FAMILY EXPERIENCES WITH COMMUNITY-BASED RESPITE CARE

Thesis for the Degree of M. A.

MICHIGAN STATE UNIVERSITY

JUDITH CAROL SIMON

1976

ABSTRACT

FAMILY EXPERIENCES WITH COMMUNITY-BASED RESPITE CARE

By

Judith Carol Simon

This study is an exploration of family experiences with a Community-Based Respite Care program, in Lansing, Michigan. Respite care is defined as short-term care, and is provided by this service to families with retarded children or adults living at home. Respite care is designed to provide physical and psychological relief to these families, and can be used for any reason, (including vacation, emergency, hospitalization, or just rest), for a time period of one to thirty days. The retarded individuals are cared for by licensed foster families, in the homes of the foster parents.

The notion of respite care emerged as professionals became aware that families with retarded children are under a great deal of stress, and often have difficulty finding caregivers for their retarded children. The concept of respite care is fairly new, and programs have just begun to develop in recent years. At the present time research that evaluates or investigates the services provided by existing programs is not available.

This study is an exploration of one particular respite care service. The program was examined through an interview technique, with emphasis on the concept of psychological relief, or relief from stress. An attempt was made to define the concept, to determine whether or not families using the service received psychological

relief, and also to obtain information about the factors leading to this relief.

All families who had used the service after their initial training phase and were willing to participate were interviewed. Thirteen interviews were completed. In addition, a telephone inquiry was conducted in order to determine the reasons that some families participated in some or all of the initial training phase and then did not continue to use the service.

The major findings of the study were: a) the program does provide a useful and needed service, b) the initial training phase is a critically important part of the program, c) psychological relief can be defined and measured, and d) the service did, in fact, provide psychological relief to nearly all of the families interviewed, in varying degrees. Implications of the findings were discussed for this and other respite care programs.

FAMILY EXPERIENCES WITH COMMUNITY-BASED RESPITE CARE

By

Judith Carol Simon

A THESIS

Submitted to

Michigan State University

in partial fulfillment of the requirements

for the degree of

MASTER OF ARTS

Department of Family and Child Sciences

1976

ACKNOWLEDGMENTS

Throughout this endeavor, a number of people have been extremely helpful to me in various ways. The chariman of my guidance committee, Dr. Donald Melcer, has given me a great deal of constructive feedback and support, as have my other committee members, Dr. Robert Boger and Dr. Margaret Bubolz. I would also like to thank Dr. Mary Andrews, who was particularly helpful during the planning stage of this project, perhaps when assistance was most needed.

Special thanks go to Sue Miller, Coordinator of the Community-Based Respite Care Program; without her enthusiastic approval and cooperation, this study would not have been possible. In addition, my appreciation goes to Rita Charron, Director of Programs for the Mentally Retarded, as well as a number of staff members of Community Mental Health/Programs for the Mentally Retarded, including Dr. Gilbert DeRath, Chris Guldager, Ken Slater, and Shirley Mitchell.

My most personal thanks go to my parents, who have supported me in all ways throughout my education, and to Jim Abelson, my best friend and loving companion; in addition to his love and support, he has served as my primary editor and most tactful critic.

TABLE OF CONTENTS

LIST OF TABLES

INTRODUCTION

Professionals in the field of mental retardation are becoming increasingly interested in the families of retarded individuals. Mental retardation is a disability that almost always has a profound effect on the family of the affected individual. Research indicates that families with retarded children experience a great deal of physical, social, and psychological stress. They are socially limited both within and outside the family, and are faced with specific types of enduring crises. Viewing the family as a system, the addition of a retarded child to the family, or the discovery that a child is retarded, is necessarily disruptive to ongoing family patterns of interaction. The nature and severity of this impact is dependent on a number of factors within and outside the family, but in all cases such a situation has extremely powerful and long-lasting effects.

As professionals have become more aware of these special problems that face families with retarded children, they have correspondingly increased their efforts towards the development of services that would alleviate these problems. One notion that has emerged from these efforts is the concept of respite care, which is defined as short-term relief from care. The purpose of respite care is to provide relief from stress by providing temporary relief from care to these families.

It was believed that since the retarded child was in some ways responsible for inducing the stress, if the families did not have to

care for the child for a short time some stress could be relieved. The need for parents to spend time away from their children for short periods exists in almost all families, regardless of whether or not there is a retarded child. For families with retarded children, however, the need is probably more acute, and the availability of other caregivers is sharply limited. This is due to the fact that many people who will care for normal children cannot or will not take care of retarded individuals.

Some residential care facilities for retardates offer short-term care, but this is not an ideal situation for two major reasons. First, many parents are hesitant or unwilling to place their child at this kind of a facility on a short-term basis, because of the vastly different environment and type of care at these facilities. The other major reason that this kind of arrangement is not ideal is that it is not conducive to the "normalization" of mentally retarded individuals, which refers to the process of integrating handicapped individuals into all aspects of community life.

So emerged the concept of community-based respite care, with the intention of offering short-term relief to any family with a retarded member living at home. Although the notion of community-based respite care is not new, actual programs have developed only in the last few years and are not widespread.

At the present time there is not available research evaluating the services provided by any of the respite care programs. It is thus unclear whether respite care acutally supplies the relief that it was designed to provide. If the concept of respite care is to grow and the relief assumed to be needed by the families of retarded

individuals is to be provided, explorations of current programs must begin.

This study was designed to explore the perceptions and experiences of families using the Lansing, Michigan Community-Based Respite Care Program. This program has been in operation since July, 1974, and is administered by Programs for the Mentally Retarded. At the present time it offers family foster care to families with retarded children and adults living at home within Clinton, Eaton, and Ingham counties.

One major goal of this study was to begin defining those factors that may be involved in psychological relief for families using a service such as respite care. It was hoped that some light could also be shed on the question of whether or not the service does in fact provide relief from stress to families using it. Furthermore, a serious attempt was made to collect data which would be meaningful and useful to the operation of this particular program, which is fairly new and still in the process of development.

Because of the nature of the data required, a personal, in-depth interview approach was clearly the methodology of choice. This is largely due to the exploratory nature of the study: the important factors are not known, and the data desired necessitates the elicitation of spontaneous emotional responses. Another relevant factor was the small sample size, limited by the fact that less than twenty families had used this service after their initial training phase.

Interviews were conducted by the author with all families who had used the service after their initial training phase, and who were willing to be interviewed. Thirteen interviews were completed. The

interview schedule consisted of questions pertaining to the parents' perceptions of and experiences with the respite care service.

This methodological approach has some distinct drawbacks, the major one being that the data does not lend itself to statistical analysis, and therefore generalizations must be highly speculative. Other disadvantages of this technique are the possibility of interviewer bias, the difficulty in collecting comparable data from all families, and the related difficulty in analyzing the data. Despite these drawbacks, it was decided that the major purpose of this study, i.e. to provide an account of the perceptions and experiences of families who have used the Lansing Community-Based Respite Care Program, would best be realized with the use of an interview technique.

tre ef

erat..r

tre ne

gerce

of Ger

Syste

cic t

tions

rists

lehr,

follo

ted t

each

a rea

by rul

whethe

CHAPTER I

BACKGROUND TO THIS STUDY

There has been no prior research that specifically explores the effects of existing respite care programs. However, there is literature relevant to this study. It is only with the understanding of the needs of families with retarded members, and the resultant emergence of the respite care concept, that this study becomes meaningful.

Relevant Literature

The basic orientation of this review stems from the perspective of General Systems Theory, and its application to the family. General Systems Theory constitutes an attempt to formulate a body of systematic theoretical constructs which address themselves to general relationships in the empirical world (Boulding, 1968).

In recent years, the family has increasingly been viewed by theorists as a system (Kantor and Lehr, 1975). According to Kantor and Lehr, a system is a set of different things or parts that meet the following two requirements: 1) they are directly or indirectly related to each other in a network of reciprocal causal effects, and, 2) each component part is related to one or more of the other parts in a reasonably stable way during any particular period of time.

