental teaching skills occurred on a weekly basis. As part of the family-focused intervention model, parents learned task analysis, how to modify intervention strategies, accurately and contingently respond to their children, and determine targeted child skills. Based on the results of the Teaching Skills Inventory, parents significantly increased their instructional skills by expanding their repertoire of feedback techniques, knowledge, and their ability to implement special educational strategies.

Parents of children with severe handicaps improved their initial low levels of teaching skills, but they displayed less creativity than parents of less impaired children. These children with severe handicaps exhibited poorly defined cues, which impacted upon the level of parental responsiveness and success of parental efforts. With increased child competence, parents responded more contingently to their children. Parental skill acquisition was achieved by modeling, emotional support, positive reinforcement, and practice.

The increases in the parents' teaching skills lessened their reported dependence upon professionals, as they acquired many of the skills used by special educators. Once again, a proactive stance was emphasized. Parents' ability to decide current and future child goals promoted their organization of the sessions, and resulted in their ability to plan goal-oriented activities for their children. Consequently, their children understood the purpose of the activities, received appropriate instruction on functional skills, and attempted to display the targeted behaviors.

The parents' enhanced repertoire of instructional skills resulted in better child-rearing skills. It would appear that the parents' abilities were associated with children's increases in displaying desired behaviors, both statistically significant results. Furthermore, the balance between child- and parent-initiated activities approximated nearly equal rates. An aim underlying the development of the Teaching Skills Inventory was the encouragement of a match between child and parental overtures. When both children and parents shared control of the interaction, greater reciprocity and pleasure within their relationships tended to exist. The results of the present study supported the earlier

research of Crawley and Spiker (1983) and Rodgers (1988), such that parental directives or teaching accelerated child competencies as well as resulted in higher levels of parental sensitivity. In conclusion, the balance between the incidence of parental requests with the infants' bids for specific activities led to mutually pleasurable relationships, improved parental teaching, and increased child behaviors.

Not only was the level of attachment (PBP scores) associated with increased parental teaching scores ( $r = .52, p < .01$ ), but the initial levels of resources experienced by families (Family Resource Scale scores) were also positively related to parents' teaching behaviors ( $r = .62, p < .05$ ). When sufficient resources existed, parents demonstrated emotional availability and interest in augmenting their children's skills. They were not overwhelmed with the task of obtaining the basic necessities. Instead, parents had sufficient energy and willingness to promote the targeted goals.

Similarly, when adequate social support and resources existed in families, enhancement of satisfying home environments was promoted (Deal et al., 1989). The Family Resource Scale measured the extent and quality of resources perceived by families. While housing, food, etc. were typically considered as "almost always adequate", parents indicated difficulties in terms of time for the family to be together, to be with individual family members and significant others and for individual activities, regardless of child functioning levels. In contrast to middle and low income, families with high SES indicated no difficulty with opportunities for personal socialization. The amount of differences between families may have been related to family costs, such as baby-

sitters, entertainment, or vacations.

During the family-focused interviews, parents frequently described their home atmosphere as one of "exhaustion", while they coped with living with handicapped children. The frequency of parental exhaustion may be associated more with the young ages of their children, than the presence of a handicapping condition. Leach (1981) reported that parents of nondisabled, young children expressed high levels of exhaustion. In order to ascertain the cause for parental exhaustion, it would be advantageous to determine the separate effects of the children's chronological ages and handicapping conditions. Furthermore, parental exhaustion may be related to the number of routines in the home. In the present investigation, parents with structured sequences of daily activities, reported better coping, utilization of time, ample opportunities to be with family members, and balancing of the needs of the entire family. Thus, a home schedule implemented on a consistent basis with additional financing for child care may improve parental attitudes.

In an effort to encourage greater interaction among family members, parents were provided with suggested ways to set aside time for family members, ideas for low cost entertainment, and travel or vacation opportunities, as well as names of potential baby-sitters, respite care centers, day care centers, and housekeeper assistance (Table 30). Even though the parents received the names of these additional resources, their needs changed over the course of the study. As a result, their responses reflected the diversity amongst the families and the necessity of the identification of individual family needs. When potential resources were delineated, families individually elected whether or not

to avail themselves of these services.

As revealed by parental responses on the post-test of the Family Support Scale (Table 11), various informal and formal sources of supports were viewed as more helpful. The support systems used by families typically involved a small network of immediate family members. Formal support systems (e. g., professionals) were used less often. Researchers, such as Trute and Hauch (1988), recommended encouragement of informal support groups, because they were continuously available to families.

In contrast, formal systems of support (e. g., professionals) may vary at different points in the children's lives. When children exhibit a transition to a new program, the professionals may change. In review of current support received from professionals, parents gave mixed reviews. They disapproved of having to demand services for their children to which they were entitled to receive. While one of the purposes of the family-focused intervention model was to encourage parental advocacy, external forces (e. g., agency requirements) could hinder implementation of this role. The need for parents to battle continuously for services could have interfered with the amount of time reserved for enjoyable familial interactions and the development of a positive relationship between agency and parents.

Several parents questioned the conflict between professionals' advocacy for the families and loyalty to agency demands. While the investigator emphasized the development of trust, especially in the area of confidentiality, interventionists from local infant programs typically stressed agency requirements. It was as if the parents had to meet the



desires of the agencies, rather than the programs requesting and attempting to fulfill family needs. Certainly, not all infant programs assumed this attitude. However, those families who displayed the most ambivalence about the assistance of professionals did not typically view these personnel as sources of assistance. Agencies should devise procedures which accommodate family needs and reasonable levels of parental advocacy.

It was interesting to note that families did not consistently utilize community resources. Parent meetings, social or religious groups were not requested nor sought after by the parents, even though they were identified as potential sources of support (cf. Cohen et al., 1989; Dunst & Trivette, 1988; George, 1988; Waisbren, 1980). When names of local parent and sibling groups were offered, parents and siblings did not want to share their personal thoughts with strangers. Many parental responses indicated that they desired their time to be spent on facilitating their children's development and on increasing the quality of the home life, rather than talking to strangers. Siblings appeared to prefer talking to their parents. In light of the findings, it would be useful to devise community workshops focusing on pertinent themes that were relevant to families.

Support to families could be extended in a variety of ways. Within this investigation, the families' abilities were reinforced by acknowledgment of their pre-existing skills. Given that each parent had individual strengths, recognition of his or her capabilities encouraged enhancement of other parental skills and trust. With the establishment of mutual respect, effective parent-professional relationships developed. From this base of mutual respect, informal exchanges were frequent,

openness was present, and support for parents' strengths was extended. As Affleck et al. (1982a, 1982b) mentioned, these informal conversations often resulted in episodes of support, reflection, and behavior change. In order to encourage effective rapport with parents, professionals should acknowledge parents' abilities by frequently discussing parental strengths in an informal manner.

Professional support was provided during the family-focused interview as parents described how they learned of their children's diagnoses. When parents were given an opportunity to relay stressful events, it acted as a support in itself (cf. Winton & Bailey, 1988). Medical personnel were consistently viewed as unsupportive by parents. In response to learning of the diagnoses, 12 families sought out additional information and utilized various problem-solving strategies as they attempted to cope with their children's diagnoses. Critical events, such as medical diagnoses, could negatively influence families' daily living patterns (McGonigel & Garland, 1988). This was evidenced by repeated hospitalizations for children and frequent appointments with professionals.

During the stressful time of diagnosis, spouses often provided positive support to each other. Adaptation by fathers seemed to comprise decreased expectations for their handicapped children, as exemplified by their depressed ratings on the Child Expectation Scale, when compared to mothers. Explanations of expectations provided by fathers included protection from possible future disappointment, assumption of realistic appraisal of the children's current rate of progress, or recitation of information gleaned from medical personnel or literature. The

perspectives of the two parents about their child's future abilities could lead to conflict and may be resolved by the delivery of concrete information about the child's individual developmental progress, needs, and goals.

