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The Impact of a Congenitally Blind Child upon Family Functioning and Interaction

Pamela S. Berryman

Western Michigan University

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THE IMPACT OF A CONGENITALLY BLIND CHILD UPON FAMILY FUNCTIONING AND INTERACTION

by

Pamela S. Berryman

A Dissertation
Submitted to the
Faculty of The Graduate College
in partial fulfillment of the requirements for the Degree of Doctor of Education
Department of Counselor Education and Counseling Psychology

Western Michigan University
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THE IMPACT OF A CONGENITALLY BLIND CHILD UPON FAMILY FUNCTIONING AND INTERACTION

Pamela S. Berryman, Ed.D.

Western Michigan University, 2002

The purpose of this study was to determine whether there was an impact of congenital blindness upon family functioning and interaction. This research investigated the level of blindness upon family adaptability, cohesion, satisfaction, and social family climate from a family systems perspective. The study analyzed data from a sample of 56 participants who were parents/care-givers of children age 0–12 years with either no vision, partial vision, or full vision.

Chi-squares were computed to determine if any of the demographic variables differed among the three groups. Respondents’ gender, relationship to child, age, child’s level of blindness, number of siblings, and household income variables differed significantly among groups ($p < .05$). Participant’s marital status, ethnicity, levels of education, residential area, people living in the household, children’s gender, people moving in or out of the home, and participant’s visual impairment did not differ among groups ($p < .05$).

To determine if the levels of blindness had significant impact on the dependent variables (i.e., family adaptability, cohesion, satisfaction, and social family climate), multiple analyses of variances (MANOVA), univariate $F$ tests, group
contrast analysis and post hoc tests (Tukey Student Standardized Range Test) were conducted for between and within groups. A statistically significant difference was found on the family satisfaction variable. Group contrast analysis indicated significant interaction, $F(1, 53) = 6.38, p = .0146$. Univariate $F$ tests and post hoc tests revealed that between and within groups levels of family satisfaction were significantly lower for the no vision group than for the partial and full vision groups. No significant differences were found on adaptability, cohesion, and social family climate.

The study was limited by its small sample size and possibility of sampling error. The results suggest that family satisfaction may be influenced by a child’s congenital blindness. Professionals providing services to families with congenitally blind children are urged to offer interventions and resources to enhance family satisfaction.
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The past three years have held times of personal and educational growth, sadness, challenge, and perseverance. Despite challenges, I have moved ahead in pursuit of educational and personal goals. I give thanks to those who played important roles in assisting and encouraging me during this process.

This dissertation is dedicated to my father, Chester Berryman. I am unable to put into words the meaning of his love, support, sacrifice, and commitment. I am eternally grateful for his fervent encouragement during difficult and discouraging times when I felt I could not complete this process.

Special thanks to my parents, Chester and Lucille Berryman, now deceased. Their nurturing and guidance helped me become the person I am today. They provided loving support and accepted my uniqueness and the limitations caused by a visual impairment. They encouraged me to persevere, do my best in every attempt, rely upon God and inner strengths, and maintain a positive attitude of life despite severely limited vision.

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Pamela S. Berryman
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CHAPTER I

INTRODUCTION

Prologue

The present study was designed to examine the effects of congenital blindness upon family functioning and interaction and generate research that will enable therapists to gain a clearer understanding of how children who are blind impact the interaction and functioning of the family. The study attempted to provide insight as to how adaptability, cohesion, social family climate, and satisfaction influence family equilibrium within the family system. This research study attempted to provide information to assist families who are adapting to having a child who is blind. This study could benefit therapists who are in the process of helping families adjust to a child with congenital blindness.

Chapter I focuses on the historical background of the problem, the family systems perspective and its related terminology, definition of legal blindness and related concepts, a brief literature review on the impact of a child with congenital blindness upon the family system, purpose and rationale of the study, statement of the problem, and research questions that this researcher explored.
Introduction to the Problem

Advances in medical science and changes in public policy have resulted in a higher survival rate of infants with chronic illnesses or disabilities. Medical professionals, social workers, psychologists, and counselors are seeing greater numbers of children with disabilities. Many professionals now face the challenge of intervention in the lives of these families.

Past researchers have concerned themselves with adaptation to stress, coping, and support mechanisms. Little research has examined the impact on the family as an interactive system when a child is born with a disability (Leyser, Heinz, & Kapperman, 1996). Moreover, a greater lack of research exists on the areas of physical or sensory deficit disabilities. Current research has begun to address this lack to some extent. The profession of family therapy views the family as a system and focuses on the interaction of all its members, including the child who is disabled (Bragg, Brown, & Berninger, 1992; Cohen et al., 1992; Foster et al., 2001; Judge, 1998). Blindness in a single individual inevitably becomes a family affair. Disabilities in children are not only problems for the child with the disability but in a real sense they affect the family as a whole. The greatest impact of a child’s disability is on the parents who have to cope with the various special needs and demands these children pose (Bolinger & Bolinger, 1996; Farber, 1979). However, a void in knowledge remains as to the impact of children with disabilities on the family system, more specifically the effects of children with congenital blindness. Therefore, there is a need for further research.
concerning the impact of children who are blind on the family’s interaction patterns and structure.

Historical Background of the Problem

As Bernier (1990) points out, the birth of a child is an exciting and joyful event for most parents. All parents have an image of the way they would like their children to look and act (Foster et al., 2001; Herring, 1996; Yura, 1987). It is common for parents to question their abilities to rear children. They may even promise themselves to do things differently from their families of origin as a means of resolving painful issues from the past and transforming conflict in a positive manner. Bernier views this process of anticipatory parenting as being typical and as a means of preparing the potential parents for a new phase of life.

The birth of a child with a disability is a circumstance that no parent would predict. When this event becomes a painful reality, it has an immense effect upon the family structure (Cohen et al., 1992; Fortier & Wanlass, 1984; Leyser et al., 1996; Yura, 1987).

Initial Reaction and Adjustment Stages

When parents initially learn of their child’s disability, they often experience anguish and extreme emotional upheaval. Researchers have noted that parents, as well as other family members, go through a series of sequential stages as they attempt to cope with and adapt to the birth of a child with a disability (Cohen et al.,
Fortier and Wanlass (1984) outlined the adjustment process according to the following stages: impact, denial, grief, focusing outward, and closure. Parks (1977) proposed the following stages in his model of the grieving process: shock, despair, guilt, withdrawal, and adjustment and acceptance. Researchers differ as to the name and number for the stages. However, there is concurrence that an adjustment process, frequently apparent with bereavement, has also been noted in parents of children with disabilities (Bauman & Yoder, 1966; Cohen et al., 1992; Featherstone, 1980; Fortier & Wanlass, 1984; Herring, 1996; Lowenfeld, 1971; Porter & McKenzie, 2000; Tuttle, 1986).

Silver and Wortman (1980) found that there is considerable variation in individual emotional responses. They postulated that there is little evidence supporting the hypothesis of stage adjustments. Affleck, Allen, McGrade, and McQueeney (1982) reported longitudinal data on the mood states of mothers of infants with severe perinatal medical complications. Thirty-eight mothers were interviewed near the time of the infants' discharge and again 9 months later. During the interviews, each mother completed the Profile of Mood States, (McNair, Lorr, & Droppleman, 1971) which is a 58-item checklist of adjectives, rated on a 5-point Likert scale (Affleck et al., 1982). Mothers differed considerably in the degree and direction of their emotional experiences. " Mothers who reported greater mood disturbance at hospital discharge of their high-risk infant also judged their infant to be more difficult to care for" (Affleck et al., 1982, p. 223). Additional differences were found in perceptions of care taking tasks, levels of social support, and coping
strategies. Although Affleck et al. found some correlation between the influences of maternal mood on perception of childcare responsibilities, the influence of other external factors cannot be ignored.

A Family Systems Perspective

Since the early 1970s, family therapists used a system lens to study families (Bragg et al., 1992; Cohen et al., 1992; Foster et al., 2001; Judge, 1998; Leyser et al., 1996; Minuchin, 1974; Whittaker, 1977; Yura, 1987). The birth of a child with a disability has enormous consequences upon both the child and the family system (Bolinger & Bolinger, 1996; Foster et al., 2001; Herring, 1996; Leyser et al., 1996). It is, therefore, important for the therapist to consider the family system as a unit, consisting of various subsystems. Hoffman (1980) creatively used the metaphor of a kaleidoscope to describe "how each piece forms a part of a cohesive unit. Yet, if one piece is altered, the whole system changes in response to the movement of one of its parts" (p. 136). In a similar manner, the reaction of the entire family system, as well as its subsystems, changes to adapt to the movement of one of its members.

Definition of Terms and Concepts

A system is a regularly interacting or interdependent group of items forming a unified whole. A family is "the social unit in which people, by mutual choice, attempt to obtain their needs" (Foley, 1984, p. 458). A family system is an organized network of interdependent individuals (Foley, 1984). A family system
operates through transactional patterns of repeated interactions, creating patterns of relating (Sauber, L’Abate, Weeks, & Buchanan, 1993).

A family system is open when energy and information are constantly taken in from and exchanged with the environment (i.e., new people, information, and support services). On the other hand, in a family system that is closed, little interchange occurs with the environment, resulting in fewer resources and restricted adaptation (Bernier, 1990).

Homeostasis refers to a system’s attempt to maintain equilibrium (Minuchin, 1985). Through feedback (i.e., emotion, behavior, information), “a family that is unbalanced, attempts to regain homeostasis either by returning to the previous set of relationships or by change and adaptation” (Bernier, 1990, p. 591). Positive feedback signals the system to continue a particular behavior, whereas negative feedback signals the need for corrective action. Neither positive nor negative feedback can be classified as good or bad. Rather, classification depends upon what the family desires and what works best in a given situation (Bavelas & Segal, 1982).

The family system consists of various subsystems (Minuchin, 1974). The parental subsystem is characterized by the interaction of parents and children within the family. The marital subsystem is the foundation of the family system (Foley, 1984) and includes various facets of interaction between spouses (Yura, 1987). The sibling subsystem is a natural consequence of the parental subsystem, affording each child the chance to build closeness with siblings. This subsystem consists of the complex interactions of all siblings within the family system. The extra family
A **subsystem** encompasses interactions with people such as extended family, friends, professionals, and significant others within the community (Yura, 1987).

Subsystems are separated by **boundaries**. “Interactions across boundaries are governed by explicit rules and patterns” (Minuchin, 1985, p. 291). Boundaries serve to maintain family rules and roles. When boundaries surrounding various subsystems are violated, *fusion* or *enmeshment* occurs, resulting in over-closeness between family members (Foley, 1984). Boundary violations may also result in members attempting to distance themselves from other subsystems.

When conflict arises between a **dyad** (i.e., two family members), and neither is able to acknowledge or cope with the conflict, they may project their problems onto a third member. Thus, a **triangle** is created that temporarily stabilizes the dyad (Bernier, 1990). Bernier further states that, “if the third party is a child with a disability, then the process can generate significant dysfunction in the mother’s and father’s ongoing adaptation to life with the handicapped youngster” (p. 593).

**Adaptability** is the ability of the family system to adjust or become adjusted to new or different conditions (Bragg et al., 1992; Olson, 1986). The family’s flexibility to modify roles and rules, as it becomes necessary, is also an important component of adaptability.

**Cohesion** is a degree of closeness or distance between two or more family members. It is considered healthy when the members are connected, but individuality is also recognized (Olson, 1986).
Adaptability and Cohesion are the two subscales from the Family Adaptability and Cohesion Evaluation Scales (FACES II) that will be used in this research to evaluate how families of children with congenital blindness, function and interact.

*Congenital blindness* refers to those children born blind or acquiring blindness before the age of 5 years.

*Legal blindness* is defined as visual acuity of 20/200 or less in the better eye with correction and/or a field of vision restricted to an angle of 20 degrees or less. Though this category includes total blindness, persons who are classified as legally blind may have useful vision (Scott, Jan, & Freeman, 1985).

*Satisfaction* is the maintenance of a positive affect toward one's family (Bragg et al., 1992). Satisfaction is the subscale from the Family Satisfaction Scale (FSS) that will be used in this research to evaluate how families of children with congenital blindness, perceive their level of satisfaction.

*Social Family Climate* is:

the general emotional atmosphere or tone in a family. At times, the emotional climate may be difficult to perceive as it truly exists, because of a façade created for others. To determine the family climate, the focus is on interpersonal relationships among family members, on the direction of personal growth emphasized in the family, and on the organization or structure of the family. (*Dictionary of Family Psychology and Family Therapy*, 1993, p. 145)

Social Family Climate is the variable that will be measured by the Family Environment Scale (FES). It will be used in this research to evaluate how families of children with congenital blindness, function and interact.
Visual acuity is the measurement of how much an eye sees under controlled circumstances, using a set distance of 20 feet for distance vision and 16 inches for near vision (Scott et al., 1985).

For the purpose of this study, the term blind will refer to both children possessing no useful vision and those possessing useful or partial (residual vision). Children having no useful vision are those with light perception (seeing light and dark) as well as those children experiencing a complete visual loss. Children having partial or useful vision (legally blind) are those with object recognition up to 20/200. Such children would be able to recognize objects, color, and read large or regular print with or without magnification.

The Impact of a Child Who Is Blind on the Family System

There is a paucity of available literature in the area of families of children with disabilities. Moreover, literature pertaining to the dynamics and functioning of families having children who are blind is limited to an even greater degree (Froyd, 1973; Gardner, 1982; Lowenfeld, 1971; Scott et al., 1985; Troster, 2000; Tuttle, 1986). The impact of children with congenital blindness is similar to the impact experienced by families with children having disabilities other than blindness (Cohen, et al., 1992; Froyd, 1973; Gardner, 1982; Herring, 1996; Scott et al., 1985). However, there are differences unique to those families having children who are congenitally blind as compared to families having children with other types of disabilities.
Adjustment to Having a Child Who Is Blind

Parents of children who are blind often face demands beyond those experienced by families having children who are not disabled. Several authors note that the experience of caring for a child who is blind can often be stressful as it is both challenging and threatening to family members (Erin, Rudin, & Njoroge, 1991; Ferrell, 1996; Hancock, Wilgosh, & McDonald, 1990; Herring, 1996; Leyser et al., 1996; Nixon, 1991; Troster, 2000; Tuttle, 1986).

Having a child with congenital blindness in the family can strain parent/professional relationships, cause worry over time involvement, create financial concerns, and cause uncertainty about the future (Herring, 1996; Leyser et al., 1996). Some researchers have also noted that a child with congenital blindness can adversely affect siblings (Bolinger & Bolinger, 1996; Correa, Silberman, & Trusty, 1986; Cohen et al., 1992; Herring, 1996; Lowenfeld, 1971; Scott et al., 1985), and create symptoms of psychological maladjustment and marital distress (Cohen et al., 1992; Ferrell, 1996; Hancock et al., 1990; Herring, 1996; Scott et al., 1985).

Leyser et al. (1996) explored the stressors that parents encountered in families having a child with a visual impairment. The researchers asked parents of children with visual impairments to report their concerns. Almost all of the parents said that their greatest concern was for their children’s future. Several parents also felt stressed due to feeling inadequate about meeting their disabled children’s needs. Other concerns reported by parents included financial problems, difficulty in finding
optimal professional care for their children with visual impairment, and not having sufficient time for themselves and their partners.

Over the past several decades, researchers found that "the nature of congenital blindness or a severe visual handicap is such that it influences every factor of the child's development" (Froyd, 1973, p. 255). Additionally, "certain times in a child's life represent changes for the entire family. These transitions may be stressful for all families and may present additional challenges for the families of visually impaired children" (Cohen et al., 1992, p. 5).

About 80% of learning occurs through vision. Sighted children use their vision to begin learning about the world from the day they are born. According to Brasher and Holbrook (1996), a sighted child learns about the environment as a result of observing people, places, and things around him or her. For example, a child with full vision observes his or her father wipe his dirty shoes on the mat upon entering the living room. In turn, the child tries to imitate the motion. Like children who are fully sighted, children with congenital blindness also begin learning about their environment at birth.

Developments of beginning speech and discovering the body occur within all infants during the first year of life (Froyd, 1973). Though children who are blind face the same developmental tasks as children who are sighted, the route taken to accomplish these tasks will be different due to the absence of vision. For families of children who are congenitally blind, new challenges at each developmental stage...
may become potential crisis-inducing factors within the family system (Ferrell, 1996; Finello, Hanson, & Kekelis, 1992).

Congenital blindness affects a child's learning by limiting opportunities to explore environments because of many objects being out of reach or not producing sound. In regard to language development, sounds and words become the basis of self-stimulation for the child who is congenitally blind, as the child's sources of stimulation are limited (Ferrell, 1996; Finello et al., 1992). Froyd (1973) emphasizes that "if language is to progress beyond this, to become a tool for reaching out to the world around him, the child must have objects to touch and identify" (p. 253).

Therefore, the child who is congenitally blind needs additional assistance to identify objects, both verbally and tactiley. This assistance includes time spent teaching the child how to handle the object, labeling the object, and learning the characteristics and function of the object for future recognition (Ferrell, 1996; Finello et al., 1992).

For a parent of a sighted child, there is a reduction in the need for parental attention as the child learns to explore and interact with the environment (Brasher & Holbrook, 1996). In contrast, this process is increasingly time-intensive for parents of children who are blind. This seemingly natural inquisitiveness to learn and explore the environment requires the parent to become actively involved with the child and the environment. It becomes necessary for the parent to spend time structuring and setting up an environment that is safe for the child. It is also necessary for parents to create stimulating environments for the child (Correa, 1987; Erchul & Turner, 1987). These necessities can be accomplished in many ways, such as placing objects.
within the reach of the child, explaining the differences in objects, and having toys with sounds (Ferrell, 1996; Finello et al., 1992).

Children who are blind can and do learn effectively by using their senses of touch, hearing, smell, and taste. However, “it requires parents to become more efficient at using experiences which emphasize use of the child’s hearing and touch, smell and taste” (Brasher & Holbrook, 1996, p. 178).

Due to the interactions of the previously mentioned factors, many parents express anxiety and concern regarding the future of their children with congenital blindness (Leyser et al., 1996; Scott et al., 1985). These parents may find it difficult to meet the needs of the family and child simultaneously as the physical, emotional and cognitive needs of the child who is blind may seem so great and demanding, or may appear overwhelming when combined with the other elements of the family’s needs (Bolinger & Bolinger, 1996; Ferrell, 1996; Froyd, 1973; Herring, 1996).

Another issue that arouses negative emotions in parents is the lack of nonverbal communication with the infant with congenital blindness (Dote-Kwan, Hughes, & Taylor, 1997; Ferrell, 1996; Kekelis & Prinz, 1996). “During the first year of life, the interactions in which sighted children engage lay the groundwork for language acquisition” (Finello et al., 1992, p. 46). Eye contact reinforces the efforts to interact with parents. At first, sighted children smile at any human face. Later, they learn to distinguish between their parents and others and will prioritize their focus on smiling at their parents. In turn, smiling reinforces parental interactions with the child and helps both parents and child to bond (Erchul & Turner, 1987;
Finello et al., 1992). Such interactions also enhance parental confidence and capabilities in their care giving role. Not only is parental involvement with their children strengthened and maintained, but also the child’s development continues to be encouraged (Goldberg, 1977).

Many parents of infants who are congenitally blind miss the opportunity of nonverbal interaction as these children do not learn signs of discrimination, recognition, preference, and evaluation normally interpreted through visual responses (Brasher & Holbrook, 1996; Finello et al., 1992).

Kekelis and Prinz (1996) studied the relationship between parents’ input to blind children and their children’s language skills. They also examined the effects of blindness on children’s abilities to respond contingently to their mothers. Conversations of four mothers and their blind and sighted children, aged 27–36 months, were evaluated during three play sessions in their homes. Throughout the course of their study, conversational parameters that included the length of speaker’s turn, balance between partner’s contribution, and mother’s use of questions and directive were investigated. Conversational analysis showed that the average lengths of speaking turns between sighted children and their mothers were comparable, but those of the blind children were considerably shorter than their mother’s turns. It was also noted that the sighted children were asked more real questions (i.e., questions that elicited information about their feelings, fantasies, or interpretations of events). In contrast, the blind children received more test questions (i.e., questions that tested their knowledge of the names, functions, and
physical characteristics of objects presented after the play episode), which serve a didactic function. Kekelis and Prinz concluded that "since the blind children were less likely to respond contingently to their mother's questions and directives, parents may need to find other linguistic strategies to encourage blind children to respond contingently" (p. 433).

Dote-Kwan et al. (1997) examined the influence of maternal behavior, home environment, and family socioeconomic status (SES) on the development of young visually impaired children. Fifteen mother-child dyads were observed in their homes during their daily routines when the children were aged 20–36 months and about one year later. Overall, these authors found that maternal behaviors had more of an impact on the children's development during the first observation, than did the other variables. Dote-Kwan et al. suggested that mothers who paced their language according to their children's abilities at age 26 months and repeated and rephrased their children's communicative intent positively influenced their children's overall development at both 26 and 41 months of age.