Thus the family is organizationally complex, and is governed by rules at any given time. Each member affects all other members, whether it be through direct or indirect communication. Any change

in one member necessarily leads to change in the system. From this perspective, a retarded child must have an impact on the family. As Kantor and Lehr (1975) discuss, the birth of any baby induces great stress within the family. There is a disruption in ongoing patterns, and new patterns between all family members must be established. The additional factor of the child's retardation, whether discovered by the family at birth or later, causes a similar stress and disruption, and also necessitates the development of new interaction patterns. The nature and severity of the impact of the retarded child on the family are dependent on a variety of factors both within the family system and between the family system and other systems.

Although no authors have yet attempted to directly apply systems theory to families with retarded individuals, there is considerable discussion in the literature, from a variety of theoretical perspectives, of the impact of a retarded child on his parents and family. The impact of a retarded child on the family begins when the family becomes aware that he is retarded. This may happen immediately after birth, or up to several months, or even years after the child is born. A large portion of the literature is concerned primarily with the initial impact on the family, i.e. when they first realize that their child is retarded. Our concern here is with the continuing effect of the child on the family, as an ongoing system. Therefore, the literature on the initial impact on the family will be discussed only as it relates to later family functioning.

Before discussing the literature itself, it is important to make a few key observations. Almost all of the literature deals with severely retarded children and their families: the effects of moderately and mildly retarded children on their families have been studied

very

is th

the m

most

can b

trast

are o

often

one w

famil

induc

to be

them.

very

pling

subje

consi

ded c

Scho

retar

nomi

inter

Great

physi

ily l

tion

very little. There are a number of reasons for this. The major one is that in the cases of families with severely retarded individuals, the results of studies are unambiguous. Since the children are almost always born with their disabilities, unusual family patterns can be attributed to the effects of the child on the family. In contrast, the disabilities of mildly and moderatley retarded children are often not discovered for some time after birth and causation is often unknown. Therefore, if unusual family patterns were found, one would not know whether the child was affecting the rest of the family system, or whether the system was affecting the child, and inducing symptoms of retardation. Another limitation of the studies to be discussed is that some methodological flaws exist in most of them. For example, control groups of "normal" families are used in very few of the studies. Another methodological problem is that sampling procedures are usually not ideal; for example, parents used as subjects often are only those belonging to parent groups. With these considerations in mind, the literature will be traced historically.

Some of the earliest studies on the impact of a mentally retarded child on the family were conducted in Great Britain and Australia. Schonell and Watts (1956) studied Australian families of school-aged retardates with IQs below 55, and found that there were severe economic, social, and emotional effects on the families. Holt (1958) interviewed families of retardates five years of age or older in Great Britain. He found that a severely retarded child placed great physical demands upon the family, and was generally disruptive of family life. Holt's study is one of the few in which careful consideration was given to the social class distribution of the families: the

same class distribution existed in his sample as did in the city where the study was conducted.

In an extensive study of the effects of a retardate upon the family, Tizard and Grad (1961) studied families with low functioning retarded children in London. Their sample consisted of two groups: those whose children lived with them, and those whose children were in an institution. They found that families with their children at home had more problems than those with their children in institutions. The problems included physical, psychological, and financial hardships.

In the United States, some of the earliest studies on the families of retardates are the result of a project directed by Bernard Farber, a sociologist. This project was carried out in 1955 and 1956, and occupies an important position in the field. It constitutes what is probably the earliest attempt to develop sociological theory in relation to families with retarded children. Because of the importance of these studies themselves, and also due to their influence on future studies, they will be discussed in a fairly comprehensive way.

Farber and his associates (1960a, 1960b) have hypothesized two types of crisis reactions of families with severely retarded children. The tragic crisis resembles bereavement in many ways: it is precipitated by the diagnosis of the child, and often continues for a substantial period of time. The tragic crisis consists of the realization by the parents that anticipated life careers will be frustrated, and that future plans for the child, and often for the whole family, will never materialize. The role organizational crisis is the inability to cope effectively with the child over a long period of time, and

results when no set of roles can be developed to organize interaction with the child in an acceptable way. Farber further hypothesizes (1960) that the tragic crisis is found mostly in families with higher socioeconomic status, and that the role organizational crisis is found in families with lower socioeconomic status. This situation evolves as a result of differing perspectives on the socialization of children by members of different classes. In general, higher status parents believe that socialization is primarily the task of the child (as opposed to the parent), i.e. the child carries the responsibility for his own socialization. A severely retarded child, however, is incapable of complete socialization, and higher class parents therefore see the child as the source of the resultant problems and frustrations. This is seen by these parents as an uncontrollable and tragic situation. Lower class parents, on the other hand, view socialization mostly as the parents' job. When the mother experiences difficulty in controlling her child, and maintaining good relationships with the rest of the family at the same time, she sees this as her problem. She regards herself as incapable of developing roles which can control interaction with the family in a way acceptable to her, and therefore experiences a role organizational crisis. Farber's data supported these hypotheses (Farber, 1960). From this viewpoint, each type of family experiences the retardation in a different way, but, in either case, the situation clearly poses problems for the entire family.

In addition to exploring the crises that families of severely retarded children experience, Farber has studied various factors and conditions affecting the impact of the child. As a result of these studies, an interesting hypothesis has emerged. In his 1959 article,

Farber proposes that the presence of a severely retarded child in the family leads to an arrest in the family life cycle. The contention is that passage through the stages of the cycle are primarily determined by mental age, and not by chronological age. The state of a family is determined by the norms and activities that they are engaging in at that time. In the case of normal children, this is not a relevant factor, because mental age and chronological age are approximately the same. A severely retarded child becomes the youngest child socially and does not progress to a maturity level beyond a normal preadolescent. Therefore the family life cycle is arrested at that stage, when the youngest child is preadolescent. The severely retarded child remains at that stage of dependence throughout his or her life, therefore keeping the parents at that level of responsibility. This hypothesized arrest in the cycle affects the development of the parents' domestic and community career, and possibly the value system of one or both parents. Although this hypothesis has not been tested, it seems to have far-reaching implications.

In a number of other studies, Farber has looked at a variety of factors in relation to their effects on the family of a severely retarded child. A large body of data support the conclusion that an enormous number of factors do in fact affect the impact of retardation on the family system. These will simply be listed: sex of child, ages of parents, ages and sex of siblings, social status of family, religion of family, personality of parents, personality of siblings, parenting strategy of parents, and parents' perception of the causation of the retardation. Although this is an extremely superficial listing, it points out the complexity of the situation. Farber has found, without

any doubt, that severely retarded children do have a negative impact on their families in many ways.

In a more recent study, Cummings, Bayley, and Rie (1966) explored the effects of a child's deficiency on the mother. Using a number of measures, they found that the experience of having a retarded child is psychologically stressful for the mother. More specifically, they found that these mothers derive less pleasure in relating to their retarded child than to their other normal children. The mothers in the study were also found to be bearing a burden of anxiety, depression, and conflict in modulating hostile feelings towards the retarded child. They had conflicting tendencies towards both rejecting and overprotecting the affected child. In addition, these mothers experienced a reduction in self-esteem with regard to their maternal role.

A number of studies have shown that families with retarded children have different patterns of social behavior than "normal" families. Holt (1958) found that forty percent of the parents in his sample (all parents of severely retarded children) reported being unable to go out together, due to their child. A smaller percentage reported not being able to take a vacation. Although a control group was not used to compare these rates with those of "normal" families, the conclusion was that these were unusually low, which intuitively seems correct. In two related studies, Schonell and Watts (1956) and Schonell and Rorke (1960) found that about half of the families reported that their social interactions were affected by the presence of their severely retarded child. About one half of the parents felt that visits to the homes of friends and relatives were reduced, and also that arrangements for shopping were more difficult. Some parents

also found it impossible to indulge in daily social activities. Tizard and Grad (1961) found that about half of the families reported that social contacts were limited as a result of their severely retarded child.

In a study of the actual behavior of families, Meyerowitz and Farber (1966) found that families with educable mentally retarded children were less likely than normal families to participate in voluntary associations and chruches. These families also had less contact with friends and neighbors, when compared with normal families.

In another recent study, McAllister, Butler, and Lei (1971) compared families with retarded children (both severe and less severe) to "normal" families, on patterns of social interaction. They found some major differences between the two groups of families, with respect to both intrafamily and extrafamily patterns. Within the family, those with retarded children reported less parent-child interaction than those with all "normal" children. Outside the family, participation in formal community organizations was not influenced by the presence of a retarded child. However, the effect of such a child on informal aspects of family-community relations was found to be very significant. The most important finding is that many more parents of retarded children than those of normal children interact seldom with their neighbors. These families also visit people outside their immediate family less frequently than normal families. These results give a picture of the family of a retarded child being restricted in interaction both within the family, and between the family and the community. This type of situation probably has broad implications for the social nature of these families, in terms of relationships between and among them.