Some parents appreciated the extent of time and simple explanations provided by a few of the medical personnel. They did not, however, receive the names of appropriate agencies, follow-up visits for more information, and positive aspects of parenting children with handicaps. Given the different capabilities of medical personnel for interpreting information to parents, continued cooperation between various service delivery systems should be an ongoing goal.

In order to shift from the negative effects of parenting handicapped children, parents were asked to cite specific skills or behaviors they had learned from their children (see Protocol for the Family-Focused Interview). This question was designed to ascertain any positive aspects of living with children with handicaps. From the parents' viewpoints, they were able to recall positive emotions (e. g., patience) or perspectives (e. g., amazement at the capability of children with handicaps). Thus, these young children engendered positive reactions from their parents.

### Sibling Behaviors

The family-focused intervention model also emphasized siblings' interactive styles in an effort to increase the frequency of positive relationships. From observations conducted on the Sibling Interaction Scale, sibling behaviors may have been influenced by their chronological ages and the responsivity level of their siblings with handicaps. The four young siblings (chronological ages 3-29 months) of the children with

severe handicaps demonstrated difficulty in responding contingently to their handicapped siblings. In response, children with severe handicaps displayed few positive behaviors. The interactions were portrayed by young nondisabled children (chronological ages of 11-29 months) performing care-taking activities or providing stimulation.

In contrast, the responses of the nondisabled siblings encompassed an array of pleasurable social games with children functioning age appropriately or functioning with moderate developmental delays. Since these nondisabled siblings ( $N = 11$ ) received frequent feedback from their siblings with handicaps, they expected them to exhibit turn-taking and respond immediately to their overtures. Therefore, the developmental ages of the nondisabled siblings appeared to influence whether they initiated age appropriate games and understood the responses of the children with age appropriate or moderately delayed functional levels.

When the chronological ages of the siblings (nondisabled and moderately handicapped) were within two years of one another, more equality in roles were established. This was not the case, however, for three out of the seven siblings of children with moderate handicaps. These handicapped children displayed frequent episodes of inappropriate behavior. When the children with moderate handicaps exhibited self-stimulatory or oppositional behaviors, siblings showed evidence of annoyance and occasionally terminated the interaction. The older brothers of child 10 occasionally attempted to engage their younger brother in their games by attempting to modify his behavior or they excluded him from their activities.

For the older brother (chronological age of 5 years) of child 2, the

child's infrequent responses to his requests and overtures were especially difficult for him to understand. As part of the intervention, the child's functional play was encouraged and his brother acquired a more realistic outlook of his capabilities. As well, discussion, positive reinforcement, and modeling encouraged the older brother's ability to initiate more developmentally appropriate games. Given the emphasis placed upon the siblings' behaviors, more pleasurable sibling interactions were observed.

In another family, the older brother of child 14 exhibited difficulty in being responsive to his younger sister with moderate handicaps. This child was previously diagnosed as having moderate mental retardation, which lessened his ability to respond sensitively to his younger sister. Short-term goals for this older brother included establishing eye contact, vocalizing to his sister, sharing toys, and allowing his parents to attend to his siblings. Throughout the intervention sessions his behaviors showed gradual improvement.

The range of behaviors of all children with handicaps were less diversified and infrequent, when compared to their nondisabled siblings. Regardless of the level of functioning, eight of the children (functioning levels ranging from age appropriate to severe handicaps) permitted their nondisabled siblings to control which activities were to occur. Three children with moderate delays or at age appropriate levels exhibited more responsiveness as "learners" on the post-test and attempted to alter the types of games presented. More balanced roles were assumed by preschool-aged nondisabled and handicapped siblings, when closer age spacing (within two years), and mild or moderate child delays were present. For the other sibling pairs, the older sibling assumed the

dominant role, while the siblings with age appropriate levels to moderate handicaps demonstrated more compliant behaviors. This lack of balanced roles was observed between nondisabled siblings, because the younger or less capable sibling was often placed in subservient roles (Lamb, 1978). In spite of this lack of role balance among the sibling relationships, the siblings encouraged appropriate behaviors from their lower functioning siblings.

In general, the nonhandicapped siblings showed different capacities to assume the perspectives of their disabled siblings. Some siblings permitted occasional relinquishment of control to their handicapped siblings, while others (preschool-age siblings) imposed their own desires for play upon the children. Preschool siblings appeared to be consumed by their own wishes for play. It is widely recognized that preschool children possess difficulty in assuming the perspectives of others (e. g., White, 1975). Generally, the older siblings tended to perform behaviors that were responsive and interesting to the handicapped children.

The siblings' play behaviors, however, may have reflected their parents' attitudes. Brody and Stoneman (1986) found that the attitudes and adaptations of siblings corresponded to the beliefs and actions of their parents. Further, the specific behaviors displayed by the children may have been a reflection of parental expectations. Parental encouragement to teach or assist with child care could have been linked to being a "good sister or brother." One parent specifically desired her older child (who had moderate handicaps) to help with child care of his younger sister, while other parents expected their children to control

the behaviors of the handicapped children or teach them specific skills. Thus, both preschool and school-age children were often given particular tasks to perform by their parents.

It was interesting to note the dichotomy of the parents' perspectives. On one hand, they expected the children to assume additional responsibilities in the care of the handicapped children. Yet, one-third of the parents during the interview phase reported that the nondisabled children had a right to their own lives and any type of added responsibilities should be self-selected. It would appear that extra duties were assumed by the siblings when the parents were at home. When the siblings eventually become adults, their parents expected them to be independent. In answer to the varying expectations, parental statements and desires could be in opposition to one another, and thus, cause the contrast between parental actions and thoughts. Further, siblings could have been expected to assist in the orderly functioning of the home environment as a member within the family unit. When the siblings' self-sufficiency is obtained, they may be permitted greater freedom to decide their own interactions. Although various interpretations could explain parental behavior, the dichotomy between sibling independence and assumption of responsibility still existed.

Siblings recognized their extra responsibilities. Given that only a few siblings were school-age, the results on the Inventory of Siblings' Perspectives should be considered as exploratory in nature. However, these children requested additional information about their siblings' handicapping conditions. This need for knowledge about children's handicapping conditions was frequently cited (e. g., Crnic & Leconte, 1986). In addition, these siblings appeared ambivalent about meeting

with peers, who had handicapped brothers and sisters. They verbalized their ambivalence about sharing personal thoughts with others, and often asked their parents how they should respond. It is plausible that as the siblings become older, the need for a peer support group could intensify (Powell & Ogle, 1985).

Siblings are an integral part of any family unit whose needs must be addressed. Simple explanations about the particular handicapping condition and its effects were provided as well as concrete examples of how to effectively interact with the children were discussed. Further, the sibling goals measured on the goal attainment scaling continua suggested an increased understanding of the children's abilities and accurate interpretation of their non-verbal cues.

In contrast, the younger preschool age siblings indicated consistently higher positive responses on the post-test of the Inventory of Siblings' Perspectives (Form B). While the older siblings perceived inadequate parental attention, the younger siblings signaled satisfaction with the obtained levels. The differences between these two ages could have been due to preschool children being at home for greater intervals of times; and thus, benefited from periodic parental attention throughout the day. Conversely, the older children arrived from school when child care and meal preparations were occurring. Further, the extent of parental time could be a salient issue for older children but not for younger ones. Over time, it would be beneficial to ascertain whether the preschool children's opinions change in response to actual or perceived amounts of parental attention. Thus, one could determine whether the differences are age-related or may reflect changes in parental behaviors.



Consistent with the preschool children's positive attitudes, their display of nurturing behaviors increased over time. Positive behaviors, such as assuming perspectives of their siblings with handicaps were realized in preschool-age siblings. Through the use of discussions, reinforcement and modeling, sensitivity and pride for their brothers and sister with handicaps were exhibited. As a result, the frequency of negative behaviors previously reported (e. g., Skrtic et al., 1984) were not found, when compared to the extensive list of positive prosocial sibling behaviors. These young siblings demonstrated warm, engaging, and reinforcing behaviors toward their siblings with handicaps.