However, during the second observation, the home environment seemed to have a greater influence on SES and had a more distinctive impact as it significantly influenced the family's ability to provide better quality home environments. Most important, however, was the finding that mothers who provided a stimulating language environment (e.g., encouraged the children to talk and listen, gave the children choices, etc.) had a more positive impact on the children's development whatever their family SES.
Though some parents find it impossible to adapt to having children who are blind, many parents have successfully adjusted to this circumstance and have even gained personal strength and satisfaction as a result. Lowenfeld (1971) attributes achievement of parental acceptance to “natural love for their child and the parents’ own feeling of security” (p. 107). Accepting parents tend to view their circumstance as a challenge and as an opportunity for special effort (Bolinger & Bolinger, 1996; Cohen et al., 1992; Herring, 1996; Lowenfeld, 1971; Scott et al., 1985). Accepting parents also encourage family cohesiveness by not becoming enmeshed with their children who are blind and respecting the privacy, individuality, and needs of the entire family (Bolinger & Bolinger, 1996; Cohen et al., 1992; Herring, 1996; Leyser et al., 1996; Scott et al., 1985).

Purpose and Rationale of Study

Although numerous studies have indicated disturbances in families with children who are blind, the specific nature of problems is vague, due to a lack of empirical research. The available literature lacks consistency, organization, validity, and general research design quality. Control groups and objective reporting measures are rarely implemented. Moreover, much of the literature fails to examine the family as a system, and this further hampers awareness of family interactional patterns that reveal important information about how families cope with a child who is blind.
Empirical vulnerability in the literature is likely to create a sense of uncertainty in regards to counseling families with members who are disabled. Reintegration and reorganization of families with members who are disabled has been substantiated in the literature. Fortier and Wanlass (1984) discuss the crisis' effect on behavioral, affective, physical, interpersonal, and cognitive levels, while Bubolz and Whiren (1984) view families holistically as ecological systems in which behavior of any part affects the entire system.

During the 1990s, a few researchers attempted to incorporate some of the basic concepts of a family systems approach when working with families having children who are blind (Bolinger & Bolinger, 1996; Cohen et al., 1992). Although this research is beginning to shed light on the stressors and strengths that affect family interaction in families of children who are blind, much more research is needed to explore family interaction patterns as well as types of intervention strategies that can benefit these families.

In addition to this limited research, some professionals lack interest in research regarding families having children with congenital blindness and choose not to involve themselves in any related research. Others may want to become involved but do not understand the unique needs and stresses that these families experience. They lack knowledge and awareness of the available resources that could help them in gaining a better understanding of limitations imposed by various visual conditions that affect not only the child who is blind but also the family as a whole. Furthermore, they may feel inadequate about how to tailor various interventions to
the unique needs of these families which could help restore control, balance, and cohesion within these family systems.

Therapeutic efforts have moved away from spotlighting the child who is blind to treatment of the family system as a whole. However, it is only the beginning of the long journey. There is a definite need for helping professionals to incorporate these families in the family system approach. Yet, few attempts to apply a family systems approach to the conflicts faced by families have been made (Bernier, 1990; Werth & Oseroff, 1987). There are few family counseling services available for families with children who are blind. Applying the family systems perspective would enable clinicians to gain additional insight into influences that may profoundly impact the degree of resolution possible within families (Bernier, 1990).

The lack of empirical research, as well as the need for understanding the unique issues that affect the interactional patterns of families having children with congenital blindness who could benefit from a family systems approach led this researcher to consider the following questions:

1. How does the impact of having children with congenital blindness affect family cohesion?

2. How does the impact of having children with congenital blindness affect family adaptability?

3. How does the impact of having children with congenital blindness affect social family climate?
4. How do family adaptability, cohesion, social family climate and satisfaction differ in families with children who are congenitally blind, as compared to families having children who are fully sighted?

Therefore, the purpose of this study was to examine the impact of blindness on family adaptability, cohesion, social family climate, and satisfaction and how these variables contribute toward maintaining equilibrium within the family system. These findings may help therapists gain a clearer understanding of how children who are blind affect the interaction patterns and structure of their families.

Summary

Chapter I briefly presented information about the increase in the survival rate of children with disabilities. This was followed by an overview of the historical background of the problem as well as the family systems perspective were discussed. Definitions related to the family systems perspective and the definition of legal blindness and related terms were also presented. A brief literature review on the impact of a child with congenital blindness upon the family system as it relates to the research problem was also presented. Chapter I concluded with the purpose and rationale of this study and research questions which will be addressed in the present research study.

This study is organized into five chapters. Chapter II provides a review of the literature relevant to the research questions, a brief discussion about limitations of previous research studies (i.e., research design, sample selection, poor validity
and reliability of the research instruments). Information about data categorization, and the research hypotheses are presented.

Chapter III describes the methodology and procedures for conducting this study. This chapter includes an explanation of the sample population, instrumentation, data collection methods, and coding procedures, research design, and data analyses procedures. Chapter IV presents the research findings. Chapter V provides a summary and interpretation of the results of this study, along with their limitations, recommendations, and implications for future research.
CHAPTER II

REVIEW OF RELATED LITERATURE

Introduction

The purpose of this chapter is to review literature as it pertains to disabilities. This chapter traces the development of family therapy and related research, discusses the family systems perspective is discussed, considers the impact of children with disabilities on the family system (i.e., parental, marital, and sibling subsystems), and notes the limitations found in previous research studies. It is the intent of the researcher that information from these various sections would provide a setting for better understanding of how families adapt with a child with disabilities.

Development of Family Therapy and Related Research

The advent of family therapy during the 1950s created an atmosphere of excitement, as well as a challenge to both researchers and psychotherapists in the mental health field. This newly developing field provided an opportunity for researchers to observe behavioral interactions among families and to gather empirical data to measure behavioral results.

The birth of a joint effort between researchers and family therapists resulted in a positive attempt to "bridge the gap" between researchers and practitioners within the mental health field (Eisler, Dare, & Szmukler, 1988). Progress, as well as
cooperation between disciplines within the field, promoted a considerable amount of research concerning family interaction during the 1960s.

Before the 1960s, the primary focus of family research investigated family process in families having a member with schizophrenia (Bateson, Jackson, Haley, & Weakland, 1956; Lidz, Cornelison, Fleck, & Terry, 1957; Wynne, Ryckoff, Day, & Hirsch, 1958). As a result of this research, the characteristic concepts and viewpoints of family therapy were established. In addition, newer forms of thinking generated from communications theory, information analysis, and general systems theories were incorporated into family therapy.

The movement away from the intrapersonal (i.e., focus on the individual) to the interpersonal (i.e., focus on family) was one major contributing factor sparking an interest in examining family interaction in the 1960s (Handel, 1965). Consequently, the concept of the family as an “interactive, goal-oriented social system” became the joint theoretical focus for both clinician and researcher alike (Eisler et al., 1988). Researchers began to study behavioral and relational interaction patterns of family members to determine the impact of these patterns upon the family system.

The shift from a linear mode of thinking toward a cyclical and circular way of thinking also facilitated the observation and examination of complex relationships within families. Researchers and therapists began to view interactive patterns within the family system as being circular (i.e., a cycle of repetitive behavior patterns among family members) opposed to being linear (i.e., a cause-effect behavior pattern
among family members) (Minuchin, 1985). This new perspective gave rise to a
deeper and clearer understanding of the nature of interactive patterns occurring in
the structural and functional dynamics within family systems (Combrinck-Graham,
1989; Maynard & Olson, 1987; Olson, Russell, & Sprenkle, 1983).

According to Hartman and Laird (1983), the concept of family systems
displaying shared characteristics commonly found in other systems (i.e.,
isomorphisms), also gained acceptance during this period of growth. Some of these
isomorphisms include boundaries, growth potential, the need for equilibrium, and
functional communication patterns.

Family therapists continued to search for psychologically meaningful
connections that explained the behavior of the individual. At the same time,
observations were viewed and interpreted from a framework of the impact on the
family (Bolton, 1984). This lens provided valuable insight into the organization,
structure, and rules that govern transactions within the family. Thus, the
symptomatic behavior of the individual was viewed as contributing to family
interactions in an effort to fulfill needs and maintain homeostasis (Eisler et al.,
1988).

As family therapists discovered that they could easily observe
communication patterns to assess family interaction, they began to investigate the
relationship between family functioning and communication. This led to further
research examining other relationships such as parent-child interactions, and stress
leading to maladjustment. Other researchers have contributed to the development
and application of the family systems perspective in their endeavors to investigate family structure and interaction (Buckley, 1967; Haley, 1967; Kirby-Green, & Moore, 2000; Minuchin, 1974; Mirfin-Veitch, Bray, & Watson, 1997; Moos & Moos, 1974; Olson, 1985; Whittaker, 1977). This perspective accounts for numerous variables when considering the complexity of the family system.

Family Therapy Research Applied to Disability

During the 1960s while family therapy was gaining full recognition in the mental health field, professionals working with populations who were disabled began to concern themselves with two major themes. The first theme was the effect of the disability on the family. The second was the importance of the family’s role in the successful rehabilitation of the member with a disability (Nelson, Ruch, Jackson, Bloom, & Part, 1992; Jackson & Lawson, 1995).

As researchers began to investigate these issues, they identified various areas of difficulty faced by persons with disabilities and their family members. Earlier research did not address the positive characteristics, which allow families to successfully adapt to the birth of children with disabilities. Thus, the lack of awareness of differences within family coping and adaptation patterns resulted in the labeling of those families as dysfunctional.

A number of studies focused on one specific disability (Dunlap & Hollinsworth, 1977; Hancock et al., 1990) or grouped a variety of disabilities into a single subject group. For example, Hanson and Hanline (1990) conducted a
longitudinal study of parental stress and adaptation related to parenting a child with a disability. For the purposes of this study, they grouped children with Down Syndrome, hearing impairments, and neurological impairments together. The improper selection of samples and the poor design of this, and other studies led to inaccurate generalizations of research results (Hanson & Hanline, 1990; Nelson et al., 1992).

Ongoing research addresses this shift from compartmentalizing disabilities into one broad group, to allocating various disabilities into individual groups. Scholars have found a substantial basis for criticizing the validity and methodology of previous research supporting this stereotypic viewpoint (Collins-Moore, 1984; Correa et al., 1986; Featherstone, 1980; Scott et al., 1985, Trute, 1990, Trute & Hauch, 1988). This critique has led to the emergence of studies recognizing the need for a clearer understanding of how families adapt to the presence of a child with a disability. It has also helped to determine the impact of the disability on the level of family functioning (Floyd & Gallagher, 1997; Foster et al., 2001).

Family Systems Perspective

A disability has an enormous impact upon the affected child as well as the family system as a unit. The typical reaction of the family system, as well as its subsystems, is to adapt to the movement of one of its members. It is, therefore, important for family therapists to view the family as a system consisting of various subsystems when helping families adapt to the birth of children who are disabled.
According to Bernier (1990), few attempts have been made to apply family system concepts to the problems faced by families having children with disabilities. The family systems perspective shifts the focus from the individual to the system; therefore, it offers a broader viewpoint about family adaptation (Hanson, Henggeler, Harris, Burghen, & Moore, 1989), in that behavioral patterns among family members are viewed as being circular as opposed to linear (Olson et al., 1983).

The family systems perspective allows researchers to examine a number of variables contributing to change within the system, as well as change between the system and the environment. The individual perspective noted in earlier research is not abandoned. Rather, both perspectives can be used simultaneously to provide the most effective therapy since they complement one another (Bernier, 1990; Brett, 1988; Foster et al., 2001; Leyser & Heinze, 2001).

There are several models which attempt to measure various concepts related to the family systems perspective. This researcher chose the Circumplex Model developed by Olson, Russell, and Sprenkle (1983) as it best represented the circularity of cause and effect in family interaction and utilized the important dimensions of cohesion and adaptability which are central to family functioning and interaction.

Family cohesion assesses the degree to which family members are separated from or connected to their family. The concepts employed within the Circumplex
Model to diagnose and measure the cohesion dimensions are: emotional bonding, boundaries, coalition, time, space, friends, decision-making, interests and recreation. Family adaptability assesses the extent to which the family system is flexible and able to change. Specific concepts utilized to diagnose and measure the adaptability dimension are: family power (i.e., assertiveness, control, discipline), negotiation style, role relationships and relationship rules (Olson, McCubbin, Barnes, Larsen, Muxen, & Wilson, 1992).

The four levels of family cohesion within the Circumplex Model are: disengaged (low cohesion), separated (balanced), connected (balanced), and enmeshed (high cohesion). There are also four levels of family adaptability: rigid (low adaptability), structured (balanced), flexible (balanced), and chaotic (high adaptability). For each dimension, the balanced levels are hypothesized to be most viable for healthy family functioning while the extreme areas are generally viewed as more problematic for couples and families over time. However, Olson (1989) began to realize that even families functioning at the extremes of the Circumplex model (disengagement/enmeshment or rigid/chaotic) were able to function well as a family unit provided they were satisfied with the attitudes and feelings within their current family.

As a result of combining the four levels of the cohesion and four levels of the adaptability dimensions, 16 distinct types of marital and family systems are identified. Four of these 16 types are moderate on both the cohesion and adaptability dimensions (balanced types). Eight types are extreme on one dimension and
moderate on the other (mid-range types) and four types are extreme on both dimensions (extreme types).

In summary, the family systems perspective focuses on the context of both individual and family responses. It has also proven useful in assisting clinicians and researchers in viewing family stress in a broader and more complex manner (Foster et al., 2001)

Benefits of the Family Systems Approach

According to developmental theorists, when transitions and critical events occur within the life cycles of a family of a child with a disability they often take on different meanings. The changes may serve to magnify the child's special needs and/or renew feelings of sorrow when parents contemplate what might have been (Fewell, 1986; Herring, 1996).

The developmental perspective theory benefits therapists by helping them examine the effects of transitional events on the adjustment process for each family member. This perspective acknowledges that parents are caught in a "double bind" which is likely to prolong sorrow. The theory also acknowledges moderator variables that effect family adjustment, such as physical help, emotional support, and social networks.

Several researchers view adjustment as a recurrent process rather than a sequence of time limited stages (Hanline, 1991; Herring, 1996; Olshansky, 1962). Olshansky (1962) proposed a model based on the concept of chronic sorrow.
According to this model, parents of children with disabilities live in a state of chronic sorrow and never reach a final phase of acceptance. Therefore, the process of adjustment is ongoing rather than predetermined. Hanline (1991) pointed out that precipitating developmental or critical events (e.g., diagnosis of disability, developmental milestones) could trigger recurrent grief.

Earlier research investigated single factor causality. However, it failed to address the impact of interactive family variables such as adaptability, cohesion, social family climate, and satisfaction on family adjustment. Bernier (1990) states that few attempts have been made to utilize a family systems approach when focusing on the problems faced by families of children with disabilities. In moving the focus of adjustment from the individual to the system, a broader and clearer perspective would enable family therapists to gain insight into the complexity of variables that can have an intense impact upon the degree of resolution reached by families adapting to children with disabilities (Bernier, 1990; Foster et al., 2001).

The present researcher was interested in examining interaction patterns of families having children with congenital blindness. Specifically, the effects of children who are congenitally blind upon family adaptability, cohesion, social family climate, and satisfaction were investigated. In order to provide a clearer understanding of how these variables affect family dynamics, it is necessary to examine the interactional patterns within individual subsystems as well as the family system as a unit.
How Children With Disabilities Impact the Family System

As family systems continue to cope with internal and external circumstances, they experience balance and stability, conflict and disequilibrium, and growth and integration. The occurrences of these processes create stress within the system. A minimal amount of stress can serve as a motivator to induce change and can also function as a catalyst to promote family unity. However, intense, prolonged stress may be overtaxing to the system and can result in a breakdown of the family unit. Therefore, adaptation to the presence of children with disabilities within the family can be either positive or negative, depending on the system’s ability to respond to stress (Bolinger & Bolinger, 1996; Bubolz & Whiren, 1984; Foster et al., 2001; Nixon, 1994; Porter & McKenzie, 2000).

The level of cohesion within a family is also an important variable in determining the family’s ability to adapt (Yura, 1987). The birth of children with disabilities may significantly affect the level of cohesiveness within the family system. The initial reaction of parents to the birth of children with disabilities is likely to set the pattern of response for other family members (Foster et al., 2001; Porter & McKenzie, 2000). Reactions to the birth can result in the family becoming totally disengaged, enmeshed, or falling somewhere in between on the continuum.

Unhealthy relational patterns increase the likelihood of marital discord, as well as increase the potential for resentment and over-protection of children with disabilities by their parents. In addition, depression, anxiety, neglect, and resentment may occur in siblings (Morgan, 1988; Yura, 1987). Unhealthy alliances may occur
which drastically increase the risk of the family becoming isolated from friends, relatives or other social support networks, and becoming a closed system (Helm & Kozloff, 1986).

Additional stressors such as the need of the child for physical care, and the lack of appropriate medical services, social support, and ancillary services can also overwhelm the system and create further dysfunctional patterns. However, families with adequate coping strategies, reliable support systems, and cohesiveness are more likely to adapt in a positive way to the presence of children who have disabilities.

Cultural Factors and Recurrent Grief

Several authors (Alston, McCowan, & Turner, 1994; Cohen et al., 1992; Florian, 1989; Hampson, Beavers, & Hulgus, 1990; Mardiros, 1989; Rogers-Dulan & Blacher, 1995; Turner & Alston, 1994) have asserted that race and culture influence psychosocial adaptation to disability. Each ethnic group is comprised of distinct cultural factors (e.g., religious beliefs and practices) that largely determine how its members react to traumatic life events such as the onset of a disability. Therefore, delineation of the cultural factors that facilitate adjustment to disability is highly beneficial (Turner & Alston, 1994).

Family systems theories take ethnic and social factors as well as transitions and critical life events into consideration. These theories also consider that factors within each culture (e.g., religious beliefs and practices, folk remedies, rituals, and
norms) play a major role in determining how individuals will respond to life changing events.

Therapists working with families of various cultural backgrounds need to recognize the tremendous impact of cultural variables on the adaptation and adjustment process (Cohen et al., 1992). Family structures vary according to the cultural background of the particular family. Therefore, it is important to determine the family composition when initiating intervention. Cohen et al. (1992) further point out that “with members of any racial or ethnic population, it is essential to view each family individually because generalizations may not be accurate” (p. 5). A therapist possessing knowledge of such cultural factors would be beneficial and highly effective in helping to facilitate family coping and adjustment (Turner & Alston, 1994).

African-American Families

Alston et al. (1994) examined a Family Strengths Model designed to depict factors related to psychosocial adjustment in African Americans with disabilities. According to Alston et al. (1994), strengths such as role flexibility, strong kinship bonds, strong education and work ethics and strong religious orientations positively contribute to successful adjustments by African American families to children with disabilities. Hampson et al. (1990) also emphasize that role flexibility is a strong contributing factor to adaptation in African American families. Family members often interchange jobs, roles, and functions in order to support one another in times
of need (Cohen et al., 1992; Hampson et al., 1990). Childrearing practices vary from
family to family. In some families several people may take responsibility for the
child, including older brothers and sisters. There may not be distinct role
delineations like those that exist in other cultures (Cohen et al., 1992). Utley and
Marion (1984) also emphasize the importance of extended family, particularly the
support of the grandparents, as being essential elements in the social support
network.

Several researchers (Alston et al., 1994; Cohen et al., 1992; Erin et al., 1991;
Hampson et al., 1990; Rogers-Dulan & Blacher, 1995) found the church to be the
most central agency among voluntary organizations providing financial, social, and
emotional support. A majority of African American families frequently seek the help
and support of ministers and “church family” before turning to mental health
professionals in times of need (Hampson et al., 1990). “The church also behaves as a
forum for the unimpeded expression of hostility, anguish and sorrow” (Turner &
Alston, 1994, p. 918) and can be viewed as providing a sanctuary for security and
comfort.

The church as a coping mechanism is notable. For instance, the doctrines of
the church emphasize optimism and promote faith that hardships will lessen and
improve over time. This doctrine is compatible with therapeutic goals which
underscore the need for individuals with disabilities to concentrate on developing
possible proficiencies, aptitudes, and capabilities while avoiding the temptation to
become preoccupied with current impairments (Turner & Alston, 1994).
Hispanic Families

Hispanic families in the United States originate from several geographical locations (i.e., Mexico, Cuba, Puerto Rico, and all Central and South American countries). These families bring varied experiences and cultures with them. It is crucial that professionals be aware of the great diversity among these families (Cohen et al., 1992).

While variability exists, in Hispanic cultures, the family's needs often take priority over the individual's needs. Cohen et al. (1992) further state that “the individual family member is a representative of the family, and the family is the source of individual identity” (p. 12). Loyalty and dignity are strongly emphasized.

In these families, the father is viewed as the authority figure and is also considered to be the head of the household. Few decisions are made without the father's knowledge and consent. According to Cohen et al. (1992), the father is not emotionally expressive and may appear somewhat aloof, reserved, and independent from other family members. He may be very close to, and affectionate with, his young children but markedly less demonstrative as they approach adulthood.

The mother's responsibility is to dedicate herself to her family, to give emotional support to her husband, and to care for the home. “Traditionally, her needs come last, and she is expected to make any sacrifice necessary for the family” (Cohen et al., p. 12). She is also the nurturer of the family, is highly respected, and is almost venerated for her role in the family. However, many Hispanic women in today's society seem to sharply shift from the traditional female role. Cohen et al.
(1992) point out that they "may feel pressure from American society to incorporate more nontraditional female roles into their behavior" (p. 12).

Within the Hispanic culture families may view the birth of children with disabilities as being "God's will" (Mardiros, 1989). Within the Hispanic culture, families take on the primary responsibility for the care of the disabled child (Correa, 1987). "One of the main purposes of the family is to care for its members in times of need" (Cohen et al., 1992, p. 12). The nuclear and extended family, close friends, the church and community, care for and protect children with disabilities (Hampson et al., 1990). The birth of disabled children is viewed as God's will because parents may believe that God is testing them, is punishing them, or has selected them for divine purposes.