Conclusions

After reviewing the literature, it becomes apparent that families with retarded children do experience a great deal of physical, social, and psychological stress. More specifically, they are socially restricted both within and outside of the family, and also may experience an arrest in the family life cycle. In addition, the parents are faced with specific types of enduring crises, and the mothers suffer considerable psychological stress. Clearly, a retarded child is disruptive to the family system, and these effects are extremely powerful and long-lasting.

Others have come to this same conclusion. For example, Ryckman and Henderson (1965) state that, "There is general agreement in the literature that the fact of having a retarded child places considerable strain on the psychological adaptive mechanisms of the parent" (p. 4). In another example, Wofensberger (1967), after reviewing a great deal of literature, concludes that a large number of families with retarded children have problems with individual and marital adjustment, child-rearing, sibling rivalry, and various other spheres of behavior. In an article on families of retarded children, Schild (1971) states a similar viewpoint, and also emphasizes the fact that many of these families are socially isolated from their communities. She attributes this fact to situational factors, and, most importantly, to negative and stigmatic societal factors. Many of her ideas seem to stem from her own personal experience in counseling these families; she provides a powerful account. In summary of her article, she states,

> Viewing the family as a system in which the common needs and purposes are met through role interactions of its members, the need for a family approach to mental retardation seems self-evident.

> The impact of retardation on the family is generally stressful and traumatic and adds to the families' vulnerability in coping with life problems. (p. 441)

Emergence and Development of the Respite Care Concept

As professionals have become more cognizant of the special problems and needs which face families with retarded members, they have intensified their efforts towards developing programs to meet these needs. One approach that has emerged from these efforts is the concept of respite care. Respite care is designed to provide relief from stress to these families by providing temporary relief from care.

It was thought that since the retarded child was in some ways responsible for inducing the stress, that maybe if the parents did not have to care for him for a short time, some of the stress could be relieved. This notion did not arise only in the minds of the professionals: Schonell and Watts (1956) found that the most desperate need voiced by the mothers was for a babysitting or day care service that would allow them to get away occasionally. Obviously, all parents use friends, relatives, and caretakers to provide this kind of a service, both on a formal and informal basis. Parents of retarded children also find their own forms of short-term relief: for them, though, a special problem exists. It is often difficult for these parents to find caretakers for their retarded child. In other cases, the parents have friends or relatives who will care for the child. Retarded children are often difficult or undesirable to care for, and parents therefore do not like to ask relatives or friends, because they feel like they are imposing.

It became apparent that some kind of a service was needed, that

would be available to all families with a retarded child. This type of a short-term service was available to some parents at residential care facilities, but, for two major reasons, a residential care facility is not ideal. The first reason is that many parents are reluctant or unwilling to place their child at such a facility on a short-term basis. One of the major reasons for this parental hesitancy is that a residential care facility is a vastly different environment from a typical home. The child would be placed in an extremely foreign situation, and parents fear that their child will be very unhappy, and perhaps not cared for adequately. Another reason that short-term residential care is undesirable is that it is not conducive to the "normalization" of the mentally retarded. "Normalization" refers to the process of allowing and encouraging the integration of handicapped individuals into the community in all ways. A short-term care service in a residential care facility does not facilitate normalization in any way. In fact, it may encourage thinking along the line that "mentally retarded people should be in institutions."

One solution to the problem is a community-based respite care program, providing short-term foster care to families with retarded members. The advantages of this type of a service are many, and apply to the child, the family, and the community as a whole.

For the child, he is given the opportunity to function in an environment different enough from his ordinary one to facilitate a learning experience, but similar enough so that he will remain comfortable. The experience of getting along in another home can be of great value to a retarded individual, especially one who has not been out of his own home much. It can also serve as a preliminary step

to the achievement of independence from his parents, at whatever level this might be possible.

For the family, there are also both short and long term advantages. Of course, the short-term advantage allows for relief from care, so that the family can engage in a wide variety of activities. These may include: pure relaxation, vacations, attending to emergencies, and spending time with the rest of the family. In the long run, respite care can provide a mechanism for the parents to begin to separate from their retarded child (who may be an adult).

For the community, respite care allows for an increasing number of individuals to be exposed to mentally retarded persons, and hopefully to accept them. This is an example of the process of normalization. As the President's Committee on Mental Retardation (1969) expressed, "We must make as great as possible integration of the retarded into normal community living and working patterns the objective of planning."

So emerged the concept of community-based respite care. A number of programs exist throughout the country. The services provided are varied, but fall into two general categories: foster care, which takes place in a home other than that of the natural family, and home-based care, which occurs in the home of the natural family. Foster care includes regular foster families, group homes, family group homes, and halfway houses. Home-based care includes homemaker services, qualified babysitting, and nursing.

The Lansing Program

In Lansing, Michigan, a community-based respite care program has been in operation since July, 1974. It is administered by Programs for the Mentally Retarded and is jointly funded by Community Mental Health and Developmental Disabilities funds. The operational cost of the program in 1975 was approximately $44,000. Most of this money is used to pay the salaries of two full-time staff members and to partially subsidize the cost of hiring foster families. It is the intention of the program that both foster and home-based care will eventually be provided. Foster care was first developed, and has been available on some basis (at first very limited) since early in the program. Family foster care is now widely available: as of March 1, 1976, thirty-four families had been served. Home based care is presently in the process of development, and will presumably be available soon. The service is available to any family having a retarded child or adult living in their home, within Clinton, Eaton, and Ingham counties. The natural families pay for the service, and fees are determined on the basis of annual taxable income. Fees range from $1.50 to $8.00 per day (for a copy of the fee schedule, see appendix).

Licensed foster families provide the service, and are trained cooperatively by the program staff and the natural families. The first step of these procedures is an initial meeting between the natural parents (or one of them) and members of the Respite Care staff, possibly including the coordinator, the administrative assistant, and graduate students at Michigan State University involved in field placements at the Respite Care office. The purposes of this initial meeting are: 1) to give the Respite Care staff an opportunity to become familiar

with the needs and desires of the family, and the degree of care necessary for the child, so that an appropriate foster family can be selected, and 2) to familiarize the natural family with the Respite Care program. During or after this meeting, the natural family decides if they actually want to use the service, and the staff determines whether a suitable foster family is available. If both of these conditions are met, the training phase continues.

The next step is a meeting between the natural parents, a set of foster parents, and members of the Respite Care staff, at the home of the foster family. The purposes of this meeting are: 1) for the two sets of parents to become acquainted with each other, 2) for the natural family to see the home that their child may be staying in, and 3) for the foster family to find out about the child. The child is purposefully left out of this meeting for two reasons. The first is that many of the children need constant supervision or are disruptive, and therefore their presence would not be conducive to a meeting. The other reason is that the behaviors of the child are discussed in depth, and in some cases this discussion might encourage the child to exhibit undesirable behaviors that are discussed.

The next step in these procedures is the beginning of the actual training of the foster family. First, the foster family, natural family (including the child), and respite care staff members meet at the foster home. The actual content of this phase is very much dependent on the degree of special care needed by the child. In cases where special procedures and methods are necessary for feeding, dressing, or special treatments, these procedures are demonstrated by the natural mother, and then practiced by the foster mother (and possibly other

members of the foster family). In cases where the children do not require specific special treatment, the foster family becomes acquainted with the child. The number of training sessions of this type needed depends on the child and both families, and can be as little as one, or as many as four or five.

When both families and the staff feel that the foster family is prepared to care for the child, a visit is made by the child, alone, to the foster home, usually for a couple of hours. If this visit turns out well, a trial overnight placement is conducted, during which the natural parents are not too far away, and accessible by telephone if needed. If this visit is successful, the training phase is completed, and all parties are ready for an actual respite stay, at the request of the natural family. Sometimes, because of time limitations, it is not possible to go through this entire procedure as described. In these cases, procedures are at times combined, or eliminated, if not seen as crucial.