#### Methodological Considerations

No statistical significance for children's test scores and parental ratings on the Child Expectation Scale, Family Resource Scale, and Family Support Scale was found. The possible reasons for the lack of statistical significance may have been due to the narrow range of parental scores or the possibility of the sample being self-selected. While statistical significance was not found between the child and family measures, the clinical meaningfulness of children's test scores and the stipulated parent scales was supported by increased ratings.

Similarly, no significant correlations between the parent and child variables were apparent. Several possible explanations could account for the lack of association and significance among the variables. First, a narrow range of highly positive scores was obtained for post-test scores on the HOME, PBP, and Teaching Skills Inventory. One-third of the parents initially had scores one standard deviation below the mean on the pretest and improved their sensitivity and responsivity, and instructional skills to the ceiling levels of the assessments on the

post-tests. The lowest parent group exhibited significant gains that approximated those behaviors of the higher group. As a result, little variability among parent behaviors was observed on the post-test, resulting in a relatively homogeneous sample. In contrast, their children exhibited the entire continuum of developmental functioning. One could speculate that parent and child behaviors had reciprocal effects on one another with no particular trend for either parents or children. For example, children's progress could influence parental coping and the amount of stimulation provided by parents. Parental behaviors could increase or limit the number of interactive behaviors displayed by their children. As a result, both parents and children affect one another's responses on an ongoing basis.

In addition, statistical significance was not found between child and parent variables due to the small number of families and the associated lack of statistical power. With a larger number of subjects, statistically significant relationships may be ascertained. Replication of this study using the same instruments and intervention model could determine if similar patterns would be found.

Another potential explanation for the lack of statistical relationships involved the multiple influences on family progress. The levels of family resources were found to mitigate the amounts of stress, and potentially affected the frequency of appropriate stimulation (Wikler, 1986). Further, events in one subsystem (e. g., parent-nondisabled child) impacted upon the other family subsystems (parent-parent, parent-child, etc.) (Belsky, 1981). In essence, there could have been multiple influences on families' behaviors and progress that were

not measured by the assessment tools. The behaviors of each family member contributed to the multi-directional effects on other family members, and resulted in no consistent direction of influence. Rather, the continuous and changing interactions depended on the fluctuating ability levels of each partner at each point in time. Each family had its own individualized set of circumstances, support systems and resources, which varied considerably across the wide range of handicapping conditions included in this study. Thus, recommended actions could include the following: (a) ascertain a larger and random sample of subjects to determine the correlations among the variables, (b) assess the effects of family variables using only one handicapping condition per analysis, (c) obtain comparison data using nondisabled subjects, and (d) replicate the study using the same procedures with another group of families having children with moderate and severe handicaps.

#### Qualitative Analyses

Other analyses included determining the parental perspectives regarding each step within the family-focused intervention model. The assessment sessions produced concrete information for parents about their children's functioning levels. Using an honest and supportive presentation of the results (Flynn & McCollum, 1989), parents learned to understand their children's strengths and needs. As well, each parent indicated improvement in their teaching and planning skills as evidenced on the Parent Satisfaction Scale.

When asked whether improvement in their family relationships occurred, some parents (independent of child functional levels) indicated that their relationships continued to be positive, while others denoted

varying levels of improvement. Parents, who felt they had established effective relationships prior to intervention, had children with varying functional levels (chronological ages = 2-28 months) and emphasized the development of an effective family unit. Thus, intervention efforts reinforced, modified, or significantly changed the quality of the interactional behaviors among the family members.

Other parental opinions regarding the family-focused intervention model were obtained through open-ended questions. Parental statements were then categorized into recurrent themes using a qualitative approach. Each theme was interpreted in reference to the characteristics associated with the model. One consistent attribute of the model was the global orientation to families' needs and behaviors. Parents typically cited that the needs of the entire family were included within the assessment, planning, and implementation of the program. As part of the family-focused intervention model, each person's responsibility was delineated in conjunction with a behavioral goal. Given this orientation, parents verbalized high levels of satisfaction with the thoroughness, specificity, organization, and implementation of the plan.

In essence, parents perceived significant progress in the ability of their families to meet the challenges of living with children with handicaps. Data analysis of child assessments and observational data confirmed these positive viewpoints. While family goals continued to be targeted upon completion of the study, parents were equipped with the necessary skills to fulfill their life functions (e. g., capability to identify new child goals). Expansion of their skills involved insuring adequate supplies of necessities, learning alternative approaches to

problem-solving, demonstrating sustained effort to accomplish the families' goals, and balancing the needs of all the family members (Turnbull, 1988).

Similarly, the siblings and children acquired functional skills that were used daily. They became more responsive to each others' bids for attention and interaction. The increase in pleasurable sibling interactions resulted in children with low functional levels responding contingently to their siblings' overtures. More positive interactions were reflected in siblings' statements and were observed clinically by their parents and the investigator.

The explanations for these positive appraisals were due to the characteristics of the family-focused intervention model. First, each family was viewed according to its specific preferences for intervention, pre-existing strengths, and family members' needs. As a result, the individualized family service plans were consistent with individual goals. In addition, collaboration between families and professionals was required. This cooperative approach encouraged families to remain in control of their plan, its implementation, and the accompanying non-intrusive methods (Kaiser & Hemmeter, 1989).

Each person's strengths were recognized. Building from a positive base, the families flourished, even in the face of ongoing stressful events. Expansion of their resources, support systems, and problem-solving skills was hypothesized to facilitate the children's development (Dunst et al., 1986b). Lastly, the family-focused intervention model was a flexible and functional approach which encouraged the development of functional skills of all family members. In essence, this model considered the diverse and changing familial needs.

### Summary

In summary, children with moderate and severe handicaps accelerated their rates of skill acquisition and increased the quality of their motor movements. Although the children with moderate and severe handicaps exhibited varying levels of responsivity, their parents and siblings were able to consistently establish and maintain effective relationships with them. In general, nondisabled children enjoyed their siblings with handicaps, but were often expected to assume child care responsibilities. In addition, parents increased the quality of their interactional and instructional skills; yet, the extent of sufficient family resources and supports was limited primarily to basic necessities and immediate family members. In spite of less than optimal scores for family resources and supports, parents perceived substantial progress in family functioning and valued the global orientation of the family-focused intervention model. Through the use of qualitative and quantitative data analyses, the effectiveness of the family-focused intervention model was ascertained for these families.

This study involved the utilization of a framework emphasizing intervention with families having children with developmental disabilities. The family-focused intervention model of Bailey et al. (1986) had been theoretically postulated. This study empirically validated the effectiveness of the model and involved operationalizing each of the purposes associated within each step of the model. Research findings from relevant literature served as a foundation for the selection of appropriate family assessments, determination of the interview questions, and specific interventions to augment optimal family

functioning. Three assessment tools were devised and field tested for the measurement of siblings' attitudes and behaviors and parental appraisal of the family-focused intervention model.

#### Implications for Future Research

The shift from a clinical focus upon the child to one that is more inclusive of the entire family is documented only recently in the psychological and educational literature (Mahoney, O'Sullivan, & Fors, 1989). Given the small number of family units included in this investigation, additional replication studies implementing the family-focused intervention model are needed. In order to ensure greater applicability of the model, it should be implemented for families having children with diverse handicapping or at-risk conditions in order to determine the model's generalizability.

The family-focused intervention model is a multi-dimensional paradigm, in which use of various child, sibling, and parent assessments illustrate individual strengths and needs. For families who desire immediate intervention with a strict child focus, the effectiveness of this model would not be realized. Similarly, governmental agencies will need to stipulate sufficient time allowances for development of each individualized family service plan, especially when parents and groups of professionals are attempting to collaboratively devise plans. Further, implementation of the family-focused intervention model has been performed using a home-based model. Use of this model with other modes of service delivery (e. g., center-based) could determine its effectiveness across early childhood special education settings and potentially influence public funding appropriations.

