Social Support Intervention for Mothers of Typical and Special Needs Infants and Toddler: An Outcome Evaluation

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LOYOLA UNIVERSITY CHICAGO

SOCIAL SUPPORT INTERVENTION FOR MOTHERS OF TYPICAL AND SPECIAL NEEDS INFANTS AND TODDLERS: AN OUTCOME EVALUATION

A DISSERTATION SUBMITTED TO THE FACULTY OF THE GRADUATE SCHOOL IN CANDIDACY FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

DEPARTMENT OF CURRICULUM, INSTRUCTION, AND EDUCATIONAL PSYCHOLOGY

BY

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complete the home interviews. My attempts at being apologetic about this were readily dismissed by the mothers—they were genuinely pleased in providing their responses. As one mother put it, "It would be nice to see more of these [kinds of] groups out there for us." I am honored to have taken part in this study of mothers and their children where so much energy, love, and commitment endured.
PREFACE

The old African quote, "It takes a village to raise a child" has resurfaced within the last few years for its subtle and not so subtle regard for relationship early in life. The poet and lecturer Maya Angelou, and first lady Hillary Rodham Clinton have drawn from this reference to emphasize the importance of interconnections—with a parent and child, an adult and another adult, a member with his/her community,... As paradigms have been known to shift with time, they have unmistakably examined elements of individuality and relationship, while embedding in it the concept of causality. As a "melting pot culture" we are provided the opportunity to learn from other cultures alternative ways of looking at our lives. As pilgrims in a free America, we have been reared all too quickly to believing that values of independence lead to success and that competition gets us somewhere. In breezing through bookstore shelves we can sense this search for "how to be" with ourselves and each other--the pull between solitude and aloneness, relationship and community. Through our
This study was chosen out of an interest in the role of social support groups, particularly their influences on mothers of young children. The mother’s relationship with her infant or toddler builds experiences that at first may appear unique to her. A mother of a child having a disability may experience further insult that leaves her feeling particularly alone. Yet it is believed that through the sharing of their stories—of their “self-as-parent” and of their self in relationship with their children, mothers are better able to value the pleasures and cope with the stresses of raising their children. And through social support, even in our fast-paced society, mothers can benefit from resources like these to re-create the village that helps in raising its children.
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ABSTRACT

The focus of this study is on the potential change a support program intervention can have on mothers of infants or toddlers. Parent and stress literature have emphasized the potential stresses threatening this relationship, and particularly with those parents having special needs children. Social support networks have been shown to be effectual in this regard to the psychological well being of distressed mothers. Social support in this study is defined as the availability of meaningful and enduring relationships that provide nurturance, security, and a sense of interpersonal commitment. Hypothetically, it is believed that these social networks may help alleviate what appears threatening through the use of better coping resources.

Maternal stress was measured through the use of the Parenting Stress Index, a parent self-appraisal and child appraisal instrument, to mothers before and after an eight-week social support group. The research sample consisted of 34 middle and upper-middle class mothers (mean age = 32)
and their infants or toddlers (6 to 36 months of age) and a comparison group matched for socioeconomic status, maternal and child ages, siblings, mother’s education, and disability. Each group consisted of no more than ten typical and special needs dyads, in a ratio of 7:3, respectively.

A quasi-experimental design was implemented to determine any changes in parent or child stresses following the intervention. Factors considered in the analyses included demographic information, inter and intrafamilial stressors as mediated by the mother, life stress, and other resource involvement. Two case studies are presented and illustrate both quantitative and qualitative variations of change following the support group intervention.

ANCOVA and repeated measures were used to relate types and levels of maternal stress and demographic variables among these groups. Little variability was found between and within treatment and comparison, and typical and special needs groups. Results suggest that this sample of mothers are generally able to cope with the stresses presented in the parenting system and that their ability to cope with these stresses remains stable following the
support group. A positive correlation ($t = .178$) was found between total stress scores and SES. It is believed that the high SES and educational levels of these mothers allow them to mobilize networks successfully, allowing them to cope effectively. While not statistically significant, elevations were found with the special needs treatment group in both total stress and child stress areas. Trends of elevation specific to child stresses were found in acceptability, adaptability, and demandingness.

The underlying assumption of this study and the parenting model is that sources of stress are multiply determined through the lens of the mother. Its subjective nature leads to unique and individual accounts of perceived stress and how to best cope. The cases presented include two mothers of special needs children—one with a severe disability and the other with a mild to moderate disability—both scoring significantly high in major stress areas prior to the intervention. Both quantitative and qualitative information is presented in these cases to help explain their decreased levels of stress following the intervention.
CHAPTER 1
INTRODUCTION

A basic assumption of this study is that mothers affect the development of their children. However, these maternal effects are not examined; rather, the focus of this study is on the potential change support program interventions produce, both directly and indirectly, to maternal outcomes. Both parent and stress literature have emphasized the potential stresses threatening this relationship, particularly, with parents of special needs children\(^1\) (Abidin, 1990; Monat & Lazarus, 1991; Crnic, 1983). Parent-child system models have identified similar factors that either support or threaten the relationship (Abidin, 1990; Webster-Stratton, 1990; Belsky, 1984). Social support networks have been shown to be effectual in this regard to the psychological well being of stressed mothers. These networks may help alleviate what appears threatening through the use of better coping resources.

Previous studies have focused on the effects of social

\(^1\) The term special needs is used categorically to include all individuals having physical, cognitive or behavioral characteristics that are atypical for their developmental levels.
support found in social networks and have discovered higher levels of positive adaptation with appropriate support (McConachie, 1994). These networks may be formed with friends, co-workers, family, or specialized groups; however, how valued the network is depends upon the individual's appraisal of the network. By definition, social support is "the availability of meaningful and enduring relationships that provide nurturance, security, and a sense of interpersonal commitment" (Shonkoff, 1985). What becomes important in conceptualizing social support is the individual's belief that there is support and that the support is reliable and effective.

Professional literature and research continue to address and identify the importance and complexity of the mother-child relationship. It is well documented that this first relationship for the child is one that resonates through a lifetime in subsequent relationships (Karen, 1994). However, along with the potential riches, there are inherent stresses. Becoming a parent for the first time involves a major life transition that results in change; successive births require additional adjustments for the mother and the entire family system. Parents may find their freedom restricted resulting in feelings of isolation, while an accustomed way of life and
its predictability are lost, and responsibilities increased (Leach, 1994). Many of these experiences are universal and involve certain adaptations and reorganizations in order to enable healthy and functional living. As with other life experiences, the mother's personal resources and her environment will affect how she adjusts and copes with the mother-child relationship (Norris, 1996; Webster-Stratton, 1990; Belsky, 1984; Hobfall, 1989).

Research studies have regularly examined the importance of the "early beginnings" of the mother-child dyadic relationship. This primary relationship is the context whereby the child learns and experiments in the safety of a secure base—the mother. If the relationship is a healthy and responsive one, the child develops feelings of security and self-esteem, becomes adjusted socially, and is developmentally supported. Longitudinal studies show the converse to be predictive of future developmental problems (Bernstein, 1991). The potential for achieving a healthy mother-child relationship is influenced by many factors and how the mother appraises these factors may determine how stressful her relationship is with her child. These factors include the mother's family life, financial conditions, and the parenting alliance of the couple (Abidin, 1995); other factors are
child-centered and focus on the child's temperament and other conditions such as having a disability (Canning, 1996; Webster-Stratton, 1990; Friedrich, 1981; Tunali, 1993). How the mother perceives and experiences these factors in her life will determine the amount of stress she is experiencing in relationship to her child.

Social support has been identified as a "buffer" to the mother-child relationship in its positive association with maternal competence (Chen & Tang, 1997; Webster-Stratton, 1990; Belsky, 1984). As a result, community programs have evolved out of professional interest and concern to develop resources for parents. These programs focus on prevention through early intervention by providing information and social support that is necessary to help alleviate parental stresses and promote adaptation.

There is a current interest to "include" special needs with typical populations at the earliest of ages into integrated programs (Chen, 1989; Bricker, 1982; Salisburg, 1991). The rationale includes but is not limited to the changes in public law requiring interventions for special needs children beginning at birth, and the benefits to both the parents and children. These benefits have resulted in increased self-esteem and coping skills, as well as changed
perceptions with typical families, where an increase of acceptance of differences and an appreciation of commonalities are expected. For the mother of the special needs child, this may help to reduce stress and promote availability with her child.

The intervention program under study provides for an environment of inclusion for all children and their mothers beginning at birth to promote an attitude of general acceptance in community activities. The program's goal is to successfully integrate infants and toddlers with and without special needs through a structured program deliberately designed to enhance cognitive and social skills among these children and their families. Emotional development is the result of awareness and acceptance of the children having special needs, their parents, and the non-disabled families involved.

In the study reported here, maternal support was examined in the integrated support setting along with the potential stressors in any mother-child system. In addition, historical events and current conditions emphasized in parent-child stress literature were explored and how they may have an impact on the mothers. A parenting system model adapted from previous research was employed to organize the complex social
variables inherent in the dyads. These social variables were examined in selected case studies.

The following hypotheses were tested in order to evaluate an early "inclusion" intervention as a successful resource of social support:

1. There is no significant difference in mother and child stress before intervention when comparing special needs families to typical populations.

2. There is no significant change in mother and child stress when comparing special needs to typical populations following intervention.

In addition, four research questions guided the qualitative analyses conducted using case study inquiry (Yin, 1994; Silverman, 1985):

1. What are the variations of perceived social support reported by the participating mothers of the special needs children?
2. What are the variations of stress levels when comparing mothers of mild-moderate special needs to those having severe special needs?

3. What are the variations in stress-related outcomes of participating mothers of special needs children?

4. What are the variations of child attributes reported by the participating mothers for their special needs children?
There are several ways of perceiving what the potential stressors are on parent-child systems. In determining these stressors, studies have identified mediational influences that appeared instrumental in coping. The stress models overall contain certain similarities. For practical purposes of this study, an integrated model of stress is used which incorporates current stress models (Lazarus & Folkman, 1985; Hobfoll, 1988; Webster-Stratton, 1990, Belsky, 1983; Abidin, 1983) of the parent-child system (see Figure 1). The integrated model assumes that the mother-child relationship is important for healthy psychosocial development. It further assumes that stresses exist in all parent-child relationships and the impact of those stresses is mediated by the quality of the mother's interactions with her child. The study will look at three stress areas: extrafamilial, interparental, and child stressors, all of which result in the need for effective coping skills.
EXTRAFAMILIAL STRESSORS

INTERPARENTAL STRESSORS

CHILD STRESSORS

PRIMARY CAREGIVER (mother)

CHILD (character)

Social Support:
- Instrumental (staff, toys, structural setting...)
- Companionship (mom/child participants)

Sense of competence
Positive Adjustment
Increased Coping

Little research has been done to compare typical with special needs groups in this area, and consequently, it is difficult to determine the role of a special needs condition regarding levels of stress (Salisbury, 1987; Sheeran, T., Marvin, R., & Pianta, R., 1997; Black & Jodorkovsky, 1994). General findings have concluded that parents of special needs children reported less satisfactory marriages (Sheeran et al., 1997), less social support (Brinker, R., Seifer, R., & Sameroff, A., 1994; Telleen, S., 1990), less religiosity (Friedrich & Friedrich, 1981), and less psychological well being (Friedrich & Friedrich, 1981; Waddington, S. & Busch-Rossnagel, N., 1992) than parents of typical children. They have also reported more overall stress and fewer psychosocial supports to help amend their stress than their parent counterpart (Shapiro, 1989; Salisbury, 1987; Weinhouse, D., Weinhouse, M., & Nelson, J., 1992).

Whether or not the mother is parenting a typical or special needs child, the magnitude of disruption to her functioning and to her interactions with her child depends on her psychological well being and personal resources such as social and family support. Social support, which is the focus of this study, may provide additional outside support to existing familial support, or it may be the only identified
support yet established for the mother. This study was interested in one such intervention, the Baby B.A.S.I.C.S. Program\textsuperscript{2}, which is intended to provide the necessary social support the mother requires to develop more effective personal coping skills, which will in turn, serve to "buffer" the effects of stress on the mother-child relationship. This service intervention to mothers consists of a support group intended to enhance social support (Weissbourd, 1987; Telleen, S., Herzog, A., Kilbane, T., 1989; Benasich, A. & Brooks-Gunn, J., 1996).

The program's structure includes a mother-child playgroup and a mother support group integrating typical and special needs children, age 6 months to 36 months according to their age groups. The model consists of 1-\(\frac{1}{2}\) hour sessions over a span of eight weeks and contains two parts: a parent-child playgroup followed by a parent support group led by an "on site" facilitator. While the play group itself contains potential benefits to the mother, the mother support group is the arena where mothers meet supportively to discuss developmental issues facing all mothers of children in the participating age groups. Its intention is to encourage

\textsuperscript{2} Additional specific information regarding this Baby BASICS Program is available on request of this author.
socialization and promote acceptance among mothers and children. As stated by Benasich et al. (1996), "Increasing the mother's social networks and/or feelings of competence, specifically targeted in a number of programs, may be a pathway through which child social and cognitive competence are enhanced (p. 1187)."

In order to evaluate maternal stress and its potential moderating effects, research literature examining the mother-child system model will be reviewed in this chapter. Divided into sections, the review will include 1) an overview of stress on the parenting system, 2) maternal characteristics on this relationship, 3) familial and extra-familial sources of stress, and 4) purpose and rationale of this study.

Review of Parenting Models and Research on Stress

Much of the research on stress and coping has come from the arduous work of Lazarus (1966) and extends into further research by Lazarus and Folkman (1984) and Monat & Lazarus (1991). What they and others have found regarding stress and coping is that they require a process of fit. It is a three part process according to Lazarus' work involving 1) one's personal appraisal of the perceived threat, 2) a bringing to mind a potential response to the threat, and 3) coping, which
becomes the actual response executed. As he describes, a person experiencing a stressful event will appraise it in such a way to evoke a particular coping response. If that response is effective, the person may appraise the event as less threatening than it was originally conceived; however, if the response is ineffective, a reappraisal may be warranted. This kind of trial-and-error may be attempted for some time until a particular level of adjustment or homeostasis is reached.

Stress is what McGrath (1970), a stress researcher, described as a substantial imbalance between environmental demands and the response capability of the organism. What these and other stress researchers agree on is that stress results from an interplay between a person and a taxing environmental event that exceeds personal resources.

What happens if experiences and available resources are imbalanced? According to stress literature the healthy response would be to seek out resources that appear to be helpful. Generally, resources that are perceived to be of aid to the individual can be advantageous and are described as "buffers" (Greenberg, 1992; Webster-Stratton, 1990). In order for an available resource to mediate effectively, French, Rodgers, and Cobb (1974) believed there must be a goodness-of-
fit. If someone desires a particular support and the need is met, an effective match has resulted.

**Stress and The Parenting System**

Within the past few decades there has been an interest by psychologists, sociologists, and childcare workers to understand the significant aspects that influence the parenting system. As a psychologically aware society we are familiar with the identified troubled or behaviorally out-of-control child who later develops into the maladjusted adult. In these instances the child’s family is left puzzled to rethink earlier alternatives. Numerous studies on child abuse from the experts (Black & Jodorkovsky, 1994; Garbarino, 1980; Gottfried, 1988) have suggested that sociological and environmental factors are at the base of the dysfunctional parenting paradigm. Due to scenarios such as these, researchers have been interested in causal issues surrounding deviant behaviors. These interests in human development lead to the person's early beginnings where potential insights may be found, notably the particular relationship of the parent and child, or the parenting system.

There are many parenting system models in existence ranging from behavioral stimulus-response models (Patterson,
1990) to linear relationship models (Abidin, 1982). From his studies on child abuse, Belsky (1984) proposed a model that included particular sociological and personality factors he viewed as having an impact on the parent's behavior. The limitations of the behavioral model make it difficult to identify why particular behaviors result, while a review of the linear relationship model is seen as a simplistic correlational view of stress and dysfunctional parenting. Belsky's efforts, however, led him to examine why parents parent as they do, resulting in a model that took into account intra-individual nuances of the parent.

Other models have expanded on Belsky's attempts by looking closely at the internal motivations of the parent. Webster-Stratton (1990) in her research with conduct-disordered children addressed the importance of the psychological well being and personal resources of the parent. Consistent with Belsky's conclusions, what seems to be particularly meaningful to her is the buffering effect the parent has by way of parental appraisal that protects the system against stress (See Figure 1). Abidin (1992) more recently developed a processing model of parenting that appears progressive and comprehensive. His model suggested that the parent's personality in relationship to the "self-as-
parent" is influenced by sociological, environmental, behavioral, and developmental variables. How the parent appraises these parental conditions determines the level of stress experienced. It appears that the earlier methodologies' focus (Mischel, 1968) on "situational" rather than personality factors opened the doors to a more holistic view of the parenting system but tended toward simplification.

The Mother-Child Relationship

The Theory of Attachment

Many theorists over the past five decades have developed their own conceptions of the mother-child relationship and its importance in the course of development. Sigmund Freud (1961) viewed the importance of this early relationship as fulfilling certain physical needs, but with an absence of socio-emotional connections between the mother and child. Anna Freud (1960) had later identified numerous roles that the mother provided within that relationship. To her, the kind of relationship developed in these early beginnings functioned as a prototype of future relationships for the child. As reported by Karen (1994), Balient, a psychoanalyst of the Budapest school, believed that the primary need beginning at birth was
unconditional love; if that need was not met, the child would seek potential mother figures throughout life in an attempt to have that need satisfied.

