National Library
of Canada

Acquisitions and
Bibliographic Services Branch

395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale
du Canada

Direction des acquisitions et
des services bibliographiques

395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

Canada

THE UNIVERSITY OF ALBERTA

Factors Influencing or Preventing Out-of-Home Placement of Children with Severe Handicaps

by

Paulette C. Killam ©

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF

Master in Education

IN

School Psychology

Department of Educational Psychology

Edmonton, Alberta

Spring, 1993

National Library of Canada
Acquisitions and Bibliographic Services Branch
395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale du Canada
Direction des acquisitions et des services bibliographiques
395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

ISBN 0-315-82104-3

THE UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR:	Paulette C. Killam
TITLE OF THESIS:	Factors Influencing or Preventing Out-of-Home Placement of Children with Severe Handicaps
DEGREE:	Master of Education
YEAR THIS DEGREE GRANTED:	Spring, 1993

Permission is hereby granted to THE UNIVERSITY OF ALBERTA LIBRARY to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only.

The author reserves other publication rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

Paulette Killam

4120 - 149 Street
Edmonton, AB. T6H 5L9

DATED: april 21 1993

THE UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled Factors Influencing or Preventing Out-of-Home Placement of Children with Severe Handicaps submitted by Paulette C. Killam in partial fulfilment of the requirements for the degree of Master of Education.

Dr. J.G. Paterson, Supervisor

Dr. H.L. Janzen

Dr. D. Richards

DATED: april 16 1993

To My Dad

Abstract

The purpose of this study was to describe the impact of a handicapped child on the family members and family functioning. Factors perceived by parents/guardians as either influencing, delaying, or preventing out-of-home placement were explored.

A selective review of the literature related to the placement of severely mentally and physically handicapped children out of their natural homes into an alternative care environment (i.e., an institutional residence) were presented. From this, two models were proposed. The first depicted the severely handicapped child's impact on the family and described four levels of influence. The second was a model of the placement process, which described the impact of the severely handicapped child on the family and the dynamics of the placement decision-making process.

Descriptive analysis of the data indicated that placement is a complicated and difficult process for parents/guardians. Further, that placement depended on a complex number of factors that were dynamic in nature. The results reinforced the need for family intervention to provide support to natural families caring for a severely mentally and physically handicapped child.

Acknowledgements

Thank you, the children and families involved in this study, for your participation and support.

Thank you, Dr. Paterson, for your guidance and encouragement.

Thank you, Dr. Janzen and Dr. Richards, members of my committee, for your helpful suggestions and comments.

Thank you, Carol, for your typing and editing, and particularly for your enthusiasm in being a part of this study.

A special thank you, Doug, for your encouragement and support, and especially for reminding me of the significance of this project.

TABLE OF CONTENTS

List of Tables

List of Figures

CHAPTER ONE

Introduction to the Study

Purpose

"The current interest of professionals, researchers, and policy makers in understanding how to support natural families caring for a mentally retarded child has tended to eclipse the fact that many families still seek out-of-home placements for their retarded child" (Seltzer & Krauss, 1984, p. 257).

Very little is known about parental reasons for out-of-home placement of mentally handicapped children with severe handicaps. The purpose of this study was to describe the impact of a handicapped child on the family and to consider the relationship of this impact to theories developed to explain the act of placement. Factors perceived by parents/guardians as either influencing, delaying or preventing their placement decision will be explored.

Analysis of these circumstances may indicate trends in placement tendency and provide insight into the question "Who places a child and why?"

Background to the Problem

A considerable amount of information regarding parental adjustment to the birth of a handicapped child is available. Parents of children with severe disabilities have a demanding and critical role in providing care for them. Although severely handicapped children constitute less than five percent (5%) of the mentally handicapped population, they are the majority of those who need full-time and life-long care and services (Landesman-Dwyer & Sulzbacher, 1981). Some cope very well, while others appear unable to manage. The types of stresses in the lives of families who have severely mentally handicapped children have been investigated for several decades (e.g., Cumming, 1976; Farber, 1959; Fowle, 1968; Waisbren, 1980). In summary, these studies have determined that the impact on the family is affected by such characteristics as the type and severity of the child's handicap, the age, sex, and birth order of the handicapped child, the social status of the family, the availability of community resources, and the ability of family members in adapting to the changed roles and expectations. Regardless of the placement however, families who manage the lifetime care of a handicapped child are often faced with overwhelming demands and stresses. Stress in families with handicapped children have been well documented (Cameron & Dobson, 1987; McCormick, Charney & Stemmler, 1986).

Although current practice is to encourage families to manage their handicapped child in the home environment, the care required by a severely multi-handicapped child and the management of the family unit has frequently resulted in the child being placed in an alternate residential placement. However, there are many unanswered questions regarding which children will be placed and about the decision-making process involved in placement.

Family reaction to a handicap is affected by a number of variables. Roberts (1984) discussed five aspects: the nature of the disability and the time of its onset, the family belief systems, the affective responses of members, the interface of the family with extended family and other larger systems and the structure of the family both before and after the onset of handicap.

The severity of the condition and the prospects for treatment influence family reaction. In the case of a diagnosis of severe mental handicap with accompanying medical conditions, parents are often faced with drastic changes in their life style. Their understanding and acceptance of their child's disability is affected by their belief systems and their expectations of society. It is these premises which help to determine the extent of which parents are able to remain involved as active participants in the ongoing care needs of their child.

The adaptation of families with a severely handicapped child is receiving considerable attention for a number of reasons. There is greater appreciation for the importance of maintaining family support and involvement in the life of the child. Families are also being acknowledged as legitimate partners in the provision of services, as seen in various legislations and policies directed at providing support for families with a handicapped child.

An examination of how parents/guardians perceived the effect their handicapped child has had on aspects of family life and their subsequent decision to place or not, may have serious implications in the future provision of health services. Their attitudes and beliefs toward the handicapped child will provide invaluable insight into the care of the child and the ability of the family to remain involved. An understanding of factors influencing and factors preventing placement may provide a description of families who are likely to place their handicapped child in an institution. This in turn, may assist in the development of optimum programs and services for handicapped children and their families.

Rationale

In studies completed to date, the placed children represented all levels of mental handicap (mild, moderate, severe, and profound). It has now been well documented that, of all children with retardation, those with severe and profound levels are more likely to be placed than are those with mild or moderate retardation (Sherman, 1988; Spreat et al., 1987). Although out-of-home placement has decreased in recent years, severely and profoundly handicapped children are still statistically at risk for placement (Meyers, Borthwick, & Eyman, 1985). Few studies have been conducted within the high-risk group of children with severe and profound retardation (Bromley & Blacher, 1991).

This study focused on out-of-home placement of mentally handicapped children and particularly those who have severe handicaps as they were most at risk for out-of-home placement. Bromley and Blacher (1991) noted that correlates of out-of-home placement of children with severe handicaps identified in more recent research (i.e., late 1970s and 1980s) are more complex.

While there is considerable research concerning out-of-home placement of children with handicaps, many of the studies occurred in the 1960s and 1970s, when policy and attitudes were much different than today. Studies by Appell and Tisdall (1968) reflected this; many children who were placed then had higher IQs than those placed within the past ten years.

Although the eighties and nineties have seen emphasis shift toward community living arrangements and away from institutional care, institutional options are increasingly being supported by parents as the "best" alternative for their child. As in past decades, they also frequently received endorsement from many physicians and medical professionals. Cole and Meyer (1989) were concerned with children identified as severely handicapped and noted that the child's level of functioning was significantly predictive of parents' future placement plans. Further, Rousey, Blacher, and Hanneman (1990) suggested that the influence of specific child characteristics on the placement decision may be different for children with varying degrees of mental handicap.

The identification of these characteristics of child and family that may increase a child's risk of out-of-home placement would assist in predicting who would place a child and why. The intent of this research was to discuss out-of-home placement in an institutional setting and to flesh out the implications of this placement decision. These findings would have significant implications for service providers and other professionals who support families in the decision-making process.

Through exploration of parental reasons for placement of children with severe handicaps, theories to explain who will place a child and why may be developed.

Research Questions

This study sought to address the following question: What are the most frequently identified reasons perceived by parents/guardians as critical in whether or not to make placement? Specifically, the following questions will be addressed:

1. What general factors emerge as important in the decision of whether or not to seek placement?
2. What influence does selected demographic characteristics have upon the placement decisions?
3. Can these factors "predict" placement tendency?

Definition of Terms

Terms which were used throughout this study are defined below. These definitions are tendered for the purpose of this study only, and may vary from meanings assigned to the same terms in other sources.

Severely handicapped: Those individuals who are severely and profoundly mentally retarded and whose handicap (e.g., medical impairment, physical disabilities, blindness, deafness) is so severe as to render them functionally retarded. Daily medical and/or nursing intervention is usually required in order to sustain life.

Institutional residential setting: A 24-hour facility which provides total care for those who reside there. For the purpose of this study, Rosecrest, a 22-bed, 24 hour institution for children was selected.

Out-of-home placement: Any residence for individuals with handicaps that is not the same residence as that of their natural family.

At risk for placement: Conditions which exist within the family, the child or the support network which predisposes the handicapped child for placement out-of-home.

Limitations

This study was designed to describe parental/guardian reasons to either place, delay or reject placement of their severely handicapped child in an institution. This study focused only on children with severe handicaps who were involved with the residential institution within a recent six-year period, specifically, 1985 through 1991.

As with most research, some caution must be taken when interpreting the results of this study. The questionnaire method of data collection employed in this study suffers from certain inherent limitations which must be considered. The following points highlight the primary research consideration when applying the data herein:

1. The questionnaire allows for a combined measure of facts, definitions, attitudes and perceptions.
2. The study is descriptive in nature.
3. The training, experiences, and background of respondents varied considerably, creating the possibility of a greater variance on many questions.
4. Respondents may inadvertently bias results in favour of answers that are perceived to support their positions.

This study, as a descriptive survey of parental/guardian perceptions of placement tendency of their severely handicapped child in an institutional residential setting, should not be considered in an evaluative sense. As no control groups were established for comparative or assessment purposes, the results of this study can only be interpreted as a statement of the experiences of the respondents who completed the questionnaire. In addition, the Factors Influencing Placement Scale and the Factors Preventing Placement Scale (Blacher, 1984) used in this study, may be inherently biased toward specific factors. Also, since the residential institutional setting is located in the Edmonton region of Alberta Family and Social Services, findings from this research are directly applicable to the children who reside in or utilize this institution for respite and their family members.

Organization of the Thesis

Following the introduction of the nature and purpose of the thesis in Chapter One, a review of related literature was presented in Chapter Two, describing the impact of a handicapped child on the family and the relationship of this impact to theories developed to explain the act of placement. In Chapter Three the design of the study was outlined, with details of subject participation, instrument preparation, and techniques of data collection and analysis. The information gathered from questionnaires, files, and statistic reports were complied and presented in Chapter Four. Finally, a summary of findings, considerations to be drawn from these, and implications for further research have been presented in Chapter Five.

CHAPTER TWO

Literature Review

Historical Overview of Services

Families or Institutions

Over the past twenty years, residential placement alternatives for severely handicapped children have received considerable attention. In the past, as a result of the philosophical belief that residential treatment centres were the most appropriate care alternatives, families were advised to institutionalize their severely handicapped children. They were often separated both physically and emotionally from their families, on the belief that parents were responsible for the condition of their children and were unable to provide the necessary care.

Currently, residential options are often unavailable and/or are inappropriate to adequately meet the extensive needs of a severely handicapped child. Families usually have had very few choices regarding available services and have faced difficulties regarding access to these services. Of paramount concern to most parents/guardians of severely handicapped children was the quality of services. While parents of older handicapped children were often nonjudgemental about the content and quality of services rendered, parents of younger handicapped children had more stringent expectations about the appropriateness of what is offered and the relationship of the material to their child's long-term growth and development (Salisbury, 1984). In the area of services, the most frequently voiced concern is that related to the capabilities of the provider to meet the needs of their child appropriately (Salisbury & Griggs, 1983; Upshur, 1982a).

Blacher and Bromley (1990) described a period of optimism mid-way during the 19th century when pioneers like Samuel Gridley Howe argued that with care and education handicapped individuals could show dramatic improvement in their functioning. However, despite his belief, the majority of residences had evolved into inhumane custodial institutions by the turn of the twentieth century. Yet, during this time when institutions were viewed as undesirable, families continued to be advised to place their handicapped children. However, the decision to place a child in an institutional setting is often very controversial. Baker (1984) noted that professionals have advised institutional placement in one decade and decried it in the next. This may be explained by the fact that philosophical beliefs regarding services to young severely handicapped children have shifted dramatically since the early 1900s.

From the early to mid-1900's, a predominant practice was to institutionalize severely handicapped children, based on the premise that the care and nurturance of these children presented an insurmountable burden for their parents (Turnbull and Winton, 1981). Wolfensberger (1970) described this viewpoint, stating that institutionalization as a form of treatment was recommended to promote positive outcomes for the family (e.g., the child is seen as having a destructive impact upon the family) as well as positive outcomes for the child (e.g., the child is presumably much better off and happier in an institution). At the time, parents were expected not to challenge the physician's recommendation. In support of this viewpoint, Butterfield (1969) reported that by 1969, over a quarter of a million mentally handicapped persons resided in public and private facilities.

During the later 1960s and early 1970s there was a dramatic change in professional thinking. Bromley and Blacher (1990) described a confluence of forces which resulted in families being advised to keep their mentally handicapped child at home. As a result of a growing body of research which suggested that institutions were developmentally regressive (Wolfensberger, 1971a, 1971b) the direction for reform was drawn from concepts of deinstitutionalization and normalization. The emphasis become "making available to the mentally handicapped patterns and conditions of everyday life which are as close as possible to the norms and patterns of mainstream society" (Nirji, 1969, p. 181).

By the 1980s, professional opinion was strongly supportive that families should raise their severely handicapped the child in the natural home. Slater (1986) noted that during the past two decades, families with handicapped children have been increasingly encouraged to raise these children within a normal home environment, because it was believed that handicapped children will achieve more normal levels of functioning by living within a mainstreaming supportive home environment. However, as families have attempted to raise their handicapped child at home, a number of concerns have surfaced (i.e., increased care responsibilities, social isolation of families, increased stress levels, marital conflicts, neglect of other siblings, financial strains, etc.). Blacher (1986) also noted that home care for mentally handicapped children is presently viewed as developmentally advantageous to the child and economically beneficial to society. However, since the presence of a handicapped child may be viewed as detrimental to family functioning, placement could benefit the family by reducing the stress. Although small in numbers, severely handicapped children continue to be placed out of the home. Thus, there is a need to examine the factors responsible for the decision to place handicapped children out of their natural homes into an institutional care environment.