Future studies should investigate whether family-focused

intervention lasting five months is a sufficient amount of time to cause sustained, positive changes in families. Longitudinal data are necessary in order to determine the long-term effectiveness of the model. The success of this study may have been a function of the investigator's previous experience. Less qualified professionals may have difficulty in acquiring the same levels of family change. The importance of establishing an effective rapport with families and utilizing well qualified professionals has been emphasized by parents.

Replication of this investigation is needed due to its inherent weakness of the investigator acting both as the interventionist and as the evaluator of family progress. Although inter-rater reliability was conducted for a portion of the family assessments, experimenter bias may have been reflected in the qualitative analyses of parent-child and sibling interactions. Thus, it is suggested that inter-rater reliability be performed in the administration of all family measures and in the analyses of spontaneous family behaviors.

In addition, statistical analysis involving the relationships of parent and child variables was unsuccessful. It was hypothesized earlier that either insufficient numbers of subjects were included in the study or one cannot expect a significant relationship due to the transactional nature of families. Additional data from other professionals using the same scales could shed more light on the types of relationships that exist among parental and child behaviors. Possibly, with the use of a greater number of families, hierarchical multiple regression could be utilized, as suggested by Dunst (1986). This procedure would help to determine the separate effects of each variable.



Further, the lack of statistical significance may have been influenced by the duration of the intervention program. Possibly, greater gains among family members could have been achieved with more intervention sessions. Therefore, it is recommended that the optimal duration and frequency of early intervention services using the family-focused intervention model be investigated. Similarly, determination of the optimal chronological age for infants' enrollment into an early intervention program should be investigated and could provide useful information to public policy decision-makers.

From the scores obtained on the Family Support Scale, one could conclude that parents' support scores were relatively low, regardless of SES and child functional levels. Given that no norms exist for parents of children with and without handicaps, further validation of this instrument is required. Questions arise as to whether these low scores are typical of other parents of children with moderate and severe handicaps, or representative of parents with children with and without handicapping conditions. As a result of intervention, parents have improved the extent of their support networks. However, comparison data are required in order to make conclusions about the services needed for families with young children with differing needs.

Further, parents in this study have not typically participated in community groups. Parent support groups are indeed available, yet these parents have chosen not to become involved with them. Possible reinforcement of small, intense support groups, as recommended by Dunst et al. (1986b), is more important to these families than attendance at a periodic community group. Support could be extended through a series of parent workshops. If parents attend a course of instruction that

addresses their immediate needs, possible support could be acquired during discussion periods. In this type of setting, parents might feel comfortable in sharing their thoughts and would acquire additional techniques or resources. Parental desires need to be ascertained and alternative sources of support be provided.

Likewise, the parents of these young children indicated insufficient time for socialization. While some underlying reasons are due to job responsibilities, other parents had difficulty in setting aside sufficient time. In order to determine if this phenomena is universal, further investigation into the underlying reasons should be conducted for families with young children with and without handicaps.

With respect to the siblings, two assessment devices have been formulated as part of this study, Sibling Interaction Scale and Inventory of Siblings' Perspectives (Forms A and B). On the Inventory of Siblings' Perspectives, contrasts between the preschool and school-age siblings revealed that the older children reported inadequate quantities of time with their parents and for community events than their younger counterparts. The differences in their responses may have been due to the additional responsibilities assumed by the older children or to the amount of time the children have available. Given that only a few older siblings completed the respective form, comparison with other school-age children having siblings with handicaps requires investigation. Possibly, rigorous observational techniques in qualitative research designs might prove helpful in describing these sibling behaviors.

In terms of the Sibling Interaction Scale, the roles assumed by nondisabled children changed over the course of the study to ones of more

equal sharing of control during the interactions. This shift may have been due to the recognition of the children's capabilities, increased child competence, or the siblings' chronological age. It appeared that intervention aimed at reinforcing the relationship assisted the gains made across preschool- and school-age siblings. Further investigation into the types of roles assumed by siblings, causes for siblings' behavioral change, and continued validation of these tools should be performed.

In addition, the experimental scales for evaluation of parental satisfaction and sibling behaviors need to be further validated. Other future efforts could involve increasing the sensitivity of medical personnel, given that they displayed difficulty in interpreting medical diagnoses to parents.

The assessment of family needs has sensitized the professional to the individual behaviors, value systems, and goals of each family. The importance of supporting entire family units has been consistently reinforced by the transactional nature of family relationships. Application of this family-focused intervention model has resulted in positive outcomes for families having children, who are at-risk for developmental delays (e. g., Down syndrome), or who have confirmed moderate or severe handicaps. Use of this model is recommended for families with children having handicaps that span the entire spectrum of developmental functioning, or who are considered socially at-risk (low SES, abuse, neglect). These types of studies could determine which populations can be served most effectively with the family-focused intervention model. Future investigations should include process data, as well as quantitative and qualitative data analyses in order to

evaluate the outcomes associated with the family-focused intervention model.

### Concluding Remarks

The family-focused intervention model has been successfully implemented for families having infants with moderate and severe handicaps. The abilities and skills of each family have been strengthened by the initial appraisal of the individual familial contexts, competencies, and value systems, and by cooperatively devising plans to meet their specific needs. The ultimate goals of improving the children's development and augmenting the functioning styles of families have been realized over a five month period. The collaborative approach of the family-focused intervention model has increased the presence of functional skills required across the life-span of the families and enhanced the quality of life for these families. Future research is necessary in order to determine whether these gains are maintained.

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### **Appendix 1**

**Critical Events Checklist, Sibling Interaction Scale,  
Inventory of Siblings' Perspectives, Protocol for Family-Focused  
Interview, and Parent Satisfaction Scale**

# Sibling Interaction Scale

(Caro & Derevensky, 1989)

Date:

Time of Day:

Context/Activity:

Age of Sibling:

Age of Targeted Child:

Handicapping Condition of Targeted Child:

## 1. Sibling body position

1	2	3	4	5
stands far away from child	briefly moves into close proximity but then withdraws	is within 3 feet for majority of time, but no attempt to achieve eye contact	is within close proximity and repeated- ly attempts to position body at child's eye level	targeted child is visually impaired but close proximity and body position mirrors child

## 2. Language

1	2	3	4	5
provides no vocal or verbal contact	verbalizes social amenities, e. g., How are you, hi; or vocalizes to child	asks questions or requests of child that does not relate to child's actions	verbalizes complex statements reflective of child's actions	adjusts complexity and length of sentence to child's level of comprehen- sion

## 3. Intensity of Involvement

1	2	3	4
No acknow- ledgement	fleeting recogni- tion	engages with child for 3 seconds	engages with child for sustained amount of time, that is commensurate with sibling's age level

## 4. Extent of Pleasure Demonstrated by Sibling

1	2	3	4	5
exhibits no evidence of enjoy- ment	states positive comment or vocalizes, but body language inconsistent with comment or sound	shows momentary pleasure with corr- esponding body language	pleasure demonstrated on 2 occasions	enthusiastic, obvious pleasure



5. In relation to child's capabilities, sibling's choice of activity:

1	2	3	4	5
chooses	chooses	intersperses	sibling allows	N/A
activity	activity	own play with	child to decide	
according	that has	with child's	which activity	
to own	been enjoyed	preferred choice	both will engage in	
desires	by child			

6. Attempts to engage child

1	2	3	4
grabs toys,	offers toy/game	repeatedly	N/A
no interest	momentarily	attempts to engage	
	and then withdraws	child in play	

7. Accuracy of reading child's behavioral cues:

1	2	3	4	5	6
no	becomes	acknowledges	attempts	changes actions	N/A
attempt	annoyed	child's	to respond	based on child's	
to react	child is	emotions	to child's	behavioral	
to	not	but does	cues, but	responses,	
child's	performing	not try to	inaccurate	accurate	
cues	desired	alter one's	assessment	interpretation	
	action	actions			