More developed and empirically supported theories led to Bowlby's use of "attachment" to describe this special mother-infant relationship. Unlike the term "bond", which had been used to describe the instant response between the mother and child after birth, attachment to Bowlby meant the development and unfolding of that relationship over time. In his description, attachment provides for physical survival, similar to that seen in the studies involving primates; in addition, from the proximity to the mother, the child feels loved, secure, and safe. It is important that a child sees that his behavior—a cry, smile, or babbling, will receive a response. At a level of response, the child gains a sense of self, or more specifically, "the self that has been experienced" (Greenspan, 1989, p. 126). Later, the safe haven provided allows the child to take the risks necessary to grow. As Bowlby and others have found (Ainsworth, 1969; Beckwith, 1990; Bretherton, 1992), these early attachments have an influence on the child's personality development and as working representations with future relationships.
Parenting Efficacy

Although many variables have been identified as influencing the parent-child system, it is more recently believed that the path of that influence has to do with what develops from parental cognitions and beliefs (Abidin, 1992; Mash & Johnston, 1990; Belsky, 1984). Mash and Johnston (1990) describe parenting efficacy much as Abidin distinguishes the concept, "self-as-parent": to express how the parent sees herself in the parenting role. Whether her contributions enhance or jeopardize her relationship with her child, it is believed that her own appraisal of the parenting role and personal attachment history are aspects of this model.

Particular studies involving abusive parents and parents of hyperactive children (Mash & Johnston, 1983; Mash & Johnston, 1990) reported that mothers' beliefs about their effectiveness in the parenting role affect the quality and quantity of attention and effort they devote to child raising and the contribution of their response. Results from one study revealed that both abusive parents and parents of hyperactive children had lower efficacy than the controls. For abusive parents, the outcomes suggest that having a sense of power played an important role along with a strong need to
protect their self-esteem. With the parents of hyperactive children, lower parental efficacy resulted from a diminution of involvement and interactions within the relationships.

Other parental risk conditions have been studied to include mothers with psychopathologies and how their conditions have impacted on the mother-child relationship. One area of research that has gained much attention has been with depressed mothers. Generally, results have shown that these mothers are less responsive and create disruptive, hostile, and rejecting environments for their children (Belsky, 1984; Beckwith, 1990). In a study conducted by Webster-Stratton & Hammond (1988) on depressed mothers, the children were perceived as disturbed by the mothers. Home observations showed these mothers as using more overt types of discipline and as being more critical toward their children. Field (1987) described depressed mothers as imitating their infants less, engaging less in spontaneous play, and having more neutral affects. The infants appeared less active, showed less contentment, and more fussiness.

As Belsky has suggested (1984), whether the parent is perceived through a psychological lens or from self-appraisals, the issues may be traced back to the parent's own
personal and attachment history. One such study by Main et al., (1985) conducted at Berkeley, addressed adult attachment and its effects on the next generation. Using the Berkeley Adult Attachment Interview, Main assessed the internal working models of parents and their six-year-olds. She found parallel patterns between adult attachment and Ainsworth's child attachment categories. The category of "secure-autonomous" was found in those parents who described their own parents as having provided a secure base and were comfortable discussing attachment themes. They were also able to describe their parents objectively to include both positive and negative qualities and had fewer self-deceptions. On the other hand, adults identified in the "dismissing of attachment" category, had difficulty viewing attachment seriously. Their responses were guarded and their descriptions of their own parents contained idealized themes. Generally, these adults tended to have avoidant defenses that resulted in emotional detachment: both the feeling of pain and the desire for love were lost or numbed out. A third category called "preoccupied with early attachments" is similar to Ainsworth's ambivalent child attachment. These adults described a strong desire to please their parents and had considerable feelings of anger and disappointment. They
discussed their challenges at role reversals where they had attempted to take care of their parents. Their self-definition in relationships appeared to be obscure.

Mother As A Buffering Agent

What appears simple to discern by observation and direct interviews yet seemingly equivocal from practicing research, is how and to what extent stress impacts on mother-child relationships. Why some parents show only temporary disrupted parenting due to a stressful life event, while others are entangled in its conflicts, has caused experts studying stress in mother-child relationships to look further into its many complexities (Norris & Kaniasty, 1996; Bretherton, 1992). As a result, many studies have chosen to focus on the causes of child mistreatment in this relationship (Belsky, 1984; Mash & Johnston, 1990; Webster-Stratton, 1990; Koeske & Koeske, 1990). One vital determinant of parental functioning described in Belsky's model (1984) has to do with the personality and psychological well being of the parent. He stated that optimal parental functioning follows a stressful event provided that the parent's personal subsystem is resourceful; substantial risk and less protection is available when the child subsystem is the single resource. Aside from
these more direct parental effects, the mother's personality and personal history will indirectly determine the quality of alternative resources available to her (Terry, 1994; Bolger & Zucherman, 1995).

Studies involving hyperactive and abused children (Trickett & Susman, 1988; Mash & Johnston, 1990) found that abusive mothers viewed their children as difficult. In one such study containing both experimental and control groups of abused and hyperactive children and non-problem children, respectively, mothers of both children in the first group identified their children as more difficult when compared to mothers of non-problematic children. The ratings of child behavior of abused children were similar in comparison to the hyperactive group. The perceptions of the abusive mothers were not confirmed by observations. Results from these and other studies (Estroff, T., Herrera, C., Gaines, R., Shaffer, D., Gould, M., & Green, A., 1984; Lahey, B., Conger, R., Atkeson, B., & Treiger, F., 1984) have identified how maternal disturbance may significantly affect the mother's perceptions of her deviant child.

Gretarsson & Gelfand's (1988) study on parents' attitudes in non-problem families found positive attributional bias for their children's actions. These parents tended to
provide credit for their children's successes and excused their failures. It is further believed (Mash & Johnston, 1990) that this positive attributional bias is not only absent with abusive parents, but that these parents blame their children's own behaviors for the failure. These same parents attribute their children's successes to luck and other external forces.

Although the study of stress as illustrated in various parenting models is best understood to be multiply-determined, the mother's role as "buffer" emerges from her own personal history and personality as she appraises her parenting role.

Possible Sources of Stress

Much of the stress research has identified various socio-ecological stressors that could negatively affect the parenting system. In each of these cases, consideration must be given to the mother's appraisal of these potential stressors in order to determine the viability of the stress and its magnitude.

Generally, these socio-ecological stressors have been reviewed by stress researchers to include socioeconomic status, life stresses, child characteristics, spousal relationships, work, and other environmental conditions
Ambiguous results occur in the research when taking into account poor living and financial conditions as an impetus of child mismanagement (Gecas, 1979). Results involving work as a stressor appear less clear and depend, in part, on the mother's appraisal of her work. Other factors contributing to various stress conditions have included the parental alliance (Abidin, 1995) between the mother and father, as well as, child factors including temperament and any known or foreseeable disabilities. In general, they are dynamic interactions (Belsky, 1984) that occur and have supportive or nocuous effects on the mother-child system. Ultimately, the mother's appraisal of these conditions will determine those effects.

**Mother's Work and Lifestyle**

Many of the studies directed at identifying the maternal effects of work on parenting have been limited (Bronfenbrenner & Crouter, 1982; Crouter, Belsky, & Spanier, 1983). Various studies have simplified its conditions and instead have treated maternal employment as a "social address" (Belsky, 1984). Scarr, Phillips, and McCartney (1989) have found that mothers work primarily out of financial necessity for the
family, and secondly, for personal growth and self-actualization.

While some mothers have career ambitions that motivate them back into the work force shortly after the birth of their children, other mothers remain employed in order to maintain the families' chosen lifestyle. The actual impact of work on the mother determines and is determined by spousal attitudes and her own perceptions toward work. Increased stress results (Anderson-Kulman & Paludi, 1986) when these working mothers receive little or no spousal support for their employment or for household maintenance and childcare. This dual-career household and its success may depend on the spouses' socialization experiences and current attitudes about sex roles (Aldous, 1982; Pepitone-Rockwell, 1980).

The mother's own appraisal of her work has been shown to have an impact on the family system. Several studies have suggested that mothers who are dissatisfied with work, compromised their parenting roles (Farel, 1980), while the satisfied mothers tended to be nurturing and appropriate in their discipline tactics (Hoffman, 1963).

While the mother's employment status has indirect effects on her own parenting and marital relationship, it also
influences the parent-child relationship. Various maternal employment studies (Douvan, 1963; McCord, McCord, & Thurber, 1963) have found mother's employment to stress the father-son relationship. The understanding developed from this is the image of an inadequate father failing to provide for the family. Daughters, on the other hand, are shown to benefit from maternal employment. Hoffman (1984) found these daughters to be more self-confident, better achievers in school, and tended to pursue careers more frequently than their counterparts. Effects resulting from maternal employment involve a dynamic interplay of variables that influence and are influenced by the contextual features of the family (Scarr et al., 1989).

**Socioeconomic Status**

The family's socioeconomic status (SES) has been studied in relationship to psychological distress. Generally, the lower SES has been viewed to have fewer familial resources (Belsky, 1984), and subsequently, more life stress (Webster-Stratton, 1990). Mothers involved in interventions with their children tended to benefit less from verbal and more from modeling techniques. Wheaton (1980) created a rationale for causal attribution tendencies and issues surrounding locus of
control. The lower SES' conceptions of their personal and external world define their reality. These tend to result in life conditions that are fatalistic and leave them impotent (Turner, R. & Noh, S., 1983). In the Turner study, 312 women from Ontario had been interviewed two to four weeks after giving birth in order to observe vulnerability and stress factors. A psychological distress measure, a life-events scale, and the shorter version of the Rotter's Internality-Externality Scale were given. Results showed that the lower SES had a heightened responsiveness to stress. In separate regressions of psychological distress on stress in all three classes, the findings suggested that within the lower SES, distress occurred at a rate of 1.6 times when compared to the other classes. Conclusions from this study illustrate that stress factors alone are not accountable for the psychological health variations found between class levels. This supports an earlier finding by Roghmann, (1975) that the occurrence of major life stressors is two to four times greater for lower SES families than for middle-class families.

Eckenrode (1983) who has also studied subgroup differences identified the more favored subgroups (middle and upper class levels) as having favorable psychological qualities such as internal control, positive beliefs, and help
seeking. These individuals were found to have the ability and adaptability to mobilize network supports and benefit from them.

The Spousal Relationship

The relationship between the father and mother is yet another possible source of stress or support for the mother. The roles have been defined even before the infant enters into the system. Within this definition the quality of individual roles is determined. According to Belsky (1984), the quality of the relationship will either promote or undermine parental competence. Several studies over the past two decades have identified the influences of marital quality upon parental competence (Belsky, 1979; Stoneman, Z. & Crapps, J., 1988; Webster-Stratton, 1990). These influences have been associated with increased abuse and discipline tactics, inconsistent parenting, high levels of irritability, and low self-fulfillment.

A family systems framework helps to conceptualize the effects of a newborn child on a couple, whether the child is normal or not. The parents affect and are affected by family and socio-ecological elements. Stress studies focusing on the family have conceived this affect to include basically two
phases (McCubbin & Patterson, 1983; Lavee & Olson, 1991). First, the disruptive phase occurs in the wave of the crisis itself, when the couple’s system is upset, that is, when the child is born; the phase of adaptation, which is the second and final phase, involves how the recovery takes shape and its adjustments afterward. It is believed that the phase of disruption varies among families, where some experience more vulnerability than others. These vulnerabilities result from increased interpersonal conflicts, difficulties in role performance, and the subsequent strain on the family resulting from these stressors. On the other hand, some families are able to experience the disruption and recover more easily to an adaptive level. Qualities of cohesion and flexibility are believed to be characteristic of these families.

Abidin (1995) has conceptualized the effects of parent and child stressors in his model of parenting stress and in his test instrument, the Parenting Stress Index (1983). He emphasizes the importance of the spousal relationship to the other child’s parent as one indication of possible stress or support on the parenting system. Several studies in addition, have focused on the importance of spousal support (Abbey & Andrews, 1995; Bailey, D., Blasco, P., & Simeonsson, R., 1992; Telleen et al., 1989) particularly during times of stress.
These elements of support are described as similar to those of intimacy: feeling validated, loved, appreciated, cared for, and understood. Spousal issues are perceived to be the second most significant cause of stress subsequent to the birth of the child for the mother.

When examining the need for spousal support for the mother of a typical or special need's child, the experiences of the father are considered. Studies comparing gender differences and effects of mothers and fathers giving birth to a special needs child (Beckman, 1991; Kazak, 1987) showed notable differences between them. Mothers typically in these studies have shown higher levels of stress, more depressive-like symptoms and problems with family functioning than their male counterparts. They are more likely, in these instances, to take on the psychological burden of caring for their infants (Weinhouse et al., 1992; Krauss, 1993). Fathers were found to become more positively engaged and considerably involved with the care demands of special needs infants (Darke & Goldberg, 1994; Rousey, A., Best, S., & Blacher, J., 1992). However, in other studies they are perceived to be less emotionally involved and less responsible for their infants (Smith, 1986; Linder & Chitwood, 1984) during the first year of life. This may have to do with the notion that some
fathers engage more with their infants at the second year, when the infants are perceived by the fathers as playmates (Clarke-Stewart, 1978). It is also possible that the fathers' own competencies, driven in part by their own personal histories, will determine the course of parental involvement and management in the family.

There is a broad range of studies emphasizing the positive role of spousal support on mothers that have led to better parental adjustment, well being, and more positive self-appraisals. Mothers who were college educated perceived more spouse support, and scored higher in well-being and personal happiness (Chandra, P., Sudha, M., Subbarathna, A., Rao, S., Verghese, M., & Channabasavana, S., 1995). Perceived and received support for mothers resulted in better family adjustment, positive self-appraisals of coping skills, and less psychological distress. As in the case of infertile couples, a high percentage of them rely on their spouses for understanding and meaning during critical processes (Abbey et al., 1995). In the case of cultures and ethnicities, outside mobilization of social support has been negatively correlated with family stress in Caucasian families, while perceptions of outside support networks in other cultures may be a less formalized option (Brinker et al., 1994).
The degree to which fathers support mothers has to do with how involved they are with their children. While they bring to parenting their own talents and skills, fathers of special needs children especially may experience feeling left out. Mothers are likely taking their children to therapists and doctors for treatment during the day and the information and involvement they experience attribute to their sense of competency. There is a danger that fathers are excluded from these events. This would suggest that the more informed and involved the fathers are with their children, the more competent they will feel and the greater the perceived support from the mothers (van der Glessen, 1991). For some fathers, this may involve personal changes in the way they perceive their roles, and subsequently expand on them. From "After the Tears, Simons (1987) quotes one couple’s frustration:

Finally I said to my husband, 'Look, I can’t do all this myself. You have to help.' He did, but it was hard for him. It shook all the patterns he’d spent a lifetime learning. "You know, it’s easier for the wife," he said. "She expects to do those activities, so she plans them in her day, but the husband doesn’t. Now I do and that makes it easier (pg. 25)."

The personal adjustments made by both spouses promote the support desired so the couple is able to regain balance and
functionality. In this sense, coping is perceived as a "slow gain" process rather than as a grand leap or as a static state. Flexibility allows for the changes necessary for family adjustment and mutual support.

Child Characteristics

Parenting a child, regardless of whether the child is disabled or not, produces stress. The parenting system (see Figure 1, p. 8) model is developed from the understanding that the parent affects the child and the child affects the parent. This dynamic has been described as "reciprocity." Several elements contribute to the quality of this mother and child relationship, and in turn, either produce harmony or stress in the relationship. Research suggests that families with disabled children experience more stress than families with non-disabled children (Dyson, 1993; Hoppes & Harris, 1990). And more specifically, the severity and type of the children's disabilities have been found to correlate with levels of parental stress (Minnes, 1988; McKinney, B. & Peterson, R., 1987).

Those children not following normal patterns of development are diagnosed as having a disability. Disabilities are broken down into two classifications by the
United States Department of Education (revised 1990): mild to moderate, and severe. Severe disabilities include those children whose abilities to provide their own life sustaining and safety needs are so limited, relative to their own proficiency at their ages, that survival is threatened. While the long-term prognosis of some disabled infants are undetermined and difficult at times to discern, categories including mental retardation, autism, schizophrenia, and cerebral palsy are included in this category. Importantly, how these children are perceived by their parents when they are infants may be quite different when they are older. A Downs Syndrome infant, for example, may later be determined as mentally retarded, but in early development, is experienced as responsive, cuddly, and engaging with the mother. By comparison, the autistic infant may have little in the way of social responsiveness and connection, and as a result, promote stressful conditions for the mother who is making an all out attempt to engage (Hoppes & Harris, 1990). It may be as Breslau, N., Staruch, K., & Mortimer, E. (1982) hypothesized, that the more restricted the mother experiences she is because of her infant's needs, the more likely she is to experience distress. While infants with physically visible disabilities such as cerebral palsy may be more physically demanding,
studies comparing them to cognitively disabled infants, shows no significant impact on these mothers. The findings across a broad range of studies show that developmentally at-risk children have better prognoses for adjustment when the families are adaptive and educated (Saddler & Hillman, 1993; Dyson, 1993; Sheeran et al., 1997).

Assuming that the mother-infant relationship is a coherent developmental system, the mother’s relationship with her infant is in part determined by the infant’s temperament and the mother’s ability to adapt. As a broad category, temperament relates to the behaviors of the child with the environment. Chess (1991) refers to temperament as an “inherited style.” Factors of fussiness, mood, adaptation or reaction, habits, and intensity of responsiveness are oftentimes included. While it may be assumed that all mother-infant relationships are affected by these temperaments, it is less clear how temperament relates to the disabled conditions of the child. Thomas and Chess (1977) found that during a child’s infancy, parental responses were strongly influenced by the child’s temperament. Since temperament influences the quality of family operations and affects the development of social landmarks, it is possible that a disabled child perceived as difficult, will promote higher levels of stress
Purpose and Rationale

Developmental Changes in Maternal Coping

The purpose of this study is to examine the construct of the parenting system, particularly the role of the mother as mediator to potential stress. While both spousal and outside support systems are likely to have an impact on the mother, and subsequently the mother-child relationship, it is the mother in the end who mediates these resources. The parenting model presented in this chapter (Figure 1, p. 8) has been adapted from several parenting system models (Belsky, 1984; Abidin, 1990; Webster-Stratton, 1990; McConachie, 1993) that take into account intra and interfamilial variables. This model suggests that the causes of parenting stress, and subsequently, child outcomes can only be understood through dynamic multivariate models. Lazarus and Folkman (1984) argue that individual appraisals of stress come from the belief that the events tax or exceed coping resources. As stated earlier, the extent the event will be appraised as stressful, depends on the resources the person has and the perceived
effectiveness of those resources. In assuming the mother as the primary caregiver, she experiences a great amount of responsibility to the child. How well she is able to cope with potential problems as a parent will be determined by her personal appraisals, resources, and perceived supports. In other words, she mediates each of these situations.