Mardiros (1989) conducted an interview study that examined the responses of Mexican American parents to having a child with a severe disability. The study consisted of 33 Mexican American parents, representing 25 family units, including 10 fathers and 23 mothers. Of the 23 mothers, 6 were not living with the child's father; the remaining 17 were married. Forty-two percent of the parents were employed full-time, and 58% had an income level below $10,000. The age range of the parents was 21–55 years, and the mean age of the children with disabilities was 8.2 years.

In examining the parents' biomedical and sociocultural beliefs concerning the causes of their children's disabilities, Mardiros (1989) found four prevalent views: premonitions, prior attitudes, past transgressions, and divine interventions.
Premonitions were reoccurring, undaunted beliefs manifested in dreams during the pregnancy that something would be radically wrong with the child. These dreams generally resulted in a strong conviction that the child would be different. As one father stated:

She [the mother] had a dream that kept repeating itself, that the child would be hurt, that something was terribly wrong. I told her not to worry, but she was right. It's the first thing I thought of when our son was born; we knew right away. (Mardiros, 1989, p. 61)

Prior attitudes referred to myths and assumptions held about people with disabilities. For example, if the parents had made fun of or had feared persons with disabilities in the past, their child would be born disabled as a result (Mardiros, 1989). As one parent so poignantly stated:

I remember us kids throwing things at this man to get him excited, get him to yell . . . Somewhere in the back of your mind you think (silence) . . . Ever since we've had (our child) I've wondered if it had anything to do with what I did back then. (Mardiros, 1989, p. 61)

Past transgressions and divine intervention were the most culturally specific views of causation and included breaking cultural taboos, going against the teachings of the Catholic church, disgracing the family, and mistreating family members (Mardiros, 1989). The discussion of folk medico-religious beliefs (e.g., indigestion, evil eye, and witchcraft), and the interaction of psychological, sociological and religious factors, affected views toward causation. Imbedded in this, is the belief that the birth of child with a disability is, in some way, divine retribution and personal atonement for past wrongdoing (Mardiros, 1989). These beliefs result in the child with a disability being indulged, spoiled, or most likely
pitted. The child may be treated as special and, in some cases, may become functionally more disabled than he or she actually is, as a result of not being permitted to function in appropriate family roles. (Cohen et al., 1992).

Asian Families

Most Asian families are patriarchal. Men occupy the dominant position within the patriarchal family. Men are the primary decision makers in these families. Women are responsible for the family’s well-being, including the teaching of oral and ethical values (Cohen et al., 1992).

By Western standards, Asian parents are inclined to be very tolerant, permissive, and quick to gratify the infant’s early dependency needs (Cohen et al., 1992). Although the Asian infant may receive immediate gratification, he or she is expected to assume responsibilities by school age. A shift from what appeared to be a very relaxed early childhood to expectations of later childhood seems to abruptly emerge. The disabled child is expected to take on the responsibility for obtaining self help skills and pre-academics. Parents in Asian families often expect unquestioning obedience from their children, and these children are taught to refrain from expressing emotion.

The child’s disability is frequently viewed as the consequence of some past action. “A disabled child may be considered a stigma within the community. Often the feeling is that the parent has committed a sin, that something happened to the mother during pregnancy, or that the baby was ‘possessed’ at birth” (Cohen et al.,
1992, p. 9). Cohen et al. (1992) mention another traditional belief regarding disabling conditions being caused by an imbalance in physiological functions in that health is maintained when the forces of yin and yang and the five elements of the body are balanced and in harmony. Thus, the family may seek a cure for their child’s disability from a traditional healer within the community.

**Middle Eastern Families**

Florian, Wiesel, Kravetz, and Shurka-Zernitsky (1988) conducted a comparative study of Arab and Israeli-Jewish youths. Participants consisted of 272 high school students from four Arab and four Jewish urban schools. Of the participants, 148 were from Arab schools, (50% males, 50% females) and 124 were from Jewish schools (45.2% males, 54.8% females). The *Disability Factor Scale* was administered to the students who participated. Florian et al. (1988) found that Jewish subjects who had relatives with disabilities held more positive attitudes than those who did not have relatives with disabilities. The opposite was found with the Arab youths. Those who had relatives with disabilities had slightly more negative attitudes than subjects who did not have relatives with disabilities. The traditionally “shame oriented” Israeli-Arab culture maintains a negatively stigmatic view of persons having disabilities. Thus, families within this culture regard children having disabilities as being a disgrace to the family (Florian, 1989).
Impact on the Parents

Life circumstances can become complicated and stressful as parents attempt to prioritize time in order to meet personal needs, the needs of the child with a disability, needs of other family members, and household responsibilities (Bolinger & Bolinger, 1996; Cohen et al., 1992; Herring, 1996; Johnson-Martin, Goldman, & Gowen, 1989). Morgan (1988) stated that families might become closed systems, thereby becoming isolated. The combination of lacking necessary coping strategies as well as needed social support can result in the parents feeling overburdened, lonely, resentful, and insecure (Floyd & Gallagher, 1997; Herring, 1996; Morgan, 1988; Tuttle, 1986).

Guilt has been found to be another common response of parents caring for children with disabilities (Ayrault, 1977; Bauman & Yoder, 1966; Cohen et al., 1992; Herring, 1996; Parker, Hill, & Goodnow, 1989; Porter & McKenzie, 2000; Trout & Foley, 1989). Parental guilt may stem from disappointment about not having a "perfect" child. Guilt can take the form of anger, which may be directed at physicians, other professionals, family members, or the child having the disability. Guilt can also lead to over-protection. Parents may try to cover up resentment and rejection by devoting their energy toward the child's welfare (Herring, 1996; Lowenfeld, 1971; Parker et al., 1989).

Ayrault (1977) and Bauman and Yoder (1966) have noted that parents may even experience a desire to destroy the child, and that such extreme emotions may lead to abandonment. For parents who genuinely love their children, these feelings
can create additional confusion and anxiety which can further lead to depression or lowered self-esteem (Parker et al., 1989).

Some researchers (Ayrault, 1977; Bauman & Yoder, 1966; Cummings, Bayley, & Rie, 1966; Parker et al., 1989) have found that mothers facing high levels of stress experience low self-esteem. Cummings et al. (1966) found that mothers of children who are chronically ill, neurotic, or have mental retardation experience lower levels of self-esteem.

Pelchat, Ricard, Bouchard, Perreault, Saucier, Berthiaume, and Bisson (1999) examined the relationship between the adaptation of parents to a disabled infant and the type of disability presented by the baby. In addition to a control group, participants were divided according to disability: Down Syndrome (DS), Congenital Heart Disease (CHD), or a Cleft Lip and/or Palate (CLP). The researchers reported that parents of infants with DS or CHD experienced significantly more stress in relation to the acceptance of their child, felt significantly more threatened by parental situations, and perceived it as more uncontrollable and more stressful than did parents of a non-disabled child or a child with CLP.

Results confirmed that the type of disability presented by 6-month-old infants had a significant impact on the adaptation of mothers and fathers and some dimensions of the stress that they experienced. In addition, Pelchat et al. (1999) strongly emphasized the importance of understanding the specific diagnosis in studying parental reactions to a child's disability as the stressors and psychological distresses are unique to a given disability. In the case of DS, the irreversibility of the
disability, the social stigma associated with intellectual deficiency, and the anticipated levels of parental care that will be needed in the future may all contribute to the stress and distress that the parents of these children experience. Yet, the uncertainty surrounding the CHD child’s health condition and survival, as well as the relatively little control that parents have over the medical treatments of their children, pose somewhat different concerns (e.g., perception of threat, unpredictability of the disease, uncertainty regarding the course of the disease, uncontrollability, self-doubt regarding parenting and child care).

Breslau (1983) investigated the relationship between mastery (i.e., mother’s generalized belief in her ability to control her environment) and level of distress. These results indicated that feelings of minimal control over the environment were associated with increased distress. Mothers of children with severe disabilities and who received little assistance from family members in sharing responsibility and care for the child, tended to feel least in control of their environment. On the other hand, mothers who had children with disabilities requiring less care, and who received support from family members felt more in control of their environments.

Little difference has been found between mothers of children with disabilities and those in control groups with regard to personality factors and parenting attitudes (Boll, Dimino, & Mattson, 1978; Gayton, Friedman, Tavormina, & Tucker, 1977; Erin et al., 1991; Featherstone, 1980; Margalit & Ankonina, 1991; Trute, 1990; Trute & Hauch, 1988). Margalit and Ankonina (1991) concluded that “under chronically stressful conditions, such as parenting a child with a disability,
active coping strategies were found to hold a strong stress resistant function in predicting positive effects, as did familial resources to a lesser extent” (p. 296). They further pointed out that parental adjustment not only depended upon the utilization of adequate coping strategies, but also was also strongly related to supportive interaction, as well as encouragement for personal growth from family members (Margalit & Ankonina, 1991). Judge (1998) found that coping strategies that emphasized seeking social support, actively solving the problem, and maintaining a positive outlook on life were related to success in adjusting to having a child with a disability. This positive relationship between social support and family strengths signifies a family’s ability to utilize internal and external resources to the family.

In one of the few studies investigating fathers’ responses to having children with disabilities, Gayton et al. (1977) compared parents of children with cystic fibrosis using the Minnesota Multiphasic Personality Inventory (MMPI). Mothers were found to demonstrate less disturbance in personality functioning than did fathers participating in this study. The fathers’ role as primary economic provider for the family places a great deal of stress and financial responsibilities upon them and emotional disturbances may be highly related to the fathers’ role as the primary economic provider.

Cummings (1976) found that fathers of children who were chronically ill or had mental retardation experienced higher levels of depression and lower levels of self-esteem compared to control group fathers. Additionally, other studies indicate that mothers are more at risk than fathers, due to being the main caregivers within
families (Ayrault, 1977; Burden, 1991; Floyd & Gallagher, 1997; Johnson-Martin et al., 1989). Floyd and Gallagher (1997) further observed that fathers have fewer responsibility for direct child care and are less stressed by these demands than mothers. The question of paternal risk of psychopathology remains unclear.

Parental adjustment can be categorized as successfully managing distress, maintaining a realistic view of the child's condition, while carrying out prescribed therapeutic activities (Allen & Affleck, 1985). Danek (1988) found adequate cognitive ability to assess the situation; adequate social support networks of family, friends and professionals; physical stamina to assist in withstanding stress; a history of successfully coping with stress; a positive outlook toward life; a sense of self-control in terms of destiny and environmental demands; a positive self-esteem, and appropriate life skills (e.g., assertiveness, problem solving, parenting) to be useful resources in promoting successful parental adjustment to children with disabilities.

Danek (1988) reported parental problem-solving ability to be an extremely critical variable in determining ability to cope adequately with stressors related to caring for a child with a disability. Comparing families who have coped adequately with a child having a disability revealed that these families did not have fewer problems than those families who did not cope successfully. Families who demonstrated successful coping exhibited an overall higher level of effective family functioning. Danek (1988) and Judge (1998) also noted that families who function effectively also had adequate social support networks of extended family, friends, and professionals. Thus, families who have a good social support network and
utilize resources both internal and external to the family are reported to be most successful in adapting to having a child with a disability (Danek, 1988; Dunst, Trivette, & Jodry, 1997; Dunst, Trivette, & Thompson, 1990; Judge, 1998).

Some authors (Erin et al., 1991; Zuk, 1959) have noted that religion has served as an important element in helping parents successfully adapt to their circumstances. Erin et al. (1991) examined the religious perceptions of 161 parents of children with visual impairments. Parents were asked to complete a questionnaire that assessed changes in religious beliefs following the diagnosis. Religious interpretations regarding the cause of the impairments as well as perceptions of support from their religious community were also examined. Results indicated that religious beliefs were a major source of support as parents worked to accept their children's visual impairment.

Guilt has been found to be an important aspect affecting religious beliefs, and religions handle it differently. It was suspected that religious background would play a significant role in determining the level of acceptance and, indirectly, the level of parental adjustment. Zuk's (1959) study attempted to show that religious background was among the many factors which affected the degree of guilt feelings experienced by parents. Zuk’s study consisted of 76 families having a child with mental retardation, residing in a Philadelphia community. Of the 76 families from which information was gathered, 39 were Catholic and 37 were Protestant and Jewish.
Data from this study revealed that of the 39 Catholic mothers, 25 were found to have accepted their child's disability and 14 had not. Of the 37 non-Catholic mothers, 5 accepted their child's disability and 32 did not. Parents were considered to be accepting if they: "(1) Displayed minimal anxiety in the presence of the child or hostility toward him/her, (2) displayed minimal defensiveness about the child's limitations, and (3) neither obviously rejected the child nor fostered over-dependence" (Zuk, 1959, p. 141). The findings of this study provided some evidence to the existence of a relationship between Catholicism and maternal acceptance of a child with a disability.

Zuk (1959) believed that Catholic mothers more readily accepted their child's disability due to the absolution from personal guilt offered by their religious beliefs. Religious doctrine provides a great deal of emotional support for parents through its insistence that every child, having a disability or not, is a very special gift of God bestowed on the parents. Therefore, "religious" parents having a child with a disability are more likely to accept the idea that the birth of the child was the result of a decision made by a higher power than non-religious parents (Alston et al., 1994; Erin et al., 1991; Florian, 1989; Hampson et al., 1990; Mardiros, 1989; Rogers-Dulan & Blacher, 1995; Turner & Alston, 1994; Zuk, 1959). Researchers (Alston et al., 1994; Erin et al., 1991; Zuk, 1959) further suggest when counseling parents of children with disabilities, psychotherapists give due consideration to the religious variable. Religious beliefs may partially determine degree of guilt and the degree to which guilt may hamper progress toward adjustment. Drotar, Baskiewicz, Irwin,
Kennel, and Klaus (1975) conducted a study to determine the course of parental reactions and attachment to the birth of a child with a disability. They interviewed parents of 20 children having a wide range of disabilities. They found that early crisis intervention counseling might be particularly crucial in facilitating positive parental attachment and adjustment.

Erin et al. (1991) also concluded that the religious community can serve as part of the social support network and should not be overlooked by therapists who work with parents of children with disabilities. Johnson-Martin et al. (1989) also emphasized the importance of counselor awareness in regard to helping parents acquire adequate support networks and appropriate resources, which are vital tools for helping parents adapt.

Burden (1991) recommends that parents receive counseling as soon as possible following the birth of children with disabilities. Counseling can provide a means of helping parents cope with issues such as the nature of the disability, initial diagnosis, and communication breakdowns between parents, family members and professionals.

In summary, there is no unidimensional explanation concerning the impact of children with disabilities on the psychological and physical well being of parents (Longo & Bond, 1984). Rather, a complexity of variables is involved. Researchers are now considering variables that are likely to affect the parental subsystem of children with disabilities (e.g., stress, psychological well being, coping strategies, social support). Few normative data are available on families of children with
disabilities (Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981). Furthermore, additional research is needed which examines the adjustment process of parents and its relationship to family functioning and interaction.

Impact on the Marriage

Several authors (Cohen et al., 1992; Gath, 1978; Herring, 1996; Lonsdale, 1978; Phillips, Bohannon, Gayton, & Friedman, 1985; Tew, Payne, & Laurence, 1974) support the idea that additional stress is often placed upon the marital relationship of parents having children with disabilities. Lonsdale (1978) interviewed 60 families having children with a variety of disabilities. His study was different from others in that where possible it was based on joint interviews with both parents. In fact, 40 of the 60 families included in the study were couples. Lonsdale (1978) found that in 55% of the cases parents thought that having a child with a disability added stress and strain to their life as a couple. Some of the contributing factors reported by the parents included poor communication, lack of time together and financial difficulties. Herring (1996) also mentioned that as a result of grief and guilt related to having a child with a disability, one or both spouses did not engage in sexual activities due to physical and/or psychological factors preventing them from being fulfilled by this intimacy.

Marital satisfaction has been found to be lower in families having children with disabilities (Lonsdale, 1978). Tew et al. (1974) assessed marital harmony of 59 parents of children having spina bifida and 58 control couples. Marital harmony was
assessed at the birth of the child and at 6-month intervals for a period of 8 to 10 years. A Likert scale was used, with 5 indicating a satisfactory relationship, 3 indicating recurrent marital difficulties or major differences of opinion, and 1 indicating a broken marriage. Tew et al. (1974) and Lonsdale (1978) concluded that marital harmony increased over a period of time in the control couples and drastically decreased in the parents of children having spina bifida.

Gath (1978) investigated the impact of a Down Syndrome child on the parental subsystem and also examined the effects on the marital relationship. Her investigation involved a comparison between 30 families with a newborn Down Syndrome baby being matched with a control group of 30 families having children without disabilities. Both family groups were followed for 1½ to 2 years. A number of differences were found. Six of the couples having a Down Syndrome baby showed severe tension, high hostility, or marked lack of warmth between husband and wife. One marriage in the Down Syndrome group ended in divorce, and one couple was permanently separated. None of the couples in the control group had problems as severe as the couples in the Down Syndrome group. Some control group couples had a few moderate difficulties.

In a similar study with 43 families having children with cystic fibrosis, Phillips et al. (1985) found that parental communication was a major problem for 28% of the mothers and only one father. Ten to 15% of the parents studied also described having major problems related to their marital relationship.
Some researchers have found the divorce rate to be higher in families having children with disabilities (Bristol, 1985; Love, 1973; Stevenson, Graham & Dornr, 1978). Turk (1964) conducted a cross-sectional study with 25 families having children with cystic fibrosis. Parents were asked to complete a questionnaire containing five forced-choice questions and six open-ended questions. The results indicated a lack of available time and energy for recreational activities and interpersonal relationships. The enormous amounts of time and energy devoted by the parents to the care of a child with a chronic illness increased marital discord. Several research studies indicate that there is distress within the marital relationship, (Featherstone, 1980; Silbert, Newburger, & Fyler, 1982; Tew et al., 1974; Turk, 1964). However, little evidence supports that this leads to dissolution or divorce (Gath, 1978; Martin, 1975; Silbert et al., 1982).

Intra-familial communication breakdown was also mentioned as a variable contributing to marital discord (Marshall, 1986). Though marital stress may have been present in some families prior to the birth of the child with a disability, the burden of caring for the child has been found to intensify marital problems (Baruth & Burggrof, 1983; Bernier, 1990; Farber, 1979).

The validity of the instruments used to measure marital adjustment or satisfaction has been challenged (Spanier, 1973). One of Spanier’s (1973) concerns is the instrument’s lack of differentiation between individual thought or ideas and the responses of the marital dyad. The lack of undifferentiated responses could be the result of either the husband or wife responding individually as opposed to the marital
dyad completing the scales together (Marshall, 1986). This may result in skewed scores based upon individual perceptions rather than couple responses.

Friedrich (1979) investigated the relationship between psychosocial and demographic variables of maternal coping abilities in families with disabled children. The subjects were 98 mothers having children with a wide variety of handicapping conditions. A stepwise multiple regression analysis indicated that marital satisfaction was the most accurate predictor of successful coping and family adaptation, accounting for 79% of the predictive ability.

Trute (1990) surveyed a cross-sectional, random sample of 88 families containing young children with developmental disabilities. Dyadic cohesion and consensus within marriage were found to be significantly linked to a heightened level of family functioning. Margalit and Ankonina (1991) concurred with this finding that cohesiveness is an important variable contributing to marital satisfaction. Trute further stated that couples with children having disabilities often have to deal with difficult circumstances and decisions, which may trigger disagreement. However, the parents in the study effectively developed skills that helped them to function as a coordinated team.

Bolinger and Bolinger (1996) suggest that spouses work together as a team in sharing emotions, keeping up with current information about the child’s disability and related needs, dividing responsibilities fairly between one another, and taking time to be a couple. Marital discord is often a logical outcome in families having children with disabilities. Longo and Bond (1984) found in their review of several
studies that the quality of the marriage tended to remain stable despite the nature of the disability or the method used to evaluate marital satisfaction. A number of researchers (Gath, 1973; Martin, 1975; Silbert et al., 1982) indicate that the divorce rate among couples having children who are disabled is no greater than among families having children without disabilities. Gordon (1980) notes that the quality of the pre-existing marital relationship plays a major role in determining the resilience of the marriage. She further states:

If the marriage had been a good, established one, living with a handicapped child could be weathered or could even strengthen the marriage. If, on the other hand the relationship was shaky and of short duration, the strains involved might shatter it (p. 42).

The lack of control groups has been found to be a problem affecting validity in a vast amount of literature (Bernier, 1990; Brett, 1988; Longo & Bond, 1984; Marshall, 1986). Despite the amount of literature indicating that children with disabilities have a deleterious effect on the marriage, often resulting in divorce, there is little empirical evidence to support this conclusion (Sabbeth & Leventhal, 1984). Hence, further research is needed in the area of clarifying marital discord, as well as investigating the relationship between marital stress and divorce.

Impact on the Siblings

When a child with a disability is born into a family, it is not only the parents who experience the pain (Herring, 1996). The birth of a child with a disability has a significant impact upon the sibling subsystem (Yura, 1987). The sibling bond is
unique among family relationships in that siblings usually share a common genetic, cultural, and experiential heritage (Pruchno, Patrick, & Burant, 1996).

Grossman (1972) investigated the psychological effects of children with mental retardation upon their siblings. Of the 83 siblings participating in this study, 37% to 45% were found to have benefited from the experience. Siblings who were considered to have benefited demonstrated more tolerance, more compassion, and were more aware of the effects of prejudice and its consequences. On various occasions, they also tended to be more focused both occupationally and personally, as compared to young adults without such experiences. However, 37% to 45% were also found to have been harmed. These siblings displayed bitter resentment toward their family's situation and expressed feelings of guilt regarding rage toward their parents and their sibling with mental retardation. They also commented about their fear of being “tainted” or “defective.” In some instances, these siblings were deprived of the time and resources needed for their development, as all family support was devoted toward the care of the child with the disability. The remaining 8% were considered to have neither benefited nor been harmed. As a result, the positive and negative effects canceled each other.