The issue of placement of handicapped children within the natural family unit, in foster care arrangements or in institutional settings has far-reaching implications. Despite ongoing advocacy to promote home environments and avoid segregated institutional placements, major barriers remain. The debate about the merits of each type of residential care has been going on for some time. But as Berridge (1985) and Parker (1988) suggested, it is helpful to view the choices as complementary parts of the same care continuum and not as competitors.

Seltzer et al. (1984) stated that although the current philosophy in the field of mental handicaps advocates the maintenance of children in the home with their families and the return to the home of children who in the past were placed in institutions, there is considerable variability in the extent to which families can successfully cope with a severely and profoundly mentally handicapped child. Turnbull et al. (1982) cautioned that "the right to live in the least restrictive environment should apply to family members as well as handicapped individuals. Thus, the concept of least restriction should be considered in the light of each family member. Placing many severely handicapped children and youth in the least restrictive environment of their families results in their family being required to live in a highly restricted manner (p. 63)."

The historical prejudices and negative attitudes which continue to be held by parents, institutional staff and members of the community regarding handicapped children and their residential placement have been frequently cited. To some, the institutional setting is the answer to the optimal provision of care for handicapped children, while others view it as unacceptable and inappropriate. However, regardless of the residential option, the formation and maintenance of progressive and positive attitudes and involvement in the provision of care has been noted as being critical in the successful development of the handicapped child.

Meyers et al. (1985) reported figures from a 1983 state wide database in California which indicated that by about age twelve, 45% of all severely mentally handicapped and 70% of all profoundly mentally handicapped individuals no longer resided in their own homes, however, the majority of the entire developmentally handicapped population was represented as residing in the natural home. These statistics suggested that out-of-home placement of severely/profoundly handicapped children is a very likely event. However, it remains to be seen what influence the availability of supports has upon the parental decision to place.

Placement: A Research Context

At present, little is known about factors influencing out-of-home placement of severely handicapped children (Blacher, 1990). The reasons that parents placed in the past were a result of the research of the time on the impact of the mentally handicapped child on the family. Farber's study in 1959 primarily noted the negative aspects of the presence of a severely handicapped child; increased marital problems, pressure on siblings, and social isolation of the family from friends and relatives. Subsequent research indicated that stresses and difficulties were likely as a result of the child's presence.

Recent philosophical and social policy changes have been responsible for the changing attitudes regarding placement. The current trend to encourage parents to care for their handicapped child in a home setting has increased dramatically. Although services to families and children have increased because of public awareness, increased support, and the impact of federal law, out-of-home placement continues to occur. Despite these forces, the challenge of a severely handicapped child to both the family and the service system is considerable. Seltzer and Krauss (1984) noted that the economic, social, psychological, and physical costs will leave families with no alternative but to secure a decent and stimulating out-of-home residential placement for their child.

The Handicapped Child - Family Impact Models

The cause and types of handicapping conditions have been studied for over a century. However, it is only recently that focus has shifted to the child's impact on family members and to the relationship with out-of-home placements.

Blacher and Bromley (1990) noted that there are surprisingly few theoretical models on the nature of the handicapped child's impact on the family. Farber's (1975) research on family adjustment following the diagnosis of a severely mentally handicapped child in 1959 and 1960 resulted in his theory of "minimal adaptation." He described six phases of family adaptation to a severely mentally handicapped child, in which family members modified roles or interactions in an attempt to ameliorate a situation that was perceived as interfering with family life and goals.

Suelzle and Keenan (1981) used Farber's model as a framework for their study on the relationship of the family life cycle to placement. They noted that families tended to plan for future out-of-home placement if they were experiencing considerable stress from their mentally handicapped child.

Crnic, Friedrich, and Greenberg (1983) proposed a model in which family adaptation to a mentally handicapped child was described as a "response to stress moderated by the interaction of available coping resources and ecological contexts" (p.133). They felt that coping resources such as support networks, income and educational level buffered the effects of stress.

As depicted in Figure 1, Blacher (1984a) developed a model of concentric circles which described four levels of the child's influence or impact on the family. This model considered the relationships between child characteristics and affected parental attitudes and behaviour. The second circle represented family relationships such as emotional climate and stress and denoted the mutual impact of the child. Formal and informal support networks were represented by the third circle, and included friends and the availability of training programs and respite care. The outer circle represented a broad focus on society in general.

Figure 1. A model representing the bidirectional levels of influence of a severely handicapped child.

REMOVED DUE TO COPYRIGHT RESTRICTIONS

Note. From Severely Handicapped Young Children and Their Families: Research in Review (p.21) by J. Blacher, 1984. New York: Academic Press. Copyright 1984 by Academic Press, Inc.

It described cultural influences and reflected value systems and public policy. As described by Blacher (1984a)

> ...if a severely impaired child has too few adaptive behaviors and too many maladaptive behaviors (Level 1), places a heavy burden for care on family members (Level 2), and if the family feels necessary professional and social supports are lacking (Level 3), then that child is at great risk for out-of-home placement, despite public policy or societal expectations (Level 4) (p.33).

Research on Family Impact

The impact of a mental handicap is never restricted to mentally handicapped individuals; members of the immediate and extended families are affected to varying degrees. (Crnic, Friedrich & Greenberg, 1983). Despite the importance of the family, most research has been concerned with the child's effect on family functioning and has not typically been described with reference to a theoretical model.

Impact On Parents

The period of adjustment following the birth of a severely handicapped child can vary but is typically affected by the parents' ability to cope with and care for the child. Gallagher, Cross, and Scharfman (1981) investigated the characteristics of parents who appeared to have made a successful adjustment to the birth of a handicapped child. The data suggested that major sources of strength were internal supports (i.e., the personal characteristics of the parents and the quality of the husband-wife relationship).

Given that severely handicapped children place great demands in terms of time and physical energy on parents, it is reasonable to conclude that the parent-child and parent-parent relationship will be affected. The burden of care often negatively influences the family system, resulting in deterioration of health, most commonly the mother, as primary caregiver. Studies by Cummings (1976) and Holt (1958) suggested that in part due to the physical burden of caring for some severely mentally handicapped children, poor parental physical and mental health has been identified as a consequence (as well as a cause) of family stress. Studies by Seltzer and Krauss (1984), noted that mothers in particular, and fathers to a lesser extent, have been reported to be fatigued and pessimistic, to have poor self-esteem, to be more anxious and/or depressed, to feel isolated, and to have poor physical health.

There are a range of views regarding whether the marital relationship suffers as a result of raising a handicapped child. However, the extended dependency of severely handicapped children often resulted in disruption of family routines and intensive time demands posed by the handicapped infant (Salisbury, 1986). These pressures may contribute to marital friction, as parents struggle with the increased levels of stress and attempt to adjust. The variability in the findings on marital satisfaction suggested that marital response is not uniform and may be dependent upon factors aside from the presence of a mentally handicapped child (Crnic, Friedrich, & Greenberg, 1983). These factors would include the severity of the handicap, the age and sex of the child, and the quality of the marital relationship prior to the presence of the child.

A sense of security has been noted to be the most significant variable associated with reduced stress of the mothers (Salisbury, 1984). This finding supported previous research with parents of handicapped children on the role of marital stability in facilitating adaptation to stress and the importance of mutual support inherent in a two-parent relationship (Beckman, 1983; Bristol & Schopler, 1984). Farber (1959) investigated the impact on parents through the comparison of families who raised their severely mentally handicapped child at home with those whose child was placed in a residential facility. He concluded that although marital integration declined with the presence of a severely mentally handicapped child, outcome was more strongly related to the marital integration of the parents prior to the presence of the child. He also found that the marital relationship was significantly poorer if the child remained at home and if the child was male. His findings were supported in a study by Friedrich and Friedrich (1981) who used the Locke-Wallace Marital Adjustment Inventory. Comparing matched groups of mothers of handicapped and nonhandicapped children, he found the former group reported lower satisfaction.

By contrast, a study by Waisbren (1980) concluded that there were no differences in marital satisfaction among 60 matched couples. Given his sample was with very young children, it may be reasonable to conclude that there would be less impact on the marriage when the mentally handicapped child was young. A distinction was also noted in research by Dunlap and Hollinsworth (1977) who found that there was less impact in families of low socioeconomic status.

A number of studies have been concerned with the role of the person primarily responsible for caring for the handicapped child at home, most often the mother. Carver and Carver (1972) and Tavormina, Boll, Dunn, Luscomb, and Taylor (1981).found that, compared to mothers of non-handicapped children, mothers of handicapped children carried extra work loads, felt extra time demands, and reported greater stress. Despite this burden, Blacher (1984) believed that presence and nature of attachment seems particularly pertinent to parenting a severely disabled child since the quality of the attachment could well relate to family discord or accord, to the early burnout of the parent as care provider, to the level and extent of parent collaboration with services available, to possible abuse or neglect of the child, or to inclination to place the child out-of-home. Comments made by a number of parents/guardians suggested that they had formed a fairly strong attachment to their children and were hopeful that they would also exhibit bonding behaviours. Blacher (1984) believed that maternal attachment may strongly influence acceptance of the severely handicapped child and willingness to raise the child at home (at least initially). She believed that child characteristics played an important role in the development and maintenance of parental attitudes and behaviour, and it may be these traits which influence a mothers' responsiveness.

Impact on Siblings

It is not unusual for brothers and sisters to assume the role of caring for their handicapped sibling. However, the impact the handicapped child had on siblings is a major concern of many parents. Several authors (Powell & Ogle, 1985; Seligman, 1983) have reviewed and analyzed much of the research on the relationship between handicapped children and their nonhandicapped siblings. Basically, this research showed that there can be both positive and negative effects for nonhandicapped child.

Studies conducted in the 1960s and early 1970s suggested that high levels of resentment and anxiety may be felt by siblings of handicapped children as a result of the increased responsibility (Farber, 1906; Grossman, 1972). However, in a recent study by Wilson, Blacher and Baker (1989), opposing views are presented. They interviewed twenty-four children aged nine to thirteen about their experiences with their younger severely handicapped siblings. Their findings suggested a consistently high level of involvement with emphasis on positive aspects of their family. The children indicated a strong sense of responsibility and did not feel unsupported in their efforts to care for their sibling. In summary, Skrtic et al. (1984) stated that whether the experience is rewarding or restrictive, siblings will be more likely to be recruited as participants in the task of caring for their severely handicapped brother or sister.

Impact On Family Activities

Much of the research clearly indicated that the presence of the handicapped child restricted family participation in a variety of events such as shopping, travelling, and day-to-day outings (Carver and Carver, 1972; Dunlap & Hollinsworth, 1977). The extended dependency of severely handicapped children often resulted in disruption of family routines, increased levels of stress, and intensive time demands posed by the handicapped infant (Salisbury, 1986). The variability in the findings are not uniform and may be dependent upon factors aside from the presence of a mentally handicapped child (Crnic, Friedrich, & Greenberg, 1983). These factors would include the severity of the handicap, the age and sex of the child, and the quality of the family relationship prior to the presence of the child.

Families generally felt that many of the activities were considerably more complicated and difficult with the handicapped child and frequently planned their outings around the need of their handicapped child.

Simeonsson and McHale (1981) stated that there is evidence that the pressure of a handicapped child can disrupt family cohesiveness or draw the family too close to allow healthy functioning. However, there are also researchers who have found that the presence of a severely handicapped child in the family may improve the family's ability to foster a sense of belonging (Klein, 1972b; Bank & Kahn, 1975).

Impact On Social Support

Many families reported reduced support from relatives and friends (Friedrich & Friedrich, 1981; Kazak & Marvin, 1984). This occurrence may be directly related to family involvement in social events and activities. Their reported reluctance to participate in a variety of social functions may preclude others from the opportunity to be supportive.

Family stress, coping and social support are critical issues in the deliberation of parents regarding placement. Even under the best of circumstances, when parents receive such services as day care, respite, training in teaching methods, or help from a close social network, the daily needs of such children are unrelenting and would produce an extra element of stress for almost anyone (Cohen & Warren, 1985; Salisbury, 1986). Cohen and Warren (1985) and Salisbury (1986) suggested that the availability of services or supports are intended to alleviate stress on the family.

Although the availability of social support to parents had increased during the past decade, it often did not adequately meet the complex and changing needs of the family. Considerably more support and attention is directed to parents of handicapped infants, however, as the child grews older, there were limited resources to access and less assistance available for the family. This is supported by Suelzle and Keenan (1981). In a cross-sectional survey conducted with parents of mentally handicapped children, results of their interviews revealed concern with the gradual reduction of parental support networks as the children grew older.

Characteristics Influencing Placement

In the absence of theoretical models, researchers have primarily concentrated on identifying characteristics of children and families who chose to place and compared them with those whose children remained in their own homes. Blacher and Bromley (1990) noted that placement research have focused primarily on the identification of family and child characteristics that increased a child's likelihood of institutionalization. Farber's earlier studies of family adjustment to a severely mentally handicapped child provided significant data on the factors influencing placement (Farber, 1959, Farber, Jenne, & Toigo, 1960).

Seltzer and Krauss (1984) have identified a number of factors related to the decision to place the child out-of-home. These factors included:

1. child characteristics (level of retardation, behavior problems, age, gender, degree of care needed);
2. family characteristics (daily stress, parental health and level of education, socioeconomic status, marital status, family size, parent-child interaction, cultural background);
3. informal social support (friends and family) and fc social support (social and psychological services to families and children, respite care, skills training).

Research findings supported the view that certain characteristics of the child, family, or social support may influence the child's impact upon the family. (Farber, 1975; Crnic et al., 1983).

Child Characteristics

As a result of Faber's studies, other researchers have examined child characteristics related to placement. Many studies reported on the negative impact of a mentally retarded handicapped child on family functioning (Carr, 1974; Farber, 1975; Fowle, 1968; Friedrich & Friedrich, 1981). Blacher (1984) noted that in nearly all cases, the handicapped child is reported as affecting in a negative way some or all of the following: the marital relationship, sibling relationships, finances, relationships with friends, and relatives, or family vacations.

Behavior problems of the child are often cited as increasing the risk of placement (Allen, 1972; Borthwick-Duffy, Eyman & White, 1987; Downy, 1965; Eyman & Call, 1977; Hobbs, 1964; Shellhaas & Nihira, 1969; Sherman, 1988; Tausig, 1985). Nihira, Meyers, and Mink (1980) studied two hundred sixty-six families of mentally handicapped children and completed several measures on environment, child functioning, and impact. Their results indicated that the severity of the child's behaviour problems were directly related to the impact of the family and the decision to place.

Child characteristics that may also influence the placement decision include the severity of mentally handicap (Eyman & Call, 1977;

Eyman, O'Connor, Tarjan, & Justice, 1972; Graliker, Koch, & Henderson, 1967, Meyers, Borthwick, & Eyman, 1985; Sherman, 1988) and the accompanying medical and/or physical problems. The severity of the handicap determined the level of physical care and supervision that the child required. Downey (1975) reported that one of the major reasons identified by parents for their decision to place their child in an institution was that the child needed more care than the family was capable of giving.