While it may be difficult to determine precisely what characterizes a well-adjusted mother under stressful conditions, the qualities associated with positive adjustment may be inferred from changes provided by the mother over time. Carried further, actual interview data collected from the mothers articulate more specifically what those qualities may be. Because primary attachments are formed within the first year or two of a child’s life with the mother, the adaptations in the family are likely to occur within and beyond that time period.

It is believed, overall, that families function better when they have both effective internal and external supports. And while it is possible that mothers not receiving support with their spouses may seek support in established groups outside of the home, mothers experiencing spousal support may continue their quest for support beyond the home because they are aware of its benefits.
Two Types of Analysis

Quantitative Analyses. In this study, maternal coping and potential changes in coping will be evaluated using a well-known standardized instrument intended to determine areas of stress on the mother. The mother’s appraisals of situations regarding her child are perceived in the literature as a mediator (Abidin, 1990; Kronenberger & Thompson, 1992; Mash & Johnson, 1990). The stresses of a mother with a special need’s infant, which are predicted to be greater than a mother of a normal infant, are also assessed for purposes of comparison. The socio-ecological experiences of the mother, namely the child, spouse, and extra-familial characteristics are assumed to have an affect. How the mother appraises these events will have to do with whether they are perceived as a help or a hindrance to her. The developmental changes found in mother’s coping are explored through a standardized instrument and evaluations before and after a social support intervention.

Case Study Analyses. The parenting system construct is further analyzed through a case study approach, providing the opportunity to explore the mother and her conditions more
meaningfully (Silverman, 1985). In order to do this, individual cases of the participating mothers with special needs children were examined regarding their roles and perceived accompanying stressors.

One purpose of examining the individual through a case study is to test theory (Yin, 1994). The parenting system model presented in Figure 1 (p. 8) embodies the theories of experts who consider the parent-child system as a whole system containing causal and synergistic activity. What becomes important here is to merge and move beyond what is quantifiable—to look more closely at the social and personal factors of the participants. Silverman (1985) refers to what Weber (1949) calls "establishing regularities" through the use of non-scientific methods. As he perceives it, universal or general information holds little value in itself. It fails to take into account culture—that which is not determined by laws or guidelines. As he describes:

Knowledge of social laws is not knowledge of social reality but is rather one of the various aids used by our minds for attaining this end; [and] because knowledge of cultural events is inconceivable except on a basis of significance which the concrete constellations of reality have for us (pg. 80).
Weber concludes that individual cases themselves should be synthesized into an analytic construct. Ideal-type constructs, as he refers to, focus on the fit of meanings attached by the subjects to the situations presented (Silverman, 1985). This coincides with several researchers' beliefs regarding social support (Greenberg, 1992; French, J., Rodgers, W., & Cobb, S., (1974); Lazarus, 1966; Lazarus & Folkman, 1984), that is, that the perceptions regarding the social support are of primary importance for effectiveness. While levels of significance through statistical methods provide us with the evidence to generalize factorial relationships, case studies provide a closer view of individuals and their situations. This perspective is consistent with several theorists in the field of child and human development who maintain an interest in the organism in a given environment. William Stern (1938), for example, referred early on to "the interplay between cultural values and norms and the child’s activity" in that space as a means for development. Lewin (1939) referred to this phenomenon as the "dynamic field." Lev Vygotsky’s concept (Wertsch, J. & Tulviste, P., 1992) known as the "zone of proximal development" combined an active individual or learner with a capable other within a given context as a catalyst for growth.
More recently, several other theorists have continued to honor this nature-nurture phenomenon—an ecological perspective of development (Garbarino, 1990; Bronfenbrenner, 1986).

In this study, two cases involving exceptional change over the course of the eight-week intervention were explored. A revelatory analysis, described by Yin (1994), using descriptive interview data provided a closer examination of mothers with special needs children. The cases are intended to broaden the theoretical understanding of these mothers and to provoke future research with this sub-population. It is believed that this approach, in addition to the statistical methods employed, will provide a thoughtful understanding of the lens these mothers see through, and will subsequently lead to a better understanding and appreciation of their conditions and behaviors.

In conclusion, given these assumptions, this study attempted to evaluate mother stressors in two groups: mothers of normal and special needs infants, and to compare the stressors between the two groups before and after a social support intervention. The ways mothers appraise and cope with these stressors are believed to affect adaptational outcomes (Folkman & Lazarus, 1988; Billings & Moos, 1981). Interviews with special needs mothers provided in depth information
regarding their perceptions. The evaluations are intended to identify personal attributes of the mothers in their relationship to supports in general. These attributes are examined through case study inquiry (Yin, 1994). Mother-infant dyads assessed include a range from six months of age to thirty-six months of age. These are sensitive time periods when both the mother and child adjust to one another, develop a relationship, and work to meet the demands of the infant (Karen, 1994; Bretherton, 1992).

The hypotheses tested in this study were:

1. There is no significant difference in mother and child stress before intervention when comparing special needs to typical populations.

2. There is no significant difference in mother and child stress when comparing special needs to typical populations following intervention.

Four research questions guided the qualitative analyses conducted using case study inquiry (Yin, 1994):
1. What are the variations of perceived social support from the participating mothers of the special needs children?

2. What are the variations of stress levels when comparing mothers of mild-moderate special needs to those having severe special needs?

3. What are the variations in stress-related outcomes of participating mothers of special needs children?

4. What are the variations of child attributes presented by the participating mothers for their special needs children?
Subjects

The treatment participants in this study included a self-selected sample of 35 mothers and their children, with 21 of the children having no known disabilities, 10 children having mild to moderate disabilities, and 4 children having severe disabilities. The period of data collection spanned from April 1992 through June 1993. During that time, four groups of mother-child dyads participated in the social support treatment. Each group included an average of ten dyads consisting of both typical and special needs children in a ratio of 7:3. The groups included two groups of 24 to 36-month olds, one group of 6 to 12-month olds, and one group of 12 to 24-month olds. The comparison group selected from waiting or agency lists, was at the same time presented with packets containing the measurements used. This comparison group had no treatment (support program) and included 34 mothers and their children, with 20 of the children having no known disabilities, 12 children having mild to moderate disabilities, and 2 children having severe disabilities.
Variables examined in both the treatment and comparison groups included socioeconomic status, birth order of the child, parents' ages, marital status, and disability category, if applicable. As measured by the Hollingshead\textsuperscript{3} two factor index (1991), both the treatment and comparison mothers were from middle to upper-middle class homes and all had spouses. Also, within both groups, 81 percent of the mothers had two or more children.

Criteria selection for determining severe disabilities was followed according to the United States Department of Education\textsuperscript{4} and included static or transitory conditions that involved basic life sustaining risks and safety needs relative to the child's chronological age. These include highly limited behaviors of attention or relatedness to others, verbal communication skills, basic physical mobility, and self-care skills. Those who met the criteria were multiply disabled, severely delayed, or had severe chromosome problems and included 13 percent of special needs sample. Those who were identified in the mild to moderate category from this study were children having Downs Syndrome, soft neurological

\textsuperscript{3}Two-factor index of social position (1991). Residence factor is eliminated.
\textsuperscript{4}ERIC Digest revision, 1990. Digest #E311. The Council For Exceptional Children.
signs, and mild verbal or motor delays. They included 87 percent of the special needs sample. Demographic information for both groups is provided in Table 1.
TABLE 1

DESCRIPTIVE SCORES OF DEMOGRAPHIC VARIABLES

TREATMENT GROUP N=35

<table>
<thead>
<tr>
<th></th>
<th>Typical</th>
<th></th>
<th>Special Needs</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MEAN</td>
<td>SD</td>
<td>MEAN</td>
<td>SD</td>
</tr>
<tr>
<td>MOTHER'S AGE</td>
<td>31.57</td>
<td>4.53</td>
<td>34.42</td>
<td>7.37</td>
</tr>
<tr>
<td>FATHER'S AGE</td>
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<td>36.86</td>
<td>7.83</td>
</tr>
<tr>
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<td>1.25</td>
<td>2.00</td>
<td>.78</td>
</tr>
<tr>
<td>FATHER'S EDUC</td>
<td>2.62</td>
<td>1.36</td>
<td>2.00</td>
<td>.96</td>
</tr>
<tr>
<td>FATHER'S JOB</td>
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<td>2.24</td>
<td>2.57</td>
<td>1.40</td>
</tr>
<tr>
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<td>.65</td>
</tr>
<tr>
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<td>0.00</td>
<td>1.29</td>
<td>.47</td>
</tr>
<tr>
<td>SIBLINGS</td>
<td>.57</td>
<td>.75</td>
<td>1.64</td>
<td>1.28</td>
</tr>
</tbody>
</table>
Table 1 shows that the mothers of typical children from both the participating and comparison groups are approximately 31 years of age prior to treatment and the mothers of special needs children from both groups are approximately 34 years of age. Husbands in all four groups are two or more years older.
than their wives. From the entire sample, all parents are
educated beyond the high school level, parents of the
comparison group are more educated than the treatments, and
fathers of special needs children are more educated than
fathers of typical children. The ages of the special needs
children are somewhat elevated from the typical children since
the criteria for group matching in this case had to do with
developmental rather than chronological age. None of the
typical children were identified as having a disability, while
both the treatment and comparison special needs groups
identified more mild-to-moderate than severe disabilities.
The mothers of typical children tended to have no or only one
other child in the family, while mothers of the special needs
mothers had up to two other children at home.

Description of the Model Program Intervention

The Baby B.A.S.I.C.S. model demonstration project\(^5\) was
developed for mothers and their children, ages six to thirty-
six months, from both city and local suburbs into integrated
settings in a ratio of 7:3 typical to special needs dyads,

\(^5\) The acronym stands for Building Accessible Services In Integrated
Community Settings (for Infants and Their Families). As noted earlier,
additional information is available on request from the author.
respectively. It is a collaborative effort involving a social service agency for families, a national therapy agency specializing in special needs children and a university center devoted to outreach and research with families. The integration intervention was spurred on by consecutive mandates of public law services for preschool children with disabilities, ending with Public Law 99-457. Part H of this law provides incentives for states to develop early intervention services for infants and toddlers with disabilities. The State of Illinois passed Public Act 87-680 in 1991 to comply with the requirements for eligibility of future funding under Part H of Individuals with Disabilities Education Act.\textsuperscript{6} The law requires that services be provided in integrated community based family-centered settings. Subsequently, the development of integrated program options becomes critical.

The Baby B.A.S.I.C.S. integrated program was located in a social service agency that provided counseling, parent education classes, several support groups, and a flexible drop-in service for parents and their children. The staff consisted of the social services director, a therapist from the special needs agency, and university faculty and graduate

\textsuperscript{6} IDEA - Public Law 101-476
students. Additional trained staff was available as needed. This program consisted of weekly sessions, meeting for an hour and a half over an eight week period, and divided into two parts: a mother-child play group component and a mother-support group component. During the play group component, children and mothers played together, guided by staff from both agencies, using the Curriculum Guide\(^7\) that follows best practice standards for key experiences in infancy and toddler development. During the second half of the morning, mothers met together in a support group that was designed to foster discussion of developmental issues facing all parents of children in their age group, thus helping to break barriers and promote mutual acceptance. The children played together under the guidance of staff, facilitating the goals of social skills and acceptance.

**Procedures**

**Data Collection**

The data for this evaluation were collected at a drop in community-based center located in a middle to upper-middle class suburb. Typical mother-infant dyads were recruited by

\(^7\) The Curriculum Guide was developed by its agency and is available on request from the author.
the family center and through a waiting list of the special needs therapeutic center, and followed up with an introductory letter (Appendix A). The collection for this research occurred over a span of fourteen months and included four groups of mother-child dyads with each group containing an average of ten dyads consisting of both typical and special needs dyads in a ratio of 7:3, respectively. The treatment groups included two groups of 24 to 36-month-olds, one group of 6 to 12-month-olds, and one group of 12 to 24-month-olds. During the orientation session, mothers were given packets that included a demographic questionnaire, consent and confidentiality research form, and two paper-and-pencil measures (the Parenting Stress Index and the pre-evaluation tool) that were to be turned in at the first group session (see Appendix B). The content of the packets were explained to the mothers and followed up by discussion and questions. At the close of the intervention program eight weeks later, the mothers were again given a packet that included two paper-and-pencil measures (the Parenting Stress Index and the post-evaluation tool) to be returned in a self-addressed stamped envelope. Of the mothers who participated to the end of the program, all 34 subjects responded to and returned the packets of information. Neither pre- or post-packets interfered with
the activity of the program. Following the group program, individual home interviews were conducted with the mothers of special needs children.

Within a similar time frame, to avoid historical and other time effects, the comparison mothers were also given pre- and post-packets containing the same contents as the treatment group. Interviews in this case were not conducted since the interview questions themselves were based on the program intervention. Similarly, post-packets were mailed to them eight weeks later. All but one comparison group subject completed the pre- and post-evaluation packets.

**Instruments**

The Parenting Stress Index is a standardized instrument intended to assess the magnitude of stress in the parent-child relationship (see Appendix B). Developed by Abidin (1986), this index is composed of a 101-item self-appraisal questionnaire that uses a 5-point Likert scale. The measure is intended both as a research and clinical tool for professional intervention. Parents with at least a fifth grade reading level are able to complete the questions within a twenty-five minute period of time. There are two domains to this scale: the Parenting Domain measures the parents
attachment to the child, sense of competence in parental role, parental depression, parent health, social isolation, restrictions in role, and spousal relations; the Child Domain measures child characteristics of demandingness, distractibility, mood, degree of reinforcement to the parent, acceptability, and adaptability. Elevated scores on the subscales and domain scores indicate greater child or parent-related stress, that is, excess causes and effects of stress. According to Abidin (1984), the normal range for the total stress score is between 175 and 245. Scores above 260 are considered to be extreme and parents should be referred for counseling. In addition, the 19-item Life Stress Domain is an optional and brief life change scale that screens for general life stress within the past twelve months and is unrelated to the normed parent stress score.

Abidin (1984) reported satisfactory internal consistency reliability data from the original standardized sample for the full test score, the domain scores, and the individual subscale scores. Reliability of the total scale is a high .95. Internal consistency for the child domain is .89 and the parent domain, .93. Test-retest reliability of the PSI from various studies has ranged from .65 for a one-year period and .96 for a period of one to three months.
A notable strength of the PSI is its validity for measuring parental dysfunction. Several research projects have included the PSI as at least one of its measures. For example, Goldberg, Morris, Simmons, Fowler, & Levison (1990) found that the PSI discriminated between a clinical sample of parents of infants having cystic fibrosis and congenital heart disease from those having healthy infants. It determined group differences arising mainly from the Child Domain where the child's illness was a primary stressor.

A study involving parents of young children diagnosed with attention deficit hyperactivity disorders (Anastopouos, A., Guevremont, D., Shelton, T., & DePaul, G., 1992) utilizing a multi-method assessment to include the PSI, showed that extremely high levels of stress exist within these families. Correlations between subscale areas of the PSI with the ADHD Rating Scale of $r = .68$, Child Behavior Checklist of $r = .25$, and the Symptom Checklist 90-Revised of $r = .45$ were significant and indicated a substantial amount of shared variance. Based on the results of separate analyses employing stepwise multiple-regression, the child and parent variables alone accounted for more variance than the overall family environment.
For purposes of this study, the overall PSI score was used as the dependent variable. Since the individual parent, child, and life stress scores are perceived to be indicators of potential sources of stress, it is important to consider any of these variables as possible contributors of stress. The analyses, therefore, included comparisons in these subscale areas.

The Pre- and Post-Evaluation Tool included approximately 30 questions addressing alternative support resources, program critique, child and parent/self-appraisal items (Appendix B). Similar questions were provided for comparison groups with the exception of the program critique. As discussed by social support researchers (Hobfoll & Lerman, 1992; Gaudin, J., Polansky, N., Kilpatrick, A., & Shilton, P., 1993; Crnic, K., Greenberg, M., Ragozin, A., Robinson, N., & Basham, R., 1983), having positive resources like social support and knowing where to get them and how to use them are important to overall sense of adjustment to and mastery of stressful situations. As stated by Deborah Belle (1991) in relation to gender differences in experiencing stress, women are more likely than men to seek out and receive both formal and informal support. Important to the findings was that "high resource women" found they benefited from high levels of
support; for "low resource women" (those who had trouble responding to the needs of network members) were more likely to be distressed under these conditions.

An informal one-on-one interview\(^8\) was conducted with the mothers of special needs infants following the intervention. The 34 question items contained in the interview included the infant's developmental and medical histories, the parent and family relationships with the infant, a "my-infant-your infant" appraisal (how one's own child is perceived in behavior and ability in contrast to other children), future predictions, and follow up reflections of the inclusionary program. While not a part of the quantitative analysis, information from the interview allowed the mother to describe and explore the finer facets of her parenting experience with her child in a more intimate exchange. The information given better defined the time commitments, extraordinary, and oftentimes, relentless experiences she was having with her infant. The case studies presented reflect the findings of these interviews.

---

\(^8\) This interview is adapted from Weissmann's (1987) interaffectivity interview.
Data Analysis

As described above, the PSI standardized instrument (used to examine the dependent variable of stress) yields both a total stress score and an independent life stress score. Both child and parent domain scores contribute to the total stress score. Within the child and parent domains, there are subscale areas identifying specific areas of stress. As discussed by Lloyd and Abidin (1985), scores on the instrument are best analyzed by first looking at the total scores and then the child/parent domains scores for significant elevations. By interpreting the scores in a top-down fashion from general to more specific, the interpreter can make better use of the information.

A factorial design was implemented in order to determine any significant variations between pre- and post-intervention stressors. Correlations between covariates and predicted stress variables with the special needs samples were then analyzed. This included comparing total stress scores to economic status and life stress. Results are predicted to reflect the extent of insult to the participants regarding environmental stressors.