Other investigators (Breslau & Prabucki, 1987; Cleveland & Miller, 1977; Gath, 1972; Hanold, 1989; McKeever, 1983; Porter & McKenzie, 2000) also support various adjustment outcomes regarding the effects of children with disabilities upon siblings. However, as Longo and Bond (1984) pointed out, “Inconsistencies in research methodology between studies make it difficult to make
direct comparisons; instead, one can only glean some general themes and conclusions” (p. 59).

The parental subsystem is the pivotal source of the family system. Therefore, it is likely that parental attitudes toward children with disabilities will affect sibling attitudes (Bernier, 1990; Correa et al., 1986; Yura, 1987). Graliker, Fishler, and Koch (1962) conducted a study with teenage siblings of children with mental retardation residing in the Los Angeles area. Interviews with the siblings revealed that in the families where both the mother and father had the same attitude toward the child with a disability, the siblings showed no substantial disturbance at home, school or social activities with peers. On the other hand, discord between the mother and father concerning the issue of the child with the disability was associated with sibling disturbance.

A lack of open communication among parents and siblings has also been related to sibling emotional reactions of fear, embarrassment, and guilt (Bolinger & Bolinger, 1996; Breslau & Prabucki, 1987; Collins-Moore, 1984; Correa et al., 1986; Featherstone, 1980; Herring, 1996; Lowenfeld, 1971). Kaplan, Grobstein, and Smith (1976) conducted a survey of 40 families in which a child received medical treatment for leukemia at the Department of Pediatrics, Stanford University Medical Center. The study was conducted to determine the impact of a serious illness on the health and functioning of family members. Kaplan et al. examined the relationship between the family's early reactions to the crisis and stress outcomes. Families who practiced open communication about the current crisis as well as other life events
adjusted with greater ease. The development of open communication skills among family members was found essential in order to avoid long-term negative consequences.

Other authors (Lowenfeld, 1971; Porter & McKenzie, 2000; Scott et al., 1985; Vadasy, Fewell, Meyer, & Schell, 1984) have also found that siblings may be reluctant to communicate feelings of shame, guilt or embarrassment for fear of being ridiculed or rejected. Therefore, open communication is important, as it serves to validate both positive and negative feelings faced by siblings (Herring, 1996; Scott et al., 1985). Steinzor (1967) conducted an exploratory study in which he interviewed 16 siblings of children with visual impairments to determine the psychological ramifications of blindness on the siblings. The interviews were structured and open-ended. The study consisted of 7 boys and 10 girls selected from families with children admitted to, or seeking admission to, a psychiatric clinic connected with an agency for the blind. The severity of siblings’ visual impairments varied. However, all visually impaired siblings suffered from additional emotional and psychiatric deficits.

Steinzor (1967) found that the sighted siblings had little contact with other blind children or adults, and exhibited stereotypic views of blindness as well as holding uncommonly negative opinions of blind people as a group. Steinzor also found that the siblings “constantly conveyed the wish to know more, to gain a better perspective on their blind siblings’ comparative abilities, on their own experience of
living with a blind person, and on the abilities and possibilities of blind people” (p. 51).

Family size appears to have some effect upon the response siblings display toward the sibling with a disability (Porter & McKenzie, 2000; Yura, 1987). Gath (1972) and Grossman (1972) found that when responses of siblings without disabilities were compared to siblings with disabilities from varying family sizes, the most maladaptive responses were from siblings in families with only two children. In reviewing the literature, McKeever (1983) found that the greater the number of siblings in the family, the greater the chance of a healthier environment because the hopes, dreams, and burden of care are dispersed among several children.

Birth order and gender of siblings has also been found to affect the level of adaptation of siblings who are not disabled, toward their siblings with disabilities (Collins-Moore, 1984; Correa et al., 1986; Featherstone, 1980; Lowenfeld, 1971; Scott et al., 1985; Yura, 1987). Lavigne and Ryan (1979) conducted a study to determine the relationship between age of the sibling with the disability, and the level of adjustment in siblings without disabilities. Two groups were used in the study, one containing 3- to 6-year-old siblings, the other containing 7- to 13-year-old siblings. Findings revealed that the younger siblings displayed higher levels of general psychopathology. This may be the result of the child with the disability assuming the role of the youngest sibling despite chronological age. Thus, the youngest sibling is “parentified,” resulting in a role reversal, taking on responsibilities normally not expected (Simeonsson & McHale, 1981).
Gath (1974) studied 122 families having school age children and a child with Down Syndrome to examine the impact of the disability on the siblings. Data were collected using a behavioral questionnaire that was administered to parents and teachers. Gath found that older siblings, particularly females from low SES backgrounds, were most affected.

Several researchers have postulated that parental neglect of siblings without disabilities has had a significantly negative effect on family adaptation (Bolinger & Bolinger, 1996; Cairns, Clark, Smith, & Lansky, 1979; Foster et al., 2001; Lavigne & Ryan, 1979). Correa et al. (1986), in a review of the literature, point out that the child who is blind often receives the majority of the attention within the family, creating stress, resentment, and feelings of neglect in sighted siblings. In Can't Your Child See: A Guide for Parents of Visually Impaired Children (Scott et al., 1985), the authors recommended that parents enlist siblings to help the child who is blind work toward independence. The authors believe this may be therapeutic for siblings who are not disabled by providing them with the sense of feeling needed and important.

In a longitudinal study of 369 families of children with severe disabilities living in the Cleveland, Ohio area, Breslau and Prabucki (1987) examined the effects of chronic stress on the psychopathology of siblings. Initial data were gathered in 1978 from the families of children having disabilities. Five years later, in 1983 and 1984, the original sample was reduced to 332 by death or relocation. Of the remaining 332, 96% were re-interviewed. The Psychiatric Screening Inventory was
administered initially to measure psychiatric disturbances in the children. The inventory was self-administered by the mothers of the children during a home interview. At the follow-up interview, data on the sibling’s psychopathology were also gathered by direct interview. Sections of the National Institute of Mental Health’s Diagnostic Interview Schedule for Children (DISC) were also used.

At follow-up, the siblings’ perception, according to the mothers’ assessment, appeared worse than during the initial period. In addition to the excess in aggressive symptoms noted initially, siblings manifested excessive amounts of depression and social isolation. During the follow-up interviews with the siblings themselves, it was observed that the siblings scored significantly higher than did the controls on depressive symptoms. The results of this study also suggest that “mothers’ psychological distress might be a mechanism connecting chronic stress in the family to children’s problems” (Breslau & Prabucki, 1987, p. 1045). This would indicate that the parental subsystem is a pivotal point of the family and that mothers’ attitudes have a strong bearing on the siblings’ attitudes. Furthermore, this study supports the idea that a combination of excessive demands placed on the mother, detracting time and attention away from siblings, is likely to cause disequilibrium within the system, creating depression and aggression in siblings.

In their review of the literature, several researchers (Breslau, Weitzman & Messenger, 1981; Collins-Moore, 1984; Correa et al., 1986; Featherstone, 1980; Morgan, 1988; Scott et al., 1985; Yura, 1987) have noted that the general mental health of siblings of children who are chronically ill or have a disability is not
necessarily impaired, but that social adjustment may be at risk. However, Horwitz
and Kazak (1990) found that this was not the case in their research study. They
conducted a comparative study to determine the impact of having a preschool
sibling with cancer versus a healthy preschool sibling. They assessed 25 preschool
siblings and families of children with cancer and a control group of 25 preschool
siblings and families of healthy children. FACES-II and standardized measures of
child adjustment were used in their study. In contrast to Breslau et al. (1981) above,
Horwitz and Kazak found that preschool siblings of children with cancer showed no
major behavioral or social problems in comparison with siblings of healthy children
or published norms.

Schwirian (1976) conducted a study to determine the impact of the presence
of a preschool child with a hearing-impairment on older siblings. Four behavioral
areas were examined: child care responsibilities, general home responsibilities,
degree of independence, and extent of social activities. The subjects were divided
into two groups. One group contained 72 older siblings of preschool children with
severe-hearing impairments. The other group contained 80 children having no such
sibling. Both groups were studied using structured interviews. The primary
conclusion of this study was that children with hearing impairments had little impact
on sibling adjustment concerning childcare, household responsibilities, social
relationships, and the child’s level of independence.

Grossman (1972) studied 83 college students with younger siblings having a
variety of disabilities. Structured questionnaires were used to gather data. Grossman
(1972) divided subjects into two groups: students attending community college and students attending a university. It was concluded that the presence of a child with a disability has proven to be beneficial for siblings by increasing their levels of maturity, altruism, and tolerance.

Based on the personal experience of having a child with a disability and her review of the literature, Featherstone (1980) also concurs that having a brother or sister who is disabled can foster personal growth within siblings. Barsch (1968), Carr (1975), Hewett (1970), and Lonsdale (1978) postulated that children having a sibling who is disabled adapt as well as those in families having children without disabilities. Lonsdale also found the percentage of behavioral disorders in children having siblings with disabilities to be approximately the same as that of the general population.

Although the available literature provides guidance for family therapists concerning sibling adaptation to the birth of a child with a disability, there are major weaknesses in the literature which restricts practical and theoretical application (Brett, 1988). A number of methodological problems contaminate the validity of these studies and also contribute to substantial inconsistencies in overall findings (Brett, 1988; Longo & Bond, 1984).

In a review of the literature, Brett (1988) found that problems concerning small sample size, instrumentation of uncertain validity and reliability as well as anecdotal and impressionistic information strongly contributed to inconsistent results. Early researchers relied upon mothers' responses in regard to siblings'
perceptions rather than interviewing siblings themselves (Breslau & Prabucki, 1987; Brett, 1988).

However, despite these limitations, the literature indicates that family therapists may safely assume that siblings of children having a disability are at higher risk for future maladjustment (Brett, 1988). How siblings respond to their siblings who are disabled will vary according to the interacting of personal, familial, and situational variables. A family systems approach would be useful in assessing interactional and coping patterns of families with children who are disabled. (Foster et al., 2001). A family systems approach could also provide the tools needed for assessing the level of family functioning. It may also assist in determining helpful intervention strategies for reconstructing family subsystems, thereby improving family interactional and coping patterns (Brett, 1988; Porter & McKenzie, 2000).

Impact on the Family

According to Reagles (1982), "A disability experienced by one family member impacts all family members within the system and influences their typical pattern of interaction" (p. 25). Traumatic and unexpected circumstances offset the family's equilibrium and create, at least temporarily, disorganization (Cohen et al., 1992; Collins-Moore, 1984; Singhi, Goyal, Pershad, Singhi, & Walia, 1990). As a result, families face the challenge of restructuring the system in an attempt to restore homeostasis (Werth & Oseroff, 1987).
Stressors Leading to Maladaptation

According to Yura (1987), the presence of an adequate support system of extended family, friends, neighbors, and professionals is a critical component in the level of adjustment and cohesion experienced by families with children who are disabled. Lipsky (1985), Kerr and McIntosh (2000), and Pain (1999) emphasized the importance of professional and parental collaboration to provide a higher level of care for children who are disabled. In a review of the literature, Munro (1985) noted individual personality factors or traits to be important predictors of the family's ability to adapt successfully to the presence of a child with a disability.

Inaccessibility of professional resources as well as marital disharmony have also been documented as factors contributing to maladjustment (Bernier, 1990; Featherstone, 1980; Johnson-Martin et al., 1989; Kerr & McIntosh, 2000; Scott et al., 1985; Starr, 1981; Trute, 1990; Trute & Hauch, 1988). Parents or siblings who tend to project their blame onto one another are likely to be at high risk for maladjustment. In addition, the costs of medical and respite care can place an increased financial burden upon families, creating stress which may result in further maladjustment of family members (Darling, 1987; Kerr & McIntosh, 2000; Leyser et al., 1996; Singhi et al., 1990).

There is a paucity of available literature pertaining to the effects of chronic illness or disability upon the family system (Collins-Moore, 1984; Leyser et al., 1996). Gayton et al. (1977) administered the MMPI to 43 families each having children with cystic fibrosis. The results showed that 32% of the fathers and 22% of...
the mothers obtained scores in the range suggestive of significant emotional disturbance. The *Family-Concept Q Sort Assessment of Family Interaction* was also administered to these families. The results indicated that the primary effect of having children with cystic fibrosis was decreased family satisfaction and family adjustment.

Meyerowitz and Kaplan (1967) also studied families having children who had cystic fibrosis. Their goal was to determine the effects of cystic fibrosis on the familial response to stress. Their study consisted of 111 families with a total of 337 children. Data were gathered by personal interviews with the parents of the children. The authors found significant changes within family role patterns and expectations following the birth of the child with a disability. Some mothers who had previously worked outside the home resigned their positions in order to care for the child after the diagnosis. Some fathers obtain second jobs due to the increased financial expenses of providing care for the child.

The dynamic nature of the family system is illustrated by these research findings which demonstrate how family members are affected by and affect others in the family. CF itself is also developmental with a progressive course. Therefore, marked changes in health stats and deterioration may have very important implications for the family, which constantly has to adapt to new demands and new challenges placed on it by the disease in daily life in general. (Foster et al., 2001, p. 360)

Singhi et al. (1990) studied the types of psychosocial problems faced by family members in 150 families. The subjects were divided into three groups: 50 families having a physically disabled child, 50 families with a mentally retarded child, and 50 families with a nondisabled child. The Semi-structured Questionnaire Interview, Kuppuswamy SES Scale (urban areas), and the Kulshreshta Scale (rural
areas) were used to assess social support, marital adjustment, and maternal
neuroticism. Findings revealed that families with disabled children perceived greater
financial stress, frequent disruption of family routine and leisure, poor social
interaction, and increased physical and mental health problems as compared to those
families in the control group. Singhi et al. believed that these findings were highly
correlated with socioeconomic conditions, sociocultural practices, parental attitudes
and views shared within the community.

Floyd and Gallagher (1997) evaluated the effects of child disability status
and child behavior problems on parent stress and care demands associated with
disability, and other types of support services used by families. They also examined
how different parenting roles influence stress experienced by parents and their use of
support services.

They noted that the presence of the child’s behavior problems was generally
more important than the type of disability in determining multiple forms of stress
faced by these parents. They also found behavior problems in children with
disabilities to be associated with the type of support services used by these families.
Physical therapy was utilized most frequently as a main form of health care service.

In contrast, Patterson, Budd, Goetz, and Warwick (1993) found behavior
problems and family disruption to be related to the type of disability or illness.
However, their findings were similar to those of Floyd and Gallagher (1997) in
noting a significant relationship between behavior problems in children with
disabilities and the type of support services utilized by their family. These
researchers reported that families having children with chronic illnesses utilize hospitals and medical services as their main health care source of support.

**Positive Aspects Influencing Adaptation**

The family systems perspective recognizes that families have both formal and informal resources that are utilized to meet their needs when adapting to stressors. It has been well documented in the literature that a strong support system has been found to be a positive contributor to successful family adaptation (Darling & Darling, 1982; Hanline, 1991; Judge, 1998; Kazak & Marvin, 1984; McCubbin, Joy, Cable, Comeau, Patterson, & Needle, 1980; Mirfin-Veitch et al., 1997; Seligman, 1979; Tröster, 2000).

In reviewing the literature, Vincent and Salisbury (1988) found that the most frequently cited resources which aid in positive adaptation to stress were: (a) self, (b) spouse, (c) extended family, (d) friends, (e) physicians, (f) educators, and (g) co-workers. Walker (1981) also concluded that family resources play an important role in mediating the crises experienced in families of children with disabilities. Therefore, as Hanline (1991) suggests, social support plays a vital role in providing the needed family and community resources to help families adapt to their circumstances.

Researchers like Dunst, Trivette, and Deal (1994) found that that all families have strengths that they can build on and that the family’s strengths, including the
social networks and informal supports already available to and within the family, should be the foundation upon which new supports are designed or provided.

Korn, Chess, and Fernandez (1978) conducted longitudinal studies beginning in 1963 of temperament in young children and children with congenital rubella in 1971. They found that most of the families they worked with were coping sufficiently, despite additional stressors entailed in caring for their children with disabilities. Adequate social support and coping strategies tended to buffer the family against the negative effects of increased stress, thus enabling families to adapt successfully to adverse circumstances.

Starr (1981) compared the differences in parent-child relationships between parents having children with cleft palates and a control group of parents having children without cleft palates. Both groups consisted of 25 parents with 2-year-old children. In addition to the age of the child, groups were matched for the sex of the child and the family's socio-economic status. The mothers completed three instruments, the Missouri Children's Behavior Checklist, the Parent-Child Relations Questionnaire, and the Locke-Wallace Marital Adjustment Test. Starr found that having a child with a cleft palate did not affect parent-child relationships.

Starr (1981) further found that the presence of a child having a cleft palate had no effect on the parenting styles of the mothers experiencing marital satisfaction. However, an association was found between marital discord and the behavior of the children in both groups. The data also indicated that differences in the behavior of the children were evident as early as 2 years of age. "Happily
married mothers rated their children as less aggressive, less active, less inhibited, and as having fewer sleep disturbances as compared with how the least happily married mothers rated their children” (Starr, 1981, p. 506).

Trute and Hauch (1988) explored positive factors enabling families of children with developmental disabilities to make successful adaptation. A sample of 40 families selected from a child development center in Manitoba, Canada participated in this study. Data collection was completed on all but four of these families (three were not accessible and one refused). Parents completed the Family Assessment Measure III and the Dyadic Adjustment Scale. Personal interviews, which averaged 2 hours, were also conducted in each family’s home and involved both parents in data collection process.

Trute and Hauch (1988) concluded that two-parent families with few children were at a distinct advantage. Positive adaptation was found to be related to the quality of functioning of the parental subsystem and skillful utilization of family, and friendship resources by parents. However, positive adaptation was not found to be related to the degree of the child’s disability or temperamental factors, and was not directly linked to income levels of the families.

The adequacy of information as well as the mode and attitude in which this information is presented from professionals and nonprofessionals have found to play a major role in helping families acquire positive attributes to adapt to having a child with a disability. Pain (1999) conducted 15 semistructured interviews with 20 parents of disabled children who had a range of physical and learning disabilities.
Five interviews were completed with both parents, and 10 interviews were with mothers only. Pain wished to explore the nature and degree of information that these families had received concerning their child's disabilities. Information needs were also explored and assessed to determine whether the information given was useful. The interviews were audiotape, transcribed, analyzed for content, and reasons for needing the information was examined for themes.

Personal communication was sited as the most frequently preferred medium for communication. Most often, parents reported that professionals were their main source of information. However, other parents of children with disabilities and voluntary organizations were also mentioned as important sources for needed information. Such information was found to assist these parents in the emotional process of adjusting to their child's disability. However, parents found information regarding assistance in how to access services, benefits, and improve their child's management of behavior to be useful but of mixed benefit some of the time.

Kerr and McIntosh (2000) explored the impact of parent-to-parent support on parental adaptation to having a child with a disability. The sample consisted of 63 families having children born with a congenital upper limb deficiency. These families were interviewed during a 5-month period. Parents were interviewed as a couple in 34 instances, and mothers were interviewed individually in 29 instances. These researchers found that most of these parents experienced times of difficulty and emotional turmoil during the early weeks and months following the birth of their infants. Although a certain amount of support was provided from contact with
families, friends, and health professionals, these parents did not believe they had obtained the quality and amount of support needed from these sources. However, contact with other parents having children with limb deficiencies "clearly exerted a powerful stress buffering influence providing much needed emotional, social, and practical support" (p. 309). The study found that parents of children with special needs are uniquely qualified to help each other when health professionals are aware of the potential benefits of parent to parent support and provide parents with information about appropriate local organizations/contacts.

Moreover, Nixon (1988) emphasizes the importance of considering the "goodness of fit" between the need for and interest in parents support groups. She further states:

Appropriate disability-related social support should involve parents in relationships with other parents that meet mutual or shared needs and goals, occur in places and represent a style of communication with which the interaction parents feel comfortable, and take into account potential problems that may occur because of differences in social or cultural backgrounds and perceptions of visual impairment and handicap. (p. 276)

Hypotheses

The research on the impact of congenital blindness on family functioning is limited. Earlier research studies lacked control groups, used invalid and unreliable research instruments and procedures, and had small sample sizes. This study was designed to address some of these concerns. Based on a family systems perspective, three research hypotheses were tested. The present study examined the interactions
of adaptation, cohesiveness, family climate, and satisfaction in relation to the impact of blindness upon the family system.

**Hypothesis 1**

1a. There is no difference in the level of adaptability or the level of cohesion between type of family (family of a child with usable vision vs. family of a child with no usable vision vs. family of a child with full vision).

1b. There is no difference within groups on the level of adaptability and the level of cohesion. (family with a child with usable vision vs. family with a child with no usable vision vs. family with a child with full vision)

1c. There is no interaction between the level of adaptability or the level of cohesion and the type of family (family with a child with usable vision vs. family of a child with no usable vision vs. family of a child with full vision).

**Hypothesis 2**

2a. There is no difference in the level of family satisfaction between the types of family (family of a child with usable vision vs. family of a child with no usable vision vs. family of a child with full vision).