This finding is supported by Seltzer and Krauss (1984) who noted that a primary problem experienced by families of a severely mentally handicapped child is the degree of physical care and supervision required by the child. In Holt's (1958) study of 201 families of severely mentally handicapped children, he identified three types of children who were particularly stressful: those who needed nursing care, those who needed constant supervision due to their unpredictable or destructive behaviour, and those who needed regular attention at night.

Conroy (1982) reported that families who had already placed their child in an institution were more likely to be opposed to their deinstitutionalization if they perceived their son or daughter to have severe medical problems.

Farber (1959) noted that the child's gender is a factor, with male children reported as being at greater risk for placement.

There have been conflicting research concerning the relationship between the age of the child and out-of-home placement. Eyman et al. (1972) reported that the mentally handicapped child who was younger would influence the placement in an institution. In this study, a much higher proportion of young children (under age 7) were found in the institutionalized group than in the community sample. In contrast, other studies have reported that older children are more at risk for placement (Borthwick-Duffy et al., 1936; Eyman & Call, 1977; Meyers et al., 1985; Stone 1967).

These contradictory findings may be accounted for by considering the coping strategies used by families. Institutional placement at a young age is a means by which families coped with the stress accompanying the care of a severely handicapped child. For those families who have chosen to have their children remain at home, stress appears to generally increase as the child grows older and to peak at transitional periods (Seltzer & Krauss, 1984). Suelzle and Keenan (1981) found that handicapped children between 6 to 12 years and between 19 and 21 years of age are institutionalized most often. They attributed this to the fact that families experienced a high degree of stress when their children enter and leave school.

Differences in these results may also be due to sampling techniques. For example, Stone (1967) studied children with Down Syndrome, who tended to be more similar to nonhandicapped children when they were very young. Therefore, placement may have been postponed longer by families in this study than if in a study of families whose children were more profoundly handicapped.

Family Characteristics

Family characteristics were also found to influence the probability of out-of-home placement. Blacher and Bromley (1990) reported that daily stress, parent health, marital status, family size, socioeconomic status, parental level of education, and cultural background may affect placement decisions. In addition to the chronic physical stresses experienced by families as a result of both prolonged and continuous care of the child, psychological stresses may develop. Wikler (1981) reported that prolongation of these children's dependency needs far beyond the period of preschool resulted in few breaks from the constant demands for the caregiver. Parents cannot look forward to the activities and milestones which normal children would participate.

It is clear that the additional stresses that a handicapped child often brings to a family may result in the decision to seek an alternative home for the child. Ellis, Bostick, Moore, and Taylor (1981) found that families reporting higher degrees of stress were more likely to place their children in long-term institutions than those reporting lower levels of stress. These findings were also supported in studies by Allen (1972), Black, Cohn, Smull and Crites (1985), Downey (1965) Spreat et al., (1987) Tausig (1985). However, families of severely handicapped children have had very few placement options other than institutions, until recently. Even now, although there are more options such as foster homes and in-home support, parental choice for these options may be absent and/or there may be reduced financial aid available.

Eyman et al. (1972) and Ellis et al. (1981) also reported that parental marital stress and/or emotional problems were higher among families who institutionalized their children than those who did not.

Attachment between mothers and their severely handicapped children has been hypothesized to moderate the child's impact on the family. Blancher (1984) stated that the presence and nature of attachment seems particularly pertinent to parenting a severely disabled child since the quality of the attachment could well relate for family discord or accord, to the early burnout of the parents as care provider, to the level and extent of parent collaboration with services available, to possible abuse or neglect of the child, or to inclination to place the child out-of-home. The parent-child interaction has been noted as being very important in the decisions made regarding the handicapped child. Downey (1965) noted that a strong attachment could influence the family to keep a severely handicapped child at home longer than they might otherwise. This development of parent-child attachment may affect, or be affected by other family members. As described by Blacher (1987), a mother's behavior toward, and cognitions about, her child are critical in her interactions with her child and her feelings regarding placement.

Black et al. (1985) and Tausig (1985) suggested that placement may be more likely to occur if parents are elderly or report their health as poor. The additional stress of caring for the child as well as themselves was often seen as unmanageable.

Research concerning family size and the decision to place is not definitive. Some studies concluded that children from larger families are more at risk for placement (Appell & Tisdall, 1968; Farber et al. 1960; Sherman, 1988; Tausig, 1985). Research in general has shown that large families and single-parent families may have more difficulty adjusting to a handicapped child (Blacher & Bromley, 1990). However, others have found that family size is not a significant predictor of placement (Hobbs, 1964; Olshansky & Schonfield, 1964).

Although the research is sparse, there has been some work completed regarding single versus two-parent families. Schilling, Kirkham, Snow, and Schinke (1986) hypothesized that the presence of a handicapped child would have a greater impact on single-parent families. However, no significant differences were noted. The results of a study by German and Maisto (1982) implied greater stress in single-parent homes, as single parents in their sample placed their children more frequently than two-parent families.

The relationship of family size to placement is equivocal. Some investigators have found that children from larger families are more at risk for placement (Appell & Tisdall, 1968; Sherman, 1988; Tausig, 1985) while others have noted that family size is not a predictor of placement (Hobbs, 1964; Olshansky & Schonfield; Thaman & Barclay, 1967).

Socioeconomic status (SES) and the accompanying norms may indirectly influence the child's impact, although the research is less straightforward. Appell and Tisdall (1968) and Shellhaas and Nihira

(1969) have noted a greater frequency of institutionalization in low SES families. This view was supported by Fotheringham (1970) who reported that Canadian families who placed their children were at a lower socioeconomic level that these who did not. Farber, Jenne, and Toigo (1960) found that in low SES families, willingness to place the handicapped child was directly related to the number of nonhandicapped siblings living at home.

In contrast, Eyman et al. (1972) reported that families who placed their children in institutions had higher incomes than those who did not.

In opposition to the studies which found that either high or low socioeconomic status had an effect on the placement decision, Graliker et al. (1965) reported no differences in level of socioeconomic status between families who institutionalized their children and those who chose to keep their children at home.

There is very little research related to parental level of education and the tendency to seek placement. However, Downy (1965) found that the higher the parents' level of education the earlier they placed a mentally handicapped child in an institution.

The family's cultural background was also reported to be a predictor of out-of-home placement by Eyman, Moore, Capes, and

Zachofsky (1970) and Eyman et al. (1972). Results of their research indicated that Anglo families were more likely to place their children than black or Hispanic families. A family's cultural background may also significantly influence the type and extent of interactions between the handicapped child and family members. The cultural perspective of a mental handicap often had a direct effect on the child's impact on the family. As noted by Crnic et al. (1983), cultural groups defined their own codes of behaviour and treatment of their members.

In summary, it is difficult to tell from these studies if race or ethnic group, education or income level influence the decision to place. However, it is worthy to note that these factors were examined during the 1960s and 1970s when the trend toward deinstitutionalization was gaining popularity. The findings suggested that families respond to the perceivedexpectations and treatment of severely handicapped children, given their particular circumstances.

Informal and Formal Social Support

Child and family characteristics are not the only variables affecting a family's decision to place the child out of the home. Seltzer and Krauss (1984) stated that the resources available to the family may also make placement more or less likely. Sherman and Cocozza (1984) supported these views and noted that community resources influenced the family's ability to maintain a dependent family member in the natural home. The lack of "supports" can influence the parents' decision to pursue an out-of-home residential placement. As Rowitz (1974) noted, "the family must be seen as part of a community network made up of other families, schools, churches, public and private agencies and so on. Each of these community sources may put pressures on a given family to make certain decisions concerning a dependent family member" (p.411).

Forms of social support or resources actually received that seem to influence the placement decision included respite care, services offered by the public schools, and spousal support (Blacher & Prado, 1986).

McCubbin et al. (1982) reported that social support reduced the burden of care and provided an emotional outlet for discussing problems regarding the child. The parents' social support network has been extensively described in various studies as a critical component in determining the child's impact. Although additional studies have corroborated the tendency for families of handicapped children to have smaller social networks than families with nonhandicapped children

(Friedrich & Friedrich, 1981), network size appeared unrelated to the effectiveness of the network itself (Kazak & Marvin, 1984).

Support may be provided informally by family and friends through provision of emotional support or formally through professionals who offer training programs or services. Despite this fact, many families with developmentally handicapped children still face problems in identifying, gaining access to (Salisbury & Griggs, 1983; Upshur, 1982b), and utilizing (Intagliata & Doyle, 1984; Wikler, 1981) social support resources. Unfortunately, there is considerably more literature on formal supports than informal support systems.

Holroyd and McArthur (1976) found that poor or limited informal support systems are characteristic of many families who have severely mentally handicapped children. In their studies, feelings of lack of social support were commonly reported by parents. The absence of services as well as their use (when they were available) often presented difficulties. Bristol and Schopler (1984) specifically identified "the lack of trained babysitters as a source of stress...reported by parents of children of all ages". Babysitters and other community child care services are generally not available to parents of severely handicapped children. Family members, relatives and friends are often unprepared and/or willing to care for the handicapped child, for even a brief period of time. Although any family serves maintenance and support functions for its members, the chronicity of the child's dependence for more needs, for far longer periods of time creates additional stress on the family unit (Sherman & Cocozza, 1984). Suelze and Keenan (1981) noted that among families of severely mentally handicapped children who lived at home the utilization of informal supports by family members declined as the child got older, while the utilization of formal supports increased over time.

In summary, little substantiated data is available about which informal supports are instrumental in preventing or delaying out-of-home placement.

Seltzer and Krauss (1984) described two aspects of formal social support services: (1) services provided to families that are intended to assist them psychologically or economically in coping with their severely mentally handicapped child at home, and (2) services provided to children to improve their skills and/or reduce their behavior problems to make them more acceptable to their families. Unfortunately, the availability and accessibility of services to families with severely handicapped children vary considerably. It is this general lack of available community services which may influence the placement decision (Allen, 1972; Downey, 1965; German & Maisto, 1982). Salisbury (1986) noted that efforts are needed to expand the number of programs willing and able to accommodate children with special needs so that the size of the potential social support base available to parents is increased.

Respite care is another type of formal social support. As Salisbury and Intagliata (1986) noted, empirical research on the impact of respite care is not in abundance, although the available literature suggested that it may help decrease the family's feelings of stress.

Salisbury (1986) stated that if parents are offered options that do not match their assessed needs, wants, or abilities to use them, then service outcomes will not reflect the true potential of the respite concept. He also noted that respite care is the support service that families with dependent children most often identify as a priority, yet the opportunities are not equally available to parents of handicapped children.

The stressors experienced by families with a severely handicapped child suggested that there is a need to develop a wide range of support services, designed to meet changing needs and circumstances. Thus, although respite has been shown to have the potential to mediate the effects of parenting stress (Joyce, Singer, & Isralowitz, 1983), problems in developing and implementing respite services still remain.

Summary

To summarize, most studies of the factors influencing placement generally reflected child and family characteristics, as well as the support networks. It is important to note that very few services were available to families in the 1950s and 1960s and out-of-home placement was seen as a reasonable alternative.

Although the current philosophy in the field of mental handicap advocated the maintenance of children in their homes and the discharge of children residing in institutions to community residences, the extent to which families can successfully cope must be considered. The decision to place may relate to complex, dynamic variables, such as family social support, parent-child attachment, and overall family adjustment as well as the specific child characteristics (Blacher & Bromley, 1990).

In conclusion, the available literature strongly suggested that the needs of both family members and the handicapped child must be considered in selecting the most appropriate residential placement. However, it does not negate the fact that families with handicapped children are at-risk for developing problems in family functioning and for subsequent out-of-home placement of their children. While there are multiple variables which may influence the placement decision, it is often difficult to associate the actual step of placing a child out of the natural home with parental responses. Blacher and Bromley (1990) noted that models to predict, and theories to explain, who will place a child - and why - are sorely needed.

Placement Theories

Only recently have parental views of placement and the factors influencing parents' decision to place been investigated. Blancher and Bromley (1986) noted that research has not typically been devoted to the development of a theoretical perspective on the family's decision to place a handicapped child out of the home.

As shown in Figure 2, a model by Cole (1986), adapted from McCubbin's and Patterson's Double ABCX model, specifically addressed both family adaptation and its relationship to out-of-home placement. He applied this model which deals with stress and coping to the specific situation of families with severely handicapped children. Cole described the birth or diagnosis of a child with a severe mental handicap as a stressor.

Figure 2. A model of the placement process.

REMOVED DUE TO COPYRIGHT RESTRICTIONS

Note. From Correlates of Out-of-home Placement of Handicapped Children: Who Places and Why? (p.24) by J. Blacher and B. Bromley, 1990. New York: The Haworth Press. Copyright 1990 by the Haworth Press, Inc.

Blancher (1986) proposed a model of placement that focused on six major contributors to placement decisions in families with severely handicapped children: the child as stressor, family characteristics, social support, parent-child attachment, availability of placement facilities, and placement tendency. The conceptual model outlined in Figure 2 is an attempt to understand the impact of the severely handicapped child in the family and the process of deciding whether to place the child or not. Briefly, the six components of the model illustrate the following constructs.

Child Characteristics: Earlier studies have identified level of retardation, behaviour problems, age, gender and degree of care needed as influencing the placement decision.

Family Characteristics: Previous research on family characteristics and placement are ambiguous. Level of education, socioeconomic status, marital status, and family size have been influential in some studies but not in others.

Social Support: The placement decision may be influenced by informal social support, such as assistance or advice from family and friends. It may also include formal social support (social and psychological services to families and children, respite care, skills training).

Attachment: The attachment between parents and a severely handicapped child may significantly affect the decision to place the child out-of-home.

Placement Tendency: Blancher and Bromley (1990) have hypothesized that placement can be conceptualized as a process, rather than as a single act.

Availability of Placement Options: Blancher and Bromley (1990) have hypothesized that the availability of placement options is a major factor influencing the placement decision. Parental consideration to place the child out-of-home may also be greatly influenced by the suitability of the alternative residential placement.

Placement: This is the main outcome variable. A child would be considered placed if he or she lives in a residential environment other than the natural home and if the parents have no definite plans to return the child home (Blacher & Bromley, 1990).

Conclusion

Placement out of the natural home is a very real possibility for families with a child who is severely mentally and physically handicapped.

While placement options may vary, there are usually not an abundance of choices. Blacher and Bromley (1990) noted that under the best of circumstances, the decision to place takes into account the interests of both family members and the handicapped child. Review of the literature indicated that placement may depend on a number of complex and dynamic factors.

CHAPTER THREE

Research Design and Methodology

In order to investigate parental reasons for out-of-home placement of mentally handicapped children with severe disabilities, a study was conducted to describe factors perceived by parents/guardians as either influencing, delaying or preventing their placement decision.