Group-by-group two ANOVA analyses were conducted to compare both treatment groups and comparison groups before and
after the eight-week intervention. The same analysis was completed for both parent and child domains since, according to PSI literature it is possible to have an average range total score with an elevated parent or child domain score. Outcomes from this analysis determine more precisely the contribution(s) of stress on the mother.

Demographic data including the age of child, mother’s age, type of disability, other siblings, and economic status were used as matching variables and further, for frequency distributions. The data are reported descriptively and independently from the pre and post PSI measure. In addition, all findings obtained from both the standardized assessments and the interviews provided sources of information for the case studies.
CHAPTER 4
RESULTS AND INTERPRETATION

Introduction

In determining whether the factors that produce stress in mothers of typical and special needs children are the same or different, and whether stress factors changed after the eight week intervention, several statistical analyses were used. The results will be presented according to the hypotheses proposed in Chapter II. An ANCOVA was implemented to control for and determine any relationships between demographic subject data and quantitative results. This is followed by simple analyses to compare treatment and comparison groups involving between-group variability and any notable changes following the intervention. A repeated measures analysis was then conducted to examine any within group differences and determine any group interaction.

Descriptive Summary

First, an ANCOVA was performed utilizing PSI total stress scores between typical and special needs groups prior to the intervention. No relationship of significance was
found with these variables, $F = 1.07, p = .305$, across treatment and comparison groups (see Table 2). Affecting this study was the sample, loaded toward the upper class status levels, creating skewed groups. A power of .05 was found to suggest that the number of groups and the small cell sizes made it difficult to determine generalized levels of significance between the demographic variables and stress scores. Although the sample distribution here contains little variability overall, analyses of the PSI stress scores among the four groups were conducted to determine any elevations in stress characteristic of these groups before and after intervention. Differences were then examined between pre- and post-intervention PSI scores to determine any changes in scores among the four groups.

**Hypothesis 1**

The first hypothesis states that there is no significant difference of mother and child stress of the treatment and comparison groups prior to intervention. In order to test this hypothesis, a $2 \times 2$ group ANOVA was conducted to compare total and sub-domain scores across these groups (see Table 3). In reviewing the pre-intervention stress mean
Table 2

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>SS</th>
<th>MS</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
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<td>2222.40</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
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<td>1.13</td>
<td>1.13</td>
<td>.00</td>
<td>.982</td>
</tr>
<tr>
<td>Group 2</td>
<td>1</td>
<td>859.72</td>
<td>859.72</td>
<td>.39</td>
<td>.536</td>
</tr>
<tr>
<td>Group x Group 2</td>
<td>1</td>
<td>2376.75</td>
<td>2376.75</td>
<td>1.07</td>
<td>.305</td>
</tr>
</tbody>
</table>

Note: Group represents typical sample of both treatment and comparison Groups. Group 2 represents both treatment and comparison special needs groups.
<table>
<thead>
<tr>
<th></th>
<th>Norms</th>
<th>Treatment</th>
<th>Comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>X</td>
<td>SD</td>
<td>X</td>
</tr>
<tr>
<td>Total Stress Score</td>
<td>221.10</td>
<td>38.90</td>
<td>241.50</td>
</tr>
<tr>
<td>Child Domain Score</td>
<td>98.40</td>
<td>19.20</td>
<td>116.29</td>
</tr>
<tr>
<td>Adaptability</td>
<td>24.50</td>
<td>5.70</td>
<td>28.14</td>
</tr>
<tr>
<td>Acceptability</td>
<td>12.50</td>
<td>3.60</td>
<td>18.64</td>
</tr>
<tr>
<td>Demandingness</td>
<td>18.10</td>
<td>4.60</td>
<td>23.57</td>
</tr>
<tr>
<td>Mood</td>
<td>9.60</td>
<td>2.90</td>
<td>9.71</td>
</tr>
<tr>
<td>Distract/Hyper</td>
<td>24.40</td>
<td>5.00</td>
<td>25.64</td>
</tr>
<tr>
<td>Reinforces Parent</td>
<td>9.30</td>
<td>2.90</td>
<td>10.57</td>
</tr>
<tr>
<td>Parent Domain Score</td>
<td>122.70</td>
<td>24.60</td>
<td>125.21</td>
</tr>
<tr>
<td>Depression</td>
<td>20.40</td>
<td>5.60</td>
<td>18.57</td>
</tr>
<tr>
<td>Attachment</td>
<td>12.60</td>
<td>3.10</td>
<td>14.07</td>
</tr>
<tr>
<td>Restriction of Role</td>
<td>19.00</td>
<td>5.20</td>
<td>21.07</td>
</tr>
<tr>
<td>Sense of Competen</td>
<td>29.20</td>
<td>6.30</td>
<td>26.14</td>
</tr>
<tr>
<td>Social Isolation</td>
<td>12.80</td>
<td>3.80</td>
<td>12.71</td>
</tr>
<tr>
<td>Relation to Spouse</td>
<td>16.80</td>
<td>5.10</td>
<td>19.00</td>
</tr>
<tr>
<td>Parent Health</td>
<td>11.90</td>
<td>3.30</td>
<td>13.64</td>
</tr>
</tbody>
</table>

**N = 600**  **N = 21**  **N = 14**  **N = 20**  **N = 14**
scores in Table 3, the typical and special needs groups are similar to Abidin's normative sample. While the comparisons showed normal range variations of stress overall, the special needs treatment group showed a difference with an elevation of 242 to suggest that higher levels of stress are characteristic of this group. While the findings do not lead to a rejection of the null hypothesis in that there is no significance among these groups, trends toward elevation found with mothers of special needs seeking treatment are in agreement with several outside findings comparing stress levels between the two groups (Weinhouse et al.; Salisbury, 1987; Tunali & Power, 1993).

There were variations in subscale scores with the special needs treatment group (see Table 4). The elevations determined in the child domain score for this group is attributed to elevations in adaptability, acceptability and demandingness. That is to say that the greatest source of stress for these parents was the array of child characteristics. Similar to other studies involving mothers of disabled children (Innocenti, M., Huh, K., & Boyce, G., 1992; Fitzgerald, M. & Kinsella, A., 1990), these mothers were found to perceive their children as
### Table 4

**Table of Special Needs Treatment Group Before and After Intervention**

(N = 14)

<table>
<thead>
<tr>
<th>Spousal Support</th>
<th>Total (H/L)</th>
<th>Child (H/L)</th>
<th>Parent (H/L)</th>
<th>Other Resource (1=Yes/2=No)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre</td>
<td>POST</td>
<td>Total (H/L)</td>
<td>Child (H/L)</td>
<td>Parent (H/L)</td>
</tr>
<tr>
<td>MAge</td>
<td>MEduc</td>
<td>M.Work</td>
<td>HRS/wk</td>
<td>Pre</td>
</tr>
<tr>
<td>Mean</td>
<td>34.43</td>
<td>2.00</td>
<td>1.50</td>
<td>14.71</td>
</tr>
<tr>
<td>SD</td>
<td>7.37</td>
<td>.78</td>
<td>.52</td>
<td>19.40</td>
</tr>
<tr>
<td>PRE</td>
<td>POST</td>
<td>Case 1</td>
<td>278 (260/175)</td>
<td>167 (122/81)</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 2</td>
<td>213</td>
<td>106</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 3</td>
<td>219</td>
<td>96</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 4</td>
<td>295</td>
<td>138</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 5</td>
<td>252</td>
<td>120</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 6</td>
<td>194</td>
<td>102</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 7</td>
<td>192</td>
<td>89</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 8</td>
<td>218</td>
<td>98</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 9</td>
<td>196</td>
<td>95</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 10</td>
<td>291</td>
<td>144</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 11</td>
<td>183</td>
<td>74</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 12</td>
<td>244</td>
<td>113</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 13</td>
<td>314</td>
<td>148</td>
</tr>
<tr>
<td>POST</td>
<td></td>
<td>Case 14</td>
<td>291</td>
<td>137</td>
</tr>
</tbody>
</table>
unacceptable and demanding, making the parenting role less fulfilling. It is the loss of the "hoped for child," the child that would meet what Beckman-Bell (1981) refers to as the cultural norms of what is considered healthy or normal for the parents. The parent domain score for this group, as well as subscale scores, fell within the expected range. Interestingly, the child acceptability score was also elevated with mothers of special needs children not involved in the treatment. This may suggest that while there is some child stress indications in the non-treatment mothers too, in accepting their special needs children, the mothers are generally more adjusted in parenting their children despite their disabilities. While these non-treatment mothers have to consider the loss of the "normal child" just as the treatment mothers of special needs children as the scores indicate, they appear to have adopted a way of coping that is effective for them.

Of the 14 treatment cases presented in Table 4, 9 of the mothers identify having other resources for support. Of the 9 mothers, 7 of them maintain total stress scores in the normal range. While this information provides a measure of network density (Stoneman & Crapps, 1988), it does not describe the quality of those resources. Still, this
finding alone may reflect the mother’s desire to change in relationship with her child, but falls short of appraising the efficacy of those supports.

No significant difference was found in the child adaptability subscale between the mothers of typical children of the treatment and comparison groups. Although there was no statistical significance in scores of the 14 mothers comprising the special needs group, 6 of the scores contained elevated scores in the child domain, and 4 of them specifically in child adaptability. Of the 4 elevated cases, all mothers described their children’s difficulty in handling eating and sleep schedules and changes in schedules. In 2 cases the children were developmentally delayed and communication with their mothers had been an issue. Of the 4 cases, 3 of the children were two years of age (the high level group), and 1 was one and one-half years of age.

Also, in 3 of the 4 cases of mothers having special needs children, elevations occurred with child acceptance. The scores of 17, 19, and 27 were considered to be high scores, suggesting a weaker quality of attachment between the mother and her child.
Child demandingness scores were elevated in 2 of the 4 special needs cases. Questions raised in this area addressed the levels of difficult behavior emanating from the child to the mother. This can come from several sources, and are likely to include the child's temperament and in this instance, the characteristics inherent of the disability. While the mothers did not report their children as temperamental for the two cases presenting elevations, both children had severely limited communication skills, making both reciprocity and tolerance in relationship with their children difficult.

Hypothesis I cannot be rejected given that there is no significant difference in stress reported by mothers of special needs and mothers of typical children. Elevations, however, were observed in total scores with the special needs group seeking treatment, but not with the comparison sample. This trend is interesting and its implications are discussed in the following chapter.

Post-test Analyses

In determining any overall significance with posttest data, an ANCOVA was run using the posttest scores as the dependent variable with covariates of SES, life stress
events, and pretest scores. As represented in Table 5, no significance was found, \( F = 2.27, p = .137 \). However, a positive correlation between the posttest scores and socioeconomic status was found, \( t = .178 \). Consistent with other studies examining stress and SES (Webster-Stratton, 1990; Canning, R., Harris, E., & Kelleher, K., 1996), an indirect relationship was found between the two variables.

According to Pearlin (1991), crucial resources made available to adults can increase psychological coping resources, and thereby, increase self-esteem. Pearlin believes that higher social status allows for better health, and thus, protects families from potential health problems, vis-a-vis, life stress. Lazarus et al., (1985) however, state that studies typically do not find strong relationships between coping and social status since there are several confounding variables involved in coping. As he and others point out, the individual's appraisal of the stress is determined by one's beliefs, goals, and perceived capabilities to meet the stress demands. This is similar to Belsky's view (1984) regarding the importance of the mother's personality traits upon her child. While personality and other intrinsic coping factors are outside
Table 5

**ANCOVA OF POST PSI WITH SES COVARIATE**

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>SS</th>
<th>MS</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within Cells</td>
<td>64</td>
<td>145645.80</td>
<td>2275.72</td>
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<tr>
<td>Regression</td>
<td>1</td>
<td>4229.78</td>
<td>4229.78</td>
<td>1.86</td>
<td>.178</td>
</tr>
<tr>
<td>Group</td>
<td>1</td>
<td>254.26</td>
<td>254.26</td>
<td>.11</td>
<td>.739</td>
</tr>
<tr>
<td>Group 2</td>
<td>1</td>
<td>940.04</td>
<td>940.04</td>
<td>.41</td>
<td>.523</td>
</tr>
<tr>
<td>Group x Group 2</td>
<td>1</td>
<td>5162.29</td>
<td>5162.29</td>
<td>2.27</td>
<td>.137</td>
</tr>
</tbody>
</table>

Note: Group represents post scores of PSI with Group 2 as SES.

**REGRESSION ANALYSIS FOR POST PSI WITH SES**

<table>
<thead>
<tr>
<th>Code</th>
<th>Adj. $\bar{X}$</th>
<th>Obs. $\bar{X}$</th>
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</thead>
<tbody>
<tr>
<td>FF Treatment</td>
<td>223.42</td>
<td>227.38</td>
</tr>
<tr>
<td>FF Comparison</td>
<td>233.36</td>
<td>233.70</td>
</tr>
<tr>
<td>Lek Treatment</td>
<td>245.09</td>
<td>244.50</td>
</tr>
<tr>
<td>Lek Comparison</td>
<td>219.79</td>
<td>216.07</td>
</tr>
</tbody>
</table>

Note: FF = typical dyads; Lek = special needs dyads. PSI Mean = 222.80, SD = 36.6.
the scope of this study, it is suggested here that social status may have some bearing on lower levels of stress, and that as Eckenrode (1983) points out, these individuals are better able to mobilize their supports.

Total post stress was covaried with life stress (see Table 6) with these groups. In assuming that life stress would increase the overall level of stress the mothers were experiencing, no significance was found $F = 2.22, p = .141$. However, in the regression analysis (Table 7), an elevation occurred with the special need treatment group. This would suggest that in addition to the stress these mothers may experience as parents of special needs children, additional demands occur, making the adjustment to their children less manageable. It is also possible that unlike their non-treatment counterpart, these mothers have sought social support because of higher experienced levels of stress. It might be added, that all groups in this sample averaged one stress event showing that generally, extraneous stress demands were rather minimal for this sample in the course of this study.

Total PSI posttest scores were then measured with pretest scores, life stress, and socioeconomic status covariates to determine relationships (see Table 8). No
Table 6

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>SS</th>
<th>MS</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within Cells</td>
<td>64</td>
<td>41205.32</td>
<td>2206.33</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regression</td>
<td>1</td>
<td>8670.26</td>
<td>8670.26</td>
<td>3.93</td>
<td>.052</td>
</tr>
<tr>
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<td>.35</td>
<td>.35</td>
<td>.00</td>
<td>.990</td>
</tr>
<tr>
<td>Group 2</td>
<td>1</td>
<td>3831.07</td>
<td>3831.07</td>
<td>1.74</td>
<td>.192</td>
</tr>
<tr>
<td>Group x Group 2</td>
<td>1</td>
<td>4890.53</td>
<td>4890.53</td>
<td>2.22</td>
<td>.141</td>
</tr>
</tbody>
</table>

Note: Group represents post scores of PSI with Group 2 as life stress events occurring within the past year.

REGRESSION ANALYSIS FOR POST PSI WITH LIFE STRESS

<table>
<thead>
<tr>
<th>Code</th>
<th>Adj. $\bar{X}$</th>
<th>Obs. $\bar{X}$</th>
</tr>
</thead>
<tbody>
<tr>
<td>FF Treatment</td>
<td>229.49</td>
<td>227.38</td>
</tr>
<tr>
<td>FF Comparison</td>
<td>231.19</td>
<td>233.70</td>
</tr>
<tr>
<td>Lek Treatment</td>
<td>246.79</td>
<td>244.50</td>
</tr>
<tr>
<td>Lek Comparison</td>
<td>214.18</td>
<td>216.07</td>
</tr>
</tbody>
</table>

Note: FF = typical dyads; Lek = special needs dyads. PSI Mean = 222.80, SD = 36.6. Relationship is ns. Elevation suggested in special needs treatment group.
Table 7

ANCOVA OF POST PSI WITH PRE PSI COVARIATE

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>SS</th>
<th>MS</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within Cells</td>
<td>64</td>
<td>36190.66</td>
<td>565.48</td>
<td></td>
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</tr>
<tr>
<td>Regression</td>
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<td>113684.92</td>
<td>113684.92</td>
<td>201.04</td>
<td>.000</td>
</tr>
<tr>
<td>Group</td>
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<td>3.93</td>
<td>3.93</td>
<td>.01</td>
<td>.934</td>
</tr>
<tr>
<td>Group 2</td>
<td>1</td>
<td>361.69</td>
<td>361.69</td>
<td>.64</td>
<td>.427</td>
</tr>
<tr>
<td>Group x Group 2</td>
<td>1</td>
<td>749.92</td>
<td>749.92</td>
<td>1.33</td>
<td>.254</td>
</tr>
</tbody>
</table>

Note: Group represents total post scores of PSI with Group 2, as total pre scores.

REGRESSION ANALYSIS FOR POST PSI WITH PRE PSI

<table>
<thead>
<tr>
<th>Code</th>
<th>Adj. $\bar{X}$</th>
<th>Obs. $\bar{X}$</th>
</tr>
</thead>
<tbody>
<tr>
<td>FF Treatment</td>
<td>229.60985</td>
<td>227.38095</td>
</tr>
<tr>
<td>FF Comparison</td>
<td>231.70239</td>
<td>233.70000</td>
</tr>
<tr>
<td>Lek Treatment</td>
<td>235.89333</td>
<td>244.50000</td>
</tr>
<tr>
<td>Lek Comparison</td>
<td>224.44682</td>
<td>216.07143</td>
</tr>
</tbody>
</table>

Note: FF = typical dyads; Lek = special needs dyads. PSI Mean = 222.80, SD = 36.6.
Table 8

ANCOVA OF POST PSI WITH PRE PSI, LIFE STRESS & SES
COVARIATES

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>SS</th>
<th>MS</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
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<td>Within Cells</td>
<td>62</td>
<td>34088.73</td>
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<tr>
<td>Regression</td>
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<td>115786.86</td>
<td>38595.62</td>
<td>70.20</td>
<td>.000</td>
</tr>
<tr>
<td>Group</td>
<td>1</td>
<td>12.32</td>
<td>12.32</td>
<td>.02</td>
<td>.881</td>
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<tr>
<td>Group 2</td>
<td>1</td>
<td>828.90</td>
<td>828.90</td>
<td>1.51</td>
<td>.224</td>
</tr>
<tr>
<td>Group x Group 2</td>
<td>1</td>
<td>746.77</td>
<td>746.77</td>
<td>1.36</td>
<td>.248</td>
</tr>
</tbody>
</table>

Note: Group represents post PSI scores.