2b. There is no difference within groups on the level of family satisfaction. (family with a child with usable vision vs. family of a child with no usable vision vs. family with a child with full vision)
2c. There is no interaction between the level of family satisfaction and the type of family (family with a child with usable vision vs. family of a child with no usable vision vs. family with a child with full vision).

Hypothesis 3

3a. There is no difference in the level of social family climate between the types of families (family with a child with usable vision vs. family of a child with no usable vision vs. family with a child with full vision).

3b. There is no difference within groups on the level of social family climate. (family with a child with usable vision vs. family of a child with no usable vision vs. family with a child with full vision)

3c. There is no interaction between the level of social family climate and the type of family (family with a child with usable vision vs. family of a child with no usable vision vs. family with a child with full vision).

To determine within group and between group variances, participants were divided into three groups: families having children who are congenitally blind with partial vision, families having children who are congenitally blind with no usable vision, and families having children with full vision.

Summary

Chapter II provided an overview of the history and development of family therapy. Therapy can provide one means of facilitating the necessary restructuring
and adaptation process since parents may lack the needed skills to compensate for their children with disabilities within the family system. It substantiated both interest and conflict pertaining to children with disabilities and their families. A family systems perspective focuses on the context of both individual and family responses and provides for understanding the impact of children with disabilities on family functioning. It is also useful in assisting clinicians and researchers in viewing family stress in a broader and more complex manner (Foster et al., 2001).

Chapter II also provided a literature review on the impact of a child with a disability upon the parental, marital, and siblings subsystems. Cultural values and life transitions, including religious beliefs, traditions, family and community support, and socioeconomic standards were also considered as they related to how families adapt to their children with disabilities. The effect of a disabled child upon the entire family system was also examined and included both negative and positive factors that play a major role in how the family adapts to having a child with a disability.

Strengths in the family system were addressed by researchers like Dunst et al. (1994) who found that all families have strengths that they can build on and that the family's strengths, including the social networks and informal supports already available to and within the family.

The literature review also revealed shortcomings in this area of research as practitioners may assume that families will anticipate serious, negative consequences with the birth of a child with a disability without focusing on the family's strengths. There is a dearth of knowledge of the unique adaptation process families undergo in
order to raise children with disabilities and adequately prepare them to become self-reliant adults (Nelson et al., 1992). Despite this limitation, strategic and sustained counseling relationships can help increase awareness, support, and stability for such families, further facilitating the development of needed skills (Judge, 1998; Werth & Oseroff, 1987). This is also shared by Pelchat et al. (1999) who suggest that therapeutic interventions be tailored to meet the individual needs, unique to each type of disability.

Chapter III describes the methodology and procedures of this research study. This chapter includes an explanation of the sample characteristics, participant recruitment methods, data collecting and coding procedures, research instruments, research design, and data analysis procedures.

Results of the study are reported in Chapter IV, including a description of the demographics of each group. Chapter V reviews the study findings, limitations of the study, and the implications of the findings for professionals working with families of children who are blind. Directions for future research will also be discussed.
CHAPTER III

METHODOLOGY

Introduction

Chapter III explains the methodology and procedures of this research study. It is divided into four sections: participant selection criteria, instrumentation and materials, data collection and coding procedures, and research design and statistical analysis. The sample, collection sites, survey instruments, and human rights protection procedure are delineated.

Participants

The participants recruited for this study were parents or caregivers of children (ages zero to 12 years) with congenital blindness. This study included 56 families: 20 families having children who were legally blind with usable vision, 20 families with fully sighted children, and 16 families having children who were totally blind. To the extent possible, the researcher attempted to control for major demographic variables. Groups were similar in term of ethnicity, level of education, marital status, gender of children, location of residence, number of people living in the home, persons moving in or out of the home, and participants’ level of vision. Groups differed, however, in participants’ gender, relationship to child, age, household income, and number of children.
Families with legally blind children were recruited from low vision clinics, service providing groups, clubs and organizations, and various intermediate school districts (ISD) in southern Michigan. Control group families in southern Michigan were selected with the assistance of school districts, organizations, and other service providing agencies. Additionally, using a snowball technique, faculty members on the dissertation committee, healthcare professionals, friends of the researcher, and those interested through word of mouth were approached to identify potential participants. Family participants were mothers, fathers, or the primary caregivers of children in the totally blind, legally blind, and full vision (i.e., control) group categories.

As blindness is a low-incidence disability, it was difficult to select a sample of families of children with congenital blindness who had no additional disabilities. Low-vision clinics, parent support groups, ISDs, community sponsored family/youth camps, and the Michigan School for the Blind were helpful resources that provided the needed assistance to access this population through their professional networks and client bases. Most ophthalmological organizations and clinics expressed genuine interest in participating in research of this kind for three reasons. First, they were willing to support the continued research that benefited their clientele. Second, most groups were aware of the potential for such studies to enhance agency networking and cooperation. Finally, research participation was thought to provide the chance for clinics and agencies to augment their own credibility.
Sites recruited families who had at least one child who was legally or totally blind between the ages of zero to 12 and with either mild or no additional impairments. The control group families were comprised of children with full vision between the ages zero to 12. Parental marital status or family configuration was not a requirement to fit the study's subject selection criteria.

Sites were selected based on geographic location with regards to proximity and accessibility. Further, sites were chosen to access a diverse sample population in terms of cultural diversity, varying age ranges, varying SES, and levels of blindness. The sites were selected based on the potential to access a sample population that met study criteria.

Research Regulations

The researcher submitted an application to Western Michigan University's Human Subjects Institutional Review Board (HSIRB) after the dissertation proposal had been approved. The study met the requirements for an "exempt" HSIRB protocol (see Appendix A).

Instrumentation and Materials

After review of existing instruments designed to assess family functioning, the researcher chose the following measures for this study: (a) the *Family Adaptability and Cohesion Evaluation Scale-II* (FACES II), (b) the *Family Environment Scale* (FES), and (c) the *Family Satisfaction Scale* (FSS). These

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instruments were used to measure the variables of adaptability, cohesion, family
social climate, and satisfaction, in families having children who were congenitally
blind. Due to their suitability and appropriateness, these instruments were chosen for
measuring the dependent variables with regard to family functioning and interaction.

The Family Adaptability and Cohesion Evaluation Scale-II

The Family Adaptability and Cohesion Evaluation Scale-II (FACES-II) was
used to measure family adaptability and cohesion. FACES-II is a self-report, 30-item
questionnaire, developed by Olson, Portner, and Bell (1982) to improve the
reliability, validity and clinical utility of FACES-I. It is designed to measure two
dimensions of family behavior: adaptability and cohesion.

Maynard and Olson (1987) define family adaptability as:

the extent to which the family system is flexible and has the ability to change.
It is the ability of a marital or family system to change its power structure,
role relationships and relationship rules in response to situational and
developmental stress. (p. 502)

Family adaptability is measured through the use of four concepts: family power (i.e.,
assertiveness, control, discipline); style of negotiation; role relationships; and
relationship rules (Olson et al., 1992). For example, items ask family members for
their perception of the ease with which family rules are changed, family members
speak their mind, and responsibilities shift among members.

Family cohesion is “the emotional bonding and the degree of individual
autonomy that family members experience” (Maynard & Olson, 1987, p. 502). The
family cohesion dimension assesses the extent to which family members are

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connected to or separated from their family members. It is measured through the use of nine concepts: emotional bonding, boundaries, coalition, time, space, friends, decision-making, interests, and recreation (Olson et al., 1992). For example, items ask family members for their perception of the ease with which they talk about problems, consult one another, and feel close to one another.

FACES-II utilizes a 5-point Likert response scale ranging from “almost never” to “almost always” (Olson et al., 1982). It may be given to those over 12 or persons reading at a seventh grade level. It can be administered individually or to couples and families seen in therapy sessions. It can also be given to couples and families participating in research projects as well as to larger groups (e.g., students taking part in a research study) (Olson et al., 1992).

FACES-II contains 16 cohesion items and 14 adaptability items, designed and used to measure idealistic and realistic perceptions of family functioning. On both the idealistic and realistic forms, evenly numbered items are summed except number 30 to arrive at a measure of adaptability, while odd numbered items plus item 30 are summed to arrive at a cohesion score. Scoring is done directly on the answer sheet. Separate scores are generated for cohesion and adaptability. These scores are then plotted on a Circumplex Model grid (Bagarozzi, 1985). When scored, the results classify family functioning into three general types: balanced, midrange, or extreme (see Appendix B).

FACES-II underwent several changes before taking its present format. The 50 items of the initial FACES-II were administered to a sample of 2,142 parents and
their 412 adolescent children in a national survey (Olson et al., 1982). On the basis of the factor analysis and reliability analysis, the 50-item scale was reduced to 30 items with 2–3 items for each of the 14 content areas (Olson et al., 1992). Cutting points on each dimension of the FACES-II were based on the mean and standard deviation for each scale. The cutting points for the four levels of family cohesion are: disengaged (15–50), separated (51–59), connected (60–70), and very connected (71–80). The last level was reinterpreted and renamed by Olson et al. (1992) as very connected because FACES II does not capture the very high categories of enmeshed. The cutting points for the four levels of family adaptability are: rigid (15–39), structured (40–45), flexible (46–54), and very flexible (55–70). The last level was reinterpreted and renamed by Olson et al. (1992) as very flexible because FACES II does not capture the very high categories of chaotic.

To assess the internal consistency reliability of the scales, Cronbach’s alpha was computed separately for the two random halves of the sample and replicated again with the total sample of family members \( (n = 2,412) \). The internal consistency (alpha) reliability of the total scores for the adaptability and cohesion were .78, .87, and .90 for the total scale, respectively (Olson & Portner, 1983). Test-retest reliability has been reported to be .80 for adaptability, .83 for cohesion, and .81 for the entire FACES-II.

Construct, discriminative, and predictive validity were also assessed by factor analysis of the normative sample in the Olson and Portner’s study (1983). A discriminate analysis was used to distinguish between balanced and extreme families.
on the Circumplex Model. A predictive analysis was then done using the other couples’ and families’ variables to see how well they could predict the balanced from extreme families. In summary, FACES II seemed to demonstrate discriminate and predictive validity (Olson & Portner, 1983).

Olson and Portner (1983) suggest that FACES-II can be used for diagnostic assessment, treatment planning, and assessment of change in family counseling and educational programs. In family therapy and education programs, it can be used to increase family members’ awareness of various types of family systems in addition to their own. FACES-II has also shown to be useful in examining special needs of high-risk families, such as those with children who have cancer (Horwitz & Kazak, 1990), adolescents with insulin-dependent diabetes mellitus (Hanson et al., 1989), and young adult offspring of concentration camp survivors (Zlotogorski, 1983). A copy of the permission letter to use Family Inventories, including FACES-II, is found in Appendix C.

Family Satisfaction Scale

The Family Satisfaction Scale (FSS) was used to measure the extent to which persons are satisfied with their families and family relationships. "The importance of studying family satisfaction derives from the need to understand how feelings and attitudes about the family emerge in both normal and dysfunctional families" (Carver & Jones, 1992, p.72). To address this issue, researchers began to use adaptability and cohesion scores to measure the level of family satisfaction in
clinical and research families. “Research and clinical work with families, however, showed that gathering information about cohesion and adaptability did not capture the character of families sufficiently” (Sundberg, 1994, p. 268). Olson (1989) noted that even families functioning at the extremes of the Circumplex Model (i.e., disengagement/enmeshment or rigid/chaotic) continued to work well as a family unit provided they were satisfied with the attitudes and feelings within their current family. This observation led Olson to develop the FSS.

“The original 87-item FSS measured four broad and conceptually overlapping experiential domains of relevance to family satisfaction” (Carver & Jones, 1992, p. 73). The four domains encompassed the following areas: the general satisfaction with family life and family members, affection and acceptance, consistency and fairness, and family commitment. This instrument was administered to 131 college students to examine the level of satisfaction in their family of origin. Standard psychometric analyses showed that the items of the FSS were highly reliable internally for the total scale and for each of the four content domains (Olson & Wilson, 1992). However, the 87-item FSS saw several changes before it reached its present 14-item format. It was reduced to 40 items, and later to a 20-item instrument, to minimize the degree of overlap among the four domains and maintain a degree of consistency.

The 14-item FSS instrument is designed to measure “how well people liked the cohesion and adaptability of their family” (Sundberg, 1994, p. 268). Individuals are asked to rate the level of family satisfaction within their families by completing a
5-point Likert scale. A single unweighted total score across the 14 items is obtained by summing the one to five weights given to each of the 14 items (Olson et al., 1992; Sundberg, 1994). The norms for the Family Satisfaction Scale was obtained from a national survey. The mean score for parental family satisfaction is 47 (Olson & Wilson, 1992).

In order to obtain one item for the 14 subscales, researchers originally developed and pilot tested a 28-item questionnaire in which each subscale was represented by two different items. The instrument was administered to 800 university students and 433 completed questionnaires were returned. The original 28 items were factor analyzed. One item was then chosen from the pair of items to represent each subscale. The final 14-item scale was arrived at by retaining one item for each of the eight cohesion subscales (i.e., emotional bonding, family boundaries, coalition, time, space, friends, decision-making, and interests and recreation) and one item for each of the six adaptability subscales (i.e., assertiveness, control, discipline, roles, negotiation, and rules) (Olson et al., 1992; Sundberg, 1994).

The instrument has a Cronbach alpha reliability coefficient of .92. The eight cohesion items and six adaptability items show alphas of .85 and .84, respectively. The test-retest reliability coefficient over a 5-week period for the total score was .75 (Sundberg, 1994).

Eigen values of the first three principal components of the Family Satisfaction Scale were 7.04, 1.06, and .91, respectively. When two factors were retained, all but two of the 14 items loaded more than .40 on the first varimax rotated principal factor. (Olson & Wilson, 1992, p. 23)
The FSS has some advantages over other family assessment instruments. In its brief format, the FSS affords an expedient method of determining the individual's overall emotional family satisfaction. This instrument could serve as a valuable research tool to investigate family development issues that have remained unexplored in the past (Carver & Jones, 1992). A copy of the permission letter to use the FSS is found in Appendix C.

Family Environment Scale

The Family Environment Scale (FES) was developed by Moos and Moos (1986) to measure the social environmental characteristics of the family. There are three forms of the FES: The Real Form (Form R) measures perceptions of conjugal or nuclear family environments, the Ideal Form (Form I) measures conceptions of the ideal family environment, and the Expectations Form (Form E) measures expectations about family settings. Form R was used in this study.

The FES is composed of 90 true-false items on 10 subscales. The 10 subscales (nine items each) are grouped into three underlying domains: (1) the relationship domain includes the cohesion, expressiveness, and conflict subscales; (2) the personal growth domain includes the independence, achievement orientation, intellectual-cultural orientation, and moral-religious emphasis subscales; and (3) the system maintenance domain includes the organization and control subscales. The system maintenance subscales measure one aspect of family adaptability (Gondoli & Jacob, 1993).
Each item on the FES is to be marked "true" or "false" according to how the individual feels about his or her family. The FES may be administered to individual family members or to just one family member representing the family. However, respondents are not to assess each of their family members separately. Rather, they are asked to give an overall assessment of their entire family (Moos & Moos, 1986). For example, respondents respond to items such as family members help one another, become so angry they throw things, and have equal say in decisions.

Raw scores for each subscale are computed in order to develop family profiles for data interpretation. This is followed by obtaining the scores for each subscale. These scores are then transformed to standard scores. The 10 FES subscales can be plotted on a standard score profile and have numerous practical applications which include comparisons of family perceptions between males and females, and comparisons of profiles between two kinds of families (e.g., achievement-oriented families and relationship-oriented families (Moos & Moos, 1986).

Moos and Moos (1994) obtained normative data for 1,432 nondistressed families and 788 distressed families. The 601 nondistressed families geographically located in all areas of the country. Family constellations included single-parent and multigenerational families, families drawn from racial minority groups, and families of all age groups. The nondistressed families were at various stages within the family life cycle; participants included newlywed couples, with preschool and adolescent children, families whose children had left home, and families of retired adults.
Moos and Moos (1994) also studied several samples of distressed families. The initial sample of 42 families who completed Form A came from a family clinic and a probation department affiliated with a local correctional facilities. Later samples included 220 families with alcohol abuse problems, 288 families with patients who were depressed, 77 families of psychiatric patients, and 161 families in which an adolescent or a younger child was in a crisis situation (e.g., ran away from home, had a conduct disorder, or had to be placed in a foster home).

"As expected, when compared with nondistressed families, distressed families were found to be low on cohesion, expressiveness, independence, and intellectual and recreational orientation while scoring higher on conflict" (Moos & Moos, 1994, p. 18). This continued to hold true after variables of socioeconomic status, family characteristics, level of education, and number of children were controlled. Moos and Moos (1994) obtained normative data for 1,432 normal and 788 distressed families. The mean relationship domain scores for normal families was 15.45 ($SD = 4.99$) and for distressed families was 13.98 ($SD = 5.98$). The mean personal growth scores for normal families was 27.77 ($SD = 8.69$) and for distressed families was 24.64 ($SD = 8.83$). The mean system maintenance domain score for normal families was 9.73 ($SD = 2.74$) and for distressed families was 9.68 ($SD = 3.86$) (Moos & Moos, 1994).

The overall true-false response rate for each item has been found to be as close to a 50-50 split as possible. Items correlated more highly with their own subscales than with any other, and each of the subscales had an approximately equal
number of items scored true and false. Moos and Moos (1981) report that evidence on construct validity comes from studies investigating the ability of the FES to distinguish family associations between family climate, life transitions, and crisis and visual loss.

Busch-Rossnagel (1985) suggests that it is important to know the relevance of the dimensions assessed by the FES for individual, psychological, and familial functioning. Having this information would be useful for obtaining evidence of predictive validity.

Jackson and Lawson (1995) found distinctive positive and negative correlations between each of the 10 subscales of the FES. Conflict and control subscales were positively correlated with distress. Jackson and Lawson discovered a high correlation in the negative direction between the cohesion and the independence subscales. They further noted a significant relationship between various characteristics of family environments in the subjects as globally measured by the GSI and BSI and concluded that the influence of the family social environment served as a predictor of adjustment to vision loss. Hence, their study showed evidence of the FES possessing construct and predictive validity.

Ongoing research and clinical work has demonstrated the effectiveness of FES as a reliable tool to measure perceptions of conjugal or nuclear family environments. The internal consistencies for the 10 subscales range from .61 to .78, and the corrected average item-subscale correlations range from .27 to .44. The
8-week test-retest reliability correlations range from .68 to .86. The 12 months stability correlations range from .52 to .89.

Lambert (1985) mentions that FES provides information on family members' perceptions of their family environment. Therefore, FES is particularly suitable for therapists and counselors with a family systems approach to whom the family as a unit has come for counseling. Profiles can be compared between the family at the beginning and following a series of counseling sessions. Interpretation can also be made of an individual's initial perception of his or her family perceptions of counseling.

The FES has proven to be a useful research tool in studies that have investigated the social family climate of families who have a family member with a disability. Some researchers have used the FES in their research to examine the types of stressors, coping strategies, and the nature of the family environment of families having disabled children (Leyser et al., 1996; Mahoney, O'Sullivan & Robinson, 1992). Mahoney et al. (1992) found that "families of children with disabilities participated less in recreational activities and had a stronger moral-religious orientation than the general population" (p. 398). Both studies revealed that parents of disabled children tended to be less involved in intellectual and cultural activities and used less structure and organization. They did employ formal and informal sources of support and personal coping strategies to deal with their stressors (Leyser et al., 1996; Mahoney et al., 1992). A copy of the permission letter to use FES is found in Appendix D.
Demographic Survey

The demographic survey, designed by the researcher, consists of short answer and multiple choice questions and answers. It has seven items under the first section, pertaining to information about the respondent and their general family information; four items under the second section, pertaining to information about the visually impaired child and the level of the child's visual impairment; and five items under the last section, pertaining to information about the entire family as a whole. The control group participants used the same demographic survey but skipped the second section. Respondents were asked to supply information regarding SES, commitment status, severity of child's visual impairment, and number of siblings. The demographic survey took approximately 15 minutes to complete. A copy of the demographic survey can be found in Appendix E.

Recruitment Packets and Explanatory Letters

Participant packets included the following materials: a participant recruitment letter (see Appendix F), signed and approved by the HSIRB Chair which explained the nature, purpose and benefits of the study; the three measures (FACES-II, FES, and FSS); a demographic survey; and a pre-addressed stamped envelope. Participant packets were numbered and color-coded. The colors of the stickers on the packets were indicative of the child's visual condition (i.e., level of blindness). Dark blue stickers indicated total blindness, gray/silver stickers indicated partial blindness, and salmon stickers on packets represented no visual impairment.
Procedures

Initial Contact With Sites

The researcher contacted 166 selected sites telephone (see Appendix G) to determine their willingness to assist in recruitment of participants for the study. A personal telephone call enabled the researcher to ascertain which sites were genuinely interested in study participation. Voice contact also set a more personal tone and encouraged a sense of collaboration between the researcher and the sites.

Of the 166 sites contacted, 136 declined to assist in recruitment. Of the 136 sites, 58 were schools or intermediate school districts, 35 were private low vision specialists and low vision clinics, 17 were parent support groups or community-sponsored camps for children with low vision, 15 were ophthalmologists in private practice, and 11 were service providing agencies. Of the 30 sites that agreed to assist in recruitment, 17 were schools or intermediate school districts, 7 were private low vision specialists and low vision clinics, 4 were parent support groups \((n = 2)\) or community-sponsored camps \((n = 2)\), and 2 were service providing agencies.