Purpose of This Study

The purpose of this study is to begin to explore the effects of Community-Based Respite Care on families using these services, by exploring family experiences with the Community-Based Respite Care program in Lansing, Michigan. The specific purposes of this study are: 1) to begin to define the concept of psychological relief, in terms of the factors that compose it, 2) to determine whether or not the families interviewed received psychological relief as a result of their use of the service, 3) to get some idea of the factors that lead to psychological, and 4) to obtain information on the perceptions and

experiences of the families interviewed that will be meaningful and useful to this program, and also to other similar programs.

Definitions of Key Concepts

Respite Care: Short-term relief from care.

Respite Care Staff: Individuals either employed or involved in field placements at the Lansing, Michigan Respite Care Program office.

Natural Family: Family with whom the child is living.

Foster Family: Licensed foster family that provides respite care, in their home.

Psychological relief, Relief from stress, (used interchangebly): Some form of relaxation, in this case, specifically related to the absence of the retarded child from the family.

CHAPTER II

METHODOLOGY

The major portion of this study consisted of interviews with families who had used the Lansing Respite Care Program. In addition, a brief telephone inquiry was conducted with families who had participated in some or all of the training steps, and then had not continued to use the service. Following a full description of the major study, the telephone inquiry will be described.

Subjects

The subjects were composed of all families who had used the Respite Care Service after their initial training phase, and who were willing to be interviewed. The final sample consisted of thirteen families.

Procedure

The procedure consisted of an interview, which was developed and conducted by the author.

Rationale

The interview technique was chosen for a number of reasons. The strengths of this methodological approach correspond with the goals of this study, and also with existing situational factors. The most important situational factor is that previous research has not been done in the area of respite care. Therefore, the important variables are not

known,
techni
allows
the si
twenty
iod.
unwil
quite
of an
inter
colle

those
using
to e
tuni
only
the
indi
whet
fami
psyc

that
to c
est
is m

known, and the study needed to be highly exploratory. An interview technique is most appropriate for an exploratory study, because it allows both for depth and flexibility. Another relevant element of the situation is that, at the time that the study began, less than twenty families had used respite care after the initial training period. Accounting for the fact that some families would be unable or unwilling to participate in the study, the expected sample size was quite small (around fifteen families). This again supports the use of an interview approach, since the entire sample could easily be interviewed in a reasonable amount of time, with a broad set of data collected from each family.

One of the major objectives of the study was to begin to define those factors that are involved in psychological relief for families using respite care. In order to meet this goal, it was necessary to elicit spontaneous emotional responses, and also to have the opportunity to probe for deeper responses. Of course, an interview is the only technique in which this was possible. Two other related goals of the study also require personal, emotional information, and therefore indicate an interview procedure. These objectives are: to determine whether this service does, in fact, provide psychological relief to families using it, and to get some idea of the factors that lead to psychological relief.

The final major goal of the study was to collect information that would be useful and meaningful to the Lansing program, and perhaps to other similar programs. This objective necessitates personal, honest, expression of the feelings and experiences of the families, which is most thoroughly gained in an interview situation.

Th

use of

tain a

care.

it was

this re

the fam

would b

Limitat

A

view t

data d

fact t

lative

interv

from a

of the

these

order

accour

the La

clearl

Develo

the a

ber o

There is one additional situational factor which supports the use of an interview technique. It is essential that the program maintain a non-threatening relationship with the families who use respite care. Since the author was connected with the program to some degree, it was important that she did not do anything that might jeopardize this relationship. The program coordinator felt very strongly that the families would be most receptive to an interview, and that it would be the least threatening research approach.

Limitations of the Study

Admittedly, there are distinct drawbacks to the use of an interview technique. The major disadvantage of this approach is that the data do not lend themselves to statistical analysis, resulting in the fact that generalizations made from this study had to be highly speculative. Other drawbacks to this approach were: the possibility of interviewer bias, and the difficulty in collecting comparable data from all families. This led to additional difficulties in the analysis of the data, in that trends were somewhat difficult to see. Even when these disadvantages were taken into account, it was decided that, in order to realize the major purpose of the study, i.e., to provide an account of the perceptions and experiences of families who had used the Lansing Respite Care Program, the interview technique was still clearly the most appropriate instrument.

Development of Interview Schedule

The interview schedule was developed in a number of steps. First, the author delineated the concepts of interest, with input from a number of sources. Next a rough draft of the interview schedule was

developed, and

were not part

a list of fa-

be particular

these famili

deal of help

Following t

(pilot inte

(For a cop

Actual Pro

Whi

ilies who

a letter

a copy o

briefly

telephon

pate. I

the case

mother)

ten in

alone p

and one

T

some fa

then di

developed, and piloted with three sets of parents, whose responses were not part of the final data. These families were selected from a list of families that the coordinator of Respite Care thought would be particularly cooperative and helpful. This proved to be true: these families were very open and cooperative, and contributed a great deal of helpful feedback about the interview schedule and procedure. Following this pilot phase, the interview was refined, shortened (pilot interviews took two to three hours), and made more objective. (For a copy of the interview schedule, see appendix.)

Actual Procedure

While the interview schedule was being revised, all intact families who had used respite care after their initial training were sent a letter by the author and Dr. Donald Melcer, the thesis advisor (for a copy of the letter, see appendix). In this letter, the study was briefly explained, and cooperation was solicited. Next, the author telephoned each family that received a letter, asking them to participate. If they agreed, an appointment was set-up, at their home. In the cases where only one parent agreed to participate (always the mother), she was interviewed. Thirteen interviews were completed, ten in which both parents participated, and three in which the mother alone participated. The interviews lasted from one-half hour to one and one-half hours.

Inquiry of Non-users

The purpose of this inquiry was to get a general idea of why some families participated in some or all of the training phase, and then did not continue to use the service. The subjects consisted of

families who had gone through some portion or all of the training phase, but never actually used the service.

The procedure involved calling each of these families, and asking one parent to answer a few questions over the telephone. If the parent agreed, they were asked to confirm that they had participated on some of the procedures, and then asked to give some idea about why they did not continue to be involved with the program. These responses were simply summarized, to provide a catalog of reasons for non-participation.

CHAPTER III

RESULTS

Results of Interview Study

Characteristics of Families

Number of children living in the home (regardless of relationship to the parents): One family had one child living at home. Six families had two children living at home, and four families had three children living at home. Two families had four children living at home. The mean number of children living in the home was 2.54 (see Table 1).

Table 1. Number of Children Living in Home

Number of Children	Number of families Having That Number of Children	Percentage of Total
1	1	8
2	6	46
3	4	31
4	2	15

The retarded children (11 of them) and adults (two of them) using respite care ranged in age from 4 to 50, with the mean age being 11.85 (see Table 2). Twelve of the thirteen retardates attended school (the one who did not is a 50 year-old adult). As classified by the

Table 2. Age of Retarded Individual Using Respite Care

Age of child	Number of Individuals That Age	Percentage of Total
4	2	15
6	1	8
7	3	23
8	3	23
11	1	8
12	1	8
22	1	8
50	1	8

respite care staff, 7 of these individuals are severely impared in their functioning at home, 5 are moderately impared, and one is mildly impared (see Table 3).

Table 3. Degree of Impairment of Individual Using Respite Care

Degree of Impairment	Number of Individuals With That Degree of Impairment	Percentage of Total
Mild	1	8
Moderate	5	38
Severe	7	54

Use of the Service, Attitudes and Feelings

Families interviewed used the service between 1 and 13 times, with the mean being 2.92. Seven of the 13 families used the service one time only. The lengths of the stays ranged from one to 10 days, with a mean of 3.76 days (see Table 4).

Table 4. Number of Times the Service was Used by the Families Interviewed

Times Used	Number of Families Using the Service That Number of Times	Percentage of Total
1	7	54
2	2	15
4	2	15
6	1	8
13	1	8

In ten of the families, the child had stayed with only one foster family. In the other three families, the child had stayed with 2 families.

Five families found out that the service was available when they were approached by the respite care staff, and three families were informed of the service through a letter from the program. One family was told of the service by a friend, and one family was introduced to respite care by a slide presentation about the service. Two families found out through other agencies, and one family was unsure how they became aware that respite care was available (see Table 5).