REGRESSION ANALYSIS FOR POST PSI WITH THREE COVARIATES

<table>
<thead>
<tr>
<th>Code</th>
<th>Adj. $\bar{X}$</th>
<th>Obs. $\bar{X}$</th>
</tr>
</thead>
<tbody>
<tr>
<td>FF Treatment</td>
<td>231.14806</td>
<td>227.38095</td>
</tr>
<tr>
<td>FF Comparison</td>
<td>230.57224</td>
<td>233.70000</td>
</tr>
<tr>
<td>Lek Treatment</td>
<td>237.01692</td>
<td>244.50000</td>
</tr>
<tr>
<td>Lek Comparison</td>
<td>222.91517</td>
<td>216.07143</td>
</tr>
</tbody>
</table>

Note: FF = typical dyads; Lek = special needs dyads. PSI Mean = 222.80, SD = 36.6.
significant difference was found, $F = 1.36$, $p = .248$, when controlling these variables. A repeated measures was then run (Table 9) on the typical and special needs group in treatment before and after intervention. No overall group effects or time effects were found, $F = .27$, $p = .604$.

**Hypothesis II**

The second hypothesis states that there is no significant difference in mother and child stress when comparing typical to comparison group dyads following intervention. Comparisons were made with these groups using a 2 x 2 group ANOVA (see Table 10). The data revealed no significant differences among the four groups, treatment and comparison, following the intervention. The scores are comparable to those of the pretest. The special needs treatment group remains elevated however, with a total mean stress score of 244. There is little variability in Parent Domain scores across groups and all scores fall within the normal range of expectancy.

The mothers of typical children in the treatment found their children to be less reinforcing to them as parents. In comparison, the mothers of special needs children did not
### Table 9

**REPEATED MEASURES OF PRE AND POST TREATMENT GROUPS**

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>SS</th>
<th>MS</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within Cells</td>
<td>33</td>
<td>98836.33</td>
<td>2995.04</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NUGRP</td>
<td>1</td>
<td>3613.87</td>
<td>3613.87</td>
<td>1.21</td>
<td>.280</td>
</tr>
</tbody>
</table>

Note: NUGRP = both treatment groups. No overcall group effects were found.

**REPEATED MEASURES OF TREATMENT GROUP BY TIME**

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>SS</th>
<th>MS</th>
<th>F</th>
<th>Sig of F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within Cells</td>
<td>33</td>
<td>12125.90</td>
<td>367.45</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>1</td>
<td>5.04</td>
<td>5.04</td>
<td>.01</td>
<td>.907</td>
</tr>
<tr>
<td>NUGRP x TIME</td>
<td>1</td>
<td>101.04</td>
<td>101.04</td>
<td>.27</td>
<td>.604</td>
</tr>
</tbody>
</table>

Note: NUGRP = both treatment groups - typical and special needs. No time effect or interactions noted.
Table 10
Comparisons of Post-Intervention PSI Means and Standard Deviations by Group

<table>
<thead>
<tr>
<th></th>
<th>Norms</th>
<th>Treatment</th>
<th>Comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>X</td>
<td>SD</td>
<td>X</td>
</tr>
<tr>
<td>Total Stress Score</td>
<td>221.10</td>
<td>38.90</td>
<td>227.38</td>
</tr>
<tr>
<td>Child Domain Score</td>
<td>98.40</td>
<td>19.20</td>
<td>101.05</td>
</tr>
<tr>
<td>Adaptability</td>
<td>24.50</td>
<td>5.70</td>
<td>25.38</td>
</tr>
<tr>
<td>Acceptability</td>
<td>12.50</td>
<td>3.60</td>
<td>12.76</td>
</tr>
<tr>
<td>Demandingness</td>
<td>18.10</td>
<td>4.60</td>
<td>17.76</td>
</tr>
<tr>
<td>Mood</td>
<td>9.60</td>
<td>2.90</td>
<td>10.10</td>
</tr>
<tr>
<td>Distract/Hyper</td>
<td>24.40</td>
<td>5.00</td>
<td>23.90</td>
</tr>
<tr>
<td>Parent Domain Score</td>
<td>122.70</td>
<td>24.60</td>
<td>126.33</td>
</tr>
<tr>
<td>Depression</td>
<td>20.40</td>
<td>5.60</td>
<td>19.29</td>
</tr>
<tr>
<td>Attachment</td>
<td>12.60</td>
<td>3.10</td>
<td>13.76</td>
</tr>
<tr>
<td>Restriction of Role</td>
<td>19.00</td>
<td>5.20</td>
<td>20.14</td>
</tr>
<tr>
<td>Relation to Spouse</td>
<td>16.80</td>
<td>5.10</td>
<td>18.81</td>
</tr>
<tr>
<td>Parent Health</td>
<td>11.90</td>
<td>3.30</td>
<td>12.52</td>
</tr>
</tbody>
</table>

N = 600  N = 21  N = 14  N = 20  N = 14
experience undue stress in this area. These mothers did continue to experience significant levels of stress in child acceptability (18.86) and in child demandingness (23.29) following the intervention; however, their elevated scores on the pretest for child adaptability (28.13) had changed at posttest (26.79), falling in the average range. It can be suggested that while these mothers remain struggling with the notion of having a child with a disability and the various demands that likely occur with having disabilities following the intervention, they have gained a new perspective of their children’s ability to adapt socially.

The results measuring posttest stress in all four groups of treatment and comparison groups show that there are no significant changes among these groups following the intervention. Therefore, Hypothesis II cannot be rejected. Notable change is found, however, with the mothers of special needs children following the group intervention in that these mothers perceive their children as more adaptive than they had prior to the intervention.

Quantitative Summary

The quantitative analyses in this study attempted to compare 37 mothers of typical and special needs children to
matched comparison groups using a quasi-experimental design. The before and after stress score comparisons were intended to show any changes occurring following the social support intervention. Initial stress levels of all the mothers measured quantitatively showed no significant stress in either Child or Parent Domains. This finding is not unusual with middle and upper-middle status families (Abidin, 1989). While some researchers have found a negative relationship between SES and stress (McConachie, 1994), others have found that higher SES individuals have a strong sense of internal control over their problems (Holahan, C., Holahan, D., Moos, R., & Brennan, P., 1997; Mouton & Tuma, 1988; Margalit, M., Raviv, A., & Ankonina, D., 1992), allowing them to mobilize networks and cope proactively.

Approximately 71 percent of the mothers felt they had received support from their spouses. This is an important finding and may help support the lower levels of overall stress in this sample. The combined factors of higher SES, older parents, and fewer children with this sample may have led to the positive effects mothers find they have with their spouses (Chandra et al., 1995).

Although no significant differences were found from quantitative analyses regarding actual stress, life stress, or
socioeconomic status, the mothers seeking support in the intervention had considerably more child stress than the comparison or typical groups. The areas of elevation were in child acceptance, demandingness, and adaptability. Child acceptance was the only area of significant stress found with the comparison group (16.79). This lack of acceptance of the child may be perceived as a "narcissistic trauma" for the mother who may be caught up in a cycle of guilt, anger, rejection, and depression (Lax, 1972; Kogan, K., Tyler, N., & Turner, P., 1974). For the mothers in the comparison group, they appear to have adjusted to the capabilities of their children regardless of their loss. This was not the case for the treatment mothers. This finding may help to explain why the special needs mothers in the treatment group joined the group in the first place. It may be that the extra stress they experienced regarding their children, particularly in the areas of adaptability and demandingness, led them to find additional information and support.

Following intervention, the treatment mothers of special needs children showed relative improvement in child adaptability, that is, they had the opportunity to see their children adjusting to the social cues and demands of the environment by participating in the program activities. Since
the intervention allowed them to observe their children's skills, they were able to appreciate, possibly for the first time, all that their children could do developmentally. Whether or not these children have abilities to develop has been a major concern for parents in this population (Kazak & Marvin, 1984; Beckman-Bell, 1981). Possibly this doubt diminished through the course of the program.

**Individual Case Studies**

Although statistical significance was not found in the overall sample of either of the two treatment groups, elevations as discussed earlier were apparent with the special needs group. Two particular cases were chosen from the special needs treatment group that had significant stress scores. And while these cases are themselves isolated profiles unable to be replicated exactly with others, they do represent the construct under study and illustrate important findings regarding support group interventions with mothers of special needs children.

An analytic approach (Yin, 1994) using revelatory case material was used for purposes of describing those issues characteristic of this population. The cases address these issues of stress as they are perceived by the mothers. As Yin
has suggested, case studies are chosen for their significance to a particular topic and because they are revelatory—real-life situations that have not been studied in the past. Recalling that of the 14 special needs treatment subjects, over half of the sample had mixed elevations of stress: 2 contained elevated Child Domain scores, 2 had elevated Parent Domain scores, and the remaining 4 had elevations in both parent and child stress. Although in the two cases, the severity of the children’s disabilities differed, both of the mothers’ child stress scores contained significantly high scores prior to the eight-week intervention.

These cases then address the qualitative research questions microcosmically: the variations as they relate to disability type, stress-related outcomes, child attributes, and perceived social support. In Case 1 the child has a severe chromosomal abnormality, whereas, in Case 2, the child has mild autism, or a possibly but yet undiagnosed, pervasive developmental disorder. Elements of the parenting construct introduced in Chapter 2 will be discussed afterward in relationship to these cases.
Case 1 - Mary, age 24 years, and Dee, age 26 months

(Case number 10)

PSI Scores⁹

Total Stress Score: Pretest - 291 Posttest - 266
Child Domain Score: 144 123
Parent Domain Score: 147 143

Presenting Issues

This case was chosen to illustrate trends toward lower overall stress following the social support intervention. Important to this case are the various and severe limitations presented by the child and the lack of resources, both personal and social, originally presented by the mother.

Para- and Post-Natal Events

Mary's pregnancy with Dee proceeded uneventfully with the exception that the fetus' size appeared smaller than its gestational age. There was no follow up by the doctor since it was believed that the due date might have been calculated incorrectly. No pregnancy tests outside of routine tests were done since Mary was only 24 years of age, medically

⁹ Normal range score for PSI total stress (2nd edition) is 175 to 245.
considered a healthy age for pregnancy. Mary was induced around her due date and the baby went into fetal distress. On the third hospital day, the baby, Dee, was diagnosed with Trisomy 18, a severe chromosomal abnormality. During that time, Mary recalls the doctor telling her to take her baby "[sic] home to die." It is more common that babies with this level of abnormality stop developing in utero. But in this case, the baby continued to reach full gestation and Mary gave birth to Dee. Back at home, Dee was on a feeding tube and was seen by a cardiologist to monitor her heart condition. She received occupational, physical, and speech therapy. An educational therapist worked to improve Dee's attention skills.

Dee's developmental milestones showed that at 15 months she learned to roll over. Other developmental areas typical of infants and toddlers to the age of two had not been reached. At the time of observation (26 months of age), Dee could bring her hand to her mouth, self-calm by hitting herself, and kick her legs. Mary perceives her daughter as "typical" when she describes her whining and moody behaviors. She adds that Dee can be playful, but reciprocity in play is very minimal. Physically, Mary sees her daughter as different. She states that Dee doesn't run
around like other two-year-olds and her coordination, strength, and visual skills are undeveloped. Babies with this diagnosis of Trisomy are expected to have a shortened life, possibly living into their teen years.

Mother’s Own History

Mary’s own mother had a crib death baby prior to giving birth to Mary. As a result, Mary experienced her own mother’s lack of support and caring. As she puts it, since the mortality of a Trisomy child is so present—that they can die from a cold—Mary believed that her mother could not face getting close to Mary and her baby. Mary shares in this feeling as she states her conscious distance with Dee, “because she is going to die.”

Mary has a high school education with additional college coursework. She works 20 hours per week in the evening while her husband, who was previously married with a six-year-old son, watches the baby. She finds that her husband and his son treat the baby “gently.” Her work as a ticket agent is a way of getting her mind in other areas, as she says, and time alone.
Assessment Data

Initial Impressions

Impressions of Mary were of a young, shy, but attentive mother to her two-year-old daughter. Her baby was oftentimes seen held in her arms, as a mother of an infant would do. She made physical contact with Dee but appeared constrained in her efforts. Mary came by taxi for each session and maintained perfect attendance. Although her shy quality appeared to hold her back from informally engaging with other mothers, she interacted well in the mother’s support group that had followed the child play session.

Stress scores for this mother fell from the high-risk category (291) prior to the intervention to a normal range score (266) following intervention. Significant changes occurred primarily in child characteristics.

Child Data

From interview and evaluation data, Mary believed that Dee was developing at an expected pace with respect to her disabling conditions. Temperamentally, Mary described her as an easygoing child who was moody at times. She found that her communication with Dee was poor, and subsequently, was not sure what Dee’s needs were. In Mary’s appraisal of
Dee she stated that like other children, Dee could be moody, attempting and communicating primitively her wants and needs. On the other hand, Mary described Dee as looking physically different from other children and not acting and developing like others her age. She said that it was not uncommon for a Trisomy child to say just four words in the span of her life. Generally, she described Dee and her future as "a big unknown." She did, nonetheless, characterize her daughter as happy, moody, and stubborn. She particularly liked it when Dee responded to her with a smile. Quite significantly for Mary, over the course of the eight-week program, characteristics of Dee that had contributed to stress in their relationship dropped considerably (see Appendix C). Prior to the intervention, high levels of stress from the PSI were in acceptance, demandingness, and parental reinforcement (scores = 31, 27, 22). Results following intervention showed that Mary found Dee to be much less demanding and more reinforcing to her as a parent. Mary still, however, maintained a high level of stress regarding child acceptance.

From the intervention, Mary saw that Dee was able to play with other children, albeit in parallel play fashion, and she, as well as the staff, could interact in play with
her daughter. She felt that Dee particularly enjoyed the scoot board, tumble form car, and bean bag activities.

**Mother Data**

Mary's overall Parent Domain score was elevated, 147, but not significantly so. Furthermore, she perceived little support from her husband before and after the intervention. Other significant areas of stress were in her perceived depression and role restriction. While depression here is not assumed to be characterological, it is suggestive at least of situational-type depression. This along with her sense of role restriction can profile her as a mother who experiences guilt, immobilization toward involvement, and sheer helplessness in parenting this child. This being the case, her posttest scores showed considerable improvement in these areas—both depression (pre: 28; post: 22) and role restriction (pre: 22; post: 19) had diminished.

**Social Support Data**

Mary's responses to pre-evaluation questions (see Appendix C) showed that she did not perceive herself as having adequate supports or information regarding her daughter. In Mary’s own words regarding her group
participation with her daughter, "I would like for everyone who comes in contact with Dee to learn about Trisomy 18 and about what a special baby she is." Mary's responses following the intervention reflect a deeper knowledge of her daughter resulting from conversations with other mothers and staff and her own observations of Dee at play with the other children. When asked to complete a statement on how her views have changed of her child, she responded, "Dee reacts more to toys shown to her...to the different textures and tastes the group had to offer." She felt respected for her parental role by other mothers. Mary said that at one point a mother asked her, "How could you do this? You're so brave." Mary added that the group forced her to talk about her experiences and felt related in some ways to all the mothers. She did emphasize that in communicating with two other mothers having special needs children, she felt identity—they were all "in the same boat."

While Mary had perceived more differences than similarities with other mothers and their children in the group, she found she was respected and validated for her struggles as a parent. In the final interview, Mary confessed that she still did not feel close to Dee and that this was based on her fears of losing her. And she remains
bitter with her family for not taking an interest in and being supportive of her and her daughter. On the other hand, Mary found that Dee has made her a stronger person and brave, that she has to fight for her.
Case 2 - Kay, age 35 years, and Robert, age 30 months

(Case number 15)

Total Stress Score: Pretest - 278       Posttest - 200
Child Domain Score:   167              120
Parent Domain Score:  111              80

Presenting Issues

This case was selected to show a downward trend in overall stress for the mother despite early fears that her son would be disruptive in the group. The benefits of social support through the inclusionary model are highlighted.

Para- and Post-Natal Events

Robert was born ten weeks prior to his due date. He had lacked oxygen and so, for two months he had remained in the hospital. He was also born with beta strep infection and placed in intensive care until there was improvement. Robert had taken part in several therapies: speech and physical therapy, and training for his vision. He continues to have asthmatic complications. Many of Robert's developmental milestones lagged—sitting at 10 months,
cruising at 15 months, and walking and talking at 18 months. Robert's parents are sure that he has developmental delays and question the possibility of mild autism.

Mother's Own History

Kay and her husband have been married for six years and Robert is the twin of a middle child, with a 5-year-old sister and a 4-month-old brother. Both Kay and her husband have their master's degrees in social work. Her husband teaches and Kay works part-time in her profession. Kay is currently pregnant with another child. Prior to the intervention she felt her social supports were inadequate, but that she did get together with other mothers often. Kay was afraid her son would not fit in with the group in that he would be disruptive and not handle the different situations.

Assessment Data

Initial Impressions

Kay presented as a poised and confident mother who easily connected with staff. Her parent involvement was limited in the beginning except during the mother's support group. She was articulate regarding her son's
characteristics both as an individual and as a family member. In the child playgroup she appeared apprehensive yet motivated with Robert in the activities.

As reflected by her pre-PSI stress scores (see Appendix C), Kay began the program having scored 295, a ceiling score. Both child concerns and parental issues were highlighted.

Child Data

Child stresses for Kay existed in Robert's inability to adapt to his surroundings and issues involving clinginess. Significant child stresses occurred in adaptability (44), acceptability (25), demandingness (37), and distractibility (35). Comparable to the responses of the other mothers of special needs, child acceptance scores were maintained at a high level throughout this study for both the treatment and comparison groups. Distractibility here is understood to imply low level attention, poor listening skills, and overactivity. Kay has referred to Robert's overt behaviors at home and how it stresses the family.