8. Level of Response by Child (based on capabilities of child)

1	2	3	4	5	6
No	fleeting	interest	sustained	actively	N/A, child is
response	response	displayed	attending	involved,	in comatose
		for 3	but no	displays	state and
		seconds	emotional	enjoyment	unable to
			response	at level of	respond
				capabilities	

9. Feedback provided by sibling:

1	2	3	4	5
None	predominantly	interested in child,	provides	provides
	negative	says neutral	positive	frequent
		comments, (Oh,	feedback	positive
		you're playing),	on at least	feedback
		vocalizes	1 occasion	

10. Role assumed by sibling

<input type="checkbox"/> teacher	<input type="checkbox"/> manager	<input type="checkbox"/> helper	<input type="checkbox"/> equal playmate	<input type="checkbox"/> no role assumed
<input type="checkbox"/> learner	<input type="checkbox"/> managee	<input type="checkbox"/> helpee	<input type="checkbox"/> provider of stimulation	

## 11. Role assumed by child

☐ teacher    ☐ manager    ☐ helper    ☐ equal playmate    ☐ no role assumed  
☐ learner    ☐ managee    ☐ helpee    ☐ provider of stimulation

## 12. Other behaviors observed by sibling and child, e. g., patience, kindness, anger, etc. (Cite specific event)

# Inventory of Siblings' Perspectives

(Form A, School-Age Version)

(Caro & Derevensky, 1989)

1. Most of the time, I \_\_\_\_\_ my sister/brother. (Check all items that apply.)

\_\_\_play with    \_\_\_watch the actions of    \_\_\_help with    \_\_\_teach  
\_\_\_feed    \_\_\_change diapers    \_\_\_baby-sit

2. The amount of time my mother spends with me is

\_\_\_not enough    \_\_\_sometimes okay    \_\_\_suits my needs    \_\_\_great

3. The amount of time my father spends with me is

\_\_\_not enough    \_\_\_sometimes okay    \_\_\_suits my needs    \_\_\_great

4. Being with my sister/brother makes me feel \_\_\_\_\_  
\_\_\_\_\_.

5. Since my sister/brother was born, I feel like I am \_\_\_\_\_  
\_\_\_\_\_.

6. The extent of my play/leisure time

\_\_\_is not enough    \_\_\_occasionally meets my needs    \_\_\_is enough, given my school work, activities, etc.

7. Our family goes to community events (e. g., movies, picnic, etc.)

\_\_\_once in a great while    \_\_\_only during school vacations    \_\_\_1 or 2 times per month    \_\_\_every weekend

8. The information I have about my sister's/brother's difficulties is

\_\_\_difficult to understand    \_\_\_easy to understand some parts, but not others    \_\_\_clear, sufficient, understandable

9. My brother/sister has learned to \_\_\_\_\_ from me.
10. Living with my brother/sister, I have learned to \_\_\_\_\_  
\_\_\_\_\_.
11. I would like to meet with people my age who have a brother and  
sister with handicaps?    ☐ Yes    ☐ No

## Inventory of Siblings' Perspectives

(Form B, Preschool Version)

(Carg &amp; Derevensky, 1989)

1. When I am with (name of handicapped child), I feel



2. When I play with (name of handicapped child), I feel



3. When I am alone, I feel



4. The time my mother/mommy spends with me makes me feel



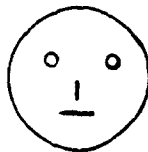
5. The time my father/daddy spends with me makes me feel



6. My family gets to do fun things



7. I understand why my sister/brother takes longer to learn.



8. I have learned from my sister/brother to \_\_\_\_\_  
(with further probing).

9. My brother/sister has learned from me to \_\_\_\_\_  
(with further probing).

## Protocol for the Family-Focused Interview

(Caro, 1989)

1. Could you tell me what your life is like with (child's name)?  
(Winton & Bailey, 1988) How has (child's name) affected your lives?  
  
(seeks information about family's schedule, emotional feelings, characteristics of the home environment, normal parenting concerns)
2. How did you learn that your child may have some problems or difficulty learning?  
  
(family tells their own story)
3. People define stressful events in different ways. What may be stressful for one family may not be so for another. Could you tell me about a stressful event and how your family dealt with it?  
  
(requests information regarding influential people, constituents of a stressful event, family coping style, successful problem-solving skills, who are the decision-makers)
4. Do you have family, friends, community services or resources that have helped you from time to time?  
  
(support system)
5. Families often request different types of services in order to make their family life better. Could you tell me about what kinds of services you would like to receive? Have you used any community services or resources that have been helpful?  
  
(needs for financial, support, information resources, etc.)
6. Could you tell me some of the things that (child's name) has taught? What have you learned about yourself?  
  
(positive and negative aspects from living with a child with handicaps)
7. You know your family best. Could you tell me a little about your other children, e. g., how they're getting along with the other family members. What kinds of things do you hope for them? What kinds of concerns do you have about them?  
  
(temperament, role assumption and expectations)
8. It is important that this intervention program fits your ideas or goals. Could you please tell me some of your plans or hopes for (child's name) for right now and in the future?  
  
(parental priorities and expectations, parental desires for

components of the intervention)

9. I do appreciate your sharing with me your priorities for the program. Could you tell me about which areas you would like your family to be involved with?

(requested level of involvement for entire family, roles parents assumed)

10. Due to the fact (child's name) is being seen by (doctor or clinic's name), could you tell me what sorts of activities/actions they have done or planning to do with (child's name)? Are you already involved with a program with (child's name)?

(critical events that impact on daily living patterns)



# Parent Satisfaction Scale

(Caro, 1989)

1. As a result of the intervention provided, my skills as a parent:

1	2	3	4
remained the same	improved a little	improved some	improved a great deal

2. The quality of the relationships within our family:

1	2	3	4
was already good	improved a bit from the suggestions provided	improved to the level at which I am satisfied	improved a lot due to input received

3. My knowledge of child development

1	2	3
was already extensive	grew some from the information received	grew a great deal above what I already knew

4. My ability to plan developmentally appropriate games for my child

1	2	3
was already extensive	was already good	was enhanced by the suggestions given

5. The quality of the program provided to my family was

1	2	3	4	5
poor	fair	good	very good	excellent

6. The skills of the interventionists are rated as:

1	2	3	4	5
poor	fair	good	very good	excellent

7. My expectations concerning the intervention program:

1	2	3	4
were not met	were partially met	were totally met	exceeded my expectations

8. Additional Comments

## Appendix 2

Table 24

Strengths Exhibited by Parents During the Assessments and the  
Family-Focused Interviews

Family Relationships

---

Attempts to balance needs of entire family (7)  
Supportive to spouse (7)  
Reflects on effect of the child on his/her siblings (5)  
Respects spouse's point of view (3)  
Treats each child according to his/her own personality (1)  
Primary focus on the family (1)  
Avoidance of abusing familial support system (1)

Parenting

Implements suggestions provided by professionals (7)  
Seeks out additional services (7)  
Seeks out additional information (6)  
Advocacy (6)  
Weighs consequences of an event (5)  
Weighs information provided by professionals and makes decision (5)  
Interested in child's development (5)  
Alters portion of an event within one's control (4)  
Aware of persistent effort to raise a child with handicaps (2)  
Familiar with child's strengths, needs, and personality (2)  
Analyzes events from child's perspective (2)  
Sensitive to child's changing physical abilities and behaviors (1)

Acceptance of Their Children with Handicaps

Loves child unconditionally (9)  
Treats child as a "normal" child (4)  
Immediately informed relatives about diagnosis (1)  
Realistic goals regarding the child's future (1)

Teaching

Enthusiastic reinforcement of child's skills (4)  
Sets aside time to be alone with the child on a daily basis (3)  
Accurate observation of the child's behavior (2)  
Encourages skills in the context of daily activities (2)  
Provides language-rich home environment (2)  
Adjusts complexity of speech to level of child's understanding (1)

Personality Characteristics

Warm and open toward professionals (10)