Sample Procedure

The sample for this study consisted of fifty-one parents/guardians who are directly affiliated with Rosecrest, a government operated facility that provides residential/respite accommodation and developmental services for severely mentally and multi-handicapped, medically fragile infants and children.

Of the fifty-one parents surveyed, forty responded (78%).

Eleven were parents/guardians for eleven children who reside permanently at Rosecrest. Twenty-nine were parent/guardians for twenty-nine children who utilized Rosecrest for varying periods of respite care throughout the year.

Method of Data Collection

Permission to conduct this study was sought by writing a letter (Appendix A) to the Manager of Services to Persons with Disabilities, Edmonton Region. Once permission to conduct the study was received, a letter outlining the purpose of the study (Appendix B) and a copy of the research questionnaires (Appendices C,D, and E) were sent to each parent/guardian. Confidentiality guidelines and freedom to say "no" to participation were mutually understood.

After the questionnaires had been out for approximately two weeks, the researcher sent another letter and/or made telephone calls to subjects, expressing the importance of participation in the study.

Description of the Questionnaires

Three specific measures were administered: The Demographics Questionnaire, Factors Influencing Placement Scale, and Factors Preventing Placement Scale.

Demographic Questionnaire

This brief questionnaire was used to secure background and demographic information about family members, including the handicapped child.

Both the Factors Influencing and Preventing Placement Scales were administered. Although there were similarities in some of the items, it was felt that both scales would provide a more comprehensive review of the process of placement. Asking only why someone placed his or her child does not provide the opportunity to respond to the more positive factors of the child that may have prevented placement from occurring earlier.

Factors Influencing Placement Scale

This is a self-administered 21-item scale consisting of 20 statements used to identify factors perceived by parents/guardians as influencing their placement decision. Each item consisted of a possible reason for placement of a child with severe handicaps (e.g., "Medical or physical problems of my handicapped child"). Parents/guardians were asked to indicate on a scale of 1 to 5 the impact of that particular reason on their decision to place, with a 1 indicating no influence and 5 indicating a strong influence on the decision. The final item was left blank to allow parents to add any other reasons for placement that were not addressed in the previous items.

The version of this scale was the product of a pilot study by Bromley and Blacher in 1989 involving twelve families and a review by parents and professionals in the field. The scale was quite reliable, with a Cronbach alpha coefficient of .63.

The items on the scale were developed by Bromley and Blacher (1991) and were designed to reflect major reasons for placement as identified in previous research: (a) child characteristics, including physical size, medical problems, and level of functioning; (b) family characteristics, including daily stress, sibling relationships, and financial considerations; and (c) social support, including lack of partner support, inadequate babysitting and respite care, and advice from professionals and friends.

Factors Preventing Placement Scale

This is a self-administered 21 item scale used to identify determinants perceived by parents/guardians as delaying the placement decision. The scale consists of 20 statements, each reflecting a possible reason for delaying placement (e.g., "I was very attached to my child"). For each item, parents were asked to indicate on a scale of 1 to 5 the influence of that particular item on keeping their child at home, with 1 indicating a strong influence and 5 indicating no influence. The final item was left blank to allow parents to add any other reasons that prevented them from placing their child sooner.

The final version of this scale was the product of a pilot study by Bromley and Blacher in 1989 involving twelve families and a review by parents and professional in the field. The scale was highly reliable, with a Cronbach alpha coefficient of .82.

The items on the scale were developed by Bromley and Blacher (1991) and were designed to reflect factors hypothesized to delay or prevent placement: (a) child characteristics, including low levels of maladaptive behavior, potential to learn new skills; (b) family characteristics, including close sibling relationships, partner against placement, strong parental attachment to the child, and feelings of guilt; and (c) social support, including adequate babysitting and respite care, and advice from professionals and friends.

Profile of Families

In this section, a family profile is drawn from the completed demographic questionnaires. A summary of this information is outlined in Table 1.

Child Data

Forty children were involved in this study. Of these, eleven resided permanently at Rosecrest, while the remaining twenty-nine utilized Rosecrest for varying periods of respite.

Admission criteria for Rosecrest included the following: newborn age to twelve years old; severely developmental impairment; non-ambulatory; extensive medical complications resulting in a need for continuous supervision by medical staff (i.e., registered nurses) and the ongoing provision of a variety of treatments (i.e., physiotherapy, oxygen therapy, suction).

As a result of the extensive dependency requirements of these children, twenty-four hour supervision was provided.

Age. The age range of the children was from 9 months to 10 years.

Sex. There were sixteen (40%) female children and twenty-four (60%) male children. Of the eleven children who permanently reside at Rosecrest, eight (73%) were male.

Table 1
Profile of Family Data

AGE

	<21	21-30	31-40	41-50	over 50
Mother (n=40)	0	12 (30%)	22 (55%)	6 (15%)	0
Father (n=36)	0	5 (14%)	20 (55.5%)	8 (22%)	3 (8.5%)

EDUCATION

	<High School	High School Grad- University	Some College/ Degree	College/ Univesity	Post University Studies
Mother (n=40)	3 (7.5%)	12 (30%)	13 (32.5%)	11 (27.5%)	1 (2.5%)
Father (n=36)	4 (11%)	15 (42%)	8 (22%)	8 (22%)	1 (2.5%)

OCCUPATION

	Full-time out-of-home	Part-time out-of-home	Full-time at home	Not employed
Mother (n=40)	8 (20%)	10 (25%)	22 (55%)	0
Father (n=36)	31 (87%)	3 (8%)	0	2 (5%)

INCOME

	$ <10,000	$ 10-20,000	$ 21-30,000	$ 31-40,000	$ >49,000
Family (n=40)	2 (5%)	4 (10%)	10 (25%)	13 (32.5%)	11 (27.5%)

RACE/ETHNICITY

	WHITE	ASIAN/PACIFIC	Black	Other (Aboriginal)
Parents/Guardians	37 (92.5%)	1 (2.5%)	0	2 (5%)

NUMBER OF CHILDREN (excluding Rosecrest Child)

	1	2	3	4	5 or more
Family (n=40)	3 (7.5)	14 (35%)	16 (40%)	5 (12.5%)	2 (5%)

SEX OF CHILDREN (excluding Rosecrest Child)

Male	Female
50 (45%)	61 (55%)

Primary Diagnosis. In all forty cases, the primary diagnosis as described by a physician indicated severe developmental delay (i.e., severe/profound retardation), with a very poor prognosis for normative development. A great majority of the children suffered from seizure disorders and all but one were non-ambulatory. All were noted to have a number of secondary diagnoses, some of which were cerebral palsy, visual or hearing impairments, physical deformities and pulmonary conditions.

Parent/Guardian Data

Age. Parents/guardians were on the average "young middle-aged," with the majority of both mothers and fathers falling in the 31-40 year range.

Parental Status. There were far more two-parent households than single parent-families among the forty cases: Thirty six two-parent, four single-parent families. Of the four single-parent families, one was a legal guardian.

Race/Ethnicity. The majority of parents/guardians were White (92.5%) with the remainder being of North American Aboriginal decent (5%) and Asian/Pacific (2.5%).

Education. The majority (62.5%) of mothers were highschool graduates with some college. College/University degrees were held by twenty-eight percent of the mothers and twenty two percent of the fathers. Less than three percent had graduate degrees.

Occupation. The majority of the mothers (55%) were full-time homemakers and were not employed outside the family. The remaining mothers were either employed part-time (25%) or full-time (20%). For fathers, the vast majority were employed full-time. A small number of the fathers (8%) were employed part-time, with five percent unemployed.

Income. The majority of families (23/40 or 57.5%) reported an annual income of between $21,000 and $40,000. Twenty seven percent (27%) indicted earnings greater than $40,000 per year.

Family Data

Number of Children. The number of children per family ranged from one to seven, with forty percent of parents reporting three children. The majority of siblings to the handicapped child were female (55%). Approximately one half of the parents had a child/children following the birth of their handicapped child.

CHAPTER FOUR

Data Analysis and Results

Severely mentally/physically handicapped children present a considerable challenge and have a significant impact on their families. The factors perceived by parents/guardians as either influencing, delaying, or preventing their placement decision which have been examined in this chapter.

For discussion purposes, parent/guardian responses to the Factors Influencing Placement Scale and the Factors Preventing Placement Scale were combined into three categories of degree of influence on the placement decisions: Very Strong/strong, Moderate, and Little/no.

The results provided strong evidence that no one factor or variable predicted which severely mentally handicapped children will be placed and which will not.

Factors Influencing Placement

In review of the data in Table 2, there were three primary factors

Table 2

Percentage of Parents (n=40) Endorsing Each Category of the Factors Influencing Placement Scale

		Degree of influence on decision to place		
	Item	Very strong/ strong	Moderate	Little/no
1.	Medical or physical problems of my handicapped child	90	5	5
2.	My partner's attitude toward placement	83	7	10
3.	Day to day stress with my handicapped child	80	0	20
4.	My child's level of functioning and potential for future learning	80	2	18
5.	Availability of respite care	63	2	35
6.	My health or my partner's health	63	12	25
7.	My child's behaviors	58	4	38
8.	My child's physical size	58	0	42
9.	Advice from professionals	53	0	47
10.	Feelings of my non-handicapped children	53	6	40
11.	Arguments with my partner	50	0	50
12.	Availability of babysitters	48	2	50
13.	Financial considerations	45	0	55
14.	No appropriate schooling or therapy offered by school or district	38	2	60
15.	Advice from friends or relatives	20	0	80
16.	Arguments and conflicts with my handicapped child	20	0	80
17.	Job opportunities for myself or my partner	20	7	73
18.	My social life and support from friends	20	22	58
19.	Knowing others who have recently placed a child like mine	18	7	75
20.	Being a single parent	5	5	85

which appeared to influence the decision to make out-of-home placement. They are summarized as follows: (1) Child handicap and level of difficulty factors; (2) Family attachment and emotional factors, and (3) Internal and external support factors.

Child Handicap and Level of Difficulty Factors

A very strong/strong influence on the decision to place was reported by ninety percent (90%) of respondents to be the "medical or physical problems of my handicapped child". Review of the demographic data and personal observation of the children in this study indicated that the severity of the handicapping conditions were extensive and required additional support and resources outside of the family unit.

Very strong/strong influences on the placement decision were reported by eighty percent (80%) of parents/guardians on two factors: "day to day stress with my handicapped child" and "my child's level of functioning and potential for future learning." Blacher (1984) noted that much has been written about stresses in families with handicapped children and in nearly all cases, the presence of the special needs child required increased parental (usually maternal) involvement with and attention to the child's daily care needs. The respondents in the survey supported Blacher's view which suggested that their inability to deal with their child's handicaps and limitations was very influential in their decision to place the child in some other residential setting. The stress experienced by families may relate in large part to daily care taking responsibilities, and these are unfortunately intensified by severe medical or physical disabilities. Crnic, Friedrich, and Greenberg (1983) stated that the overprotective attitudes of parents of retarded children appeared to have significant implications for children's skill development. The severity of mental handicap and medical complications of the children in this study may well discourage parents to invest time and energy in the extensive care required for even minimal learning to take place.

Two items reported to have a very strong/strong influence on the placement decision for fifty-eight percent (58%) of parents/guardians were "my child's behaviours" and "my child's physical size". As discussed earlier, the physical burden of caring for a totally dependent child may result in a high degree of stress and the need for an alternate residential placement. Seriously handicapped children, by virtue of the severity of their condition, often displayed either unpredictable or destructive behaviours. Aside from the total basic care which must be provided for the child, the families must adapt and cope with a variety of behaviours which often complicate family life. Given the complete dependence of the child on others to provide life-sustaining care and their inability to assist, the child's physical size may negatively impact on the caregivers. The resulting poor parental mental and physical health often plays a significant role in the decision to seek out-of-home placements.

These factors were viewed as most influential for parents/guardians in their decision to place, and were rated in the top eight of twenty items.

Family Attachment and Emotional Factors

Parents/guardians rated eight factors related to family attachment and emotional issues as very influential in their decision to place their child in an institutional setting.

Results indicated that "my partner's attitude toward placement" and their views regarding the impact of the child on the family had a very strong influence on the decision to place out-of-home.

Seltzer and Krauss (1984) reported that the pressures brought to bear on families who have seriously handicapped children are at times extreme and may result in a high degree of stress, personal tension, and intrafamilial conflict. Parent/guardian responses indicated that partners were generally supportive of the placement decision. Unfortunately, the data does not indicate whether the partner's attitude was primarily responsible for the decision to place, or whether they were merely amenable to placing the child in an institutional setting.

Closely related to the concern expressed by respondents regarding their partner's attitude, was the role that "arguments with my partner" had in influencing the decision to place their child in an institution.

Research on families with a handicapped child has had a long and meaningful history with social and behavioural scientists searching to understand the hardships and difficulties these families experience (Cubbin et al., 1982). The birth of a handicapped child necessarily causes adaptations in family structure and roles.

Similarly, respondents indicated that "their health or that of their partner's" had a very strong/strong influence on their decision to place their child. Levy and Levy (1986) reported that most people depend on the support and companionship of their spouse, relatives and friends during times of stress and crisis, when they are feeling very isolated. This support is often not available or may not be sufficient.

Parents/guardians responses indicated that "feelings of my non-handicapped children" also played a key role in the placement decision.

Determining the impact of a handicapped sister or brother on non-handicapped siblings can be a complicated process. Skrtic et al. (1984) stated that the factors which contributed to the impact on siblings of severely handicapped children cannot be documented simply as quantitatively greater than the impact on siblings of moderately handicapped children. He explained that a mildly handicapped child will be in situations where the non-handicapped sibling may face embarrassment, or feel a need to protect his brother/sister (e.g., mainstream classroom). In contrast, the future ability of severely handicapped children to function "normally" is generally not expected and so is not an issue. In these cases, siblings need not expected and so is not face situations which necessitate an explanation of the handicaps to peers.

Reports from parents/guardians in this study suggested that they were generally unwilling and unable to devote the majority of their time and attention in caring for their handicapped child, especially at the expense of their other children. Further, they did not want to burden their other children with added child-care responsibilities.

Families of severely handicapped children have been found to have increased financial problems, which added to the stress they experience. (Seltzer & Krauss, 1984). Almost one half of parents/guardians reported that financial considerations strongly influenced their decision to place their child. A number of studies have noted the increased everyday costs incurred by families in the care of a seriously handicapped child (Holt, 1958; Maroney, 1981; Turnbull et al., 1982).

A number of factors related to family attachment and emotional issues were rated by parents/guardians as having little or no influence on their decision to place their child in an institutional setting.