Kay perceives Robert dimensionally. In comparing her son to other children she states that he has tantrums, runs and plays outside with other children, is affectionate with
his family, and likes to eat. His differences relate to his language delays and the minimal interactions he has with other children. She adds that if Robert does not like being in a situation, he will cut off all communication. Kay describes him as smart, affectionate, and temperamental. He is a slow to warm up child who “can be set off by little things.” Regarding his future, she fears that because he is unable to build social rapport, Robert will have a difficult time forming relationships, doing well in school, getting married, and holding a job. She fears he will be compared to his brother though, who tends to excel.

Mother Data

Kay’s Parent Domain score prior to the intervention fell in the normal range. This suggests that her significant total stress score is attributed to her appraisal of her son. Both pre and posttest data show that her spouse has been favorable in his support and assistance with Robert. Subtest Parent Domain scores changed following the intervention but showed variable improvements. Some of her pretest responses illustrated her as a restricted parent, unable to have time and energy for herself. Robert’s fussiness led her to believe that she was the
responsible agent. And she felt socially isolated, affirmatively responding to statements suggesting low resources of help and advice and little time with other mothers. She doubted she was an adequate parent to Robert. However, following the intervention, her responses changed in these areas. Kay not only perceived herself as an effective parent, but she found herself connecting with other mothers and gaining new friends. She felt more informed and pleased about Robert's growth.

Social Support Data

Research Question 1: What are the variations of perceived social support reported by the participating mothers of the special needs children?

Kay's responses to pre-evaluation questions (see Appendix C) suggested that she knew little about Robert's conditions and their impact on his development. She voiced concerns about how her son would affect other family members. Most importantly, she felt uninformed regarding his skills—she was not sure how to engage with him in play or that he could engage successfully. Kay feared that they would have to quit the group once Robert began to act up. These perceived fears ended for Kay in that she not only
observed Robert's involvement with toys and other children, but that his temper tantrums had diminished. Kay conversed often with the staff and other mothers regarding developmental concerns and abilities, as well as, her own experiences as a mother. Following the intervention, Kay described having a different sense of Robert. She found she was not as nervous about his social behavior, allowing her to leave the house more often. And while Kay continues to perceive Robert as "different" from other children, she finds he has unique contributions to make socially.

Summary and Discussion of Cases

The underlying assumption of these cases, as well as the study, is that the sources of stress are multiply determined through the lens of the mother. This assumption is well illustrated in the Parenting System Model (Figure 1) with the mother serving as the buffer or mediator of the stress she experiences. Its subjective nature leads to unique and individual accounts of perceived stress and how to best cope. DeMaso, D., Campis, L., Wypij, D., Bertram, S., Lipshitz, M., & Freed, M. (1991) conclude that the severity of a disability is not necessarily as important a predictor of stress, as the quality of the mother-child
relationship. The second assumption is that each mother appraises the nature of her stress and utilizes some method of coping. However, how she chooses to cope is based on her personal resources, personality structure, past history, and other phenomenon that take ecological and psychological factors into consideration (Belsky, 1984). While personality factors are not addressed in this study, it can be assumed that the mothers participating in the intervention are responding "actively" to their stress (Jarvis & Creasey, 1991) by seeking out support and attempting to reappraise their relationships with their children. The two cases presented are particularly interesting in that the mothers' pretest stress scores were extreme and had significantly improved following the program intervention, altering primarily child qualities.

Overview

Research Question 2: What are the variations of stress levels when comparing mothers of mild-moderate special needs to those having severe special needs?

Both Mary and Kay share a similar problem in that neither is able to communicate in a satisfying manner with her toddler. The quality of their communication is different
of course, determined by the type and extent of the disability (Beckman-Belle, 1981; Maccoby, 1992). On the subtest measuring child reinforcement, Mary's score was significantly high, suggesting a weak bond with Dee: low appreciation and parent efficacy had been identified. Considering that typically developing two-year-olds engage with their peers in constructive play and begin separating from those closest to them, these mothers instead, experience ongoing dependency from their children. While it is reasonable that Mary's child would be needy and dependent for her survival, Kay also shares in this perception of Robert who is a mildly disabled child. But unlike Mary, Kay appears to benefit in some ways when interacting with her son. The extreme demands and lack of adjustment trouble these mothers. Mary and Kay discuss their lack of resources—both informational and social—in dealing effectively with their children and hope the group experience will meet these needs.

Mary perceives her own parental role as yet another contributor to overall stress with her daughter. Kay does not. Her scores are significantly high in depression and attachment, two rather direct factors affecting the quality of her relationship with Dee. And prior to the intervention,
both mothers revealed their concerns about "fitting" into the group, albeit, for different reasons, but both felt their children took too much of their energy.

The life stress scores of these mothers when viewed quantitatively show increases following the intervention. The changes involved in these outside stresses for them can be viewed as qualitatively different. Substance abuse in Mary's home took its toll on her immediate family, while for Kay, her husband had changed jobs, which had subsequently increased his salary. While any type of change can be stressful, negative events are more likely to create ongoing adjustment problems. Despite these increasing stresses, both Mary and Kay were able to benefit from the group and alter their perceptions of their children.

Like the other participants, Mary and Kay joined this group for support and information, in hopes that their experiences would change. What these mothers came to share by the end of the intervention, was a different and more positive attitude about their children and themselves, the "self-as-parent." As the stress literature points out, discovering improved methods of coping likely promoted parent efficacy and family harmony (Mouton & Tuma, 1988; Abidin, 1992). In order to discuss the variations before
and after intervention of these two cases, and for purposes of theory development (Yin, 1994), stress variables from the Parenting System Model are used.

Perceptions of Child

Research Question 3a: What are the variations in stress-related outcomes of participating mothers of special needs children?

Mary and Kay found that their children contributed significantly to their levels of stress. This is in agreement to the responses provided by over half of the treatment mothers having special needs children and supported by parent-child stress studies (Dyson, 1993; Friedrich & Friedrich, 1981; Kazak & Marvin, 1984).

Interestingly, this was not the case with the non-treatment special needs group. It is likely that the increased frequency of child stresses in the treatment group motivated the mothers' participation in the intervention. Mary and Kay found their children to be highly demanding and not well adapted to situations. These negative qualities are quite commonly perceived by parents of special needs children (Frank et al., 1991; Telleen et al., 1989; Brinker et al., 1993) and more likely have to do with the extra effort and
medical appointments required than of the disability itself. During the interviews, both of these mothers described taking their children to more than two therapies on a regular basis. Child acceptance, a term related to positive or negative human qualities such as attractiveness, remained high throughout the course of the intervention. This was also true of mother’s responses in the special needs comparison group (mean = 17.86). When combined with other high scores in the child domain, or to high scores such as parent attachment or depression, a low quality of attachment may be considered. There is reason to be considerably concerned with Mary’s pretest profile. She experiences her daughter as a significant contributor to her overall stress. Like Mary, Kay’s appraisal of her son is a considerable source of stress. With characteristics of mild autism (Hoppes & Harris, 1990), Kay feared that Robert was socially deficient, insensitive to others and too self-focused. She had also felt a loss of affective involvement with her son in play. In either case, because of the significant levels of total stress and child stress, these mothers (Abidin, 1995) would be referred on for counseling.

The overall child appraisal scores remained significant for both cases following the intervention, but they
relatively improved, dropping more than one standard deviation. Most important were the variable changes in the subtests. Both mothers perceived their children as more adaptive following the intervention. Mary commented that although Dee could not respond socially in the playgroup, she was surprised to see her responding to the music and some of the tactile toys. She was able to experience her daughter’s participation, however limited, in the group. Kay, too, was pleased to see her son respond to the toys and play appropriately with peers. She articulated that some children of disabilities could participate in playgroups with typical children. Kay found that by the end of the eight-week program, Robert’s attention span and socialization seemed to improve, and that his temper tantrums had ended.

**Parent Perceptions**

**Research Question 3b:** What are the variations in stress-related outcomes of participating mothers of special needs children?

Parent Domain scores as described by Abidin (1995) are more likely to be high sources of stress with mothers who are young or inexperienced with children. Mary fits both of
these descriptions in that as a twenty-four year old mother, Dee is her first child. Mary's Parent Domain score, while not significant at pretest, was elevated (147). She profiled as a mother who was depressed and frustrated by the needs of her daughter. Her sense of attachment with Dee was also threatened and reflected by her high score in this area. Certainly, Mary's own attachment history with her mother may impact this relationship, and that her own real or perceived feelings of parental efficacy with a severely disabled child makes it difficult for her to trust her own instincts. Kay, on the other hand, is an experienced and older mother of three other normally developing children. Her Parent Domain score, despite the stresses she experiences from Robert, is within the normal range (111). Her subtest scores suggest that she is confident in her parental role and interested in making some changes in relationship to her son.

Research Question 4: What are the variations of child attributes reported by the participating mothers for their special needs children?

Following the intervention, Mary remains distraught by her daughter's physical appearance, her low level of development, and fleeting bright affect, but perceives Dee
as "doing more than expected." Mary states she enjoys more the physical contact with Dee. Her continued sense of role restriction is undoubtedly a real one, possibly stemming from her ongoing cycle of anger and guilt (Abidin, 1995).

Although Kay’s scores remain within the normal range in this area, her responses and comments regarding her son have changed. There are possibly several reasons for her change in attitude about Robert. The playgroup allowed Robert to easily access peers and toys as he chose, while Kay observed his involvement. She was surprised to see how easily he thrived in that environment. Kay stated in the mother’s support group how the program provided her with child development information, staff and peer support, and became a catalyst for her own growth as Robert’s mother.

Final Comments

The concept of social support according to several researchers (Telleen, 1990; Holahan et al., 1997), is an opportunity provided with the intention of helping individuals cope with problematic situations. How effective the support is, is multiply and uniquely determined. Literature on this topic has described the importance of “fit” between the participant and group (Belle, 1991), a
match that appears to be quite individualistic. It is believed that for any individual joining a group, there is a willingness on some level to risk. All participants in a group enter with certain expectations. With good will they risk betrayal for acceptance, disrespect and rejection for approval, and fear for fulfillment. As with other mothers of special needs children, Mary and Kay risked themselves for the possibility of change. It may be difficult with foresight to determine exactly what those changes will be, but the desire to have the relationship better than it is guides their membership. In hindsight, nothing in the order of developmental change has necessarily occurred for the children over the eight-week period. Rather, if the group has been effective, the mother’s own attitudes—about her child and herself as a parent—has changed. As child development literature point out, the relationship between the parent and child is a reciprocal process, and therefore, what is changed in one, certainly changes for both.
CHAPTER 5
CONCLUSIONS

The present study examined the kinds of stress inherent in mothers of both typical and special needs children.\(^{10}\) The stressors considered have been those previously identified by researchers interested in stress and the parent-child system (Belsky, 1984; Webster-Stratton, 1990; Hobfall, 1989; Abidin, 1995). A heuristic model accompanying this study reflected the multiplicity of factors involved as potential stressors. The purpose of this study was to determine any patterns of change involving stress in mothers having typical children and those having special needs children. Certainly, while there are stresses involved with any mother parenting a child, there is convincing evidence that mothers having special needs children are particularly engulfed by many responsibilities. This study is based on certain assumptions: (1) Appraisal for stress is determined by the mother, the one mediating

\(^{10}\) The term special needs is used categorically to include all individuals having physical, cognitive and/or behavioral characteristics that are atypical for their developmental levels. This is distinguished from the typical category presented in this study and used for purposes of comparison.
the experience, (2) all mothers are potentially stressed with the birth of a child, (3) a mother-child relationship is affected, in part, by the mother's appraisal of potential stressors, and (4) social support systems have the potential for assisting mothers by meeting important needs. In order to evaluate the possible stressors impacting these mothers, a pre-post design was implemented to determine the between and within group differences. The treatment mothers involved in the eight-week social support intervention consisted of parents of both typical and special needs children, while the comparison group--matched by mother and child ages, marital status, other children, socioeconomic status, and disability level--volunteered for evaluations before and after the eight-week period.

Discussion of Findings

The treatment mothers were compared to the non-treatment group across areas of stress; in addition, mothers of typical children were compared to mothers of special needs children. Both demographic information and personal appraisals of stress were considered variables. Quantitative findings determined the gross and generalizable meanings of these groups, while the qualitative case studies
drew valuable information regarding subgroup trends. In order to draw conclusions from this study, it is best to revisit its findings briefly.

Results from this study showed there to be no significant differences in total stress between the mothers of typical and special needs children prior to the social support intervention, \( F = 1.07, p = .305 \). There are several possible reasons for this lack of difference. A positive correlation exists between the total stress scores and class status level of this sample. The middle to upper-middle class sample represented here may be provided with opportunities not apparent with a lower SES group (Riley & Eckenrode, 1986). With more available resources, age-related maturity, prior parenting roles, and greater education, it appears that these mothers were generally able to manage the stresses of their parenting. Also, spousal support was more frequent with this class status and all subgroups represented showed healthy spousal relationships (mean = 18.88, standard deviation = 4.93). Qualitative feedback showed that many of these mothers had prior experience with group support. The ability to mobilize resources has been perceived as a key factor in reducing overall stress. It appears from these data that overall, these mothers either
possess or can actualize resources necessary for support and adjustment.

While the sample is similar to Abidin's (1986) norms on the PSI, the lack of significant difference in stresses may have to do with the sample size. Low statistical power made it difficult to determine levels of significance between demographic and stress data. Although significant differences were not found between the typical and special needs groups, trends in elevations were. Similar to other studies using the PSI instrument involving special needs children, elevations occurred in the Child Domain area with this subgroup. Most representative of this group was the loss of the perfect or hoped for child. This stress was reflected in the acceptability score, an area of elevated stress for both the special needs treatment and comparison groups. What is different between the mothers of these two groups is that the treatment group maintained additional stresses in child demandingness and adaptability. For these mothers, it was difficult to consider taking their children out in public, to perceive the uniqueness and skills of their children, or to expect that their children could play well with other children. It was more frequently the case that these parents had more involvement with the health care
system and informational therapies that took up their time and energy (Kazak & Marvin, 1984; Goldberg, S., Morris, P., Simmons, R., & Levison, H., 1990). And in contrast to these demands, was the support group where mothers were given the opportunity to "test the waters" safely, to either justify or dispel their beliefs.

For the mother, it may not only be that the needs imposed by her child are extensive, but the possibility that she is unable to understand or communicate her child's needs in the first place. This appeared to be true of the two cases presented in this study and may relate with child adaptability concerns. Furthermore, mothers having these experiences with their children are prone to low parental efficacy that can negatively affect the mother-child relationship. In following with the concept of social support, it is not surprising then that the treatment mothers of special needs children matriculated into the program. The connection between individuals could serve to improve adaptive competence, as well as provide specialized information.

For many of the children and particularly the older children, the integrated playgroup provided the opportunity for social skills and involvement with other children and
adults. Children having physical limitations like cerebral palsy, developmental delays, or cognitive impairments were able to play alongside of typically functioning children. At times, they were seen sharing in the same activity. Some having communication and regulatory difficulties were able to adapt themselves more in this setting. In other instances, children learned for the first time how to share their mothers with other children and adults. As one mother said, “I now know that [my family] can go visit relatives or go out to a restaurant. I know he’ll be alright.” Other mothers expressed relief in knowing that their children will be able to cope with the social demands of schooling later.

It was of interest in this study to determine if there were any differences in stress for mothers of children having mild or moderate to more severe disabilities. Since 87 percent of the special needs population fell into the mild and moderate group, answers involving hard data were not possible. While the sample size was insufficient, the qualitative findings held interest. There was no apparent trend suggested between the level of the child’s disability and the mother’s level of stress in these instances. Upon a closer look into the qualitative responses from the mothers, it appeared that the attributional meaning (Terry, 1994;
Venters, 1981; Shapiro, 1989) they gave to the presence of the special needs child in their home, that is, how they defined their situations, affected their stress appraisals. As a matter of coping, forming a meaning to the disability is known to provide resolution, and from it, certain attitudes (Terry, 1994). One such mother had a child with combined hydrocephaly and hypotonia who met the criteria for a severe disability. She had pre and post total stress and subdomain scores that fell in the average range. The mother's responses during the interview shed light on her perspective. She found that the presence of her child had provided more love in her family, and that she maintained hope for her child's future. This appraisal reflects the internal meaning (Lazarus et al., 1985) used by this mother that allowed her to live with and find purpose in her experiences. It remains questionable whether this attributional tendency is more likely with upper than lower SES families. As DeMaso et al. (1991) and others have shown, the severity of a disability may not be as important to healthy adaptation as is the quality of the mother-child relationship.

The posttest total stress scores following the eight-week intervention showed little change overall, $F = 2.27$, $p$
= .137. There was no significant difference in the stress scores between the mothers of typical and special needs children. As detected from the pretest analysis, child acceptability remained stressful for both the special needs treatment and comparison groups; however, the elevated stress score in adaptability (28.14) had dropped to the normal range. This change may have to do with the mothers' participation in the program where opportunities existed to observe their children at play. Regardless of the activity, the children were able to use the skills they had to engage with the toys. In this setting, the mothers were able to see their children's successes both in playing with the toys and in playing with or alongside their peers. For some mothers, this may have been their child's first public and social experience.

Implications for Future Studies

This study showed that the treatment sample composed of 21 mothers of typical children and 14 mothers of special needs children have no overall significant levels of stress before or after the social support intervention. The findings in and of themselves show that there is a normal range of stress for these mothers of middle to upper social strata. For this sample, there were evidently several
environmental buffers. The average mother had at least post high school education and several of them had graduate training. They were married and perceived their spouses as supportive partners in parenting. Combined with the resource opportunities available to them, the self-selection process itself attributed to the positive group profile (Telleen, 1990) regarding stress. It is likely that these mothers are generally effective mobilizers of resource support, that is, that they can initiate themselves in resolving their needs.