An agency recruitment letter (see Appendix H) along with an agency response letter (see Appendix I) were sent to 30 sites expressing a willingness to assist with the study. The recruitment letter explained study procedures and the respective agency’s role in the recruitment process. Agencies who confirmed participation by signing and returning the agency response letter in the attached pre-paid envelope were sent a follow-up acknowledgement letter (Appendix J) thanking
them for their willingness to assist with the study. Each agency was also sent a sample packet of survey materials. The agency response letter was signed by the agency coordinator and returned to the researcher as a final confirmation of agreement to assist the researcher with the recruitment process. Copies of participant solicitation flyers (see Appendix K) for distribution to potential participants were also sent to these agencies along with information deadlines for participants to contact the researcher either via the agency or directly. Over 500 flyers were distributed to various sites.

The flyer mentioned that each participant who returned completed survey materials in the self-addressed return envelope to the researcher would be compensated with a $15.00 personal check for their time. The potential participants, while expressing their interest in participating in the study, also indicated whether they were interested in receiving a copy of the summary of the findings of the study.

Participating sites recruited mothers, fathers, and primary caregivers meeting the research requirements. Participants were recruited using the following steps:

1. Agencies distributed flyers compiled by this researcher to potential subjects, and requested those who were interested to contact the researcher by email, letter, or phone. Some participants chose the option to contact the original site directly to give the site coordinator permission to forward names and addresses to the researcher.

2. Parents/caregivers of children with congenital blindness who participated in this study assisted in recruiting additional participants by sharing information
verbally, via email parent support group listservers, or by providing information via the recruitment flyer.

3. Those participants who contacted the researcher expressing an interest in taking part in this study were sent a packet containing a copy of the HSIRB approved invitation letter to participants, explaining the nature and purpose of the study, along with a participant packet containing a copy of the three survey instruments and the demographic survey as well as a pre-addressed, stamped envelope. Survey instruments were completed and returned to the researcher in the enclosed envelope which was pre-addressed to the researcher.

Control group participants (i.e., Full Vision Group) were recruited with the assistance of school districts and other service-providing agencies within southern Michigan. Parents/caregivers of children with congenital blindness who chose to participate in this study were also asked to help recruit control group participants from parents/caregivers of children without vision impairment. Information was shared verbally or by providing information from the recruitment flyer.

In addition, using a snowball technique, faculty members on the dissertation committee and friends were approached to identify potential participants. Faculty members and friends who agreed to assist in the recruitment process were given copies of the Letter to the Participants to distribute to potential participants. Interested potential control group participants contacted the researcher by e-mail, letter, or phone to receive a study packet. Procedures for completing and returning the questionnaires were the same as with the experimental groups.
The researcher distributed 500 flyers, and 350 potential participants expressed interest in participating in the study. Eighty-three out of 350 participants completed the instrument packets sent to them after their initial indication of interest in the study. During follow-up contact with those who did not complete instrument packets, potential participants cited a busy schedule as the main reason. Of the 83 participants completing and returning instrument packets, 56 of them met the research criteria. Twenty-seven potential participants were excluded from the study because their child with congenital blindness had additional significant impairments other than blindness.

Packet Distribution

Family participants were mothers, fathers, or the primary caregivers of the child with congenital blindness. A primary care giver refers to the person who has legal guardianship and is responsible for the care and welfare of the child with congenital blindness.

Families were recruited with assistance from the previously mentioned sites. Once potential subjects had contacted the researcher, they were sent a participant packet. These packets contained a recruitment letter, the three survey instruments, including instructions for completion, a demographic survey, and a self-addressed stamped return envelope. Subjects had the option of declining to participate at any point.
Upon receiving the packet, participants were instructed to complete the three objective-type measures (FES, FSS, and FACES-II) and the demographic survey. The estimated time needed to complete all instruments was approximately 90 minutes. Participants returned survey materials to the researcher in the pre-addressed, postage-paid envelope.

The researcher used a coding system to organize, identify, and track the data as well as to aid in the follow-up process. The coding system functions were as follows: (a) sites were assigned a specific range of numbers (e.g., packets 1–25 were assigned to Clinic A) to assist in matching participant packets with the appropriate site; (b) each piece of material in the packet was also numbered to aid the researcher in the identification of data for each participating family; and (c) upon categorizing the data, packets were color-coded upon being returned to the researcher to indicate the family type (dark blue for no usable vision, gray/silver for usable vision, and salmon for full vision).

Follow-up

Confidentiality of participating respondents was always protected. In order to facilitate and expedite the follow-up process, the researcher kept a confidentially-coded master list (Appendix L) matching a participant name with a specific packet number (e.g., the Jones family, packet #2). The number code enabled the researcher to identify the participant to be contacted about the missing materials. Those participants who did not return whole packets were sent a reminder post-card (see
Appendix M) requesting them to return the completed packet of materials. They were also requested to get in touch with the researcher if they had either misplaced or lost their packets so that another packet could be substituted with the packet number previously assigned to them. They were also reminded that they would be compensated for their time with a $15.00 personal check from the researcher.

Agencies also requested participants to return completed survey packet materials to the researcher by sending them a similar reminder on the agency's own stationery (see Appendix N). This letter was also drafted by the researcher to help ensure correct and accurate wording and also save time and effort on the agency's part. When information was not forthcoming after 3 weeks, the researcher considered the participant a nonrespondent.

The researcher kept a confidentially coded master list matching a participant name with a specific packet number. In addition, the data collection instruments were also coded in the top right hand corner, and the codes were linked to the participant mailing list. Upon receiving each participant's completed packet, the researcher snipped the right hand corner from the instruments. By matching the corner codes of the instruments with the appropriate participant's name on the mailing list, the researcher had a record of replies received without having an identity attached to the data.
Research Design and Statistical Analysis

**Independent and Dependent Variables**

A quasi-control-experimental design was used to gather data. The independent variable was the type of family, differentiated by level of usable vision. The dependent variables were levels of family adaptability, cohesion, social family climate, (i.e., relationship domain, growth domain, and system maintenance domain) and satisfaction.

The variables of family climate were measured by the FES. The variables of adaptability and cohesion were measured by FACES II. Family satisfaction was measured by the FSS. These instruments were used to measure the nature of the relationships within and between grouped families, based on the previously mentioned variables.

Data were categorized according to predetermined groupings: families who had children who were legally blind with no usable vision, families with children who were legally blind with partial vision, and a control group with families who had children with full vision.

Chi-square tests were used to analyze the demographic data. The chi-square test statistic is the sum of the squares of the differences between the observed and expected frequencies, with each squared difference divided by the corresponding expected frequency. All testing was done with a 5% level of significance.
Responses to the surveys were examined using a Multifactor Analysis of Variance (MANOVA). A MANOVA is a "technique used for assessing group differences across multiple metric dependent variables simultaneously, based on a set of categorical (nonmetric) variables acting as independent variables" (MANOVA [definition of], 2002, ¶1). The researcher used a MANOVA to determine whether an overall difference existed between groups. The between group factor was family type (no usable vision vs. partial vision vs. full vision). The within-group factors were the subscales from the completed instruments (i.e., FACES-II, FSS, and FES). Particular emphasis was given to the statistically significant interactions, which denoted group by measure differences.

When statistically significant interactions existed on one or all of the analyses, a post hoc multiple comparison test was conducted. Post hoc multiple comparison tests maintain the Type I error ($\alpha < .05$) when a series of comparisons are made among sample means (Hinkle, Wiersma, & Jurs, 1988). The Tukey Student Standardized Range Test was conducted to denote which means were markedly different from the other means, to determine the specific nature of the relationship/relationships. The Tukey post hoc test tested whether the significant $F$ ratio was due to differences between pairs of means or perhaps to some more complex combinations of means (Hinkle et al., 1988).
Summary

Chapter III presented an outline of the methods which were to be used to answer the research problem posed in Chapter I. The independent variable was defined as the level of blindness and levels of this variable were discussed by describing the types of participating families. The dependant variables, adaptability, cohesion, social family climate and family satisfaction, were discussed by describing the procedures by which the variables would be measured. The steps in the development of the demographic instrument were described. A discussion of the various research instruments used in this study (FACES-II, FSS, FES, and a demographic survey) revealed the content and format of each of the instruments and the data analyses procedures utilized.

Chapter III also included a description of the data collection procedures and subject characteristics. Chi-squared tests were used to analyze the demographic data. Responses to the surveys were examined by using a MANOVA. The Tukey Student Standardized Range Test was conducted to denote which means were markedly different from the other means to determine which groups were significantly different on the dependent variables.

Results of the study are reported in Chapter IV, including a description of the demographics of each group. Chapter V will discuss the study findings, limitations of the study, and the implications of the findings for professionals working with families of children who are blind. Implications for future research will also be discussed.
CHAPTER IV

RESULTS

Introduction

Chapter IV presents the results of this research. Information regarding sample characteristics and the findings on hypotheses will be presented. In order to test the null hypotheses, mean scores were obtained for the three groups (i.e., No Vision, Partial Vision, and Full Vision) on the dependent variables of adaptability, cohesion, social family climate (i.e., relationship domain, growth domain, and system maintenance domain) and family satisfaction. The multivariate analyses of variance (MANOVA), univariate $F$ tests, group contrast analysis and post hoc tests (i.e., Tukey Student Standardized Range Test) were used to test for differences for main effects and interactions between groups (interdependent variables) on each of the dependent variables.

Description of Sample

Of the 56 participants, 16 were parents/caregivers of a child with no vision, 20 were parents/caregivers of a child with partial vision, and 20 were parents/caregivers of a child with full vision. Surveys were categorized into the "No Vision Group" when participants described their child as having total blindness, able to see light but unable to detect its source, or having some light perception. Surveys were
categorized into the “Partial Vision Group” when participants described their child as seeing shapes/shadows; able to see objects or bright colors; able to see objects/persons within 10 feet, but not recognize the fine details; or able to read large print or regular print when held close to the eye, but were classified as legally blind.

Demographic factors of the three groups were compared to determine similarity. Chi-square tests revealed no differences in marital status, ethnicity, participant’s visual impairment level, levels of education, residential area, and the number of persons living in the home ($p < .05$). The groups also did not differ in children’s gender or in the number of persons moving in or out of the home. Table 1 shows these demographic variables and the numbers and percentages of participants in each group.

Participants also reported impairment(s) in addition to visual impairment of child and family stressors occurring within the last year. Forty-four percent of the participants in the No Vision Group, 35% of participants in the Partial Vision group, and 40% of participants in the Full Vision group reported family stressors or additional impairments. Table 2 lists the impairments and stressors by groups. The groups differed on participants’ gender, relationship to child, and age; children’s level of blindness and number of siblings; and level of household income. Table 3 shows the cross tabulations, chi-square statistics, and levels of significance for the demographic variables that varied among the groups.
## Table 1

Demographic Variables Not Differing by Groups

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Full Vision</th>
<th>Partial Vision</th>
<th>No Vision</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married-Partnered</td>
<td>18</td>
<td>32.14</td>
<td>15</td>
<td>26.79</td>
</tr>
<tr>
<td>Single</td>
<td>0</td>
<td>0.00</td>
<td>2</td>
<td>3.57</td>
</tr>
<tr>
<td>Divorced</td>
<td>2</td>
<td>3.57</td>
<td>3</td>
<td>5.36</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>35.71</td>
<td>20</td>
<td>35.72</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>3</td>
<td>5.36</td>
<td>2</td>
<td>3.57</td>
</tr>
<tr>
<td>Asian-American</td>
<td>0</td>
<td>0.00</td>
<td>0</td>
<td>0.00</td>
</tr>
<tr>
<td>Caucasian</td>
<td>16</td>
<td>28.57</td>
<td>17</td>
<td>30.36</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0</td>
<td>0.00</td>
<td>1</td>
<td>1.79</td>
</tr>
<tr>
<td>International</td>
<td>1</td>
<td>1.79</td>
<td>0</td>
<td>0.00</td>
</tr>
<tr>
<td>Non-U.S. Resident</td>
<td>1</td>
<td>1.79</td>
<td>0</td>
<td>0.00</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>35.71</td>
<td>20</td>
<td>35.71</td>
</tr>
<tr>
<td><strong>Visual Impairment of Participant</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>17</td>
<td>30.91</td>
<td>18</td>
<td>32.73</td>
</tr>
<tr>
<td>Yes</td>
<td>3</td>
<td>5.45</td>
<td>2</td>
<td>3.64</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>36.36</td>
<td>20</td>
<td>36.36</td>
</tr>
<tr>
<td><strong>Participants' Level of Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>2</td>
<td>3.57</td>
<td>6</td>
<td>10.71</td>
</tr>
<tr>
<td>Some College/Associate's Degree</td>
<td>5</td>
<td>8.93</td>
<td>7</td>
<td>12.5</td>
</tr>
<tr>
<td>Undergraduate or Graduate Degree</td>
<td>13</td>
<td>23.21</td>
<td>7</td>
<td>12.5</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>35.71</td>
<td>20</td>
<td>35.71</td>
</tr>
<tr>
<td><strong>Gender of Participants' Children</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11</td>
<td>18.64</td>
<td>13</td>
<td>22.03</td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
<td>15.25</td>
<td>8</td>
<td>13.56</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>33.89</td>
<td>21</td>
<td>35.59</td>
</tr>
<tr>
<td><strong>Location of Residence</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>City</td>
<td>8</td>
<td>14.55</td>
<td>7</td>
<td>12.73</td>
</tr>
<tr>
<td>Suburban</td>
<td>10</td>
<td>18.18</td>
<td>9</td>
<td>16.36</td>
</tr>
<tr>
<td>Small town/Rural</td>
<td>1</td>
<td>1.82</td>
<td>4</td>
<td>7.27</td>
</tr>
<tr>
<td>Total</td>
<td>19</td>
<td>34.55</td>
<td>20</td>
<td>36.36</td>
</tr>
<tr>
<td><strong>Number of People Living in Residence</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>7.84</td>
<td>2</td>
<td>3.92</td>
</tr>
<tr>
<td>4</td>
<td>7</td>
<td>13.73</td>
<td>7</td>
<td>13.73</td>
</tr>
<tr>
<td>5</td>
<td>8</td>
<td>15.69</td>
<td>4</td>
<td>7.84</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>1.96</td>
<td>4</td>
<td>7.84</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>39.22</td>
<td>17</td>
<td>33.33</td>
</tr>
</tbody>
</table>
Table 1—Continued

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Full Vision</th>
<th>Partial Vision</th>
<th>No Vision</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Persons Moving In or</td>
<td>16</td>
<td>29.09</td>
<td>15</td>
<td>27.27</td>
</tr>
<tr>
<td>Out of Residence</td>
<td>4</td>
<td>7.27</td>
<td>5</td>
<td>9.09</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>36.36</td>
<td>20</td>
<td>36.36</td>
</tr>
</tbody>
</table>

a One participant had two children with Partial Vision: one girl and one boy.
b Three people from the Partial Vision group and two from the No Vision group did not answer this question.
c One person from the No Vision group did not respond to this question.

Analysis of the Dependent Variables

A MANOVA was conducted to determine if there were any differences or interactions on family functioning between family types (No Vision vs. Partial Vision vs. Full Vision) within groups on the levels of adaptability and cohesion, social family climate, and family satisfaction. To test for group differences in the mean scores for adaptability, cohesion, social family climate (i.e., relationship domain, growth domain, and system maintenance domain), and family satisfaction, a three-factor design was employed.

MANOVA results indicated whereas there were no statistically significant differences or interactions on family functioning between family types and within groups on the levels of adaptability, cohesion, and social family climate, there were statistically significant differences and interactions on family functioning between family types and within groups on the levels of family satisfaction. Table 4 provides the MANOVA summary for family satisfaction. Group contrast analysis indicated
significant interaction for family satisfaction, $F(1,53) = 6.38, p = .0146$. Univariate $F$
tests and Tukey post hoc tests revealed that the between family types and within
groups levels of family satisfaction were significantly lower ($p < .05$) for the no

Table 2

Reported Family Stressors and Additional Impairments

<table>
<thead>
<tr>
<th>Group</th>
<th>Participant</th>
<th>Family Stressor</th>
<th>Impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Vision</td>
<td>1</td>
<td>Grandfather diagnosed with prostate cancer</td>
<td>Overweight</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Aunt diagnosed with breast cancer</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mother in bed for 5 months due to pregnancy</td>
<td>Mild cerebral palsy</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Death of a close relative who had daily contact with child</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Mother underwent radiation treatment for pituitary tumor</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5</td>
<td></td>
<td>Left hemiparesis One leg shorter than other</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>Divorce (two years ago)</td>
<td></td>
</tr>
<tr>
<td>Partial Vision</td>
<td>1</td>
<td>Child's dog died</td>
<td>Albinism</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Child's uncle died</td>
<td>Mild developmental delay</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Grandfather diagnosed with Alzheimer's</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Death of grandmother</td>
<td>Knee surgery/abnormal knees and tissue damage</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Grandfather critically ill</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Grandmother ill</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5</td>
<td></td>
<td>Deaf in right ear</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>Child diagnosed with epilepsy</td>
<td>Mild cerebral palsy</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>Child’s uncle committed suicide</td>
<td></td>
</tr>
<tr>
<td>Full Vision</td>
<td>1</td>
<td>Divorce (within past 2 years)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2</td>
<td></td>
<td>Child may have neofibroid mitosis</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Death of uncle</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Massive TMJ problems for mother</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Divorce</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6</td>
<td></td>
<td>Mild mental impairment</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>Death of a relative</td>
<td></td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>Death of parent’s niece and death of premature son (within 4 year span)</td>
<td></td>
</tr>
</tbody>
</table>
### Table 3
Demographic Variables Differing by Groups

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Full Vision</th>
<th>Partial Vision</th>
<th>No Vision</th>
<th>Total</th>
<th>Chi-square</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>20 (5.71%)</td>
<td>19 (33.93%)</td>
<td>12 (21.43%)</td>
<td>51 (91.07%)</td>
<td>7.423</td>
<td>0.024*</td>
</tr>
<tr>
<td>Male</td>
<td>0 (0.00%)</td>
<td>1 (1.79%)</td>
<td>4 (7.14%)</td>
<td>5 (8.93%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>20 (5.17%)</td>
<td>20 (35.71%)</td>
<td>16 (28.57%)</td>
<td>56 (100.00%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relationship to Child</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>20 (5.71%)</td>
<td>18 (32.14%)</td>
<td>10 (17.86%)</td>
<td>48 (85.71%)</td>
<td>10.88</td>
<td>0.028*</td>
</tr>
<tr>
<td>Father</td>
<td>0 (0.00%)</td>
<td>1 (1.79%)</td>
<td>4 (7.14%)</td>
<td>5 (8.93%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grandparent</td>
<td>0 (0.00%)</td>
<td>1 (1.79%)</td>
<td>2 (3.57%)</td>
<td>3 (5.36%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>20 (35.71%)</td>
<td>20 (35.71%)</td>
<td>16 (28.57%)</td>
<td>56 (100.00%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age of Parent</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–28</td>
<td>0 (0.00%)</td>
<td>0 (0.00%)</td>
<td>1 (1.79%)</td>
<td>1 (1.79%)</td>
<td></td>
<td></td>
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<tr>
<td>28–38</td>
<td>11 (9.64%)</td>
<td>6 (10.71%)</td>
<td>2 (3.57%)</td>
<td>19 (33.93%)</td>
<td>15.98</td>
<td>0.014*</td>
</tr>
<tr>
<td>38–48</td>
<td>9 (16.07%)</td>
<td>14 (25.00%)</td>
<td>10 (17.86%)</td>
<td>33 (58.93%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Over 48</td>
<td>0 (0.00%)</td>
<td>0 (0.00%)</td>
<td>3 (5.36%)</td>
<td>3 (5.36%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>20 (35.71%)</td>
<td>20 (35.71%)</td>
<td>16 (28.57%)</td>
<td>56 (100.00%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Number of Siblings</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>0 (0.00%)</td>
<td>0 (0.00%)</td>
<td>1 (1.79%)</td>
<td>1 (1.79%)</td>
<td>24.24</td>
<td>0.005*</td>
</tr>
<tr>
<td>1</td>
<td>1 (1.79%)</td>
<td>13 (23.21%)</td>
<td>7 (12.50%)</td>
<td>21 (37.50%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>11 (19.64%)</td>
<td>11 (21.15%)</td>
<td>7 (12.50%)</td>
<td>19 (33.93%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>8 (14.29%)</td>
<td>6 (10.71%)</td>
<td>1 (1.79%)</td>
<td>15 (26.79%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>20 (35.71%)</td>
<td>20 (35.71%)</td>
<td>16 (28.57%)</td>
<td>56 (100.00%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Household Income</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$12,000</td>
<td>0 (0.00%)</td>
<td>0 (0.00%)</td>
<td>2 (3.85%)</td>
<td>2 (3.85%)</td>
<td>5.663</td>
<td>0.047*</td>
</tr>
<tr>
<td>$12,001–$24,000</td>
<td>2 (3.85%)</td>
<td>2 (3.85%)</td>
<td>0 (0.00%)</td>
<td>4 (7.69%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$24,001–$36,000</td>
<td>0 (0.00%)</td>
<td>3 (5.77%)</td>
<td>3 (5.77%)</td>
<td>6 (11.54%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$36,001–$48,000</td>
<td>1 (1.92%)</td>
<td>2 (3.85%)</td>
<td>4 (7.69%)</td>
<td>7 (13.46%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;$48,000</td>
<td>16 (30.77%)</td>
<td>11 (21.15%)</td>
<td>6 (11.54%)</td>
<td>33 (63.46%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>19 (36.54%)</td>
<td>18 (34.62%)</td>
<td>15 (28.85%)</td>
<td>52 (100.00%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*One participant from the Full Vision Group, 2 participants from the Partial Vision Group, and 1 participant from the No Vision Group did not answer this question.
vision group (group 1) than for the partial vision group (group 2) and full vision group (group 3). Table 5 presents the Tukey post hoc test findings for family satisfaction between groups.