"Arguments and conflicts with my handicapped child" were viewed as have little/no influence on the decision to place. Given the functioning level of the children in this study (i.e., none/limited verbal ability), arguments would be very infrequent. Further, the type of conflict, if any, would be related to the need to meet the extensive physical demands of the child, and not as a result of intention on the part of the child to cause conflict.

Parents/guardians also generally indicated that "job responsibilities for myself or my partner" did not have a strong influence on the placement decision. This view is not supported in the literature. Parents whose children cannot be served in appropriate day programs (e.g., child care) are often precluded from employment and social opportunities (Boggs, 1979, Bristol & Schopler, 1984; Kenowitz et al., 1977; Seltzer & Krauss, 1984). The reason for this may be that jobs or promotions may be lost as a result of the increased demands made by the child on time and energy and/or of the unavailability of appropriate child care services. Being a single parent was also reported as having little/no influence on the decision to place out-of-home. This was supported in studies by Schilling, Kirkham, Snow, and Schirke (1986), although they had hypothesized that the presence of a mentally handicapped child would have greater impact on single-parents families. However, German and Maisto's (1982) study indicated that single parents in their sample placed their children more frequently than two-parent families. It should be noted that four (4) of the parents/guardians who participated in this study reported to be a parent having custody alone (single/widowed). The larger percentage of responses were from married/common-law individuals who by virtue of not being single, would have rated this item as having very little influence.

Internal and External Support Factors

Internal and external support factors were seen to have an important effect on the decision to place. However, it was interesting to note that four of the seven items were external or community related and were rated ahead of the three internal or personal items.

The four external factors were: "Availability of respite care," "advice from professionals," "availability of babysitters," and "no appropriate schooling or therapy offered by school or district."

Sixty-three (63%) of parents/guardians reported that the "availability of respite care" had a very strong/strong influence on their placement decision. Levy and Levy (1986) stated that the availability of respite or temporary short-term care, had repeatedly been cited by both parents and professionals as both a critical preventive and emergency service, allowing families with members who have developmental disabilities the necessary relief to maintain family integrity and stability. Parents/guardians responses in this study strongly supported this notion. As noted earlier, continuous care for a severely handicapped child will often produce physical, psychological, and social stress within the family. The lack of respite support can lead to a number of negative consequences for the family unit, and may hasten the family to seek residential placement for the handicapped child.

Approximately fifty-three percent (53%) of parents/guardians indicated that "advice from professionals" had a very strong influence on their placement decision.

Kadushin (1980) stated that while the dominant trend in the human services is to maintain the integrity of the family unit, the challenge to both the family and the human service system presented by a severely profoundly handicapped child is enormous. Although there are an increasing number of early intervention programs and support and training groups to assist families, it often is not enough. Seltzer and Krauss (1984) stated that a substantial number of families will continue to exist for whom the costs - economic, social, psychological, and physical - of raising a severely or profoundly retarded or otherwise handicapped child will overwhelm their resources. As a result, many of these family are advised by professionals, primarily medical, to secure a out-of-home residential placement for their child. Unfortunately, the question of where the child should live does not have an easy answer.

The availability of babysitters, and the absence of appropriate schooling or therapy offered by the school are closely related.

"The availability of babysitters" was noted to be stressful for parents. The absence of these services as well as their use (when they were available) often presented difficulties. Bristol and Schopler (1984) specifically identified "the lack of trained babysitters as a source of stress reported by parents of children of all ages".

Many parents voiced problems with the availability of training, schooling or therapy options for their children. In many communities, resources are very limited, so parents may find themselves considering placement of their child in a large city where there is a greater likelihood of an established residential or training facility. However, the location of services and the type of programs may not be appropriate. Parents/guardians in this study expressed concern regarding the lack of appropriate therapy and/or training for their children. Their severe handicapping conditions and often intensive medical requirement were reported to preclude their participation in many programs.

The remaining three support-related items may be described as internal or personal. It is interesting that these were rated by respondents as having less influence than the previous four external factors.

"Advice from friends or relatives", "my social life and support from friends" and "knowing others who had recently placed a child like mine" were reported not to have a strong effect on the parents/guardians decision to place their child. The adaptation level within each family was critical in determining how they would approach the long term care of their child. It is clear that the needs of the family were considered in light of the handicapped child and the rest of the family members, with very little influence from friends or relatives. Intervention would be proposed based on their level of adjustment and emotional readiness to receive additional services (O'Hara, Chaiklin, & Mosher, 1980). The families in this study who chose to place their child in an institution had accepted the reality of their child's handicap and limitations and decided that they were unable to meet the demands and changing needs of their child.

Summary

Review of parental/guardian responses indicated that child characteristics played a key role in influencing out-of-home placement. Also critical were emotional and attachment issues, particularly as related to the attitudes and feelings of the partner and their non-handicapped children. These two factors accounted for the primary reasons for placement of a handicapped child out-of-home. Somewhat less influence was reported regarding supports, although external support (i.e., respite care, availability of babysitters, and advice from professionals) appeared to have more impact than internal support (i.e., my social life, or advice from friends).

Factors Preventing Placement

In addition to the factors previously described as influencing the placement decision, a number of variables need to be considered which may prevent the out-of-home placement of a handicapped child. Some of these factors may also have served to delay the placement decision, as parents/guardians wrestled with the options available to them and their handicapped child.

The percentage of parents/guardians endorsing each category in the Factors Preventing Placement Scale are summarized in Table 3.

Review of the data in Table 3 indicated three primary factors which appeared to influence the decision to make out-of-home placement. They are summarized as follows: (1) Family attachment and emotional factors, and (2) Internal and external support factors and (3) Child handicap and level of difficulty factors.

Table 3

Percentage of Parents (n = 34) Endorsing Each Category of the Factors Preventing Placement Scale

	Item	Degree of influence on decision not to place Very strong/ strong	Moderate	Little/no
1.	I was very attached to my child.	82	6	12
2.	Thoughts of placement made me feel guilty or that I was a bad parent.	80	0	20
3.	Thoughts that someone else would be raising my child.	77	5	18
4.	My partner helped me a lot with our handicapped child at home.	74	0	26
5.	My child would never understand placement or would think he was unloved.	68	0	32
6.	Availability of babysitters	65	5	[illegible]
7.	No satisfactory placements were available	59	0	[illegible]
8.	Availability of respite care	59	9	[illegible]
9.	My non-handicapped children got along with their handicapped sibling	59	9	32
10.	I knew I wouldn't get to see my child often	[illegible]	0	41
11.	My partner's attitude toward placement	56	23	21
12.	child didn't present any particular problems	50	9	41
13.	I couldn't find a nice enough placement	44	0	56
14.	Appropriate schooling was available for my child	44	12	44
15.	My child learned skills that made it easier to have him at home	32	3	65
16.	Advice from professionals	24	11	65
17.	I didn't know how to get a placement	18	3	79
18.	Raising this child did not differ from raising my other children	15	20	65
19.	Advice from friends to raise my child at home	12	12	76
20.	My religious beliefs made placement difficult	12	30	82

Family Attachment and Emotional Factors

Concerns related to family attachment and emotional issues were reported by parents/guardians as being critical factors in their decision to delay or refuse to place their child. Six of the first ten items fall into this category.

The three items rated by respondents as first, second and third in importance were related to attachment and emotional issues: "I was very attached to my child, thoughts of placement made me feel guilty or that I was a bad parent, and thoughts that someone else would be raising by child."

Eighty two percent (82%) of parents/guardians indicated that a very strong/strong influence on keeping their child at home was "I was very attached to my child."

Blancher (1984) stated that the presence and nature of attachment seems particularly pertinent to parenting a severely handicapped child since the quality of the attachment could well relate to family discord or accord, to the early burnout of the parent as care provider, to the level and extent of parent collaboration with services available, to possible abuse or neglect of the child, or to inclination to place the child out-of-home. Comments made by a number of parents/guardians suggested that they had formed a fairly strong attachment to their child and were hopeful that he/she would also exhibit bonding behaviours. Blacher (1984) believed that although maternal attachment may strongly influence acceptance of the severely handicapped child and willingness to raise the child at home (at least initially), child characteristics play an important role in the development and maintenance of parental attitudes and behaviour. It may be these traits which influence a mothers' responsiveness.

Downey (1965) noted that a strong attachment could influence the family to keep a severely handicapped child at home longer than they might otherwise. Parents' reactions to the thoughts of someone else providing care to their child were frequently personalized and were expressed in very possessive terms. Solnit and Stark (1961) discussed the mourning process and indicated that there was a large component of guilt experienced especially by the mother. They suggested that some parents may attempt to ward off the grieving process by forming a guilty attachment to the child. Based on a number of comments expressed by the parents/guardians in this study, this viewpoint was strongly supported. Respondents felt that they were often ill-equipped to deal with the birth of their handicapped child, but attempted to manage as best as possible. The parents/guardians reported to blame themselves and subsequently felt inadequate, guilty, and anxious. Most indicated that the periods of initial shock and intense emotional upset were followed by gradual adaptation and a sense of calm.

This development of parent-child attachment may affect, or be affected by other family members. "Thoughts of placement made me feel guilty or that I was a bad parent" and "thoughts that someone else would be raising my child" were reported by a large majority of parents/guardians as having a very strong/strong influence in preventing placement.

Clinical observations have suggested that the emotional trauma experienced by parents upon discovering that their child was handicapped aroused anxieties, fears, and guilt not generally associated with the birth of a normal child (Wright, Granger, & Sameroff, 1984). This was strongly supported by comments made by parents/guardians: "I'm concerned that other people could not give as good care as I can provide; I feel nobody else could care for my child like I do...it took lots of encouragement and positive thoughts to influence me to even use respite."

The previous two items are very much related. The issues surrounding who should be providing the care and what reflection that has on the parents/guardians of the handicapped child is a very complicated one. While it may not be deemed as appropriate by professionals for parents to make their decision to place based on guilt or what others might think, the reality is that parents/guardians often experience considerable anxiety and guilt regarding this decision.

A majority of respondents were concerned that "my child would never understand placement or would think he was unloved". This view was expressed by sixty eight percent (68%) of parents/guardians who felt that this had a very strong/strong effect on their decision not to place their child. As a result, the parents made a concerted effort to adjust in order to ensure that their child assumed a valid role as a member of the family. Turnbull, Summers, and Brotherson (1983) noted that initially after the birth of a child who is handicapped, parents are concerned with "obtaining an accurate diagnosis," "informing siblings," and "establishing routines to carry out family functions." This implied that families who chose not to place their handicapped child out-of-home felt a sense of commitment and devotion and the need to maintain the integrity of the family. As previously discussed if maternal attachment is strong, acceptance of the severely handicapped child would delay or prevent an out-of-home placement. As a result, parents/guardians would not be able to place their child because of their strong desire to show love, affection, and acceptance.

"My non-handicapped children got along with their handicapped siblings" was also reported by parents/guardians to have had a very strong influence on their decision not to place. The impact of the handicapped child on the siblings was a major concern of many parents. Several authors (Powell & Ogle, 1985; Seligman, 1983) have reviewed and analyzed much of the research on the relationship between handicapped children and their nonhandicapped siblings. Basically, this research showed that there can be both positive and negative effects [illegible] nonhandicapped child.

Many different factors may have contributed to this relationship. As some parents/guardians indicated in this study, their non-handicapped children were able to cope with and positively contribute to family functioning. Further, they helped delay or prevent the decision to place the handicapped child out-of-home by providing support, both to their sibling and to their parents.

A majority of respondents (59%) indicated a strong influence not to seek placement because they "knew I wouldn't get to see my child often". There was an overwhelming belief expressed by respondents that placement in an institutional residence would mean a relinquishing of parental control and decision-making authority. In some cases, it was felt that geographical distance of available placements would make the families feel removed from the lives of their handicapped children.

Parents/guardians felt that their religious beliefs had very little influence on their decision to place and rated it as the item having the least impact. Respondents expressed concern regarding the severity of the physical and medical aspects of their child's handicapping conditions and felt that religious views were irrelevant, for the most part.

Internal and External Support Factors

Ten items were noted to be related to support factors. These were dispersed evenly throughout the twenty items, which suggested that, in general, supports to families with severely handicapped children are viewed as essential.

Seventy four percent (74%) of parents/guardians indicated that because "my partner helped me a lot with our handicapped child at home", the decision to place out-of-home was either delayed or prevented.

Drotar et al. (1975) were concerned with factors influencing the extent and rate of adjustment and noted that several mothers in his study reported that emotional and physical support systems played an important role. The maintenance of a satisfactory relationship between the parents was cited as a crucial aspect of their positive adaptation. Intimate support from a spouse has been associated with enhanced adjustment to a disabled child. (Salisbury, 1984). Friedrich (1979) administered a variety of stress, social support, and demographic measures to a sample of ninety eight mothers of handicapped children and found that feeling secure in the marital relationship was the most significant variable associated with reduced stress of the mothers. This view was expressed by the majority of parents/guardians who did not place their child out-of-home, as seen in comments such as "The birth was such a crisis but it brought us closer together." It is reasonable to conclude that parents who were able to communicate and provide mutual support would be able to adapt more successfully.

Fifty six percent (56%) of parents/guardians indicated that "my partner's attitude toward placement" was a key factor in the decision not to place. This suggested that at least one partner (but likely both, to some degree) were supportive of each other in the provision of care of the handicapped child at home. This also implied that the stability of the partnership may be such that the presence of the handicapped child did not have a deleterious effect on marital integration and family functioning. It is interesting to note that a greater number of parents/guardians (83%) responded to the same item on the Factors Influencing Placement Scale and indicated that it had a very strong influence on the placement decision. Although appearing contradictory, it may support the fact that the partner's attitude, whatever it may be, can be very influential in whether to seek placement. Further, if the partner's attitude is to keep the child at home and they provides support and assistance, the issue of placement may be delayed or may not even be an issue.

Sixty five percent (65%) of parents/guardians felt that the "availability of babysitters" had a very strong/strong influence on their decision not to place, which implied that there were sufficient availability of relief resources to the family. This finding was contrary to much of the literature which stated that families of the mentally handicapped child are less likely to have support from babysitters, neighbours or relatives who provide brief periods of child care (Wikler, Hanusa, & Stoycheff, 1986). A possible explanation for this discrepancy may be that the parents/guardians in this study were a homogenous group and were able to consistently secure relief support from Rosecrest.

It is also interesting to note that responses by parents/guardians to the Factors Influencing Placement Scale indicated that approximately forty-eight percent (48%) felt strongly that the availability of babysitters influenced their decision toward placement. These apparent discrepancies may be due to the fact that families who had chosen to delay or refuse placement out-of-home may have done so as a result of the assistance and support from people who provided temporary relief. Furthermore, the rank order of this item was considerably higher (5/20) as a strong influence on the decision not to place, as opposed to influencing an out-of-home placement (12/20).