To improve on this study, a larger sample size would be necessary for considering the number of variables involved in the stress construct. It would be interesting to include a lower SES sample with the sample used here to compare areas of stress in an inclusionary setting. Also, when considering a sample of mothers of special needs children, would there be stress differences between first time mothers and mothers having other children? In other words, does the mother’s experiences with her other children help buffer the effects of her experience with her special needs child? How might “parental efficacy” be different given this perspective?
Future studies implementing a quasi-experimental design involving similar interventions may determine additional findings involving resolutions of stress through the use of longitudinal evaluations. While it has been suggested that the middle and upper social classes are able to appraise their personal situations in briefer time periods, changes in perspective and behavioral systems are likely to take time. As Lazarus (1985) and others have pointed out, psychological defenses are a common experience to initial threat until new experiences discount previously held beliefs. Lazarus describes this as "feeling worse before feeling better." It is a process of grieving and requires the experience of each stage. The new perspective reached by the mother of a special needs child, aside from the immediate truths she may have gained from the group, will require these truths to be tested again and again on the outside with her child if the truths are to live on. Changes in stress and adaptation fit into this time sequence and would likely be reflected in longitudinal data.

Less is known about internal controls, socioeconomic status and their relationship to attributions, that is, in how mothers might perceive their special needs children. Is there a relationship between the opportunities afforded the
middle and upper class and attributional meaning? Or is it related more to personality factors, spousal alliance, or the mother’s own personal and attachment history? It has been said that economically challenged individuals have a tendency to perceive control as an external event, causing them to experience themselves as victims. If this is assumed, does this also relate to attributions or are the constructs different?

Stress and coping are best understood as individual and subjective experiences. Any mother taking on the responsibilities of her child is faced with stress and attempts ways of coping with that role. Belsky’s work (1984) has opened the doors of parental stress by looking closely at personality factors, what the individual brings to the stressful situation, rather than the situation in and of itself. It may be concluded that what is stressful to one mother may not be stressful to the other. The situations that these mothers are faced with, whether or not they possess the backgrounds and environments conducive to healthy parenting, cannot determine whether or not stress exists. It is because of its subjective nature that stress is best measured in transactions between individuals and situations than in isolated forms. The purpose of case
studies then, in determining these subjective truths, allows for the development of theory that is multiply determined. The case studies presented here unveiled some of the social concerns mothers have for their special needs children. Future studies may focus on the frequency of these concerns as important issues in early childhood interventions.

Research has shown that parental knowledge and support involving their children—ranging from information about typical development or special needs concerns to support from other parents—influence the ways they understand and behave with their children. Findings have also revealed that if parents of special needs children adjust to accept their children’s diagnoses, they are more likely to have secure attachments with their children. These early programs then become important as preventative intervention services in fostering healthy parent-child relationships. As Meisels (1992) has suggested, highly individualized programs are necessary to meet the needs of children and their families in context. The intervention then becomes a whole and systemic process for the parent and child that takes into account the quality rather than the quantity of its services.
APPENDIX A

CORRESPONDENCE LETTERS
Dear Parent,

We're glad you'll be participating in Baby BASICS, a mother/toddler integrated play group and mother's support group sponsored by Lekotek and District 65 Family Focus. This unique experience is a time when children with typical and special needs and their mothers come together to play and share time.

We are fortunate that this group is part of a research project being conducted by Loyola University Chicago. The goal of the project is to study and improve the Baby BASICS concept, with the hope that this program will eventually serve as a model for other programs.

Parent participation in the research project will include completing two questionnaires and two evaluations, one each at the start and at the end of the program.

A more complete description of the project will be discussed at the orientation meeting and at that time your questions can be answered and consent forms circulated. While we certainly hope that you will participate in the research project, it is not a requirement for participation in the Baby BASICS program.

Here are the dates and scheduling information you'll need:

**ORIENTATION:** Friday, January 15; 10:30-11:30 a.m.

**Baby BASICS:** Friday, January 22 thru Friday, March 26
10:00-11:30 a.m. (no session on February 19 or March 19)

All meetings and group sessions will be held at District 65 Family Focus, located at 1942 Dempster in the Evanston Plaza (next to Cussini Shoes). We're looking forward to sharing this time with you and your child!

Sincerely,

Randi B. Wolfe
District 65 Family Focus

Deborah Blake-Krueger
Loyola University Center for Children and Families

DISTRICT 65 FAMILY FOCUS
NATIONAL LEKOTEK CENTER
LOYOLA UNIVERSITY CENTER FOR CHILDREN & FAMILIES
Dear Parent:

We appreciate your interest in participating in the Baby BASICS Integrated Developmental study. As you know, the purpose of this project is to document and evaluate the Integrated Developmental Play Group/Family Support Group Model sponsored by the National Lekotek Center and District 65/Family Focus. Because this will take up some of your time, we will compensate you with $25.00.

Your participation will include completing paper-and-pencil questionnaires at two times, eight weeks apart. One set is enclosed in this packet and the next set will come to you in eight weeks. You are asked to complete and return them on the specified date.

In this mailing you will find a consent form, a form asking about family information, and two questionnaires. Each of the forms should take you no longer than 20 minutes to complete, or 40 minutes all together. As the directions will state:

1) sign and date the Consent Form, and complete the family information form.

2) complete the PSI (Parenting Stress Index) by responding to each question on the separate answer sheet provided. Fill in the circle corresponding to your answer by putting down the first answer that occurs to you. Please be sure to answer all of the questions.

3) Complete the Pre-evaluation form by circling your best answer from the choices provided.

The second mailing will be sent to you eight weeks after you have completed the first. The packet will contain the same PSI questionnaire and another evaluation form. Directions again will be included. After you return the second set of questionnaires, a $25.00 check will be mailed to you.

Please sign and date both Consent Forms (keep one for your records), fill out the forms and return everything in the self-addressed stamped envelope as soon as possible, but no longer than a week.

If you have any questions, please feel free to call me at 708/475-4623.

Sincerely,

Deborah Blake Krueger, M.A.
Center for Children and Families
LOYOLA UNIVERSITY CHICAGO
CENTER FOR CHILDREN AND FAMILIES
Consent Form

Project Title: Evaluation of An Integrated Infant-Toddler Developmental Play Group/Parent Support Group Model

I, ___________________________ (Name of Signatory),
the parent or guardian of ___________________________ (Name of Minor Subject),
a minor of ________ (months) (years) of age, hereby consent to participate in, and consent to her/his participation in a research project being conducted by Lenore Weissmann, Ph.D. and Deborah Blake-Kruger, M.A.

Purpose

The Purpose of this project is to document and evaluate the Integrated Developmental Play Groups sponsored by the National Lekotek Center and District 65/Family Focus. Each group will meet for a ten week period, and consists of play group and support group components. The benefits of a family centered program which integrates children with disabilities and typically developing children and their families will be evaluated for potential contribution to family development and for the possibility of extending the benefits to others through replication.

Procedures

1. I will be asked to fill out questionnaires prior to the first session of the 10 week program, and following the last session.

2. I understand that the parent support component of the first meeting and of the last meeting will be audiotaped.

Possible Discomforts

No discomforts are anticipated.

Potential Benefits

Knowledge concerning factors which contribute to successful programming by community based family programs has the potential to lead to the development of other such programs. Families and children with and without disabilities may benefit from the opportunity to interact within a natural setting in an accessible family support program.

Alternatives

None.
Risks

No risk is involved.

Confidentiality

I understand that information which is obtained in connection with these procedures and which can be identified with me will remain confidential and will be disclosed only with my written permission. I understand that information may be used for research, education and training purposes. My records will be identified by a number rather than by my name, and this number code will be available only to the researchers.

I understand that any question I may have regarding this research study will be answered.

I understand that no risk is involved, but that in any case I may withdraw myself and/or my child from participation at any time without prejudice.

(Signature of Parent)

(Date)
SUMMARY DESCRIPTION

RATIONALE

Changes in public laws require that services for children with disabilities (aged 0-3 years) be provided in integrated community based family-centered settings. Currently, two community agencies, both with a "family support" philosophy, are collaborating in the operation of such a program. One agency has a long tradition as a resource center for children with "special needs" and their families; the other is a community agency with a history of providing parent support and family directed activities.

This project proposes to document the development and operation of an Integrated Infant-Toddler Developmental Play Group/Parent Support Group Model and evaluate it through assessment of parental growth of self-esteem, increase in coping skills, and change in parental perceptions of their own and other children. It is hypothesized that such changes will occur for parents of all children in the group. The evaluation will add valuable information to a research base that is in itself in its infancy, serve as a model to be replicated in family centers through the country, and provide a curriculum guide and evaluation plan to monitor progress.

RESEARCH PROTOCOLS

Data will be collected through observation and questionnaire.

Observation Data: During both the Play Group component and the Parent Support component, staff will observe interactions among children, among parents with each other and with staff, and note changes over time through an observation guide (attached). The first and last of the 10 weekly parent support groups will be audiotaped to aid in documenting change. This documentation will be part of the process evaluation.

Questionnaire Data: At least two questionnaires will be distributed to each participant both before the first session and following the last session. These will include an evaluation form Pre-, and an evaluation form, Post-, designed for the study (attached), and the Parental Stress Inventory (PSI), a standardized instrument for use with parents. The differences noted between the beginning and end of participation in the group, as revealed by differences in the questionnaires, will contribute to outcome evaluation.
Summary Description

SUBJECT POPULATION

The research project will take place in what is a continuation of a program which has been in operation for over 18 months. Over the last two years, each agency has recruited participants from its own population. It is anticipated that the individual agencies will continue to successfully recruit participants.

The subject population will consist of groups of parents of typical children and children with disabilities in a ratio of 7:3, forming groups of 10 dyads. The groups will be structured as follows:

- An infant group for babies 6 to 12 months
- A toddler group for children from 12 to 24 months
- A 2 year old group for children between 24-36 months

In addition, a group of 2 year olds will be formed in April, 1992; this group will serve as a pilot group. All of the procedures proposed for the Study will be piloted during this session.

POTENTIAL RISKS

There are no risks associated with this project.

PROCEDURES TO BE USED TO OBTAIN INFORMED CONSENT

All parents will receive information about the research project at an orientation meeting, and be asked to sign the attached informed consent form. They will understand that their questions will be answered, and that they may withdraw at any time without prejudice.

SAFEGUARDING OF SUBJECTS' WELFARE AND CONFIDENTIALITY

Parents will be informed when recruited that research is being conducted in order to evaluate the success of the group, and that although their participation is very important, they are not required to participate. The project will be explained at the orientation session, prior to the first meeting of the 10 week play group. The issue of confidentiality will be stressed. All records will be identified only by number, with identity known only to the research team. Participants may withdraw at any time. The Informed Consent will include that statement that information which is obtained in connection with the study and which can be identified with subjects will remain confidential and will be disclosed only with written permission.
Summary Description

ASSESSMENT OF POTENTIAL BENEFITS

Benefits to subjects

Benefits to subjects derive from their participation in an innovative program offering opportunities for social development among their children, creative play opportunities for their children, and a family support group. Families and children with and without disabilities may benefit from the opportunity to interact within a natural setting in an accessible family support program.

Other Benefits

Other benefits occur on many levels.

On the agency level, the benefits to all concerned include not only leadership in the provision of a needed service to the community, but the opportunity to disseminate the benefits of the program as a model for other agencies to emulate.

On the Family Level, both families with and without a special needs child benefit from an integrated program, particularly during the earliest years of a child's life.

Staff, as part of the larger society, as well as in their professional roles, benefit from the opportunities to recognize that children with special needs are children first, and that many of their needs and the needs of their families are similar to those of the children and families with which they are already familiar.

In addition, the field itself benefits from the opportunity to build on a successful model, and from the development of evaluation methods to monitor the success of such programs.

SUMMARY OF RISK-TO-BENEFIT RATIO

The risk/benefit ratio, given that there are no risks, is one completely of benefits.

Lenore Weissmann, Ph.D.
March 3, 1992
ADDENDUM TO IRB Form A

CONCISE STATEMENT OF RATIONALE FOR THE STUDY

Changes in public laws require that services for children with disabilities (aged 0-3 years) be provided in integrated community based family-centered settings. This project proposes to document the development and operation of such a program through collaboration between a resource center for children with "special needs" and a community agency providing parent support and family directed activities. The study will also evaluate the program through assessment of change in parental perceptions and coping skills. The evaluation will add valuable information to a research base that is in itself in its infancy, serve as a model to be replicated in family centers through the country, and provide a curriculum guide and evaluation plan to monitor progress.

DESCRIPTION OF RESEARCH PROTOCOLS

Data will be collected through observation and questionnaire. Observation Data: During both the Play Group component and the Parent Support component, staff will observe interactions among children, among parents with each other and with staff, and note changes over time through an observation guide (attached). The first and last of the 10 weekly parent support groups will be audiotaped to aid in documenting change.

Questionnaire Data: At least two questionnaires will be distributed to each participant both before the first session and following the last session. These will include an evaluation form Pre, and an evaluation form Post, designed for the study (attached), and the Parental Stress Inventory (PSI), a standardized instrument for use with parents.

DESCRIPTION OF SUBJECT POPULATION

The subject population will consist of groups of families of typical children and children with disabilities in a ratio of 7:3, forming groups of 10 dyads. There will be three groups, beginning in September, 1992, structured as follows:

- An infant group for babies 6 to 12 months
- A toddler group for children from 12 to 24 months
- A 2 year old group for children between 24-36 months

In addition, a group of 2 year olds will be formed in April, 1992; this group will serve as a pilot group. All of the procedures proposed for the Study will be piloted during this session.

DESCRIPTION OF ALL POTENTIAL RISKS
There are no risks associated with this project.

PROCEDURES TO BE USED TO OBTAIN INFORMED CONSENT

All parents will receive information about the research project at an orientation meeting, and be asked to sign the attached informed consent form.

DESCRIPTION OF HOW SUBJECTS' WELFARE AND CONFIDENTIALITY WILL BE SAFEGUARDED

Parents will be informed when recruited that research is being conducted in order to evaluate the success of the group, and that although their participation is very important, they are not required to participate. The project will be explained at the orientation session, prior to the first meeting of the 10 week play group. The issue of confidentiality will be stressed. All records will be identified only by number, with identity known only to the researchers. Participants may withdraw at any time. The Informed Consent will include that statement that information which is obtained in connection with the study and which can be identified with subjects will remain confidential and will be disclosed only with written permission.

ASSESSMENT OF POTENTIAL BENEFITS

Benefits to subjects

Benefits to subjects derive from their participation in an innovative program offering opportunities for social development among their children, creative play opportunities for their children, and a family support group. Families and children with and without disabilities may benefit from the opportunity to interact within a natural setting in an accessible family support program.

Other Benefits

Other benefits occur on many levels. On the agency level, the benefits to all concerned include not only leadership in the provision of a needed service to the community, but the opportunity to disseminate the benefits of the program as a model for other agencies to emulate. On the Family Level, both families with and without a special needs child benefit from an integrated program, particularly during the earliest years of a child's life. Staff, as part of the larger society, as well as in their professional roles, benefit from the opportunities to recognize that children with special needs are children first, and that many of their needs and the needs of their families are similar to those of the children and families with which they are already familiar. In addition, the field itself benefits from the opportunity to build on a successful model, and from the development of evaluation methods to monitor the success of such programs.
SUMMARY OF RISK-TO-BENEFIT RATIO FOR THIS INVESTIGATION

The risk/benefit ratio, given that there are no risks, is one completely of benefits.
APPENDIX B

QUANTITATIVE AND QUALITATIVE MEASURES
Please complete the following information:

**Mother:**

- **Date of birth:** / / (mo. day yr.)
- **Education (highest degree attained):**
  - Elementary School __
  - High School __
  - Associate's Degree __
  - Bachelor's (B.A.) __
  - Master's (M.A.) __
  - Doctorate (Ph.D.) __
  - Technical Trng. ( # of yrs.)__
  - Other_ __

**Profession/Career:**

**Is the mother presently working?** __yes__ __no__

- **If so, # of hours/wk.:** __

**Marital status of parents:**

- __ Living together__
- __ Separated__
- __ Single Parent__
- __ Married__

- __ Divorced__
- __ Remarried__

**Date of marriage:** / / (month year)

- **Were either of the parents previously married?** __yes__ __no__

- **Who is living in the home?** _____ number of people

- **Relationships (siblings, parents, grandparents,...):**

  Ages and sex of siblings?

  **Are any of your children adopted?** __yes__ __no__

  **Is there any language other than English spoken in the home?**

  **Yes** __no__

  **What other language(s)?**
PARENT INTERVIEW

Date of interview:
Respondent: 
Interviewer: 
Child's name: 
D.O.B.: 
Age: ___/___ yrs. mos.

I. Child's Developmental History
1. Tell me about your child's developmental milestones. (When he/she began walking, talking,... and with what ease or difficulty it happened)

2. Tell me about your child's problem.

3. When did you first know about his/her problem?

4. Can you give me some medical history? 
   Specialists:

   Therapy:

   Medication:
5. How would you describe the medical support/intervention your child is receiving? (helpful, problematic,...)

6. Is your child currently receiving any other services or enrolled in other programs?

7. In what way(s) do you see your child being similar to other children? (behaviors, activity, temperament,...)

8. In what way(s) do you see your child being different from other children?

9. Overall, do you feel your child's problem will significantly impede the quality of his/her life? Explain.

10. Think of 3 words (adjectives) that would best describe your child.

______________________

______________________

______________________

Explain why you chose those descriptions of him/her.
II. Parent/Family Relations

11. How many members are in your family? (adults, siblings, ...)
List members and their ages.

12. How would you describe ______ as fitting into ______
the family? (child's name)

13. How do family members accept him/her?

14. (Question posed to mother): What about your child would you
say is the most difficult to handle?

15. (Question posed to mother): What about your child do you
gain the most pleasure from?

16. (Question posed to mother): Do you work aside from your
caregiving responsibilities? ______ How much time?

If yes, how do you meet your daycare needs?
III. Mainstream Program

A. Selection/Expectations:

17. How did you first hear about this program?

18. Why did you choose this program?
   a. in terms of the child's needs?
   b. regarding your own and family needs?

19. Did you expect services to be individualized for your child? Did it happen?

B. Support/Networking:

20. What kinds of contact (if any) have you had with the Lekotek staff outside of this group?

21. How accepting do you feel the participants were in the group? (to include staff, adults, children,...)

22. Did you feel any kind of discomfort or resistance from anyone in the group?

23. Did you feel any particular support from others?
24. In what ways has the program made you feel that you and your child are welcome?