Perseverance displayed in encouraging children's skills (5)  
Deals with uncertainty using available information and sharing  
concerns with professionals, relatives, and spouse (4)  
Articulate regarding questions, strengths, and needs of child and  
family (5)  
Reflective about their children and their role as parents (4)  
Sense of humor (4)  
Analysis of life's events (3)  
Creativity (2)  
Patience toward children (2)  
Adapting to life in a new country (2)  
Sensitivity toward child's nonverbal behaviors (1)  
Flexibility in meeting needs of a young infant (1)

---

Note. (Number) = Number of families that displayed each strength

## Appendix 3

Table 25

Concerns of Parents Verbalized during Intervention SessionsProvincial/Governmental Services

Delayed reimbursements for prescriptions (2)  
 Difficulty with obtaining bilingual services (1)  
 Restriction on type of professionals providing services to infants (1)  
 Paucity of integrated public schools (1)

Early Intervention Services

Inadequate preparation by school personnel for child's enrollment (2)  
 Lack of systematic instructional approach (1)  
 Use of only well-recognized techniques to be used with child (1)  
 Little feedback and few goals targeted for the child (1)  
 Diminished level of enthusiasm by educator (1)  
 Incompetence of educator (1)  
 Two sets of goals presented to the family (1)  
 Lack of intervention over the summer months (1)  
 Few evening services (1)  
 Use of outdated assessments (1)  
 Parental rejection of the role as an evaluator of her child's behavior (1)

Other Professionals

Distrust of ill-informed medical personnel (2)  
 Negative outlook of geneticist regarding future outlook of the child with Down syndrome (1)  
 Inability to sufficiently explain medical terms to the parents (1)

Parental Teaching Skills

Future skills to emphasize with the child (2)  
 Use of bilingualism in the home (1)  
 Parental approach being too structured for the child (1)  
 Sufficient level of stimulation being provided (1)

Children's Bodily Functions and Behaviors

Feeding (8)  
 Constipation (2)  
 Nonfunctional play (2)  
 Understanding of the handicapping condition (1)  
 Aggressive acts (1)  
 Loss of previously acquired skills (1)  
 Medication (1)

**Familial Characteristics**

Lack of spousal support and interest in spouse and child (2)  
Sibling-sibling interaction (2)  
Relief that both parents' presence was not required for the sessions  
(1)  
Relative's illness (1)  
Inability for the entire family to live in the same country (1)  
Pessimistic attitude of spouse (1)

**Children's Future Abilities**

Future school placement (2)  
Investigator's expectations for the child (1)  
Child's ability to learn (1)

**Miscellaneous**

Safeguarding each room's contents (1)  
Toys to buy (1)

---

**Note.** (Number) = number of families citing each concern

## Appendix 4

Table 26

Observations and Quotations Verbalized by Parents Concerning  
Parent-Infant Attachment

7/3/89 (6a) "I'm burnt out. I want to be partly a teacher and partly a parent. You know some parents do better with older children." (Context: Toward the end of the session, we were discussing what the upcoming week was going to be like for the family and what goals the parent wanted to emphasize.)

7/3/89 (6b) Observation of the father spontaneously implementing a pleasurable game of lifting the child in the air. The father smiled, verbalized and provided affection to the child. (Context: Within the intervention session, the father wanted to show me a game he taught his child after the child demonstrated success with three goals.)

7/5/89 (1b) "Let me hold her. I haven't held her all day." (Context: After coming home from work and the entire family was in the living room, the father verbalized the statement.)

7/5/89 (9a) "I think he's clever." (Context: Child demonstrated an approximation of a targeted skill that was presented by the interventionist.)

7/19/89 (1a) Observation of the child vocalizing more often with her mother when compared to the rate with the interventionist. (Context: Interventionist and then mother attempts to obtain vocalizations from the child during vocal play games.)

7/19/89 (1b) "(Mother's name) and (child's name) have a strong love affair." (Context: The father verbalized this statement as we observed the child in her mother's arms while we seated in their living room.)

7/19/89 (9a) "Anyone would want to marry (child's name), because he is so lovable and tries so hard." (Context: Mother spontaneously verbalized about her previous marriage and then made comment about her child toward the end of session. She described her present situation and then referred to her child.)

7/20/89 (8a) "He's so cute." (Context: Mother mentioned this statement as she observed her child spontaneously and enthusiastically play with a toy. The child has a repaired cleft lip and palate.)

7/26/89 (11b) "She (child) would be accepted with whatever (functional) level she got. We won't hold her back if she goes further. We will treat her as a normal child." (Context: Interventionist stated specific targeted weekly goals were accomplished and the father made the statement at the end of the session.)

7/26/89 (1a) "Look at all she can do. I have to brag." (Context: Mother stated this remark upon arrival to their home.)

8/7/89 (6a) "I always try to do the best for him." (Context: Toward the end of the session, the mother and the interventionist were targeting goals to emphasize over an interim of one week.)

8/7/89 (12a) Observations of spontaneous social games being enthusiastically presented to the child by the mother in order to elicit social responses and vocalizations.

8/9, 8/16, 8/30, 9/6, 9/13/89 (11b) Observations of father's enthusiastic teaching of his child as he repeatedly tried to engage her in play, spontaneously provided affection and reinforcement, and maintained consistent eye contact with his child.

8/16/89 (1b) "(Child's name) and I became very close. We were together for a week while (mother's name) was away. I loved being with her." (Context: The father's statement was made when asked at the beginning of the session, "How was your week?")

8/23/89 (9a) "He's so smart." (Context: Child just displayed a skill to criterion and mother verbalized pride in her son's actions midway through the session.)

9/18/89 (7a) "Is she in pain with her seizures?" (Context: Mother and interventionist observed the child having a seizure and mother asked the interventionist about the effects of the emergence of seizures.)

9/25/89 (8a) "I treat the children as two different children. (Younger child's name) right from the start had much more eye contact. Even now with (child's name)'s looking, she has more eye contact. You just can't compare." (Context: Mother just lifted her new infant into her arms, while her older child was spontaneously crawling in and out of empty cupboards in the kitchen.)

9/28/89 (8a) "I don't dwell on (child's name) handicap. I don't enjoy visiting with the parents at the center that often, because the parents rehash how their children were diagnosed. I don't like to dwell on that. Sometimes I cry when I think about it." (Context: The mother was asked how occupational therapy was going at a local establishment midway through the session.)

10/2/89 (6a) "Am I providing enough stimulation?" (Context: The mother asked this question during a discussion about the child's self-stimulatory behaviors, once the interventionist and mother observed the child spinning his toys.)

10/4/89 (11a) "(Child's name) is worth two children. I work with her everyday on all the goals, and especially the ones checked." (Context: The interventionist asked how the mother was managing with the four targeted goals for the week at the beginning of the session.)

10/23/89 (6a) "I feel guilty I didn't present any of the goals."  
(Context: In response to a question about the week's events, mother verbalized this statement at the commencement of the session.)

10/25/89 (7a) Observation of the mother lying on the floor next to her child in order to achieve eye contact with her unresponsive child.

10/25/89 (7b) Observation of the father bending down in order to achieve eye contact and close proximity to his child. This was significant, because the father rarely acknowledged his child upon arrival to the home.

10/26/89 (8b) "You want to be with daddy?" (Context: Father made this statement as he observed his child crawl toward him, while the interventionist, father, and child were in the child's bedroom.)

10/29/89 (13a) "I constantly had to check-up on him, which I did with pleasure and love." (Context: The interventionist telephoned the family in order to ascertain the family's well-being following the death of the child. Mother rehashed what child care responsibilities she had to assume.)

11/13/89 (7a) "I am so pleased the children are now able to play with one another. Thank you." (Context: A discussion of the progress achieved on the goals concerning the siblings' relationships was initiated by the interventionist. The reasons for the emphasis on the sibling relationships was described the interventionist. The mother, then verbalized her pleasure with the intervention that occurred with the siblings. This discussion occurred in the dining area of the home with the three children present.)