Parental/guardian belief that "no satisfactory placements were available" had a very strong/strong influence on the decision not to place for approximately fifty nine percent (59%) of respondents. As discussed previously, residential or program options are often unavailable and/or are inappropriate to adequately meet the extensive needs of a severely handicapped child. Families usually have very few choices regarding available services and may also face difficulties regarding access to these services. Of paramount concern to most parents/guardians of severely handicapped children is the quality of services. While parents of older handicapped children are often nonjudgemental about the content and quality of services rendered, parents of younger handicapped children have more stringent expectations about the appropriateness of what is offered and the relationship of the material to their child's long-term growth and development (Salisbury, 1984). Given that the issue of attachment to the child, feelings of guilt, and the focus on the provision of care were seen as encompassing the top three items which delayed or prevented out-of-home placement, it is not surprising that parents/guardians chose to keep their child at home in the absence of satisfactory options. In the area of services, the most frequently voiced concern is that related to the capabilities of the provider to meet the needs of their child appropriately (Salisbury & Griggs, 1983; Upshur, 1982a).

"Availability of respite care" was also reported by fifty-nine percent (59%) of respondents to have had a very strong influence on their decision to delay or prevent out-of-home placement of their handicapped child. This factor was rated almost equally as one which influenced the decision to seek placement (63% of respondents). This suggested that although respite care is seen to be important (ranking 7/20 to refuse placement and 5/20 to seek placement), it's availability and utilization may be interpreted very differently by families.

The remaining items related to Internal and External Support Factors were rated as having little influence on the decision to place the handicapped child out-of-home.

In keeping with parent/guardian reported beliefs that they were able to provide the necessary care, it is not surprising that they experienced difficulty in identifying a suitable alternative residential placement for their handicapped child. Equally as influential, was the notion that "appropriate schooling was available for my child". Again, the availability of training programs served to provide support to the families, as well as focusing on the child's development. Regarding the implications for the education of handicapped children, the use of public schooling served as respite for parents (Blacher & Prado, 1986). The parents/guardians in this study who had access to program options for their child expressed satisfaction.

"Advice from professionals," "advice from friends to raise my child at home," and "I didn't know how to get a placement" did not exert a strong influence toward out-of-home placement. Despite the presence of strong opinions from professionals, the responses from parents/guardians in this study indicated that they wanted and had some degree of control over the care their child would receive. The decision about whether to institutionalize a handicapped child was never an easy one for families. Professional advice regarding this problem is often strongly partisan and, if one can judge from the reports of parents, heavily weighted in favor of institutionalization (Caldwell & Guze, 1960). A number of parents/guardians in this study expressed a concern regarding the implied lack of sensitivity for parental feeling regarding the decision whether to seek placement or not.

Child Handicap and Level of Difficulty Factors

Two items were related to child difficulty levels: the behavior problems of the child and that the child learned skills that made it easier to remain at home. Parents/guardians rated these as having only a moderate influence on their decision to keep their handicapped child at home.

For a wide variety of reasons, parents/guardians did not negatively identify with the care needs or demands of their handicapped child. It may be hypothesized that their feelings of attachment to the child and guilt may have been responsible for mediating the extent of the problems. However, comments by parents/guardians suggested that they would not be inclined to place their child primarily based on the problems, since they believed they could manage and provide the necessary care to adequately meet their child's needs.

Respondents indicated that "my child learned skills that made it easier to have him at home," but these were not specified. However, given the functioning level of children, it may be hypothesized that the skills referred to here are related to attachment behaviors. Further, that the child likely did not present with significant behavior problems, which would negatively interfere with development.

Summary

In summary, emotional and attachment issues appeared to be very important in parents/guardians decision to delay or refuse placement for their handicapped child. Supports (external more than internal) were also influential in the decision to make placement.

In contrast to what was reported as being very influential in the decision to place, were the characteristics of the child and difficulty level associated with care. These differences may be explained by the fact that if parents/guardians perceived that their child's handicap was severe, they were very likely to feel unable to meet the child's needs and would seek placement. If however, there was significant emotional attachment, families appeared to look past their child's difficulties and refused to place out-of-home since they believed they were able to provide the necessary care.

Demographic Factors

For the most part, the parents/guardians in this study closely patterned family statistics of previous research (Blacher, 1984; Blacher and Bromley, 1990)

In this study, there were more two-parent households than single parent-families (i.e., thirty-six of forty). This may not be entirely reflective of the general population, where one might expect a higher representation from single parent families. However, this study did not explore how the two-parent families evolved, and whether second marriages were a factor. If this were the case, there would be reason to hypothesize that the birth of a handicapped child precipitated the creation of a single parent home, if even for a short period of time.

Race/ethnicity was reported in this study to be predominately White (92.5%) which again may be reflective of the population at large. Parents/guardians level of education and occupational status were also reported to be closely patterned with previous studies of families (Blacher, 1984).

Regarding the number of children in families, a range from one to seven was reported. The majority of families (75%) reported having either two or three children. Slightly more indicated three children (sixteen) as opposed to two (fourteen). This number is similar to studies of families in the 1970s and early 1980s when the average number of children were reported to be three (Carver and Carver, 1972).

In summary, the families in this study were a fairly representative group. The major differences were noted in the characteristics of the child. As previously noted by Blacher and Bromley (1991), few studies had been conducted within the high-risk group of children with severe mental handicaps.

CHAPTER FIVE

Discussion and Conclusions

Overview

Research on families with a handicapped child has had a long and meaningful history with social and behavioral scientists searching to understand the hardships and difficulties these families experience. Recently, there has been a concerted effort to examine how families faced with the long-term care of these children are able to handle the financial, psychological, and interpersonal demands placed upon them. This interest in families represents a major shift in emphasis from the study of family problems and failures to the assessment of how families cope with and adapt to a very difficult situation. This study represented a continuation of this recent trend and emphasized the complementary relationship between the medical treatment of severely handicapped children and support of families responsible for these children. Although the family's role is difficult to assess, it is viewed as a vital part of the total care for children with severe handicaps.

Data in this study regarding parents/guardians institutional placement closely paralleled data found in related research. For the most part, related research (Blacher, 1984) supported the views expressed by participants in this study.

The main focus of this study was to describe the impact of a severely handicapped child on the family with respect to theories developed to explain the act of placement. Of interest, was insight into the question "Who places a child and why?"

The Placement Decision

Blacher and Bromley (1990) suggested that no one factor or variable predicted which severely handicapped children will be placed and which will not. Rather, placement may depend on a complex constellation of factors that are dynamic in nature -- family-child interactions, family environments, perception of burden of care. Furthermore, there are factors that operate to prevent or delay placement -- parental attachment to child, parental feelings of guilt. These contentions were supported by this study.

Many researchers (Seltzer & Krauss, 1984; Conroy, 1982; Holt, 1958) have noted that a primary problem experienced by families of a severely mentally handicapped child was the degree of physical care and supervision required by the child. This was supported by this study since parents/guardians noted that the " medical and/or physical problems" of the child were the primary factors influencing their decision to place the child outside of the home.

Many studies have also reported on the negative impact of a mentally handicapped child on family functioning (Carr, 1974; Farber, 1975; Fowle, 1968; Friedrich & Friedrich, 1981; Salisbury, 1986; Crnic, Friedrich & Greenberg, 1983). Blacher (1984) noted that in nearly all cases, the handicapped child was reported as affecting in a negative way some or all of the following: The marital relationship, sibling relationships, finances, relationships with friends, and relatives, or family vacations. Views expressed by parents/guardians in this study suggested that communication between partners and the availability of support systems within the home were critical elements in the decision to place the child.

External support factors for the families in this study had varying degrees of influence. However, parent/guardian responses regarding the importance of respite services supported literature findings which stressed that respite care is a critical preventative service which parents require. Salisbury (1986) noted that the absence of services, as well as their use, can be stressful for parents. Furthermore, studies reviewed by Seltzer and Krauss (1984) indicated that the extent of formal support (respite) provided to severely mentally handicapped persons who lived at home and to their families was considerably less than that provided to persons in out-of-home placements. Given these findings, it may be questionable why families would opt to maintain their handicapped child at home.

Advice from professionals was also viewed as important by some respondents in this study. However, the current climate in rehabilitation service is not as definitive as in the past, and a wider range of options are available to families. This in many ways has increased the difficulty faced by parents in deciding to place their child out-of-home. Baker (1984) noted that professionals have advised institutional placement in one decade and decried it in the next. This may be explained by the fact that philosophical beliefs and policies regarding services to young severely handicapped children have shifted dramatically since the early 1990s.

From the early to mid-1990s, a predominant practice was to institutionalize severely handicapped children, based on the premise that the care and nurturance of these children presented an insurmountable burden for the parents (Turnbull and Winton, 1981). At the time, parents were expected not to challenge the physician's recommendation.

Although it is thirty years later, and despite the trend toward community-based residential placements, the parents/guardians in this study indicated a strong preference for institutional-based placements. It is interesting that only approximately one half of the participants felt that professional advice was significant in influencing their decision to place. There may well be a growing discontent for the "shifting" philosophical view from professionals and a corresponding reliance of parents on their own support systems for advice and counselling.

Overall, the majority of parents/guardians who participated in this study reported the general absence of services as being important in their decision to place their child in an institution. Their views are supported in the literature, which noted that community resources can influence the family's ability to maintain a dependent family member in the natural home (Seltzer & Krauss, 1984; Sherman & Cocozza, 1984). Salisbury (1986) has noted that efforts are needed to expand the number of programs willing and able to accommodate children with special needs so that the size of the potential social support base available to parents is increased.

The presence of external or community-type supports was rated consistently as having significant influence on the family's decision not to place their child. The availability of babysitters, respite care and satisfactory placements played a key role in keeping the handicapped child at home. Salisbury (1986) agreed, indicating that if parents are offered options that do not match their assessed needs, wants, or abilities to use them then services outcomes will not reflect the true potential of the respite concept. Parents/guardians in this study expressed strong views that the development of respite services should be designed the meet their needs and those of their child. Salisbury (1986) noted that respite care is the support service that families with dependent children most often identify as a priority, yet the opportunities are not equally available to parents of handicapped children.

The stressors experienced by families with a severely handicapped child suggested that there is a need to develop a wide range of support services, designed to meet changing needs and circumstances. Thus, although respite has been shown to have the potential to mediate the effects of parenting stress (Joyce, Singer, & Isralowitz, 1983), problems in developing and implementing respite services still remain.

Personal or internal supports such as help given by the partner, the partner's attitude toward placement and advice from friends were important factors as well. This was consistent with other research with parents of handicapped children on the importance of mutual support inherent in a two-parent relationship (Beckman, 1983; Bristol & Schopler, 1984). Several mothers in this study express strong opinions that they would be unable to cope with the situation if they were either faced with caring for the child alone (without support from their partner) or living without their partner. Overall, it seems evident that the partner's attitude, whatever it may be, can be very influential in whether to seek placement. Further, if the partner's attitude is to keep the child at home and they provide support and assistance, the issue of placement may be delayed or may not even be an issue.

Comparatively, internal or personal supports were viewed by parents/guardians as having less influence than external or community supports. This is in contrast to what is generally written regarding the importance of personal supports to families. This may be because the families in this study who chose to place their child in an institution had accepted the reality of their child's handicap and limitations and decided that they were unable to meet the demands and changing needs of their handicapped child. Baker (1984) noted that friends and relatives have offered platitudes rather than say nothing and those who could help have often felt helpless themselves.

In viewing placement from the perspective of keeping the child at home, responses in this study noted that emotional factors and attachment issues were critical in determining whether or not a chid would be placed. The parents' reaction to the thought of someone else providing care to their child were frequently personalized and were expressed in very possessive terms. This is consistent with Solnit and Stark (1961) who discussed the mourning process and suggested that there was a large component of guilt experienced especially by the mother. They suggested that some parents may attempt to ward off the grieving process by forming a guilty attachment to the child. Based on a number of comments expressed by the parents/guardians in this study, this viewpoint would be strongly supported. Respondents felt that they were often ill-equipped to deal with the birth of their handicapped child, but attempted to manage as best as possible. The parents/guardians reported to blame themselves and subsequently felt inadequate, guilty, and anxious. Most indicated that the periods of initial shock and intense emotional upset were followed by gradual adaptation and a sense of calm. However, there would be considerable emotional resistance to an out-of-home placement, as it would be difficult for parents/guardians to imagine that someone else could better raise their child. Also related, is the belief of parents/guardians that their child would never understand placement or would think he was unloved. Considerable research supported the impact of maternal attachment and parental adjustment (Turnbull, Summers, & Brotherson, 1983).

The impact of the handicapped child on non-handicapped siblings was also reported to be a concern of parents/guardians. While studies by Powell and Ogle (1985) and Selligman (1983) indicated both positive and negative effects, results of this study indicated that influence was primarily positive. Parents/guardians reported that the assistance and support of their non-handicapped children was influential in the decision not to place their handicapped child.

Closely related were the parent/guardian beliefs that they would not see their child often if he/she were placed out-of-home. There was little research on this, but it is reasonable to assume that given the importance of attachment, parents/guardians might feel that the geographical distance between them would be a significant factor in keeping them apart.

Philosophical Directions Regarding Placement

The prevailing philosophical recommendations of the decade regarding placement of severely handicapped children has also had a profound impact on parents/guardians. Slater (1986) noted that during the past two decades, families with handicapped children have been increasingly encouraged to raise these children within a normal home environment, because it was believed that handicapped children would achieve more normal levels of functioning by living within a mainstreaming supportive home environment. However, as families have attempted to raise their handicapped child at home, a number of concerns have surfaced (i.e., increased care responsibilities, social isolation of families, increased stress levels, marital conflicts, neglect of other siblings, financial strains, etc.).

Slater's views were supported by respondents in this study. Most parents/guardians expressed extreme anguish over the impact of their handicapped child on the family and the resultant stress that **could** lead to an out-of-home placement. Clearly, the impact of the severely handicapped child on the family and the dynamics of the placement decision-making process clearly constituted a matrix of complex issues that not only involved the child.

Seltzer et al. (1984) had noted that although the current philosophy in the field of mental handicaps advocated the maintenance of children in the home with their families and the return to the home of children who in the past were placed in institutions, there was considerable variability in the extent to which families could successfully cope with a severely mentally handicapped child. In support, Turnbull et al. (1982) cautioned that "the right to live in the least restrictive environment should apply to family members as well as handicapped individuals. Thus, the concept of least restriction should be considered in the light of each family member. Placing many severely handicapped children and youth in the least restrictive environment of their families results in their family being required to live in a highly restricted manner (p. 63)."

As this quote suggested, the needs of both the family and the child must be considered in selecting the optimal residential placement for a severely mentally handicapped child. Providers of services need to consider family strengths in adapting to the care of the child while accommodating family differences. It will be necessary to lessen stress by providing intervention which will strengthen the family unit.