Of the families that were not approached by the respite care staff,

Table 5. Sources of Information About the Availability of Respite Care

How Family Found Out That Respite Care was Available	Number of Families Finding Out That Way	Percentage of Total
Approached by respite care staff	5	38
Letter from respite care program	3	23
Other agencies	2	15
Told by friend	1	8
Slide presentation about service	1	8
Unsure	1	8

three contacted the staff a week or less after finding out about the service, and two contacted the service within a week to a month. One family contacted the staff between a month and three months after finding out that the service was available, and for two families this time period was more than three months. Of these same eight families, five reported that they contacted the service because they wanted the security of knowing that someone else could and would care for their child: these families did not have a specific use of the service in mind. Two families contacted the service because they were planning a vacation, and wanted someone to care for the child during that time. One family initiated contact with the service because an emergency trip was necessary (see Table 6).

In one family, the child first stayed with the foster family by request a week or less after the initial contact with the service. In one family, this first stay was a week to two weeks after the first contact, and in two families, the first respite stay occured between

Table 6. Reason Given for Contacting Respite Care Service (inculdes eight families that were not approached by Respite Care Staff)

Reason	Number of Families Giving That Reason	Percentage of Total
Security	5	63
Planning vacation	2	25
Emergency trip	1	12

two and four weeks after the initial contact. In eight families, this first stay was more than a month after the initial contact.

Other Care Arrangements

Eleven families reported that their retarded child had at some time been cared for by relatives for at least an entire day. Six families reported that they had left their child with friends, and also six families reported leaving their child with babysitters. Four families said that their child had been cared for at a residential treatment facility, either on a short or long term basis. Two families reported that they had never left their child with anyone besides respite foster families for as long or longer than a day (see Table 7).

In terms of alternatives to respite care at the time that the families began contact with the respite care staff, a different picture emerges. Nine families reported that they did not perceive having any available people or agencies to care for their child, for at least an entire day. Three families cited relatives as an alternative, one family reported that a residential care facility was an alternative,

Table 7. Types of Care Used Other Than Respite Care

Type of Care Used	Number of Families That Had Used That Type of Care
Relatives	11
Friends	6
Babysitters	6
Residential care facility	4
None	2

and one family reported that they could leave their child with a babysitter for that length of time (see Table 8).

Table 8. Available Alternatives to Respite Care at the Time of the Interview

Alternatives	Number of Families Citing This as an Alternative
None	9
Relatives	3
Residential care facility	1
Babysitter	1

Advantages and Disadvantages

The eleven families that reported having left their child with someone at some time were asked to compare these types of arrangements to respite care, in terms of the advantages and disadvantages of each

one. A wide variety of responses were offered. The two most frequent advantages of respite care mentioned were competence and accessibility, each factor being mentioned by five families. In talking about competence, the parents explained that when they used respite care they felt more confident that the caretakers were able to handle the child, as compared with private or institutional care (many of them expressed that they believed that this was due to the training procedure). Two of the three families that had left their child at a residential care facility on a short-term basis reported very unsatisfactory experiences: they felt that their child had not been cared for adequately. Both of these families said that they would not leave their child at this facility again. The other family reported satisfactory experiences, and did plan to use that short-term service again. When accessibility was discussed, the families said that it was difficult for them to find people other than respite foster families to care for their child when they wanted the care. Another related advantage of respite care compared to private arrangements is that when relatives or friends cared for the child the family often felt as though they were imposing, and that the people may not have wanted to care for the child, but did so out of family or friendship loyalty. This was mentioned by four families. With respite care, they felt that the foster families wanted to care for their children, and if not, they would say no. Some other advantages of respite care mentioned were: distance (foster families are closer than the residential care facility, and therefore more convenient), the fact that the child went elsewhere, which was sometimes more convenient, the cost (cheaper than babysitters), and the freedom of the

child to do what he wanted (see Table 9).

Table 9. Advantages of Respite Care

Advantages	Number of Families Citing This as an Advantage
Competence of foster families	5
Accessibility of foster families	5
Assurance that they were not imposing	4
Child cared for out of home	2
Distance	1
Cost	1
Freedom of child	1

In discussing the disadvantages of respite care, a number of factors were also mentioned. As compared with private arrangements, distance was mentioned by two families: the respite foster homes were farther away than friends and relatives with whom the child stayed. Another disadvantage was the fact that respite care could only be used by the retardate, so that the family often had to find additional care for their other child or children. In addition, two of the families stated that having the child stay somewhere other than at home was a disadvantage of respite care in some situations. Cost was also mentioned as a disadvantage by two families, compared to residential care, which was less expensive, and private arrangements, which were often free. One family mentioned competence as a disadvantage of respite care. They felt that in their one experience,

the foster family was not adequately trained, and therefore could not care for their child. This experience was very unsatisfactory for the family--they were telephoned a number of times by the foster family, and were finally asked to pick up their child several days early (see Table 10).

Table 10. Disadvantages of Respite Care

Disadvantages	Number of Families Citing This as a Disadvantage
Distance	2
Multiple caregivers required	2
Child cared for out of home	2
Cost	2
Competence of foster families	1

Thoughts and Feelings About Foster Families and Training Phase

When asked about their thoughts and feelings when they first met the foster family, a wide variety of responses was elicited, with about equal numbers of positive and negative answers. When asked their first impressions of the foster family (more than one answer possible), ten families felt that they seemed competent, and three said that they seemed relaxed. In addition, two families said that the foster family seemed different from themselves in some way. Four families used the following descriptors, with one attribute given by each family: cool, trustworthy, neutral, and incompetent. All families in the sample went through a period of time when they were

getting to know the foster family, before they acutally used the service, and all families said that this procedure had a positive influence on their satisfaction with the placements. Most of the families described this process as increasing their confidence in the foster family's ability to care for the child.

Thoughts and Feelings About Actual Placement

When asked what factor was most influential on their satisfaction with the first respite care placement, five families reported this as competence of the foster family. Four of these saw the foster families as being very competent, while the other family did not (this experience was described above). Three families reported that the most important influence was the positive reaction of the child to the situation. Two families each cited attitudes towards the child and personality of the foster family or its members as the most important factors, and one family said that the involvement of the whole respite foster family influenced their satisfaction the most (see Table 11). Other factors cited as influencing satisfaction with respite placements, but not being of primary importance were: the availability of the service (whether or not it is available when they want it), the safety of the child, the cleanliness of the home, and the fact that the foster family was black (they would have rather had a white foster family).

When asked how the child responded to the foster family when he or she first met them, nine families said that the child responded in a positive way. Two families said that the child seemed neutral, and two indicated that the child was unable to respond.

Table 11. Factor Most Influential on Satisfaction with the First Placement

Factor Most Influential	Number of Families Citing This Factor	Percentage of Total
Competence of foster family	5	38
Child's reaction	3	23
Foster family's attitude toward child	2	15
Personality of foster family	2	15
Involvement of entire foster family	1	8

For the first respite stay, six mothers reported that they alone brought the child to the foster home. Four sets of parents brought the child to the foster home together, and in three cases, the child was brought to the foster home directly from school, through special transportation arrangements. Of those families or individuals who brought the child to the foster home, four reported that they felt reluctant about the child, and three reported feeling reluctant about the foster family. Three families said that they felt comfortable, one family reported not feeling anything in particular, and one family indicated not remembering their thoughts or feelings at that time.

All families who brought the child to the foster home for any of the respite stays were asked to describe what the foster family did at that time. According to these ten families (one using two foster families, eight foster families responded in a positive way

when the child was delivered; behaviors reported were friendliness, having made special provisions for the child, and showing the child around the home. The remaining three foster families were reported to have made no particular responses at that time.

When asked whether the child was aware that he or she was going on a respite stay, eight families responded in the affirmative. Four families indicated that the child was not aware, and one family could not tell whether the child was aware or not. Of those children who were aware that they were going on a respite stay, four indicated positive feelings in anticipation, and two indicated negative reactions.

Twelve of the thirteen families interviewed reported that things were different in the family while the child was on a respite stay. These twelve were asked how things were different: they responded in terms of what they did, who they spent their time with, and the general tone in the home. The most frequent answer, given by seven families, was that they went out more while their child was on a respite stay. Other activities reported were: vacationing (five families), entertaining (two families), and hospital stays by a member of two of the families. Regarding who time was spent with, six sets of parents reported that they spent more time with each other during the respite stays, and five families said that they spent more time with their other children. Two families indicated that more time was spent with relatives other than the immediate family, and two families spent more time with friends. Concerning the general tone in the family, six families reported that their family was more relaxed during the respite stay (see Table 12).