Table 4
MANOVA Summary Table for Family Satisfaction

<table>
<thead>
<tr>
<th>Source of Variation</th>
<th>df</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>F</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between Groups</td>
<td>2</td>
<td>704.31</td>
<td>352.16</td>
<td>3.39</td>
<td>0.041</td>
</tr>
<tr>
<td>Within Groups</td>
<td>53</td>
<td>5511.69</td>
<td>103.99</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>6216.00</td>
<td>456.15</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 5
Tukey's Studentized Range Confidence Interval for Family Satisfaction

<table>
<thead>
<tr>
<th>Comparison</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full Vision versus Partial Vision</td>
<td>(-5.726, 9.826)</td>
</tr>
<tr>
<td>Full Vision versus No Vision</td>
<td>(0.390, 16.885)</td>
</tr>
<tr>
<td>Partial Vision versus No Vision</td>
<td>(-1.660, 14.835)</td>
</tr>
</tbody>
</table>

Table 6 presents group means and standard deviations for family satisfaction. Based on national norms, the mean parent score on the FSS is 47, corresponding to a 49–52 percentile rank. The No Vision group mean of 43 corresponds to a 31–34 percentile rank. The Partial Vision group mean of 50 corresponds to a 64 percentile rank. The Full Vision group mean of 52 corresponds to a 70–73 percentile rank (Olson & Wilson, 1992).
The other dependent variables (i.e., adaptability, cohesion, relationship growth, personal growth, and system maintenance) did not significantly differ by groups. Table 7 presents the MANOVA summaries for the $F$ statistic and corresponding level of significance for the nonsignificant dependent variables.

### Table 6

**Group Means and Standard Deviations for Family Satisfaction**

<table>
<thead>
<tr>
<th>Group</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Vision, $n = 16$</td>
<td>43.06</td>
<td>11.21</td>
</tr>
<tr>
<td>Partial Vision, $n = 20$</td>
<td>49.65</td>
<td>8.96</td>
</tr>
<tr>
<td>Full Vision, $n = 20$</td>
<td>51.70</td>
<td>10.51</td>
</tr>
</tbody>
</table>

### Table 7

**MANOVA Summary Table for Nonsignificant Dependent Variables**

<table>
<thead>
<tr>
<th>Source of Variation</th>
<th>$df$</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>$F$</th>
<th>$p$-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adaptability</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>2</td>
<td>74.70</td>
<td>37.35</td>
<td>0.71</td>
<td>.50</td>
</tr>
<tr>
<td>Within Groups</td>
<td>53</td>
<td>2777.18</td>
<td>52.39</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>2851.88</td>
<td>89.74</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cohesion</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>2</td>
<td>238.77</td>
<td>119.39</td>
<td>1.43</td>
<td>.25</td>
</tr>
<tr>
<td>Within Groups</td>
<td>53</td>
<td>4428.18</td>
<td>83.55</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>4666.96</td>
<td>202.94</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>FES - Relationship</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>2</td>
<td>16.92</td>
<td>8.46</td>
<td>1.57</td>
<td>.22</td>
</tr>
<tr>
<td>Within Groups</td>
<td>53</td>
<td>548.50</td>
<td>10.34</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>565.42</td>
<td>18.80</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>FES - Personal Growth</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>2</td>
<td>52.25</td>
<td>26.12</td>
<td>1.57</td>
<td>.22</td>
</tr>
<tr>
<td>Within Groups</td>
<td>53</td>
<td>881.30</td>
<td>16.63</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>933.55</td>
<td>32.75</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>FES - System Maintenance</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>2</td>
<td>8.60</td>
<td>4.30</td>
<td>3.39</td>
<td>.67</td>
</tr>
<tr>
<td>Within Groups</td>
<td>53</td>
<td>559.23</td>
<td>10.55</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>567.83</td>
<td>14.85</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 8 presents the group means and standard deviations for family adaptability and cohesion, and family environment. According the Circumplex Model, the cohesion and adaptability means describe flexibly connected families that are moderately balanced. The group means for relationship, personal growth, and system maintenance domains of family environment are higher than those reported for national samples (i.e., 15.45, 27.77, 9.73, respectively) (Moos & Moos, 1994).

### Table 8

<table>
<thead>
<tr>
<th>Group</th>
<th>Univariate F Statistics</th>
<th>No Vision N = 16</th>
<th>Usable Vision N = 20</th>
<th>Full Vision N = 20</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>Family Adaptability</td>
<td></td>
<td>46.22</td>
<td>7.19</td>
<td>46.45</td>
</tr>
<tr>
<td>Family Cohesion</td>
<td></td>
<td>62.13</td>
<td>9.75</td>
<td>63.30</td>
</tr>
<tr>
<td>Family Environment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship</td>
<td></td>
<td>16.75</td>
<td>3.32</td>
<td>15.55</td>
</tr>
<tr>
<td>Personal Growth</td>
<td></td>
<td>28.38</td>
<td>4.12</td>
<td>30.75</td>
</tr>
<tr>
<td>System Maintenance</td>
<td></td>
<td>10.69</td>
<td>3.53</td>
<td>11.50</td>
</tr>
</tbody>
</table>

The study hypotheses were as follows:

1a. There is no difference in the level of adaptability or the level of cohesion between types of family (family of a child with partial vision vs. family of a child with no vision vs. family of a child with full vision).
1b. There is no difference within groups on the level of adaptability and the level of cohesion (family with a child with partial vision vs. family with a child with no vision vs. family with a child with full vision).

1c. There is no interaction between the levels of adaptability and the level of cohesion and the type of family (family with a child with partial vision vs. family of a child with no vision vs. family of a child with full vision).

2a. There is no difference in the level of family satisfaction between the types of family (family of a child with partial vision vs. family of a child with no vision vs. family of a child with full vision).

2b. There is no difference within groups on the level of family satisfaction. (family with a child with partial vision vs. family of a child with no vision vs. family with a child with full vision).

2c. There is no interaction between the level of family satisfaction and the type of family (family with a child with partial vision vs. family of a child with no vision vs. family with a child with full vision).

3a. There is no difference in the level of social family climate between the types of families (family with a child with partial vision vs. family of a child with no vision vs. family with a child with full vision).

3b. There is no difference within groups on the level of social family climate. (family with a child with partial vision vs. family of a child with no vision vs. family with a child with full vision).
3c. There is no interaction between the level of social family climate and the
type of family (family with a child with partial vision vs. family of a child with no
vision vs. family with a child with full vision).

The null hypotheses 1a, 1b, and 1c and 3a, 3b, and 3c were accepted because
no differences were found between or among groups and no interaction effects were
found. The null hypotheses 2a, 2b, and 2c were rejected, because they were
statistically significant indicating that differences were found between or among
groups and interaction effects were found among groups.

Summary

A MANOVA was computed for the three hypotheses to determine statistical
significance. Two research hypotheses were accepted (no significant differences
within and between groups on the variables of adaptability, cohesion, and social
family climate) and one hypothesis on family satisfaction was rejected because a
significant difference within groups and between groups was found. Univariate $F$
tests, group contrast analysis and post hoc test (the Tukey Student Standardized
Range test) were conducted to determine which groups differed and interacted
significantly on the variable family satisfaction.

Chapter V will discuss the statistical findings and limitations of this study.
Recommendations for professionals who work with families of children who are
blind, and implications for future research will also be discussed.
CHAPTER V

DISCUSSION

Little research relating to blindness and its effects on the family exists. Much of this research has mainly focused on the mother’s perspective of parenting a visually impaired child (Hancock et al., 1990; Herring, 1996; Scott et al., 1985). Studies to date still focus largely on individual family members rather than focusing on the child with congenital blindness within the context of the family. A family systems perspective allows researchers to examine a number of variables contributing to change within the system, as well as change between the system and the environment. This present study was an attempt to enlarge the scope of research in this area to include an examination of the impact of blindness on family adaptability, family cohesion, social family climate, and family satisfaction.

To investigate how congenital blindness influences family functioning and interaction, a sample was recruited from southern Michigan with the help of low vision clinics, service providing groups, various ISDs and RESAs, Michigan School for the Blind, Commission for the Blind, and other related clubs and organizations. To determine within and between group differences, participants were divided into three groups according to the child’s level of vision. Participants completed a demographic questionnaire and three instruments measuring family functioning. The following discussion addresses the similarities and dissimilarities of the groups’
demographic variables, and the results of the statistical tests. Limitations of the research, implications for practitioners, and future research are then considered.

Demographic Characteristics

Demographic variables of the three groups were compared to determine similarity of the sample across groups. The goal of the research was to have homogenous groups except for the variability in the level of a child's vision in order to compare group responses to the dependent variables. The groups were similar across eight demographic variables and different across five demographic variables. The small sample size and the resulting chi-square values do not permit a conclusive interpretation of the observed differences and similarities in demographics and their relationship to the dependent variables. However, results of the study are intriguing in that the groups differed on one dependent variable and not the others.

Group Similarities

Participants were homogeneous in ethnicity, residential location, levels of education, visual impairment level, marital status, child’s gender, number of persons living in the home, and the number of persons moving in or out of the home. A majority ($n = 46, 82\%$) of the respondents were white. A more ethnically diverse sample may have resulted in other demographic differences and perhaps observed differences in adaptability, cohesion, social family climate and satisfaction given
varying cultural beliefs, family constellations, traditions, roles, expectations, and attitudes regarding blindness and other disabilities.

Another factor that may have influenced the results of this study was the residential location of the participants. Most of the participants lived in suburban areas and were middle class. A sample with more city or rural representation may have resulted in differences in social family climate, given greater or lesser opportunities for family leisure and cultural activities.

Over 80% of participants had some college education or more. Education may have played a role in the families' adaptation to having a child with impaired vision. Education may have positively influenced family problem-solving skills, communication, and empathy in order to deal with therapeutic, medical, social, cognitive, and educational issues concerning their child with a visual impairment (Bolinger & Bolinger 1996; Danek 1988; Dote-Kwan & Hughes, 1994; Herring, 1996; Nixon, 1994).

Group Differences

Groups differed on the variables of participants' gender, relationship to the child, age, number of children, and level of household income. Only females were represented in the Full Vision group, while 25% of the No Vision group was male. Though mothers and fathers may share similarities in how they react to having a child with congenital blindness, there are some noted differences that may be related to gender. Gayton et al. (1977) suggested that a great deal of stress, financial
responsibilities, and emotional disturbances that some fathers experience may be highly related to the fathers' role as the primary economic provider. Meanwhile, mothers may feel overburdened by the amount of time devoted to the child who is blind while also attempting to meet other children's needs and finding quality time to be with their husbands. These gender-related stressors may affect level of family satisfaction and could be contributing factors toward participants' lower family satisfaction in the No Vision group (Ayrault, 1977; Bauman & Yoder, 1966; Breslau, 1983; Cummings et al., 1966; Parker et al., 1989).

The groups showed significant difference in the age of participant. Forty-five percent of participants in the Full Vision group, 70% of participants in the Partial Vision group, and 81% of participants in the No Vision group were 38 or older. The No Vision Group was the only group to have a participant under age 28 and to have participants over the age of 48. The difference in age may account for the Full Vision and Partial Vision group participants feeling more satisfied than the parents in the No Vision group (Bolinger & Bolinger 1996; Danek 1988; Dote-Kwan & Hughes, 1994; Herring, 1996; Nixon, 1994).

Interaction between the participant relationship to the child with congenital blindness and the level of family satisfaction may also exist. The Full Vision group was the only group to have all mothers as participants. Perhaps mothers in the No Vision group experienced greater dissatisfaction than those in the other groups due to the stress and burden of being primary caregivers (Ayrault, 1977; Bauman & Yoder, 1966; Breslau, 1983; Cummings et al., 1966; Parker et al., 1989). Gayton
et al. (1977) point out that fathers may also experience greater stress as a result of additional care for a child who is disabled which could lower the level of satisfaction. On the other hand, Floyd and Gallagher (1997) suggest that fathers are less stressed than mothers, since they have fewer responsibility for direct child care and household demands. Grandparents may be directly involved with caring for the child with congenital blindness or may be more of a support to the family and not directly involved in the care of the child. Thus, the nature of the grandparent role could affect the level of family satisfaction among groups.

It is possible that the number of siblings in the family may have indirectly affected the level of family satisfaction among groups, particularly in the No Vision and Full Vision groups. Gath (1972) and Grossman (1972) noted that siblings of a child with a disability were most dissatisfied in families with two or fewer siblings. The majority of the participants \( n = 14, 88\% \) in the No Vision group reported having two or fewer siblings in their families, whereas the majority of participants in the Partial Vision and Full Vision groups reported having two or more siblings in their families. Perhaps participants in the No Vision group felt most dissatisfied because of having fewer siblings to share the additional care-taking responsibilities required by a child with congenital blindness. In such cases, siblings often report feeling resentful and overwhelmed. Also, a lack of quality time with parents and the entire family can result in siblings feeling neglected (Bolinger & Bolinger, 1996; Foster et al., 2001). The child who is blind often receives the majority of the attention within the family, potentially leading to stress, resentment, and feelings of
neglect in sighted siblings (Corea et al., 1986). Negative sibling reactions may have contributed to the lower level of family satisfaction in the No Vision group.

It is possible that interaction between the level of household income and the level of family satisfaction exists. Eighty-four percent of participants in the Full Vision, 61% of participants in the Partial Vision, and 40% of participants in the No Vision group reported annual incomes over $48,000, slightly higher than the $43,066 median household income in Michigan for 1997–1999 (Northeast-Midwest Institute, 2001). Financial strain may not be as prevalent in the Full Vision and Partial Vision groups as in the No Vision group. Children with partial vision may have more opportunities than children with no vision to receive adaptive devices and toys and to be involved with the family in cultural or leisure activities, as well as more opportunities for personal growth through extracurricular activities such as music or dance lessons. The potential for these opportunities would also apply to the children of parents in the Full Vision group. Even if incomes were similar, participants in the No Vision group may be under greater stress due to financial difficulties, given that a child with congenital blindness requires additional medical and personal care. In addition, these parents may accrue expenses by purchasing adaptive aids and equipment to help their children with congenital blindness function at the maximum level of independence. Parents have reported experiencing financial stress and feeling inadequate to meet the needs of a children with a visual impairment (Leyser et al., 1996), which may account for the lower level of satisfaction in the No Vision Group.
Findings

Three null hypotheses were developed to test the following research questions: (a) Does having a child with congenital blindness affect family adaptability and cohesion? (b) Does having a child with congenital blindness affect family satisfaction? and (c) Does having a child with congenital blindness affect social family climate?

A significant difference was noted among the means of the three groups on the level of satisfaction. The largest difference was seen between the Full Vision and No Vision groups. It is possible that the large number of females responding in this study could have strongly contributed to the low level of satisfaction between groups. It is possible that the viewpoints and perceptions of the participants were based on perspectives related to feminine roles in the family. In many instances, the mother is expected to maintain the home while caring for the children. She may become dissatisfied as a result of the stressors becoming too demanding. If both parents are employed, further strain may be placed on one spouse to care for the children, adding even more frustration to the situation. Perhaps the Full Vision families had less stressors in not having a child with congenital blindness for whom to care. Much added time is need in raising a child who is blind. A great amount of time spent in helping children develop cognitive, social and daily living skills, as teaching and learning require "hands-on" experiences, detailed verbal descriptions and repetition of tasks for mastery. These necessities can lead to dissatisfaction among spouses and siblings as time is taken from meeting their unique needs.
Some parents are burdened with financial limitations that can drastically affect family functioning (Leyser et al., 1996). The participants in the No Vision group reported annual incomes below the Michigan median, whereas the participants in the Partial and Full Vision groups reported annual incomes above the Michigan median. The difference in income among these groups may account for the difference in levels of family satisfaction. It is common for parents of a child with congenital blindness to report feeling dissatisfied with family life due to concerns over meeting the expenses related to the child's congenital blindness (Froyd, 1973; Herring, 1996; Leyser et al., 1996).

No significant differences were found in the level of adaptation among the No Vision, Partial Vision, and Full Vision groups. Perhaps level of education, income, coping strategies, and informal and formal support systems enabled participants to respond to new roles and circumstances, such as a child's vision difficulties, with flexibility. No significant difference was found on the level of cohesion between and within groups. It appears that these families might engage in various activities as a family and support one another in time of need. Such cohesion supports problem-solving and open communication when addressing medical, social, cognitive, and educational issues concerning their child with a visual impairment (Bolinger & Bolinger 1996; Danek 1988; Dote-Kwan & Hughes, 1994; Herring, 1996; Nixon, 1994).

No significant differences were found between or among groups in any of the domains of family environment: relationship, personal growth, and system
maintenance. The three groups are similar in how they describe the social climate or family environment of their families. This lack of difference may be due to demographic similarities, such as level of education. In other studies, scores on the FES (which combine with scores on expressiveness and conflict make up the relationship domain) were correlated with cohesion scores on FACES-II (see Moos & Moos, 1994).

Limitations of Study

Caution is advised in interpreting the results of this study due to four primary limitations. First, the sample size was small, even after concerted efforts were made over the course of a year to recruit participants. Although the use of a MANOVA was possible with the size of sample obtained, large differences in-group means would have been necessary to reject the null hypotheses. The small sample size did not allow for consideration of gender, racial, or cultural variations. Moreover, a lack of demographic homogeneity in the sample means that any observed differences and lack of differences in the dependent variables cannot be clearly explained by level of children's vision.

Second, having a much better representation of other cultures could have made a difference in how the results were presented in the areas of adaptability, cohesion, social family climate, and satisfaction. Cultures in which the emphasis is on group support and the family being the most important concern over the individual's concern could have produced higher levels of cohesion and adaptability.
within these families (Alston et al., 1994; Utley & Marion, 1984). Satisfaction could also be greater due to cultural attitudes regarding disability, stigma of having a child with congenital blindness, or, in some families, acceptance of the child with congenital blindness as God's will or Divine intervention.

Third, the instrumentation also posed a problem for interpretation. The section of the demographic questionnaire that containing a question relating to the child's level of blindness was confusing to some participants. Many of the participants from the Full Vision group failed to respond because they felt this question did not apply to their children. A separate question inquiring about children having full vision would have added clarity to this section. The FES was long and could have prevented some participants from completing it or even deciding to complete the packet of instruments, thus affecting sample size. Some participants also indicated confusion over whether to respond to the questions in the instruments as they perceived the family or to respond as they believed their child viewed the family.

Finally, it was extremely difficult to find participants who had children with no additional disabilities other than blindness. Blindness is a low incidence disability; affecting less than 0.1% of the total school-age population of children (Dote-Kwan et al., 1997); therefore, there are only a small number of children who are legally blind as compared to children having other types of disabilities. The number of children who are blind without any additional impairment is even smaller, making it very difficult to find children who are visually impaired and have no additional
impairments (Froyd, 1973). Several potential participants who would have qualified for this study did not meet the requirements due to the fact that their child with congenital blindness had severe physical or mental impairments or both. The researcher included some children with mild additional physical, emotional, and educational impairments in order to meet sample size requirements. It is possible that these additional impairments affected the dependent variables.

Implications for Professionals

Many professionals may wish to become involved in working with families of children who are blind but lack the knowledge and insight concerning the dynamics of blindness and how it impacts family functioning and interaction. Furthermore, they may lack awareness of how to obtain resources that could help them to better understand how family members initially react to the birth of a child who is blind, how to assist parents in helping the infant or toddler to achieve developmental milestones, and how to help parents and family members to work with the child to develop cognitive, social, daily living, and education skills. Professionals who are unfamiliar with visual impairment are also in need of resources that provide information about limitations imposed by various visual conditions that affect not only the child who is blind but also the family system as a whole. Professionals may feel inadequate about how to tailor various interventions to the unique needs of these families that could help families gain control and equilibrium. It is hoped that this research will provide some helpful information that will assist professionals in
their work with such families and give better insight into the unique dynamics and needs of such families.

The birth of a child who is blind can be very devastating to parents and other family members. Some authors have indicated that professionals fail to offer support and often provide the parents with incomplete or incorrect information (Cohen et al., 1992; Gardner, 1982; Herring, 1996; Leyser et al., 1996; Scott et al., 1985; Tröster, 2000). Family members often feel overwhelmed and isolated as they attempt to cope with this traumatic situation. One way that family therapists can help these families is to provide counseling, support, and interventions that will help them to work through a grieving process.

Parents of children with congenital blindness are faced with additional challenges in helping their children reach crucial developmental stages. Many parents are at a loss of how to go about assisting their children to accomplish tasks (e.g., identifying and reaching for objects, crawling, walking, searching for objects) that enable them to work through various stages of development. Early intervention from family therapists and other professionals is essential to provide parents with adaptive techniques, strategies and resources. Engaging in such learning can enhance family cohesion and adaptability. It may also address the stress mothers experience who are generally the care provider for the child with congenital blindness. Intervening early in the adaptation process may also provide the opportunity to address family satisfaction.
Mental health professionals, ophthalmologists, low vision specialists and rehabilitation counselors could benefit from this research by becoming more sensitive to the potential impact of a child with congenital blindness on family satisfaction. Addressing family satisfaction would enable professionals to view the child and family holistically as they offer their expertise and rehabilitative interventions to help the child to maximize potential capabilities.