11/20/89 (5a) "I would still love him whether he is behind." (Context: In response to the investigator stating that an assessment will occur next week and the child is expected to display near age appropriate skills, the mother made the statement at the close of the session.)

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Note. (number) = subject number, (a) = mother, (b) = father



## Appendix 5

Table 27

Parental Statements Regarding the Future Outlook of Their Children

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7/18/89 (10a) "I am disappointed and concerned about the (assessment) results, but I am hopeful he will accomplish all the goals." (Context: The statements were verbalized immediately following the delivery of the diagnostic assessments and the individualized family service plan at the beginning of the session.)

7/26/89 (10a) "I know the (assessment) results are not final." (Context: The mother was asked how she was dealing with the assessment results at the beginning of the session.)

8/16/89 (1a) "I am even more optimistic."

(1b) "I was hoping she (mother) would become more realistic, but she came back even more optimistic." (Context: Discussion with both parents occurred. The mother had just returned from a week long workshop on the child's handicapping condition. The interventionist asked how the conference was.)

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Note. (number) = subject number, (a) = mother, (b) = father

## Appendix 6

Table 28

Behaviors Displayed by Siblings of Children with HandicapsPositive Behaviors

6/14/89 (1a) Observation of the older female sibling spontaneously giving toys to the child and engaging the child in play.

6/29/89 (4a and 4b) Observation of the older male siblings engaging the child in their play. They interspersed their own play with the child's choice of activities.

7/5/89 (13c) "I have learned just to play with him." (Context: Interventionist reinforced sibling for enthusiastically presenting a social game to the child.)

7/6/89 (10a) Observation of the older male sibling's delight in watching the child's responses. The sibling was observed to attempt to redirect the child's attention to task, whenever it wavered during the session.

7/6/89 (10b) "He's trying. Good (child's name)." (Context: Sibling made statement upon observation of the child approximating a targeted skill.)

8/9/89 (14a) "(Child's name) makes me feel good." (Context: Interventionist commented to sibling how she enthusiastically presented a social game to the child.)

8/23/89 (1a) Observation of the sibling asking her mother to hold the child. The sibling was observed to hold the child (a young infant) securely in an upright position.

8/23/89 (11a) "(Child's name), look at me." (Context: Older female sibling spontaneously implemented a game of peek-a-boo.)

8/28/89 (16a) Observation of younger male sibling smiling at and observing the fine motor actions of the child for ten continuous seconds.

8/30/89 (9a) Observation of younger male sibling maintaining close proximity to the child, spontaneously giving him toys, and vocalizing to him in an attempt to establish joint play with the child.

9/5/89 (13a and 13b) Observation of the older male siblings consistently watching the activities presented by the interventionist and the parent. Their observation was significant, because they exhibited difficulty in spontaneously engaging the child in play.

9/20/89 (1a) "I love you." (Context: After older female sibling finished feeding the child, she was observed to kiss her and verbalize the statement.)

10/10/89 (2a) "(Child's name) did this. I didn't even get to paint."  
(Context: Older male sibling brought the child's painting to the interventionist and subsequently made the statement with enthusiasm.)

10/18/89 (4a) Observation of the older male sibling consistently observing the child's behavior. At one point, he sat down with the child on a chair as he put his arms around him. The older male sibling was observed to smile at the child's achievement of skills.

11/1/89 (1a) When asked, "How do you you know (child's name) has had enough playing?", the older female sibling said, "She cries when she's had enough." When asked, "How do you know when (child's name) wants to play?", the sibling said, "She looks at me or pulls my clothes."

### Negative Behaviors

6/29/89 (4b) "I can do that. That's baby stuff." (Context: The sibling was observing the assessments being administered to the child and verbalized the statement midway through the session.)

7/5/89 (11a) Observation of the older female sibling interrupting the parents' speaking to the interventionist in order to have the sole attention of her parents and to direct attention away from the child.

7/6/89 (10b) "He (child) can't do that. Boy, he's dumb." (Context: Older male sibling made statement as he was observing the assessment being administered to the child.)

7/26/89 (11a) Observation of the older female sibling exhibiting annoyance when the child did not perform the game as the sibling desired.

10/10/89 (2a) Observation of the older male sibling calling attention to himself by performing acts that were directly forbidden by the mother. The mother's attention was directed toward the child.

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Note. (number) = subject number, (a,b c) = ordinal spacing of siblings within each family

## Appendix 7

Table 29

Positive Comments Regarding Investigator's Behaviors

6/21/89 (1a) "I'm so pleased you came into our lives." (Context: Statement made upon arrival to home.)

6/29, 7/3, 9/18, 10/25 (4) (7) Pleasure exhibited by siblings when they were included within the intervention sessions.

7/3/89 (1a) "I'm going to frame this list of strengths." (Context: The parents were given the list of strengths they displayed.)

7/6/89 (10a) "You are perceptive regarding the children's relationships." (Context: Interventionist described her concerns about the siblings' tenuous relationships.)

8/3/89 (8a) "I could really use your support. When he goes to the P.T., I have a hard time seeing him upside down and then seeing the fear on his face." (Context: A phone call received by the mother and she asked the interventionist to go to the therapy sessions with the children and her.)

8/8/89 (3a) "I'm going to send this list (of strengths) to my husband." (Context: In response to receiving the list of strengths, the mother was going to mail the list to her husband living in another country.)

8/9/89 (9a) "I now accept the (assessment) results and realize I was teaching him wrong." (The interventionist began discussion about the parent's disagreement about the assessment results. The mother then verbalized the statement.)

8/10/89 (8a) "I'm going to treasure this list of strengths." (Context: Upon receipt of the list of strengths, the mother made this statement.)

8/30/89 (2b) "You wrote up a very complete program. A very professional job." (Context: Father made this statement upon arrival to the family's home and he had reviewed the plan for a week.)

10/2/89 (7a) "I was angry about the assessment results. I now like the way you structure the session to emphasize specific skills." (Context: Mother made this statement midway through the session as the interventionist was engaging the child.)

10/4/89 (9a) "I like the way you provide services. (Other educator's name) is too structured." (Context: Mother made statement at the commencement of the session.)

10/18/89 (11b) "When (child's name) was born, the door was closed. But you opened the window." (Context: Father made statement as the interventionist was about to leave the home.)

10/18/89 (8a) "I really want you to come to the christening, because I have talked about you to my entire family." (Context: Mother handed an invitation to the interventionist for the christening at the beginning of the session.)

11/1/89 (11a) "We love the way you get so excited about (child's name) successes." (Context: Interventionist enthusiastically reinforced the child's approximation of a targeted skill midway through the session.)

11/6/89 (7a) "I don't know what I am going to do without you. I like your methods. I can really talk to you." (Context: Mother made statement after she was asked how the services of the other educator were progressing at the end of the session.)

11/6/89 (12a) "I read the plan and I continue to encourage different skills from it." (Context: Mother described her continual referral to the plan as she encouraged more mature behaviors from her child.)

11/7/89 (14a) "I could talk to you all night. It's easy to talk to you." (Context: Mother and investigator were talking about the family as a unit and the family's upcoming plans for the weekend.)

11/9/89 (8a) "It's very hard to put in a few words how grateful [grateful] I am to you. Your [You're] so easy to learn from, and work with. I admire what you do, but I'm amazed at how good you are. I feel very lucky you found us. In the future, let's keep in touch. If there's ever anything I can do for you, it would make me so happy to help you." (Context: Statements written on a card given to interventionist four weeks prior to the termination of services.)

11/9/89 (8b) "We can't thank you enough for all your precious help you've brought to this family. It's amazing how much someone's day to day work can bring hope and improve the quality of life of a family like ours. We, especially (child's name) will miss you very much and I'm sure we'll never forget what you've accomplished for him. Thanks again and best of luck for everything you do." (Context: Written statements on a card made by the father, given four weeks prior to the termination of services.)

11/14/89 (3a) "I am sad you will not be with us for a long time. But, I know the skills you have shown me, I can do them with my (child's name) by myself." (Context: Mother described her conversation with another parent three weeks prior to the end of services.)