Eleven families reported that they thought about the child a

Table 12. Ways That Things were Different in the Family During the Respite Stays

What Families Did	Number of Families Reporting
Went out more	7
Vacationed	5
Entertained	2
Hospital stay by one family member	2
Who Time Was Spent With	**Number of Families Reporting**
Spouses spent more time together	6
Parents spent more time with other children	5
More time with other relatives	2
More time with friends	2
General Tone in Family	**Number of Families Reporting**
More relaxed	6

lot during the respite stay, while two families said that they did not think much about the child. Seven families were curious about how the child was doing, three were worried about the child, and two families felt relieved that the child was not there. One family said that they missed the child, and one family said that they felt strange without the child there.

Six families said that their other children did not say anything about the respite stays, and in five families the other children did

comment on the respite stays. These comments were varied, ranging from missing the child to enjoying not having the child at home.

Thoughts and Feelings at the Time of the Interview

When asked if their present feelings or attitudes about the respite care service or staff were different than they had been at the beginning of their contacts, nine families responded in the affirmative, and four in the negative. Of the nine families whose viewpoints had changed, six had become more positive, and three had become more negative. The positive changes consisted of becoming more confident, comfortable, and appreciative of the service. The three negative changes in attitudes were each different. One family had a bad experience with a babysitter that she said was recommended by the respite care staff, and therefore lost confidence in the service. Another family felt that the staff was not doing enough to get more foster homes, but was satisfied with their experiences with respite care. The third family had a bad experience when using respite care, as described above, but did say that they might use the service again.

Six families felt that their use of respite care had helped their child in some way, while seven did not. Four of the families felt that the benefit to the child was in allowing him or her to adapt to new people and situations. One of the other families said that his stay "gave him a lift," because during the stay he (a 50 year-old adult) taught another retarded adult how to make terrycloth pillow covers. The remaining family just said that their adult retardate came back from the stay happier. Only one family reported

that they had actually noticed changes in their child after using respite care; this was the family with the adult retardate who taught pillow-making. Only one family reported that their feelings about the child had changed since using respite care; after using it, they reported, they are usually more patient with their retarded child.

Future Use

Eleven families said that they planned to use respite care again. One family said they did not plan to use it again, and the other was unsure. Of the families that said they would use respite care again, eight did not know when (three of these said possibly during the summer). One of the other four families said that they planned to use the service within a month, and the other three said not for several months. The families were also asked the conditions under which they might use the service again; eight said that it would be for a vacation or weekend trip. Three families named the following conditions under which they would use respite care, with one family naming each: emergency, entertaining friends, and relaxation at home. Two families did not say why they might use respite care again.

When asked if they had recommended respite care to other families, eight respondents said yes, and five said no. Three of these five said that they would recommend the service if given the opportunity. Three families said that their use of respite care had prevented short-term residential placement of their child.

Suggestions and Comments

When asked for suggestions about the respite care service, some common responses were: that a home-based respite care program be

developed (four families), that foster families be recruited who lived closer to the homes of the natural families, especially in outlying areas (five families), and that more foster families be recruited. A number of the other suggestions had to do with characteristics of the foster families or their homes: that the foster families should not have pets, that the foster homes should all be clean, that the foster families should be trained and able to handle particularly difficult children, and that there be foster homes in quieter neighborhoods. Other suggestions were: that the families be given the opportunity to get to know the foster families better, that the foster families be better acquainted with the child, that the respite care service arrange for the child to be transported for the respite stay (and charge a fee for this), and that the foster family provide things such as diapers and food, and that a fee be charged for these supplies (see Table 13).

Table 13. Suggestions About the Respite Care Program

Suggestion	Number of Families Making This Suggestion
Foster families be recruited who lived closer to the natural families	5
Home-based respite care be made available	4
Suggestions dealing with characteristics of foster families and their homes	4
Suggestions dealing with procedures conducted	4

Additional comments about respite care were asked for: one mother said that she had wanted a rest and didn't get one (discussed

above), and another mother said that she still felt hesitant and unsure about using the service (not for any specific reason). Five families had very positive comments, including: the training and payment system were very good, the service was very good and the staff sincere, and the service as a whole was fantastic.

Inquiry of Non-users

Six families that had participated in some or all of the training phase but did not actually use the service were contacted by telephone by the researcher. Two families reported that they had placed their child either in a residential care facility or a permanent foster home shortly after their contacts with respite care, and since the child no longer lived in the home, they did not have a need for respite care any longer. One family reported that they had called the service a number of times, but a foster family could not be found that would care for the child. One family said that they had planned to use the service once, but one of the children in the foster family became ill, and the arrangements had to be cancelled. Since then, they have not needed the service. Lack of need was reported as the reason that another family had not used respite care. The remaining family said that other families needed the service more than they did because they had other available sources to care for their child. This family expressed the feeling that respite care was a fantastic service, and if it were more available, they would use it.

CHAPTER IV

DISCUSSION

In this chapter the major findings of the interview study and of the telephone inquiry will be discussed, followed by a discussion of the implications of this study.

Major Findings of Interview Study

Most families who were interviewed had retarded children (as opposed to adults), and all but one were either severly or moderately retarded. Families used the service an average of 2.92 times, with the average stay lasting 3.76 days. Most children stayed with only one foster family. The families found out about the service in a variety of ways, with no single response in the majority. Of the families that were not approached by the respite care staff, most of them initiated their use of the service because they wanted the security of knowing that someone else could and would care for their child. This is a significant point because it seems, that for these families, this security is of some psychological relief in itself. This finding is presumably related to the fact that at the time that they began contact with respite care, most of the families (69%), did not feel that there were any other people or agencies that could and would care for their child for at least an entire day. This produces a rather dim picture, and seemingly very different from a family with only "normal" children. It seems that the notion that

families with retarded children have trouble finding care for their children, discussed in the first chapter, is borne out in this sample. If the general assumption is accepted that all parents need to spend some leisure time away from their children, regardless of whether they have a retarded child, then these results demonstrate the need for a respite care program.

Most of these families had at some time left their children with other people or agencies, but for some reason did not feel that these were viable alternatives any longer. Some of these reasons were indicated when the families were asked to compare respite care to other care arrangements. Some families said that they felt that the respite foster families were more competent to care for their children than were other individuals or agencies, and therefore they felt more confident leaving the child at a respite foster home than somewhere else. A number of families said that sources other than respite care were quite inaccessible (some mentioned that as the child got older, it became increasingly difficult to find able and willing caregivers). Another factor is that some families did not like to ask relatives or friends to care for their child, because they felt that it was an imposition. These comments give some insight into the reasons why families with retarded children often feel that no one else is available to care for their child.

Some of the disadvantages of respite care shed light on the reasons that some families do not use it more often. All except one disadvantage mentioned were practical things, as opposed to attitudinal variables. These included: distance of the foster homes, the fact that respite foster parents could not care for the other children

in the family, the fact that the child had to go to another home, and the cost. One family cited competence as a disadvantage of respite care; they were the family who had a very unsatisfactory experience the time that they used the service, but did say that they might use the service again.

One important result of the interviews has to do with the initial training phase; all families reported that there was a period of time when they were becoming acquainted with the foster family before they actually used the service, and all families felt that this process had a positive influence on their satisfaction with the placements. This is an especially important finding, because the purpose of the training phase is to make the families more comfortable with using the service, and, for this sample, that seems to be just what this process did.

Competence of the foster family was the single most frequent factor cited as most important in influencing satisfaction with the first placement. This implies that the training phase does play an important role, in that the training phase increases confidence in this competence. Another factor mentioned by a number of families was the positive reaction of the child to the situation.

Most of the families (69%) reported that the child responded in a positive way when he or she first met the foster family, and in no families was the response of the child reported as negative. Since the response of the child was cited as important to some families in influencing their satisfaction with the placements, this is an important factor to attend to.