Family Functioning With a Severely Handicapped Child

It is only recently that a comprehensive picture of the impact of a severely handicapped child upon the family unit has been investigated. In reviewing the observations reported in this study and in research, family functioning may be affected by a severely handicapped child in the following ways:

Altered relationships with friends and neighbours due to their reactions to the child along with parental and sibling embarrassment at how the child looks and acts leading to family social isolation.

Major changes in family activities, such as reduced options for family vacations, reduced flexibility in the use of leisure time, and shared family tasks and responsibilities.

Medical concerns related to parents learning more specialized medical procedures, home treatment responsibilities, and problems with handling equipment.

Intra-family strains including overprotectiveness, rejection of child, ongoing worry about the child's safety and care, concerns about the extended parenthood, increase in the amount of time focused on the child at the possible expense of other family members, as well as discrepancies between children as a result of uneven physical, emotional, social, and intellectual development. Additional strains emerge from extended family members who may lack the understanding and appreciation of the concerns that parents and siblings of severely handicapped children have.

Medical expenses arising from the costs of specialized treatment and equipment.

Specialized child care needs and difficulties related to limited community resources, difficulties in finding the best care and services, and the extra costs of specialized care.

Time commitments that disrupt family routines, such as extra appointments to medical facilities, consultations associated with special education programs, and the predictable although disruptive situation of extra demands on family life due to the handicapped child's personal and emotional needs in the home settings.

Summary of Family Functioning

Families are constantly under pressure to the ever changing needs of their severely handicapped child. Consequently, family responsibilities to tasks shift in response to both the child's changing medical condition and his or her developmental needs. Over time, these demands may become extremely difficult to manage, and may result in parents/guardians seeking an out-of-home place for their child.

Recommendations and Suggestions For Further Research

Despite the hardships and responsibilities associated with the care of a handicapped member, families who chose to keep their child at home were able to maintain a sense of mastery over the demands. In other words, these families appeared to develop a sense of competence in their ability to manage whatever hardships and problems they encountered. This sense of internal strength was not related to family income or to parents' level of education, but rather to their cohesive feeling among family members. This family characteristic was complemented by the family's sense of emotional stability and a positive assessment of the physical health of family members.

As attention is shifted from the statistics presented to the potential implications of the findings outlined in this study, a basic set of conclusions and recommendations may be developed.

First, given the continued stressors of a considerable number of burdens (i.e., time, financial, physical) on families with severely handicapped children, it is important to acknowledge the value of the existing support programs and resources available to these families. However, the data clearly indicated the need for additional supports, both in terms of relevance and in availability. Future research should explore family resilience in raising a child with severe handicaps. It is also recommended that social support networks be further developed and expanded (i.e., respite services) as a strategy that may help mediate the effects of high levels of unresolved stress.

Second, the reported influences of guilt, attachment, and the extensive care requirements of the handicapped child suggested the need for additional family-oriented counselling. The findings also suggested that help for these families should not be limited to the hardships surrounding the medical situation and the direct care of the handicapped child. Other sources of stress have an impact on the family's ability to attend to the specialized needs of the child and, equally important, to care for other members and family itself.

The realistic limitations on family time and energy and that of attending medical specialists, emphasized the importance of using behavioral scientists, such as psychologists and social workers, as part of the medical team working with these families. Their training and expertise in the areas of psychological and interpersonal functioning may serve as additional primary resources to strengthen families with a severely handicapped child. This suggestion does not ignore the importance that these professionals already play, but rather unscores their important role and encourages an expansion of their role and increased application of their professional abilities.

Third, family counselling would be a helpful service to augment the medical support and guidance families receive through personal physicians and clinics. To encourage this kind of family counselling, information from this and other research investigations need to be more widely available to professionals.

Certainly, the research findings call attention to those important aspects of family life, stress, and coping. It is critical that future intervention with families with a handicapped child shift focus from family failures to family strengths. In doing so, the focus will be on family counseling, support, and crisis intervention.

However, considerable research is required in order to understand more fully how these families are able to do so well in the face of such difficulties. With the increased emphasis on family counseling and the growing awareness of the critical role families play in the rehabilitative process, there is a need for more information about what coping behaviors parents employ and under what conditions.

As a final note, research and policy design should focus on the development of a continuum of family support services which families can match to the fluctuations in their needs and circumstances. Continued research into the relationships between a severely handicapped child and family functioning will provide invaluable information to service providers regarding the support necessary to assist families in the care of their handicapped child.

BIBLIOGRAPHY

Allen, M.K. (1972). Persistent factors leading to application for admission to a residential institution. Mental Retardation, 10, 25-28.

Appell, M.J., & Tisdall, W.J. (1968). Factors differentiating institutionalized from noninstitutionalized referred retardates. American Journal of Mental Deficiency, 73, 424-432.

Baker, B.L. (1984). Intervention with families with young, severely handicapped children. In J. Blacher (Ed.), Severely handicapped young children and their families: Research in review. New York: Academic Press.

Bank, S., & Kahn, M.D. (1975). Sisterhood-brotherhood is powerful: Sibling sub-systems and family therapy. Family Process, 14, 311-337.

Beckman, P. (1983). Influences of selected child characteristics on stress in families of handicapped infants. American Journal of Mental Deficiency, 80, 150-156.

Blacher, J. (Ed.), (1984). Severely handicapped young children and their families: Research in review. Orlando, Fl: Academic Press.

Blacher, J. (1984a). A dynamic perspective on the impact of a severely handicapped child on the family. In J. Blacher (Ed.), Severely handicapped young children and their families: Research in review (pp. 3-50). Orlando, FL: Academic Press.

Blacher, J. (1986). Placement of severely handicapped children: Correlates and consequences. Washington, D.C.: National Institute of Child Health and Human Development.

Blacher, J. (1987, April). Attachment between severely impaired children and their mothers: Conceptual and methodological concerns. Paper presented at the meeting of the Society for Research in Child Development, Baltimore.

Blacher, J. & Bromley, B.E. (1990). Correlates of out-of-home placement of handicapped children. Who places and why? In L. Masters Glidden (Ed.), Formed families: Adoption of children with handicaps, (pp.3-40). New York: The Haworth Press.

Blacher, J., & Prado, P. (1986). The school as respire for parents of children with severe handicaps. In C. Salisbury & J. Intagliata (Eds.), Respite care: Support for persons with developmental disabilities and their families (pp. 217-234). Baltimore: Paul H. Brooks Publishing Co.

Blacher, J. Nihira, K., & Meyers C.E. (1987). Characteristics of home environment of families with mentally retarded children: Comparison across levels of retardation. American Journal of Mental Deficiency, 91, 313-320.

Black, M.M., Cohn, J.F., Smull, M.W., & Crites, L.S. (1985). Individual and family factors associated with risk of institutionalization of mentally retarded adults. American Journal of Mental Deficiency, 90, 271-276.

Boggs, E. (1979). Allocation of resources for family care. In R.H. Bruininks & G.C. Krantz (Eds.), Family care of developmentally disabled members. Minneapolis: University of Minnesota.

Borthwick-Duffy, S., Eyman, R.K., & White, J.F. (1987). Client characteristics and residential placement patterns. American Journal of Mental Deficiency, 92, 24-30.

Bristol, M.M., & Schopler, E. (1984). A developmental perspective on stress and coping in families of autistic children. In J. Blacher, (Ed.), Severely handicapped young children and their families Research in review. New York: Academic Press.

Butterfield, E.C. (1969). Basic facts about public residential facilities for the mentally retarded. In R.B. Kugel and W. Wolfensberger (Eds.), Changing patterns in residential services for the mentally retarded, (pp.15-33). Washington D.C.: President's Committee on Mental Retardation.

Caldwell, B.M., & Guze, S.B. (1960). A study of the adjusments of parents and siblings of institutionalized and noninstitutionalized ratarded children. American Journal of Mental Deficiency, 64, 845-861.

Carr, J. (1974). The effect of the severely subnormal on their families. In A.M. Clarke & A.D. Clarke (Eds.), Mental deficiency: The changing outlook. New York: Free Press.

Carver, J.N. & Carver, N.E. (1972). The family of the retarded child. Syracruse, NY: Syracruse University Press.

Cohen, S., & Warren, R.D. (1985). Respite care: Principles, programs, and policies. Austin, TX: Pro-Ed.

Cole, D.A., & Meyer, L.H. (1989). Impact of needs and resources on family plans to seek out-of-home placement. American Journal on Mental Retardation, 93, 380-387.

Conroy, J.W. (1982, November). Reactions to deinstitutionalization among parents of retarded adults and children. Paper presented at the Working Conference on Deinstitutionalization and the Education of Handicapped Children, Minnapolis.

Crnic, K.A., Friedrich, W.N., & Greenberg, M.T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. American Journal of Mental Deficiency, 88, 125-138.

Cummings, S.T. (1976). The impact of the child's deficiency on the father: A study of mentally retarded and chronically ill children. American Journal of Orthopsychiatry, 46, 245-55.

Downey, K.J. (1965). Parents' reasons for institutionalizing severely retarded children. Journal of Health and Human Behaviour, 6, 147-155.

Drotar, D., Baskiewicz, A., Irvin, N., Kennell, J., & Klaus, M. (1975). The adaptation of parents to the birth of an infant with congential malformation: A hypothetical model. Pediatrics, 56, 710-717.

Dunlap, W.R., & Hollinsworth, J.S. (1977). How does a handicapped child affect the family? Implications for practitioners. The Family Coordinator, 26, 286-294.

Ellis, N.R.., Bostick, G.E., Moore, S.A. Taylor, J.J. (1981). A follow-up of severely and profoundly mentally retarded children after short term institutionalization. Mental Retardation, 19, 31-35.

Eyman, R.K. & Call, T. (1977). Maladaptive behaviour and community placement of mental retarded persons. American Journal of Mental Deficiency, 82, 137-144.

Eyman, R.K., O'Connor, G. Tarjan, G., & Justice, R.S. (1972). Factors determining residential placement of mentally retarded children. American Journal of Mental Deficiency, 76, 692-698.

Eyman, R.K., Moore, B.C., Capes, L., & Zachofsky, T. (1970) Maladaptive behaviour of institutionalized retardates with seizures. American Journal of Mental Deficiency, 75, 651-659.

Farber, B. (1959). Effect of a severely mentally retarded child on family integration. Monographs of the Society for Research in Child Development, 24, (2, Serial No 71).

Farber, B. (1960). Family organization and crisis. Maintenance of integration in families with a severely retarded child. Monographs of the Society for Research in Child Development, 25, (1, Serial No. 75).

Farber, B. (1975). Family adaptations to severely mentally retarded children. In M.J. Bagab & S.A. Richardson (Eds). The mentally retarded and society: A social science perspective (pp. 247-266). Baltimore: University Park Press.

Farber, B., Jenne, W.C. & Toig, R. (1960). Family crisis and the decision to institutionalize the retarded child. Council for Exceptional Children Research Monograph, 1 (Series A).

Fotheringham, J.B. (1970). Retardation, family adequacy, and institutionalization. Canada's Mental Health, 18, 15-18.

Fowle, C.M. (1968). The effect of the severely retarded child on his family. American Journal of Mental Deficiency, 73, 468-473.

Friedrich, W.N., & Friedrich, W.L. (1981). Psychosocial assets of parents of handicapped and nonhandicapped children. American Journal of Mental Deficiency, 85(5), 551-553.

Friedrich, W.N., (1979). Predictors of the coping behavior of mothers of handicapped children. Journal of Consulting and Clinical Psychology, 47, 1140-1141.

Gallagher, J.J., Cross, A., & Scharfman, W. (1981). Parental adaptation to a young handicapped child: The father's role. Journal of the Division for Early Childhood, 3, 3-14.

German, M.L., & Maisto, A.A. (1982). The relationship of perceived family support system to the institutional placement of mentally retarded children. Education and Training of the Mentally retarded, 17, 17-23.

Graliker, B.V. Koch, R., & Henderson, R.A. (1965). A study of factors influencing placement of retarded children in a state residential institution. American Journal of Mental Deficiency 69, 553-559.

Grossman, F.K. (1972). Brothers and sisters of retarded children: An exploratory study. Syracuse, NY: Syracruse University Press.

Hobbs, M. (1964). A comparison of institutionalized and non-institutionalized mentally retarded. American Journal of Mental Deficiency, 69, 206-210.

Hoffman, L.W., & Manis, J.D. (1978). Influences of children on marital interactions and parental satisfactions and dissatisfactions. In R.M. Lerner & G.B. Spanier (Eds.), Child influences on marital and family interaction: A life span perspertive (pp. 165-213). New york: Academic Press.

Holroyd, J., & McArthur, O (1976). Mental retardation and stress on the parents: A contracts between Down's syndrome and childhood autism. American Journal of Mental Deficiency, 80, 4.

Holt, K.S. (1985). The home care of severely retarded children. Paediatrics, 22, 744-755.

Intagliata, J., & Doyle, N. (1984). Enhancing social support for parents of developmentally disabled children. Mental Retardation, 22(1), 4-11

Johns, N. (1971). Family reactions to the birth of a child with a congenital abnormality. Medical Journal of Australia, 1, 277-282.

Joyce, K., Singer, M., & Isralowitz, R. (1983). Impact of respite care on parents' perceptions of quality of life. Mental Retardation, 21(4), 153-156.

Kadushin, A. (1980). Child Welfare Services (3rd ed.). New york: Macmillan.

Kazak, A.E., Marvin R.S. (1984). Differences, difficulties, and adaptation: Stress and social networks in families with a handicapped child. Family Relations, 33(1), 67-78.

Kenowitz, L.A., Gallagher, J., & Edgar, E. (1977). Generic services for the severely handicapped and their families: What's available. In E.Sontag & J. Smith (Eds.), Educational programming for the severely/profoundly handicapped (p.p. 31-39). Reston, VA: Council for Exceptional children

Klein, S.D. (1972b). Brother to sister/sister to brother. Exceptional Parent, 3(2), 24-27.

Landesman-Dwyer, S., & Sulzbacher, F. (1981). Residential placement and adaptation of severely and profoundly retarded individuals. In R.H. Bruininks, C.E. Meyers, B.B. Sigford, & K.C. Lakin (Eds.), Deinstitutionalization and community adjustment of mentally retarded people. Washington, DC: American Association on Mental Deficiency.

Levy, J.M., & Levy, P.H. (1986). Issues and Models in the delivery of respite Services, In C.L. Salisbury & J. Intagliata (Eds.), Respite Care: Support for persons with developmental disabilities and their families. Baltimore, Maryland: Paul H. Brookes Publishing Co.

McCubbin, H.I., Nevin, R.S., Cauble, A.E., Larsen, A., Comeau, J.K., & Patterson, J.M. (1982). Family coping with chronic illness: The case of cerebral palsy. In H.I. McCubbin, A.E. Cauble, & J.M. Patterson (Eds.,). Family stress, coping, and social support (pp. 169-188). Springfield, IL: Charles C. Thomas.