11/14/89 (2a) "I like the guidance of the weekly goals. When I had a spare minute, I would look at the sheet and know what to do."

(2b) "Having a plan allowed me to see what (child's name) needed on a weekly basis as well as on the long term. I think (child's name) needs a focused and direct approach." (Context: Discussion with the parents about their requests for future services.)

11/14/89 (14b) "I don't want (child's name) to miss any of your sessions." (Context: Mother's query to the father as to whether the

visitors will have left by the time of the next home visit.)

11/15/89 (9a) "I think that the efforts of you and (the educator's name have really helped (child's name). He has really done well." (Mother's spontaneous statement as she was given a description of the pending assessment session.)

11/21/89 (2a) "Our sincerest thanks for your excellent services. We'll surely miss you very much." (Context: Unsolicited comment written on a greeting card.)

11/22/89 (9a) "You're really good at this (teaching). You should do teaching a long time. Usually, it takes longer for (child's name) to adjust to someone new, but he did it in a shorter time with you. You taught me to see (child's name) in a new way. I look at his skills differently." (Context: Acknowledgement of the child's gradual acquisition of a cognitive goal was discussed by the interventionist and the mother.)

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Note. (number) = subject number, (a) = mother, (b) = father  
educator = other interventionist from local programs working with the child  
interventionist = investigator

## Appendix 8

Table 30

List of Activities Conducted for Case Management

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Referral to Additional Personnel

Speech and language pathologist (3)  
Developmental Pediatrician (2)  
Educator (2)  
Psychologist (2)  
Additional Early Childhood Programs (1)

Services to Families

Anticipation of future goals for the child (15)  
Baby-sitting (5)  
Procurement of toys from public agencies (3)  
Literature on handicapping conditions (3)  
Housekeeper assistance (2)  
Respite care (1)  
Travel/vacation opportunities (1)  
Day care placement (1)  
Explanation of letters from governmental agencies (2)

Change in Parent Behaviors

Organization of the children's home environment (6)  
Adaptive materials and positioning devices (4)  
Removal of household hazards (2)  
Problem-solving and decision-making (1)  
Token economy (1)

Transition to New Programs

Inter-agency coordination (4)  
Transition to a new educator (1)

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Note. (number) = number of families provided each service

## Appendix 9

Table 31

Results of the Parent Satisfaction Scale


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Question No.	Maximum	Mean	Standard Deviation
1	4	3.47	0.64
2	4	2.53	1.18
3	3	2.47	0.64
4	3	2.93	0.26
5	5	4.93	0.35
6	5	4.93	0.26
7	4	3.60	0.63

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## 8. Additional Comments

(2) The interventionist has been fantastic. Her very professional and skillful service will be greatly missed.

(3) The help was great. I am very satisfied. I would like to have the teacher longer, because she helped me a lot.

(4) The quality and orderly fashion in which the program was presented helped me to understand more what areas I should concentrate on with (child's name) and what he is expected to know at his age level. It also somehow encouraged me to work harder with (child's name) by giving me the proper direction and goals to work toward.

(5) (Investigator's name) is very helpful and resourceful. She is very good with children; very enthusiastic.

(7) I like all the structure so we know what (child's name) has learned.

(8) (Investigator's name) got closer to (child's name) and made better contact than any other educator or therapist we've worked with. (Child's name) has made more progress in the past four months than he's ever made in such a short time.

(11) Thank you so much for everything.

(15) I think the program helped a lot with (child's name). I see a change in (child's name). I think it was good for (child's name). I hope to follow the same things to get better progress.

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Note. N = 15, (number) = refers to parents of the child.



## Appendix 10

Table 32

Parental Statements Regarding Family-Focused Intervention Model

Each statement refers to an individual set of parents.

Program Approach - refers to overall aims of the program.

"It is a more organized approach with a variety of areas addressed than we had before."

"The approach was easier, cleaner than we received before. So, we made fewer mistakes and obtained better results. With all the explanations, it became easier for parents to work with their children."

"The approach made everyone aware and gave ideas for the family."

"The approach was more concentrated due to the organization and the list of goals."

"There was concentration on the entire family."

"You take a more global approach than we've had with others."

"You taught all of (child's name)."

"A persistent and consistent approach was used to make sure (child's name) acquired the skills."

Program Planning - refers to manner in which the plan was devised and written.

"It was good the way a well rounded program occurred so she didn't have any more splinter skills. Now, her performance is more even in all areas."

"A broader range of areas were included, so the total child was treated."

"We decided what the goals are for (child's name)."

"The program was more detailed than we received from the other educator."

"The specificity of the program was excellent for (child's name)."

"The detailed plan was good."

"I liked the organization. We had a program. Each problem was worked on piece by piece. You wrote down ideas to do and then suggested other ideas if they didn't work."

Program Implementation - manner in which the individualized plan was implemented on a weekly basis.

"I like the way you included all the children in the session."

"The goals worked on each session were integrated across all areas. One goal led to another or several goals were accomplished in one activity."

"A balance between structure and warmth was made with continual growth in goals. It fit the personality of (child's name)."

"You provided me with suggestions as to what to do with the inappropriate behavior of (child's name)."

"The structure was excellent, because (child's name) had so many low skills."

**Resources** = denotes the names of potential personnel and agencies provided to the family.

"The extent of resources were valued and the information was received immediately."

"I liked the way you got us the names of agencies, etc. right away."

"I liked the way you found out about baby-sitting and other services."

"I like the tons of information I received about baby-sitters, schools, and vacation spots."

**Case Management** = denotes the activities conducted to ensure coordination among agencies.

"We were glad you came to the meeting at (agency's name) and spoke about (child's name)'s strengths and needs."

"The referrals to other programs and specialists were helpful."

"I appreciated receiving information about the local resources and the specialists, who are available."

"I like how you advocated for our desires with the local agencies."

**Family Relationships** = interactions among the family members.

"You made us grow as a family. The children now get along well."

"The relationship among the children has improved a lot."

"I liked the intervention for the children's relationships."

"I liked the way you worked on the boys' (siblings') relationship."

"The children are playing so well together. I am so happy."

**Family Goals** = refers to the parent and sibling goals devised for each family.

"The family goals were excellent. They improved everyone's behavior."

"The goals for the family were good, because the methods were written down, so it was easy to follow."

**Parent Education** = teaching provided to parents in order to enhance the quality of family interactions, instructional competence, and parenting skills.

"You taught me how to be an advocate for (child's name). I now have developed inner strength."

"You taught me how to decide the goals I should work on with (child's name). Now, I don't have to be totally dependent on professionals."

"I loved learning new skills by watching you, talking to you, and trying the things you suggested."

"I liked the teaching goals for the parents, because we learned."

"The parent goals had a wide scope. I was given more to work on than before. The more you gave me, the more we achieved. You didn't ask too much. You always asked something realistic."

"We liked working on the parent goals. We liked the structure. We went from A and from there. It's not haphazard. I like the structure, because I am structured."

"I liked learning the teaching skills. They were realistic and important."

for his development."

"I liked the parent goals, because it made me happy when he (child) did something I learned."

Parental Attitude - parent perspective regarding the family members and services.

"It changed my way of thinking. I became more realistic about (child's name)'s skills and needs."

"I know he needs physio (physiotherapy) and it's important, but I am more optimistic when he has this class."

Characteristics of Investigator - refers to the behaviors of the investigator.

"To the other educator, it's a job. But to you, it's a profession."

"You've had more schooling and it shows."

"When a request or a question was made, you put it into effect or found the answer right away. If one idea didn't work, another idea was immediately put in. The wealth of ideas is due to your extensive experience."

"Your support was incredible. Your expertise was continually appreciated."

"I liked your gentle approach."

"Your imagination and your ability to be closed with him (child) taught me how to do different things with (child's name)."

Similarities with Other Current Services - indicates the similar activities conducted by other professionals and the investigator.

"The short-term goals were similar."

"You played with (child's name) just like the other educator."