Perhaps more important are the parents' and children's feelings

and reactions at the time of the actual respite stays. Some children were not brought to the foster homes by their parents (they were brought by special transportation), and therefore the parents were not able to report what happened when the respite stay began. Of those families and individuals that did bring the child to the foster home (for the first stay), most of them felt some reluctance about either the foster family or the child. Of the children who were aware that they were going on a respite stay, as reported by their parents, half of them responded positively. Of the others, half responded negatively and half responded in a neutral way or not at all. These reactions, like the initial responses of the child, are probably quite important influences on satisfaction.

All but one of the families said that things were different in the family while the child was away. The families did leisurely things that they did not normally do with the child there, such as going out more, vacationing, and entertaining. In a few families, one member went to the hospital during the respite stays. Most families spent more time than usual with the family members other than their retarded child, and/or with other relatives and friends. Nearly half of the families indicated that the general tone in the family was more relaxed during the respite stays. These findings seem to imply that at least physical relief was received by most of the families; the statements that the tone in the family was more relaxed seems to indicate psychological relief.

Most of the families reported that they thought about the child during the respite stay. While a small number of families said that they were worried about the child, the others were either curious about

how the child was getting along, glad that the child was not there, lonesome for the child, or felt strange that the child was not there.

Most of the families interviewed indicated that their feelings or attitudes about the respite care service had changed since the beginning of their contacts with the service, and the changes were mostly in a positive direction. This is an encouraging finding; however, the negative changes in feelings and attitudes are also important to consider.

About half of the families reported that their use of respite care benefited their child in some way. This is important because it seems that if parents feel that their child is gaining something from the use of respite care, perhaps they will be more eager to use the service, and also may get more psychological relief from this use.

The fact that most families said that they planned to use the service again is an indication that they are gaining enough from their use of the service to warrant using it again (or at least reporting these plans). Eight families reported that they had recommended the service to other families, and three others said that they would, if given the opportunity. This results in eleven families saying that they think highly enough of the service to recommend it.

Another significant finding is that, for three families, the use of respite care prevented short-term residential placement. Although this is a small percentage (23%), it does show that institutionalization is being prevented, which, as discussed in the first chapter, facilitates normalization of retarded individuals into the community.

Psychological Relief

One of the major goals of the study was to begin defining those factors that may be involved in psychological relief for families using respite care. A number of specific questions included in the interview schedule seem especially important to the author as indicators of psychological relief. These are: whether things were different in the family during the respite stay; if they were, in what ways (especially were things more relaxed) 'did the family worry about the child' and do the parents feel that their use of the service helped the child in any way.

With these particular areas in mind, each interview was studied as a whole and rated on the degree of psychological relief received: very low, moderate, high, or very high. The interviews were each looked at as a whole because in some cases families expressed feelings and experiences spontaneously which indicated the degree of relief, instead of in response to the specific questions mentioned above. The results indicated that three families received a very high degree of psychological relief, four families were rated high on this relief, five families received a moderate amount of psychological relief, and one family's relief was judged as very low.

In order to get some ideas about the factors that might lead to psychological relief, characteristics of the families that were rated as receiving a high degree of psychological relief were compared with characteristics of the other families. It should again be pointed out that these judgments are subjective, and highly speculative. The families were looked at on the following dimensions: acceptance of the handicap of the child (which was rated by the interviewer after each

interview, as a general judgment), severity of the child's retardation, reasons for use, number of times used, child's reaction to the respite stays, and feelings when the natural families met the foster families for the first time.

The results of these comparisons showed that the two groups of families differ on three of these characteristics: acceptance of the handicap, the reaction of the child to the respite stays, and the feelings of the parents when they first met the foster family. In general, families who received a high degree of psychological relief had accepted the handicap of their child to a greater extent than the other families. In addition, these families reported that their retarded children responded better to the foster families and the respite stays than did the families receiving moderate or very low relief. The other difference between these two groups was that all but one of the families receiving moderate or very low relief reported feeling apprehensive when they first met the foster family. Thus, it seems that psychological relief may, in part, be a function of characteristics of the families themselves, and their feelings both about their children, and about using a service such as respite care. Also, psychological relief may be highly influenced by the child's reaction; if the child seems to enjoy it, the families may also feel the freedom to enjoy. This may be related to guilt feelings, which many parents of retarded children are presumed to have, and which was also mentioned by some of the families as a reason why other families don't use the service.

Inquiry of Non-users

The results of the telephone inquiry do not lead to any clear conclusions. Four of the six families reported that they did not need the service, and one of the other families said that they did not need the service as much as other families, so did not use it. The author feels that some of the families perhaps were not totally honest about or aware of the reasons that they had not continued with the program. In order to obtain a clearer picture of the factors involved in initiating contact with the service but never using it, a more extensive study is needed.

Implications for This and Other Respite Care Programs

Clearly, the extent to which generalizations can be drawn from this study is limited by the small sample size and the subjective nature of much of the data. As a result, conclusions drawn in this section must be considered speculative. However, these limitations must not be allowed to obscure a number of important implications derived from the study.

The results of this study indicate a number of characteristics about this program. First, it seems that this program provides a needed service, as indicated by the fact that most of the families reported that they did not have any other available sources to care for their child. The results also demonstrate that most families do, in fact, receive psychological relief from their use of the service, and that the following factors seem to be related to this relief: acceptance of the handicap of the child by the parents, the child's reactions to the situation, and the feelings of the parents when they

first met the foster family. The researcher hypothesizes that acceptance of the handicap and feelings when meeting the foster family are related variables, in the following way: the less the parents accept their child's handicap, the more reluctant they are to use a service such as respite care, and this reluctance is manifested in their first meeting with the foster family. This is presumably related to the notion that less acceptant parents have more guilt feelings about their child being retarded, and therefore also feel guilty about having others care for their child.

If these assumptions and hypotheses are accepted, then certain courses of action are implied for the staff of the program, if a greater degree of psychological relief is desired. These implications are also applicable to encouraging families who would like to use the service, but because of their own feelings (i.e. guilt), do not. Probably the most important thing that the staff can do is to be aware of these hesitancies, and to express this awareness to the families. Perhaps these families can discuss these apprehensions, if they want to, either with a staff member, or with another family who has used respite care. This requires a great deal of flexibility, and a highly individualistic approach. For example, one mother who was particularly hesitant said that she would feel more comfortable if she was better acquainted with the foster family. This information is important, but will probably not be volunteered by the mother, but instead would only be revealed if asked for.

The third factor found to be related to psychological relief was the child's reactions to the foster family and to the respite stay. The implication, of course, is that the staff pay particular

attention to the reactions of the child because these reactions are important to the family. Especially in the cases of particularly hesitant families, the staff should do everything possible to insure that the child has a positive experience. Related to this is the issue of benefits to the child. Again, hesitant parents may be encouraged to use the service if they feel that it will benefit their child. With all families, it would probably be advantageous for the staff to point out that, by using the service, the child will benefit in the following ways: having the opportunity to adapt to new people, places, and situations, and eventually, becoming less dependent on their family.

Both the positive and the negative aspects of this program have implications for the development and formation of this and other respite care programs. One outstanding feature of the Lansing Respite Care program seems to be the training phase: all families felt that this process had a positive influence on their satisfaction with the service. In fact, some families said that they would not have used a service that did not have some type of training phase. None of the families indicated that the training phase was too long and involved, but a few expressed that they would like to become better acquainted with the foster family, and would also like their child to get to know the foster family better. For this program and others these findings imply that a training phase should be an integral part of a respite care program, for two reasons: to train the foster families, and to allow both families to become more comfortable with using and providing the service. These findings further imply that the natural families should be directly involved in the training phase,

and that the length and intensity of the training period should be determined by the needs and wishes of both families.

Other positive aspects of the program mentioned by the families interviewed can give ideas about continuing and developing programs. Accessibility was mentioned by a number of families--the fact that the care was available when they wanted it. This should, of course, be a goal of any service.

Some factors were indicated as disadvantages in some situations or by some families, and as advantages in others. One example is distance; for some families, the respite foster homes were farther away than other care arrangements, and for others, they were closer. In any case, the closer the foster families were, the better this was for the natural families.

Another factor that was seen as both an advantage and a disadvantage was the cost; respite care is cheaper than some other arrangements and more expensive than others. This has no implications other than the obvious: the cheaper a service, the happier consumers will be.