25. Have you had any contact with other parents from this group? Would you wish for more?

26. Do you belong to any other programs with your child's disability?

Any networks resulting from those programs?

C. Evaluation:

27. What is your feeling about mainstreaming special needs children into the play group/support group program?

28. In what ways do you see this program benefitting your child?

29. Over the course of the 8 weeks did you see any changes in your child?

30. In what ways do you see this program benefitting yourself?

31. In what ways do you see this program benefitting your family?
32. How satisfied were you with the procedures?

Was there anything you would have liked done differently?

33. Strengths/weaknesses of program:
What did you especially like?

What else would you have liked to see happen...

for your child?

for yourself?

IV. Future

34. What are your future expectations and plans for your child?
BABY B.A.S.I.C.S.
BUILDING ACCESSIBLE SERVICES IN INTEGRATED COMMUNITY SETTINGS
FOR INFANTS AND THEIR FAMILIES
PRE-EVALUATION FORM

DIRECTIONS:

Your responses are important; they help us provide a quality program and determine the future direction of the program. We would appreciate it if you would answer the questions attached in as thorough and thoughtful a manner as you can. If you are not sure of a question, please ask for help. Please be sure to answer all of the questions.

As you progress through the evaluation, you will see one of the following boxes:

<table>
<thead>
<tr>
<th>NA = Not At All</th>
<th>SD = Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>s = seldom</td>
<td>d = disagree</td>
</tr>
<tr>
<td>o = often</td>
<td>a = agree</td>
</tr>
<tr>
<td>VO = Very Often</td>
<td>SA = Strongly Agree</td>
</tr>
</tbody>
</table>

The boxes provide the definitions of the letters following each question. Please circle the letter which most closely matches your feelings about the question.

Although for most questions you will circle the answer, some questions will require a short answer in your own words.
PRE-EVALUATION FORM

For Office
Use Only

Name __________________________ Date __________________________

Child's Name ___________________ Child's d.o.b. __/__/__

At what age did your child: (circle approximate age)

<table>
<thead>
<tr>
<th>At what age did your child: (circle approximate age)</th>
<th>In Months</th>
<th>In Years</th>
</tr>
</thead>
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<tr>
<td>Sit</td>
<td>6---9---12---15---18---21</td>
<td>2--3--4--5</td>
</tr>
<tr>
<td>Creep</td>
<td>6---9---12---15---18---21</td>
<td>2--3--4--5</td>
</tr>
<tr>
<td>Walk</td>
<td>6---9---12---15---18---21</td>
<td>2--3--4--5</td>
</tr>
<tr>
<td>Say 1st Words</td>
<td>6---9---12---15---18---21</td>
<td>2--3--4--5</td>
</tr>
<tr>
<td>Feed Self</td>
<td>6---9---12---15---18---21</td>
<td>2--3--4--5</td>
</tr>
<tr>
<td>Bladder Control</td>
<td>6---9---12---15---18---21</td>
<td>2--3--4--5</td>
</tr>
<tr>
<td>Bowel Control</td>
<td>6---9---12---15---18---21</td>
<td>2--3--4--5</td>
</tr>
</tbody>
</table>

1. I believe my child is developing at an expected pace. (circle) Y N

2. To the best of your knowledge, does your child have adequate visual and auditory acuity? Y N

3. Do you believe you have adequate social supports to meet your current lifestyle? Y N

4. I have been in a group like this before.
   A. Just a child play group. Y N
   B. Just a parent support group. Y N
   C. Both a child play group and a parent support group. Y N
5. How often would you say you get together with other moms? NA s o VO

6. How often do you take your child(ren) with you? NA s o VO

7. How often (approximately) do you interact with your child when you are visiting with other moms? NA s o VO

8. How often (approximately) do you interact with other children at those visits? NA s o VO

9. What topics(s) would you like to discuss at this support group?

10. Would you say that when you have the opportunity, you seek out "professional" information relating to parent/child issues? NA s o VO

11. What professional information would you like to have that you may not currently have or may be difficult to find?
12. Group membership. Please respond to each question.

a. I felt it was a convenient place to meet other moms.  
   SD d a SA

b. It forces me out of the house.  
   SD d a SA

c. I want to learn more about my child and his/her development.  
   SD d a SA

d. I want my child to learn to play along with other children his/her age.  
   SD d a SA

e. I feel the staff here can help me with issues pertaining to my child.  
   SD d a SA

f. I want to feel more comfortable in joining in play with other parents' children.  
   SD d a SA

g. I feel I can learn more about my child from conversing with other moms and their children.  
   SD d a SA

h. I believe I will learn more about myself as a parent by attending these groups.  
   SD d a SA

PLEASE GO BACK AND CIRCLE THE LETTER OF THE THREE CHOICES THAT ARE THE "MOST IMPORTANT" REASONS FOR HAVING JOINED THE GROUP.

Other reasons I have decided to attend this group (not given above) include:
13. I find more value in talking with other parents than I do in reading professional material. SD d a SA

14. I feel I have a good sense of what my child's capabilities are. SD d a SA

15. Most of the time I feel I can communicate with my child. SD d a SA

16. I have a good sense of my child's wants/needs. SD d a SA

17. I feel comfortable when interacting with other parents. SD d a SA

18. I feel open when in conversation with "child experts" about my child. SD d a SA

19. I believe I have a comfortable relationship with my child considering his/her behavior, attitude, temperament,... SD d a SA

20. I believe my child's temperament may be described as:
   ___ Easygoing ___ Difficult ___ Slow to warm up
21. If there are any comments you would like to make that haven't been addressed, please feel free to make them here. These may include your perceptions about your child, parent groups, child play groups,... Your comments will be of benefit to us in striving to improve our services to you and your child.

Thank You

7/17/92
Dated
BABY B.A.S.I.C.S.
BUILDING ACCESSIBLE SERVICES IN INTEGRATED COMMUNITY SETTINGS
FOR INFANTS AND THEIR FAMILIES
POST-EVALUATION FORM

DIRECTIONS:

Your responses are important; they help us provide a quality program and determine the future direction of the program. We would appreciate it if you would answer the questions attached in as thorough and thoughtful a manner as you can. If you are not sure of a question, please ask for help. Please be sure to answer all of the questions.

As you progress through the evaluation, you will see the following box:

<table>
<thead>
<tr>
<th>SD</th>
<th>d</th>
<th>a</th>
<th>SA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td>disagree</td>
<td>agree</td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>

The box provides the definitions of the letters following each question. Please circle the letter which most closely matches your feelings about the question.

Although for most questions you will circle the answer, some questions will require a short answer in your own words.
POST-EVALUATION FORM

Name ___________________________ Date ___________________________

Child's Name ___________________________

The number of sessions I attended of this group were ______(#)

1. I had no difficulty in making the group sessions on time. SD d a SA

2. If I had the opportunity to join a group like this again, I would do it. SD d a SA

3. I would describe this as an "appropriate" play group for my child in which (s)he was able to interact and contribute. SD d a SA

4a. I felt the number of children in the group was appropriate. SD d a SA

4b. An ideal number of children for this group would be ______(#).

5a. The types of toys/activities were appropriate to the developmental levels of the children in the group. SD d a SA

5b. I would like toys/activities that would be on a level than what was presented at the play groups.

   LOWER      THE SAME      HIGHER (circle one)

6. I enjoyed taking part in my child's play group time. SD d a SA
7. Regarding the play groups, rank the following in their order of importance to you: (1 - "Most Important"... to 7 - "Least Important")

   a. Watching the staff playing/interacting with my child.   
   b. The types of toys/activities that were presented.   
   c. Getting to play with my child during this time.   
   d. Getting to play with other moms' children.   
   e. Conversing with staff about child related issues.   
   f. The opportunity for my child to play with other children.   
   g. The opportunity to socialize with other mothers.   

   State anything else you enjoyed about these play groups that are not given above.

8. I feel that my child enjoyed the toys/activities available at each of the play groups. 
   SD d a SA

9. The staff assisted me in explaining how to use the different activities presented as we moved from one activity to another. 
   SD d a SA
10. I have felt comfortable interacting with:
   a. Staff
   b. My child
   c. Other children
   d. Other moms

11. I felt the staff had constructive comments/suggestions/ideas in dealing with children's behaviors.

12. I usually felt that the staff was there to assist me with any issues I could bring up related to child rearing.

13a. The play group staff members were knowledgeable in planning activities for all developmental areas.

13b. List the 3 toys/activities that you and your child enjoyed the most:

   __________________________________________
   __________________________________________
   __________________________________________

14. The topics discussed in the parent groups were topics I found helpful.

   Here are suggestions I feel would be helpful to discuss in future parent groups:
15. I find I am getting together more with other moms than in the past.  
SD d a SA

16. Group membership. Please respond to each question.
   a. I felt it was a convenient place to meet other moms.
      SD d a SA
   b. It forced me out of the house.
      SD d a SA
   c. I have learned more about my child and his/her development.
      SD d a SA
   d. I wanted my child to learn to play along with other children his/her age.
      SD d a SA
   e. I felt the staff here could help me with issues pertaining to my child.
      SD d a SA
   f. I have felt more comfortable in joining in play with other parent's children.
      SD d a SA
   g. I feel I have learned more about my child from conversing with other moms and their children.
      SD d a SA
   h. I feel I have learned more about myself as a parent by attending these groups.
      SD d a SA

PLEASE GO BACK AND CIRCLE THE LETTER OF THE THREE CHOICES THAT ARE THE "MOST IMPORTANT" REASONS FOR HAVING JOINED THE GROUP.
Other reasons (not given above) for maintaining my membership in this group include:

17. My view of my child has changed since the beginning of this group.  

SD d a SA

Complete this statement if there is noticeable change:
This view has changed in that ____________________________

Complete this statement if there is no noticeable change:
This view of my child is the same in that ____________________________

18a. "My child seems to be very content with what it is (s)he can do."

SD d a SA

18b. "My child is different from other children his/her age."

SD d a SA

18c. "My child has a unique contribution to make which I can see when (s)he is playing or interacting with another person."

SD d a SA

18d. "My child has a bright future because of the decisions we (the parents) will make for him/her."

SD d a SA
19. Through participating in this group, I have learned to give more value to what other moms have to offer about their experiences.

20. I have a different sense of what my child's capabilities are after participating in this group.

Please explain:

21a. I feel my sense of my child's wants and needs has improved over the group time.

21b. I feel a change in my ability to communicate with my child over the group time.

22. I feel fairly open when in conversation with "child experts" about my child.

23. I currently feel fairly open when in conversation with other moms about my child.

24. I believe I have a comfortable relationship with my child (i.e. behavior, attitude, temperament,...).
25. If you had to state the most important thing you learned from the INTEGRATED PLAY GROUP, what would that be?

26. I believe my child's temperament may be described as: (check one)
   ____ Easy going  ____ Difficult  ____ Slow to warm up

27. If you have anything you would like to add that you feel is important to say at this time or may be of value to our groups in the future, please make additional comments below.

Thank you.

8/29/92
Dated
APPENDIX C

PSI PROFILES OF CASES 1 AND 2
# Parenting Stress Index

Profile Sheet and Norms-Form 6

R.R. Abidin-University of Virginia

Parents Name ____________________ Parents Sex ______ Parents Date of Birth ____________ Date ____________
Childs Name ____________ Childs Sex ______ Childs Date of Birth ____________ Age ______

<table>
<thead>
<tr>
<th>Raw Score</th>
<th>Percentile Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>29.9</td>
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**TOTAL STRESS SCORE**

<table>
<thead>
<tr>
<th>Child Domain Score</th>
<th>Percentile Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptablity</td>
<td></td>
</tr>
<tr>
<td>Acceptability</td>
<td></td>
</tr>
<tr>
<td>Demandngness</td>
<td></td>
</tr>
<tr>
<td>Mood</td>
<td></td>
</tr>
<tr>
<td>Distract./hyper.</td>
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<tr>
<td>Reinforces Parent</td>
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<table>
<thead>
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<th>Parent Domain Score</th>
<th>Percentile Ranks</th>
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<tr>
<td>Depression</td>
<td></td>
</tr>
<tr>
<td>Attachment</td>
<td></td>
</tr>
<tr>
<td>Restrict. of Role</td>
<td></td>
</tr>
<tr>
<td>Sense of Competence</td>
<td></td>
</tr>
<tr>
<td>Social Isolation</td>
<td></td>
</tr>
<tr>
<td>Relat. Spouse</td>
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<td>Parent Health</td>
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**Life Stress**

(Optional Scale)

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<th>Percentile Ranks</th>
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*When two raw scores were equidistant from the percentile interval, the higher number was selected.*
# Parenting Stress Index

**Profile Sheet and Norms-Form 6**  
R.R. Abidin - University of Virginia

<table>
<thead>
<tr>
<th>Parents Name</th>
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<th>Parents Date of Birth</th>
<th>Date</th>
<th>Age</th>
<th>Childs Name</th>
<th>Childs Sex</th>
<th>Childs Date of Birth</th>
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<tbody>
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## TOTAL STRESS SCORE

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<td>x S.D. 222.8 36.6</td>
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</table>

## CHILD DOMAIN SCORE

- **Adaptability**
- **Acceptability**
- **Demandingness**
- **Mood**
- **Distract./hyper.**
- **Reinforces Parent**

## PARENT DOMAIN SCORE

- **Depression**
- **Attachment**
- **Restr. of Role**
- **Sense of Competence**
- **Social Isolation**
- **Relat. Spouse**
- **Parent Health**

## LIFE STRESS

(Optional Scale)

<table>
<thead>
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<th>Percentile Ranks</th>
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*When two raw scores were equidistant from the percentile interval, the higher number was selected.*
Parenting Stress Index
Profile Sheet and Norms-Form 6
R.R. Abidin-University of Virginia

Parents Name ____________________________ Parents Sex ______ Parents Date of Birth ___________ Date ___________
Childs Name ____________________________ Childs Sex ______ Childs Date of Birth ___________ Age ___________

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Norms
N=2633

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<tr>
<td>Mood</td>
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<tr>
<td>Distract./hyper.</td>
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<td>Relat. Spouse</td>
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<td>Parent Health</td>
<td>11.7 3.4</td>
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<th>LIFE STRESS (Optional Scale)</th>
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*When two raw scores were equidistant from the percentile interval, the higher number was selected.*
## Parenting Stress Index
### Profile Sheet and Norms-Form 6
R.R. Abidin-University of Virginia

Parents Name ________________________ Parents Sex _______ Parents Date of Birth _____________ Date ________
Childs Name ________________________ Childs Sex _______ Childs Date of Birth _____________ Age ________

### Raw Percentile Ranks

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### Total Stress Score

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### Child Domain Score

<table>
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<th>Mood</th>
<th>Distract./hyper.</th>
<th>Reinforces Parent</th>
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### Parent Domain Score

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### Life Stress

(Life Stress Score)

<table>
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<th>Percentile Ranks</th>
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<tr>
<td>1 5 10 15 20</td>
<td>30 35 40 45 50 55 60 65 70 75 80 85 90 95 99+</td>
</tr>
</tbody>
</table>

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*When two raw scores were equidistant from the percentile interval, the higher number was selected.*
REFERENCES


Deborah A. Blake Krueger was born in a western suburb of Chicago in 1954 to Maryann and Stan Blake. She had attended parochial and public schools through the twelfth grade. She is an alum of Nazareth Academy High School in LaGrange Park.

In November of 1976, Mrs. Krueger graduated with a Bachelor of Arts degree from DePaul University in classical literature and secondary education. She minored in speech and theatre.

In June of 1980, Mrs. Krueger graduated with a Masters in Education from DePaul University in reading and learning disabilities. She served as a graduate assistant in the learning disability’s clinic and in the writing program.

Mrs. Krueger began her career in 1976 as a high school English teacher in the areas of literature and writing. She taught in the Chicago suburbs and in Michigan. From 1980 to 1986, Mrs. Krueger worked as an educational therapist in two private psychiatric hospitals in the Chicago area and taught undergraduate courses to educators at DePaul University. She maintained clinical practice at the DePaul site.
following her graduation. Mrs. Krueger was a contractual psychoeducational diagnostician for hospitals and private therapy organizations on the North Shore, as well as, a child advocate. During that time she was the director of the special education department at Old Orchard Hospital in Skokie.

Since 1987, Mrs. Krueger held various part-time assistantships at Loyola University Chicago. She performed psychoeducational assessments in the Department of Pediatrics at Loyola’s Medical Center in Maywood; she held a neuropsychology clerkship, performing psychological and neuropsychological assessments, at Loyola’s Doyle Center in Chicago; and she was co-developer and co-facilitator of the Baby ‘N Me mother-infant group at Loyola’s Mallinckrodt Campus.

During the 1996-97 academic year, Mrs. Krueger completed a one-year internship as a school psychologist with the Winnetka Public Schools. She performed psychological assessments, individual counseling, and led student support groups.

As a certified school psychologist, Mrs. Krueger currently works as a contractual school psychologist for the Winnetka Public Schools and for a private learning center in
Northfield. She also teaches undergraduate and graduate courses part-time at Loyola University Chicago.

Mrs. Krueger is a member of the Association for the Advancement of Therapeutic Education, the National Association for School Psychologists, the Society of Personality Assessment, the Illinois School Psychologist Association, Professionals in Learning Disabilities, and a student affiliate member of the American Psychological Association.

Mrs. Krueger has presented both the Baby B.A.S.I.C.S. Program and the social support model at the 72nd Annual Meeting of the American Orthopsychiatric Association (April, 1995), The Chicago Metropolitan Association for the Education of Young Children (January, 1995), and the Tenth Anniversary Conference of the Illinois Association for Infant Mental Health (October, 1993).
DISSERTATION APPROVAL SHEET

The dissertation submitted by Deborah Blake Krueger has been read and approved by the following committee:

Carol Harding, Ph.D., Director
Professor of Counseling Psychology, Loyola

Lenore Weissmann, Ph.D.
Adjunct Professor of Special Projects, Loyola

Jack Kavanagh, Ph.D.
Professor of Counseling Psychology, Loyola

The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

3/30/98  Director’s Signature