Potential areas for professionals to address are grief, financial strain, social support, and limited time for personal needs. For example, low vision specialists could be sensitive to the type of low vision aid that are prescribed and what not to prescribe in situations where the parents or the child have not reached a point of accepting the visual impairment. Some parents of children with partial vision tend to underestimate their child’s level of vision and accompanying assets and limitations. In doing so, they may place too much pressure on the child and feel uncertain as to what demands to make of the child (Tröster, 2000). The low vision specialist could help family adaptation, cohesion, and satisfaction by taking the time to communicate and listen empathically to both the parent and child and by offering support, suggestions, and possible low vision rehabilitation that take into account each family’s particular situation.

As professionals become more aware of the unique needs of families of children with congenital blindness, programs and interventions could be tailored to improve the level of family satisfaction. Professionals and family members could explore what types of programs would add to their experiences of satisfaction (e.g., respite care, increased financial
resources, parent support groups). On an individual family level, professionals can explore family adaptability, cohesion, social family climate, and satisfaction in order to enhance family interactions and positive coping patterns (Brett, 1988; Foster et al., 2001; Porter & McKenzie, 2000).

**Future Research**

Future research assessing functioning of families having children with congenital blindness needs to address the difficulty in obtaining adequate samples of children without additional major impairments. To obtain a larger sample, recruitment efforts may need to occur within multiple states and/or include participant families having children up to 18 years of age. Qualitative studies may also provide a means by which researchers learn more about the perceived impact of a child with congenital blindness on family functioning. Such studies would allow families to answer questions in a less structured, more informal and conversational manner. Using short, open-ended questions that inquired about attitudes, most difficult coping areas, major concerns, relationships between siblings, and the blind child and family strengths would also provide more specific insight into the impact of the variables on satisfaction. Financial limitations experienced by this researcher may be overcome by the acquisition of grant monies to support travel and more extensive recruitment efforts. Providing clear and explicit directions participants regarding whose perspective (child’s vs. parent’s) to use when completing the instruments may help to alleviate some confusion.
Future studies should focus on the comparison between children with partial vision (i.e., 20/70 to 20/200) and those who are legally blind with usable vision (i.e., object perception to 20/200) in order to determine how the problems they experience are similar or dissimilar to one another. Such information would provide mental health professionals, low vision specialists, teachers, parents and significant others who interact with these children additional knowledge and better direction as to how modifications of interventions may be made according to the level of personal, social, and academic functioning. Having an understanding of how family variables (i.e., cohesion, adaptability, social family climate, and family satisfaction) impact family functioning and interaction in families of children with congenital blindness will help professionals and clinicians to be more confident and qualified to develop programs, tailor interventions, and identify available resources to assist families in achieving their quality of life (Foster et al., 2001). A family systems approach also provides the tools for assessing the level of family functioning. It may also assist in determining helpful intervention strategies for family subsystems, thereby improving family interactions and coping (Brett, 1988; Porter & McKenzie, 2000).

Summary

The purpose of this study was to examine the impact of blindness on family adaptability, cohesion, social family climate, and satisfaction. In addition, the researcher examined how adaptability, cohesion, and social family climate were related to satisfaction
in families with children who are congenitally blind. To determine within group and between group variances, participants were divided into three groups: (1) families having children who are congenitally blind with no usable vision, (2) families having children who are congenitally blind with usable vision, and (3) families having children who are fully sighted. The variables of social family climate was measured by the Family Environment Scale (FES). The variables of adaptability and cohesion were measured by the Family Adaptability and Cohesion Evaluation Scales II (FACES II). The variable of satisfaction was measured by the Family Satisfaction Scale (FSS).

MANOVA and follow-up tests revealed that groups differed in the levels of family satisfaction but were similar on the variables of adaptability, cohesion, and social family climate. Chi-square analyses revealed that these groups were similar in marital status, ethnicity, participant’s visual impairment level, and levels of education, residential area, number of persons living in the home, child’s gender, and the number of persons moving in or out of the home. Chi-square results also indicated that the groups differed on the variables of gender of the participant, participant’s relationship to the child, participant’s age, the number of siblings, and the level of household income. Limitations of this study were related to a small sample, limited ethnic diversity, participant difficulties with interpreting instruments, and difficulty recruiting families of children with congenital blindness without additional impairments.

Implications for professionals and clinicians who work with families of children with congenital blindness were discussed. Suggestions were offered about ways to address the unique needs of these families, including grief counseling, early
intervention, family counseling, respite care, financial resources, and parent support
groups. The importance of implementing interventions that could increase the level
of family satisfaction were also discussed. Finally, recommendations for improving
this research were given, and future research recommendations were presented.
Appendix A

Human Subjects Institutional Review Board
Letter of Approval
Date: 25 September 2000

To: Karen Blaisure, Principal Investigator
   Pamela Berryman, Student Investigator for dissertation.

From: Sylvia Culp, Chair

Re: HSIRB Project Number: 00-08-09

This letter will serve as confirmation that your research project entitled "The Impact of Congenitally Blind Children upon Family Functioning and Interaction" has been approved under the expedited category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may only conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: 1 September 2001
Appendix B

Circumplex Model of Marital and Family Systems
In plotting the couple or family into the Circumplex Model, mark the specific location that most accurately reflects the actual scores.

---

Family Social Science
290 McNeal Hall, University of Minnesota, St. Paul, MN 55108

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Appendix C

Permission to Use Family Adaptability and Cohesion Evaluation Scales and Family Satisfaction Scale
Permission to Use Family Inventories

I am pleased to give you permission to use the instruments included in the Family Inventories Manual. You may have my permission to duplicate these materials for your clinical work, teaching, or research project. You can either duplicate the materials directly from the manual or have them retyped for use in a new format. If they are retyped, acknowledgements should be given regarding the name of the instrument, developers' names, the University of Minnesota, and Life Innovations.

In exchange for providing this permission, we would appreciate a copy of any papers, thesis, or reports that you complete using these Inventories. This will help us in staying abreast of the most recent development and research with these scales.

In closing, I hope you find the Family Inventories of value in your work with couples and families. I would appreciate feedback regarding how these instruments are used and how well they are working for you.

Sincerely,

David H. Olson, Ph.D.
Appendix D

Permission to Use the Family Environment Scale
Dear Ms. Berryman,

This letter is to verify that we Consulting Psychologists Press have authorized you to purchase and administer the Family Environment Scale by Rudolf H. Moos and Bernice S. Moos for your dissertation.

Sincerely,

Rachel Birkenseer
Customer Relations Advisor
Consulting Psychologists Press
800-624-1765
INVOICE

Consulting Psychologists Press, Inc.
Davies-Black Publishing
3803 Y handful Ave. P.O. Box 10396 P.O. Box 49156
San Jose, CA 95161-9156
(650) 969-8901 (800) 624-1765 Fax (650) 969-8608

INVOICE: IN 407319
INVOICE DATES: 01/03/01 - 01/23/01
DUE DATE:

TERMS: MasterCard Prepayment

BILL TO: PAMELA BERRYMAN

SHIP TO: PAMELA BERRYMAN

ORDER: 362556
ORDER DATE: 05/23/01
CUSTOMER PO:
CARRIER:
FREIGHT TERMS: FEDEX PRIORITY

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DAVIES-BLACK PUBLISHING
PO BOX 49156
SAN JOSE, CA 95161-9156
USA

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GROSS AMOUNT: 90.30
INVOICE DISCOUNT: 0.00
NET AMOUNT: 90.30
TAX AMOUNT: 0.00
DOWN PAYMENT: 90.30
NET AMOUNT DUE: 0.00

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Please see back for return information.

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Visit our website at www.cpp-db.com

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Please see terms and conditions enclosed.

** Returns must be accompanied by a copy of the CPP Packing List. Please see back for return information.**

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Appendix E

Demographic Survey
THE IMPACT OF A CONGENITALLY BLIND CHILD UPON FAMILY FUNCTIONING AND INTERACTION

Pamela S. Berryman

Instructions
One parent or caregiver is asked to fill out this survey.

I. Information about you (circle one):
   Male
   Female

   A. Circle the box that describes how you are related to the child:
      a) Mother
      b) Father
      c) Grandparent
      d) Other (Please describe) _______________________________

   B. Circle the age group closest to your age:
      a) 18 – 28
      b) 28 – 38
      c) 38 – 48
      d) Over 48

   C. Circle the letter that best describes your marital status:
      a) Married/Partnered
      b) Single
      c) Divorced
      d) Widowed

   D. Circle the letter that best represents your ethnicity (race).
      a) African-American
      b) Alaskan Native
      c) American Indian
      d) Asian-American
      e) Caucasian (White)
      f) Hispanic
      g) International/Non-U.S. Resident
      h) Multiracial
      i) Pacific Islander
      j) Other __________

   E. Do you have a visual impairment?
      a) Yes
      b) No

If you answered yes, briefly explain how your impairment affects your day-to-day life:

__________________________________________________________________________
F. Please circle the letter that best describes your highest level of education:
   a) Elementary school
   b) Middle school/Junior high school
   c) High school
   d) Some college
   e) Associate degree
   f) Undergraduate degree
   g) Graduate degree or higher

   If employed, please provide your job title: ________________________________

II. Information about your child with a visual impairment:
   A. Is the child with the visual impairment (circle one):
      a) Male
      b) Female

   B. What is the age of the visually impaired child? ______________________
      At what age was your child first diagnosed with a visual impairment? _______

   C. What is the level of blindness of the visually impaired child? Circle the Level that is closest to your child's degree of vision.

      **Level I: NO USEFUL VISION**
      Unable to see light; able to detect light in a room but unable to determine its source; bumps into objects when moving about the house; requires a white cane when traveling outdoors.

      **Level II: SOME USEFUL VISION**
      Able to see shapes/shadows but not identify the object; able to see bright colors; able to read large print; uses a white cane when traveling in specific situations (e.g., crowded mall, crossing streets, poorly lit areas); able to travel without a white cane or assistance from a sighted person.

      **Level III: FULL VISION**

   D. Does the child with the visual impairment have any other physical, medical or educational impairments?
      a) Yes
      b) No

   If YES, please note when the disability was diagnosed and briefly explain the nature of the impairment:

   __________________________________________________________________________
   __________________________________________________________________________
III. Information about your family:
A. Circle the letter that best describes the area your home is located in:
   a) City
   b) Suburban
   c) Small town/Rural

B. Please indicate how many people live in your home: _______________________

In the table below, please note the age and gender of any children (other than the child with the visual impairment). Also, list any physical, educational or medical impairments a sibling experiences, if any.

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C. Circle the most applicable annual household income
   a) Less than $12,000
   b) $12,001 - $24,000
   c) $24,001 - $36,000
   d) $36,001 - $48,000
   e) $48,001 or more

D. Has there been any death, divorce, or major illness in the family within the last year? Please discuss briefly.
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

E. Has any one moved in or out of the home in the past year?
   a) Yes
   b) No

If yes, please discuss briefly how this has affected the family.
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
Appendix F

Participant Recruitment Letter
Western Michigan University
Department of Family and Consumer Sciences and
Department of Counselor Education and Counseling Psychology
Principal Investigator: Karen Blaisure
Student Investigator: Pamela Berryman

You are invited to participate in a research project entitled, "The Impact of Congenitally Blind Children upon Family Functioning and Interaction" designed to provide useful insight into how families with children having congenital blindness adapt and function despite their difficulties. Study findings would result in increased insight for professionals who work with families such as yours. Results would also provide a clearer understanding of family strengths that enable or enhance positive adjustments. It is being conducted by Dr. Karen Blaisure and Pamela S. Berryman from Western Michigan University, Department of Family and Consumer Sciences. This research is being conducted as part of the dissertation requirements for Pamela S. Berryman.

The study consists of four surveys:
- The first asks for a true or false response to 90 questions, and will take approximately 30 minutes.
- The second asks for a response to 30 questions on a scale of 1 (almost never) to 5 (almost always) and will take approximately 20 minutes.
- The third asks for a response to 14 questions on a scale of 1 (dissatisfied) to 5 (extremely dissatisfied) and will take approximately 10 minutes.
- The fourth asks for responses to 21 multiple choice or fill in the blank question and will take approximately 15 minutes.

The total response time should be approximately one hour and 15 minutes.

Your replies will be completely anonymous, so do not put your name anywhere on the forms. You may choose not to answer any question and simply leave it blank. Returning the surveys indicates your consent for use of any of the answers you supply.

If you choose not to participate in this survey, you may either return the blank surveys in the enclosed postage-paid envelope or discard them.

If you have any questions, you may contact Dr. Karen Blaisure at (616) 387-3663, Pamela S. Berryman at (616) 353-1001, e-mail at 98berryman@wmich.edu, the Human Subjects Institutional Review Board at (616) 387-8293 or the vice president for research at (616) 387-8298.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board as indicated by the stamped date and signature of the board chair in the upper right corner. You should not participate in this project if the corner does not have a stamped date and signature.
Appendix G

Telephone Script
Telephone Script

Receptionist: “This is ________ agency how may I direct your call?”

Pamela: “This is Pamela Berryman calling from WMU. I would like to speak with someone concerning your agency’s participation in my doctoral dissertation research project. Who would that be?”

Receptionist: “That would be Dr. _______. Just one moment, please. I’ll see if she is available…. Go ahead please.”

Pamela: “Hello Dr. _______, this is Pamela Berryman. I’m a doctoral candidate at WMU, working on my dissertation, The Impact of Congenitally Blind Children on Family Functioning and Interaction.

Dr. ____:

Pamela:

Dr. ____:

Pamela:

Dr. ____:

Pamela:

Dr. ____:

Pamela: Thank you for your time. You will be receiving the information packet in the mail within a couple of weeks.
July 13, 2001

Dr. XYZ, M.D.
1234 Michigan Avenue
Kalamazoo, MI 49001

Dear Dr. XYZ:

I am a visually impaired Doctoral Candidate at Western Michigan University. I am requesting your participation in my Doctoral Dissertation Research - The Impact of Congenitally Blind Children upon Family Functioning and Interaction. The study entails parents/caregivers of children who are legally blind and a control group of parents/caregivers of children who are fully sighted, completing three objective type instruments, Family Environment Scale (FES); Family Satisfaction Scale (FSS); and Family Adaptation and Cohesion Evaluation Scale II, (FACES-II), as well as a Demographic Survey.

I would greatly appreciate your willingness to assist in the recruitment of subjects (parents/caregivers of legally blind children and parents/caregivers of fully sighted children) by:

1. distributing flyers compiled by this researcher or sharing information verbally to potential families, and
2. requesting those who are interested to contact the researcher by letter or phone.

If you are interested in participating in this study, please feel free to use or modify the sample reply letter enclosed for your convenience. Due to the time frame set by the Human Subjects Institutional Review Board (HSIRB) and my dissertation committee, I would like to receive your response at your earliest convenience within the next two weeks.

If you have any questions, you may contact me at (616) 353-1001 or e-mail me at 98berryman@wmich.edu. You may also contact my Major Advisor, Karen Blaisure, Ph.D. at (616) 387-3663, the Chairperson of the Human Subjects Institutional Review Board at (616) 387-8293, or the Vice President for Research at (616) 387-8298.

Sincerely,

Pamela S. Berryman, MA LPC
Doctoral Candidate
Appendix I

Agency Response Letter
ABC Eye Institute has been selected to participate in Pamela Berryman’s doctoral dissertation, “The Impact of a Congenitally Blind Child upon Family Functioning and Interaction.” Our perception is that this research is intended to study how a child with a visual impairment affects the family’s ability to interact and function.

Phone conversations and the cover letter, which accompanied this form, have provided insightful information regarding the nature and purpose of Ms. Berryman’s research. Our Agency/Clinic will assist the researcher with subject identification and recruitment, with regard to the following:

- Designating someone associated with our Agency/Clinic to act as the study coordinator, serving as a link between the agency and the researcher.
- Distributing flyers compiled by this researcher to potential families, requesting those who are interested to contact the researcher by letter or phone.
- The researcher will send the participants a packet consisting of a cover letter explaining the nature and purpose of the study, survey instruments, and a consent form.
- Forwarding all questions and inquiries about the study to the researcher.

ABC Eye Institute is fully aware that all data collected by the researcher will be kept anonymous. Once the data are collected and analyzed, the list of participants will be shredded. Data will be stored in a locked cabinet in the Principal Investigator’s office for three years.

ABC Eye Institute is aware that our contribution to this research will help in our understanding of families’ coping with children who are visually impaired. Findings from this research will also enable mental health professionals to gain better insight of how children with congenital blindness affect the interaction and structure of the family.

Any questions or concerns we have about this research will be addressed to either Pamela Berryman at (616) 353-1001 or Dr. Karen Blaisure at (616) 387-3663. The signature below indicates that our Agency/Clinic realizes the purpose and requirements of the study and agrees to participate.

Signature:

Print Name: Dr. XYZ, M.D.

Date: July 18, 2001
Appendix J

Acknowledgment Letter to Agency
July 25, 2001

4504 Ridgeway Circle
Kalamazoo, MI 49006

Dr. XYZ
1234 Michigan Avenue
Kalamazoo, MI 49001

Dear Dr. XYZ:

I would like to thank you for promptly sending me back your Agency Consent Form expressing your willingness to participate in my doctoral research. I am sending you some flyers of my Dissertation Study for distribution among potential families.

If you have any further questions, please feel free to call me at (616) 353-1001 or email me at 98berrym@wmich.edu and I shall be happy to answer them.

I’d like to thank you once again for your willingness to assist me with my subjection selection for my doctoral research.

Sincerely,

Pamela S. Berryman
Doctoral Candidate—WMU
Appendix K

Participant Solicitation Flyer
To Parents/Caregivers of Children Who are Visually Impaired

My name is Pamela Berryman and I am a doctoral candidate in Counselor Education/Counseling Psychology at Western Michigan University. I am seeking your help with my dissertation research study, "The Impact of Congenitally Blind Children upon Family Functioning and Interaction."

I would like to survey families having at least one child (birth to age 12) who is legally blind, and at least one sibling with full vision residing in the home. Persons participating in the survey will be compensated for their time.

I am also seeking your help in recruiting control group participants from among parents/caregivers of children with full vision. Details may be shared verbally or by providing information from this flyer. Potential control group participants would then contact me by e-mail, letter or phone.

Your participation would be greatly appreciated. In addition to helping families of children with congenital blindness, this research also can benefit professionals who work with these families. Please be assured that your responses will be kept anonymous.

Pamela Berryman, Doctoral Candidate-WMU
4504 Ridgeway Circle Apt. # A
Kalamazoo, MI 49006
Phone: (616) 353-1001 e-mail: 98berrym@wmich.edu

---

PLEASE RETURN THIS FORM TO:
Pamela Berryman
Doctoral Candidate-WMU
4504 Ridgeway Circle Apt. # A
Kalamazoo, MI 49006

CALL OR E-MAIL HER AT:
Phone: (616) 353-1001
e-mail: 98berrym@wmich.edu

Yes, I am interested in learning more about your research and possibly participating. Please send me more information.

Name ____________________________

Address ____________________________

City/State/ZIP ____________________________
Appendix L

Coded Master List Form
THE IMPACT OF A CONGENITALLY BLIND CHILD UPON FAMILY FUNCTIONING AND INTERACTION

Pamela S. Berryman (616) 353-1001
E-mail: 98berryman@wmich.edu

Clinic Name: __________________________

Contact Person: ________________________

Master List of Selected Subjects

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Appendix M

Subject Follow-up Reminder Postcard
Doctoral Dissertation Study, "The Impact Of Congenitally Blind Children Upon Family Functioning and Interaction".

May 11, 2001

Dear Dissertation Research Participant:

I would like to thank you for willing to participate on my doctoral dissertation study, "The Impact Of Congenitally Blind Children upon Family Functioning and Interaction".

A few weeks ago, I had sent you a research packet containing the Family Environment Scale, the Family Satisfaction Scale, the Family Adaptation and Cohesion Evaluation Scale II, and a Demographic Survey. I had also included a self-addressed pre-paid return envelope. Please send me the completed instruments at your earliest convenience. You will receive a check for $15 for your time and effort in completing the instruments, as soon as they are received by me. Should you have any questions, please feel free to contact me at (616) 353-1001 or e-mail me at 28berryman@wmich.edu.

Pamela S. Berryman, MA LPC
Doctoral Candidate – WMU
4504 Ridgeway Circle, Kalamazoo, MI 49006
Appendix N

Agency Follow-up Reminder to Subjects
You were recently invited to participate in Pamela S. Berryman's Doctoral Dissertation Research Project entitled, "The Impact of Congenitally Blind Children upon Family Functioning and Interaction". Not only will this study immensely help families such as yours, cope with children with congenital blindness, but this research will also benefit professionals who work with these families. As a visually impaired person herself, the researcher feels the pressing need to conduct research in the area of congenital blindness, where counseling resources, education and awareness still leave a lot to be desired.

The study entails parents or caregivers of children who are legally blind, 0–12 years of age, completing three objective type instruments: Family Environment Scale (FES); Family Satisfaction Scale (FSS); and Family Adaptation and Cohesion Evaluation Scale II, (FACES-II), as well as a Demographic Survey.

The researcher will send you a check for $15 for participating in her Research Study. All your responses will be kept anonymous and completely confidential. A summary of the research findings will be made available to you, upon completion of Data Collection.

If you have already received her pre-paid, self-addressed, stamped packet, please take the time to complete the same and return it to her, at your earliest convenience. If you have any questions or need a survey packet, please either email her at 98berryman@wmich.edu or call her at (616) 353-1001, and she will be happy to assist you further.

Sincerely,

Dr. XYZ, M.D.
BIBLIOGRAPHY