Meyers, C.E., Borthwick, S.A., & Eyman, R.K. (1985). Place of residence by age, ethnicity, and level of retardation of the mentally retarded/developmentally disabled population of California. American Journal of Mental Deficiency, 90, 266-270.

Moroney, R.M. (1986). Family care: Toward a responsive society. In P.R. Dokecki & R.M. Zaner (Eds). Ethics of dealing with persons with severe handicaps (pp. 217-232). Baltimore: Paul H. Brookes Publishing Co.

Nihira, K. Meyers, C.E. & Mink, I.T. (1980). Home environment, family adjustment, and the development of mentally retarded children. Applied Research in Mental Retardation, 1, 5-24.

Nirje, B. (1969). The normalization principle and its human implications. In R.B. Kugel and W. Wolfendberger (Eds). Changing patterns in residential services for the mentally retarded Washington D.C.: President's Committee on Mental Retardation.

Olshansky, S., & Schonfield, J. (1964). Institutionalization or pre-school retardates, Mental Retardation, 2, 109-115.

Powell, T.H., & Ogle, P.A. (1985). Brothers and sisters - A special part of exceptional families. Baltimore: Paul H. Brookes Publishing. Co.

Rousey, A.M., Blacher, J., & Hanneman, R. (1990). Predictors of out-of-home placement of children with severe handicaps: A cross-sectional analysis. American Journal on Mental Retardation, 94, 522-531.

Salisbury, C.L. (1986). Parenthood and the need for respite. In C.L. Salisbury & Intagliata, J. (Eds). Respite care. Support for persons with developmental disabilities and their families. (pp. 3-28). Baltimore: Paul H. Brookes Publishing Co.

Salisbury, C.L. (1986). Generic community services as sources of respite. In C.L. Salisbury & J. Intagliata (Eds.), Respite care: Support for persons with developmental disabilities and their families. (pp. 195-216) Baltimore, Maryland: Paul H. Brookes Publishing Co.

Salisbury, C.L. & Griggs, P. (1983). Developing respite care services for families of handicapped persons. Journal of The Association for Persons with Severe Handicaps, 8,(1), 50-57.

Salisbury, C.L. & Intagliata, J., (Eds.), (1986). Respite care: Support for persons with developmental disabilities and their families Baltimore: Paul H. Brookes

Scheerenberger, R.C. (1982). Public residential services, 1981: Status and trends. Mental Retardation, 20, 210-215.

Schilling, R.F., Kirkham, M.A. Snow, W.H. & Schinke, S.P. (1986). Single mothers with handicapped children: Different from their married counterparts? Family relations, 35, 69-77.

Seligman, M. (1983). Siblings of handicapped persons. In M. Seligman (Ed.), The family with a handicapped child: Understanding and treatment (pp. 147-174). New York: Grune & Stratton.

Seltzer, M.M., Krauss, M.W. (1984). Placement alternatives for mentally retarded children and their families. In J. Blacher (Ed,), Severely handicapped young children and their families: Research in review, New York: Academic Press.

Shelhaas, M.D. & Nihira, K. (1969). Factor analysis of reasons retarded are referred to an institution. American Journal of Mental Deficiency, 74, 171-179

Sherman, B.R. (1988) Predictors of the decision to place developmentally disabled family members in residential care. American Journal on Mental Retardation, 92, 344-351.

Sherman, B., & Cocozza, J.J. (1984). Stress in families of the developmentally disabled: A literature review of factors affecting the decision to seek out-of-home placements. Family Relations, 33, 95-103.

Slater, M.A. (1986). Respite care - A national perspective. In C. Salisbury & J. Intagliata (Eds.), Respite care: Support for persosn with develomental disabilities and their families (pp. 69-88). New York: Grune & Stratton.

Solnit, A.J., & Stark, M.H. (1961). Mourning and the birth of a defective child. Journal for the Psychoanalytical Study of the child, 16, 523-537.

Spreat, S., Telles, J.T., Conroy, J.W. Fienstein, C., & Colombatto, J. (1987). Attitudes toward deinstitutionalization: A national survey of families of institutionalized mentally retarded persons. Mental Retardation, 25, (267-274).

Stone, N.D. (1967). Family factors in willingness to place the mongoloid child. American Journal of Mental Deficiency, 72, 16-20.

Suelzle, M., & Keenan, V. (1981, August). *A family career and individual life cycle perspective on planning residential and vocational options for mentally retarded children.* Paper presented at the annual meeting of the Society for the Study of Social Problems, Toronto, Ontario

Tausig, M. (1985). Factors in family decision-making about placement for developmentally disabled individuals. *American Journal of Mental Deficiency, 89,* 352-361.

Thaman, A., & Barclay, A. (1967). Parental attitudes toward institutionalization of mentally retarded children. *Child Welfare, 64,* 156-159

Turnbull, A.P., Summers, J.A., & Brotherson, M.J. (1983). *Working with families with disabled members: A family systems approach*. Monograph, The research and Training Centre inIndependent living, University of Kansas, Lawrence, KS.

Turnbull, A.P., & Winton, P.J. (1984). Parent involvement policy and practice: Current research and implications for families of young, severely handicapped children. In J. Blacher (ed), *Severely handicapped young children and their families:* Research in review. New York: Academic Press.

Ulshur, C. (1982a). Respite care for mentally retarded and other disabled populations: Program models and family needs. *Mental Retardation, 20,* 2-6.

Ulshur, C. (1982b). An evaluation of home-based respited care. *Mental Retardation, 20,* 58-62.

Waisbren, S.E. (1980). Parents' reaction after the birth of a development mentally disabled child. *American Journal of Mental Deficiency, 84,* 345-351.

Wikler, L. (1981). Chronic stresses in families of mentally retarded children. *Family Relations, 30,* 281-288.

Wickler, L., Hanusa, D., & Stoycheff, J. (1986). Home-based respite care, the child with developmental disabilities, and family stress: Some theretical and pragmatic aspects of process evaluation. In C. Salisbury & J. Intagliata (Eds.), Respite care: Support for persons with develomental disabilities and their families. Baltimore, Maryland: Paul H. Brooks Publishing Co.

Wolfensberger, W. (1971a). Will there always be an institution? I: The impact of epidemiological trends. Mental Retardation, 9, 14-20.

Wolfensberger, W. (1971b). Will there always be an institution? II: The impact of new service models: Residential alternatives to institutions. Mental Retardation, 9, 31-38.

Wright, J.S., Granger, R.D., & Sameroff, A.J. (1984). Parental acceptance and developmentally handicap. In J. Blacher, (Ed.,), Severely handicapped young children and their families: Research in review. New York: Academic Press.

APPENDIX A

PERMISSION TO CONDUCT STUDY

APPENDIX A
Permission to Conduct Study

ALBERTA **MEMORANDUM**

ALBERTA FAMILY & SOCIAL SERVICES

FROM: Paulette Killam DATE: Feb. 12, 1992
Executive Director
Eric Cormack/Rosecrest Centres

TO: William Winship
Manager,
Services to Persons with Disabilities

SUBJECT: **ROSECREST PARTICIPATION IN A SURVEY**

As you are aware, I am in the process of completing my Masters in Educational Psychology. To that end, I am requesting permission to survey Rosecrest parents/guardians regarding out-of-home placement (or not) of their child.

I am sending you a copy of the Ethical Review forms which are required by the U of A, which includes specifics about the project.

Thanks Bill.

Paulette Killam
Executive Director
Eric Cormack/Rosecrest Centres

PK/cgm

APPENDIX B

LETTER TO PARENTS/GUARDIANS

APPENDIX B
Letter to Parents/Guardians

9835 - 112 Street
Edmonton, Alberta
T5K 2E7

Dear

This letter is written to invite your participation in a survey exploring factors influencing and factors preventing out-of-home placement.

Very little is known about the factors influencing out-of-home placement of severely handicapped children. Research conducted in the 1960s and 1970s does not provide accurate information on the processes of placement in the 1980s and 1990s. Typically, researchers have not taken into account the role of moderating circumstances in the parents' decision. Thus, this literature tells us little about which severely handicapped children will be placed and about the factors influencing the decision.

The primary purpose of this study is to describe parents'/guardians' reasons for either choosing or delaying placement. The identification of those characteristics of child and family that may increase a child's risk of out-of-home placement would assist in predicting who will place a child and why. These findings would have significant implications for service providers and other professionals who support families in the decision-making process.

Please find enclosed three questionnaires, each with instructions for completion.

1. <u>Family Data Sheet</u> - to secure background and demographic information about family members.
2. <u>Factors Influencing Placement Scale</u> - to identify factor perceived by parents/guardians as influencing their decision to place or not.

.../2

.../2

3. Factors Preventing Placement Scale - to identify factors perceived by parents/guardians as delaying the placement decision.

The information received from these questionnaires will be kept strictly confidential. There will be no references made which would identify individuals or families. I would be pleased to share the results of this study with you when it is completed. If you agree to participate, please complete the enclosed consent form. Your decision not to participate will have no influence on the care received by your child at Rosecrest.

A stamped addressed envelope has been included for your convenience.

Please feel free to contact me at 427-2764 should you require clarification or have any questions.

Thank you in advance for your participation.

Sincerely,

Paulette Killam
Executive Director
Eric Cormack/Rosecrest Centres

PK/cgm

APPENDIX C

DEMOGRAPHIC QUESTIONNAIRE

APPENDIX C

DEMOGRAPHIC QUESTIONNAIRE

I. CHILD DATA

1. Name of Child:______________________________ Sex: ______

2. Child's Birthdate: Month______ Day______ Year_________

3. Rosecrest Admission Date:______________________________

4. Primary Diagnosis:__________________________________

II. PARENT/GUARDIAN DATA

5. Name and address of parents/guardians

Relationship:__________________

Name:______________________

Address:_____________________

6. Parental Status

__ Married/Common-law

__ Parents divorced and parent having custody living alone

__ Parents divorced and parent having custody remarried

__ Parent having custody alone (single/widowed)

7. Race/Ethnicity

__ White

__ Asian/Pacific

__ Black

__ Other

8. Age	<21	21-30	31-40	41-50	Over 50
Father	__	___	___	___	____
Mother	__	___	___	___	____

9. Education	<High School	High School Graduate	Some College/ Univ.	College/ Univ. Degree	Post Studies
Father	_	__	__	__	___
Mother	_	__	__	__	___

10. Occupation	Full time Out-of-Home	Part time Out-Of-Home	Full time At home	Not Employed
Father	_	__	__	__
Mother	_	__	__	__

11. Income

__ Less than $10,000

__ 10,000 to 20,000

__ 21,000 to 30,000

__ 31,000 to 40,000

__ Over 40,000

III. FAMILY DATA

12. Number of Children (excluding Rosecrest)

__ 0

__ 1

__ 2-4

__ 5 or more

13. Ages and sex of Children (excluding Rosecrest)

i____ Male___ Female___

ii___ Male_ _ Female___

iii___ Male___ Female___

iv___ Male___ Female___

v____ Male___ Female___

APPENDIX D

FACTORS INFLUENCING PLACEMENT SCALE

APPENDIX D

FACTORS INFLUENCING PLACEMENT

Please indicate below how much impact each of the following factors has/had on your decision whether to place your child or not.

Mark an "X" in the box under the category that shows how much impact each factor has/had.

	No Impact On Decision	Slight Impact	Same Impact As Anything Else	Some Moderate Impact	Strong Impact On Our Decision
1. My partner's attitude toward placement					
2. Feelings of my nonhandicapped children					
3. Medical or physical problems of my handicapped child					
4. My health or my partner's health					
5. Job opportunities for myself or my partner					
6. My social life and support from friends					

	No Impact On Decision	Slight Impact	Same Impact As Anything Else	Some Moderate Impact	Strong Impact On Our Decision
7. My child's physical size					
8. Availability of babysitters					
9. Availability of respite care					
10. Advice from friends or relatives (other than partner)					
11. Advice from professionals					
12. Financial considerations					
13. Arguments with my partner					

	No Impact On Decision	Slight Impact	Same Impact As Anything Else	Some Moderate Impact	Strong Impact On Our Decision
14. Day to day stress					
15. Others who have recently placed (friends or acquaintances who have a child like mine					
16. My child's behaviours					
17. My child's level of functioning and potential for future learning					
18. Being a single parent					
19. Arguments and conflicts with my handicapped child					
20. No appropriate schooling or therapy offered by school or district					

	No Impact On Decision	Slight Impact	Same Impact As Anything Else	Some Moderate Impact	Strong Impact On Our Decision
21. Other					

(Cronbach alpha coefficient of .63)

APPENDIX E

FACTORS PREVENTING PLACEMENT SCALE

APPENDIX E
FACTORS PREVENTING PLACEMENT

Please indicate below the reasons you either didn't place your child sooner or you have chosen not to place your child.

Mark an "X" in the box under the category that shows how much influence each factor had in keeping your child at home as long as you did, or what influenced you to keep your child and not seek placement.

	Strong Influence On Keeping My Child at Home	Moderate or Some	SO SO Neither More Nor less Than Anything In Our Lives	Hardly Any	No Influence On Keeping My Child at Home
1. My partner's attitude toward placement					
2. No satisfactory placements were available					
3. My child didn't present any particular problems					
4. Availability of respite care					
5. Availability of babysitters					

		Strong Influence On Keeping My Child at Home	Moderate or Some	SO SO Neither More Nor less Than Anything In Our Lives	Hardly Any	No Influence On Keeping My Child at Home
6.	My non-handicapped children enjoyed/got along with their handicapped sibling					
7.	Thoughts of placement made me feel guilty or that I was a bad parent					
8.	Free, appropriate public schooling was available for my child					
9.	At school, my child learned skills and adaptive behaviours that made it easier to have him or her at home					
10.	I didn't know how to go about getting a placement					
11.	My religious beliefs made placement difficult					

	Strong Influence On Keeping My Child at Home	Moderate or Some	SO SO Neither More Nor less Than Anything In Our Lives	Hardly Any	No Influence On Keeping My Child at Home
12. Doctors and other professionals advice					
13. I couldn't find a placement that was nice enough for my child					
14. My partner helped me a lot with our handicapped child at home					
15. I was very attached to my child					
16. Advice from friends to try raising my child at home					
17. Raising this child was no more difficult that raising any of my other children					
18. Thoughts that someone else would be raising my child					

		Strong Influence On Keeping My Child at Home	Moderate or Some	SO SO Neither More Nor less Than Anything In Our Lives	Hardly Any	No Influence On Keeping My Child at Home
19.	I felt my child would never understand why he/she was no longer living at home or that he/she would think he/she was unloved					
20.	I knew I wouldn't get a chance to see my child very often					
21.	Others					

(Cronbach alpha coefficient of .82)