One factor that does have implications for the delivery of services is where the care will be given. Some families cited the fact that the child was cared for in a home other than his own as a disadvantage, while others cited this as an advantage. The implication of this, of course, is that flexibility should be one goal of the service. Clearly, many families do want "home-based" care, but others prefer to have the child taken out of the home, and for others, their preference depends on the situation (i.e. their plans during that time). This issue is related to one of the main disadvantages mentioned of

respite care; the fact that only the retardate could go on a respite stay, and it was often necessary to find additional care for other children in the family.

There is one other negative aspect of the program that seems to have implications for the future of this and other programs. Through the course of a number of interviews, the interviewer became aware that some of the families would have liked to meet other foster families, but did not perceive that this option was available to them unless they expressed dissatisfaction with the foster family that they had used. They were not dissatisfied with the foster family they had used, but seemed to think that they might be more satisfied with another family. For some reason they did not express this to the staff; perhaps they felt that it would be asking too much. If the families expressed this, and it were possible for them to meet other foster families, satisfaction might increase.

Implications for Future Research

This study brings up a number of directions for needed research. As discussed in the first chapter, the research on the impact of a retarded child on the family system in many cases consists of studies with poor sampling procedures and a lack of control groups of normal families. Comprehensive basic research is needed, so that an accurate assessment can be made of the family systems of retarded children, and their needs.

In the area of respite care there has been no previous research, so the research needs are inexhaustible. Studies with larger samples in the following areas are specifically indicated by this study:

studies indicating the needs and desires of families using respite care; studies measuring family stress before, during, and after using respite care; studies further defining and measuring the concept of psychological relief; comparative studies of families with retarded children who use and don't use respite care; and comparative studies of respite care programs following different procedures, especially regarding the initial training phase.

CHAPTER V

SUMMARY AND CONCLUSIONS

This study was an exploration of the Lansing, Michigan Community-Based Respite Care Program. Respite care is defined as short-term relief from care, and is provided to families with retarded children or adults living at home. In this program, care is provided to the retarded individuals by licensed foster families.

The purpose of respite care is to provide relief from stress, or psychological relief, to these families by providing temporary relief from care. The fact that these families are experiencing a great deal of stress, and therefore are in need of this relief, is indicated by research findings, and is also generally agreed upon by professionals in the field of mental retardation.

Although the concept of community-based respite care is not new, actual programs have developed only in the past few years and are not widespread. At the time of this study, there was no available research evaluating the services provided by these respite care programs.

The purpose of this study was to begin to explore the effects of respite care on families using these services. This was done by studying the Lansing Respite Care program in particular, with the use of an interview technique. Interviews were conducted with all families who had used this service after their initial training phase and who were willing to be interviewed. Thirteen interviews were completed.

The specific goals of this study were: 1) to begin to define the concept of psychological relief for these families, in terms of the factors that compose it, 2) to determine whether or not the families interviewed received psychological relief as a result of using the service, 3) to get some idea of the factors that lead to psychological relief, and 4) to obtain information on the perceptions and experiences of these families that would be helpful to this and other similar programs.

The objectives of this study were met. It should be pointed out that, because of the small sample and subjective nature of the data, conclusions drawn from this study must be considered speculative. The author was able to define psychological relief as the combination of a number of responses to questions included in the interview schedule, concerning perceptions and feelings during and after the respite stays. It was found that almost all families interviewed received psychological relief as a result of using the service. In addition, factors leading to psychological relief were delineated.

A great deal of information was gained that hopefully will be meaningful and useful to this respite care program, and also to other similar programs. Two important findings of this kind were: 1) respite care provides a badly needed service, which is demonstrated by the fact that nine of the thirteen families interviewed (69%) reported that, other than the respite foster families, they did not have any available sources to care for their child; and 2) the initial training phase is a critically important part of the program. Implications for the Lansing Respite Care program, for other similar programs, and also for future research were discussed.

APPENDIX

PROGRAMS FOR THE MENTALLY RETARDED

RESPITE CARE

FEE SCHEDULE

The schedule of fees to natural families for the use of respite care will be based on their taxable income and applied against a sliding scale. Respite stays of 4 days or more can be planned with a reduced fee.

Taxable Income	Daily Charge For Planned Respite Care Less Than 4 Days	Daily Charge For Planned Respite Care 4 Days Or MOre
$0 - $2,500	$2.00	$1.50
$2,500 - $5,000	$4.00	$3.50
$5,000 - $10,000	$6.00	$5.50
$10,000 & above	$8.00	$7.50

Fees can be paid on an installment basis with payments distributed over as long as one year.

The fee schedule is based on all available information including comparable fee schedules, respite care budget limitations and consideration of financial concerns of the families using the service.

INTERVIEW SCHEDULE

Before we get started with the interview, I'd like to explain a few things. I'm a graduate student at Michigan State, studying family experiences with respite care as research for my masters degree. I have done field work, as a part of my coursework, with the respite care program, but I'd like to emphasize that what I am doing now is research, under the direction of Michigan State, and not respite care. All of the information that I collect from you and the other families will remain strictly confidential, and anonymous. The information that I collect will hopefully contribute to the development of the respite care program, but will only be revealed to the respite care staff in terms of general trends. I would like to tape record this interview, so that I can play it back for myself, and so that I do not have to take a lot of notes. No one besides myself will have access to the tape. If you have any objections to the taping, I won't tape the interview.

Do you mind if I tape? M F

___ Yes ___

___ No ___

To begin, I'd like some background information about your family, and your use of respite care:

How many children do you have? _____

What are their names and ages? _____

_____

_____

Which child has been in respite care? _____

Will you describe <u>child</u> briefly, in terms of what he/she can do?

_____

_____

Does he/she go to school? ___ Yes ___ No

If yes where? _____

If yes, in what program? _____

_____

For how long have most of those stays been? _____

How many foster families has child stayed with? _____

Thinking back to your original information about respite care, how did you first find out that the service was available?

M F M F M
___was approached___ ___told by PMR staff___ ___told by PMR letter

F M F M F M
___ ___told by school personnel___ ___ told by GLARCA___ ___told by

F M F M
friend___ ___slide presentation___ ___

OTHER _____

How much later did you first contact the respite care staff?

___ week or less ___ week to month ___ month to three months

___ more than three months ___ was approached OTHER _____

_____

What specifically led you to contact the respite care staff?

___ emergency-physical ___ emergency-psychological ___ wanted rest

___ vacation ___ illness-hospitalization ___ illness-nonhosp.

___ security-insurance ___ did not contact--was approached

OTHER _____

About how long after your first contact with the respite care staff did you actually use the service? By this I mean the first time that child stayed with the foster family at your request?

___ week or less ___ week to two weeks ___ 2-4 weeks ___more than

month OTHER _____

What alternatives did you have, at that time, in terms of other agencies or people to care for child?

___ Hillcrest ___ Other residential facilities ___ friends

___ relatives ___babysitters ___ None

Have you ever left child with friends, relatives, babysitters, or other agencies for as long or longer than an entire day?

___ no ___ friends ___ relatives ___babysitters ___ agencies

OTHER _____

If yes, can you compare private arrangements to respite care, by talking about the advantages and disadvantages of each? _____

_____

_____

I'd like you to remember back to the first (few) contact(s) you had with the foster family(s) that has (have) cared for your child. Many people have a lot of considerations when going into a new situation like this one. Can you tell me something about your thoughts and feelings at this (these) time(s)? _____

_____

_____

What was your first impression of the foster family(s)?

#1 __warm __cool __trustworthy __different __similar __competent

__incompetent OTHER _____

Was there a period of time when you were getting to know the foster family(s) before you actually used the service? ___yes ___no

If yes, do you think that this process of getting acquainted influenced your satisfaction with the placement? ___yes ___no

If yes, in what ways? _____

_____

If no, do you think that a process of getting acquainted would have influenced your satisfaction with the placement? ___yes ___no

If yes, in what ways? _____

_____

What was the most important thing that influenced your satisfaction with the first placement?

M F M F M F M F M
__staff__ __personality__ __family involvement__ __knowledge__ __

F M F M
accomodations__ __competence-availability of care__ __attitudes towards

F M F M F M
child__ __reactions of child__ __freedom of child__ __similiarity of

F
families__

OTHER _____

What are the most important things about the foster family(s) that influence your satisfaction with the placement(s)?

M F M F M F M F
__personality__ __family involvement__ __ knowledge__ __accomodations__

M F M F M F
__competence-av. of care__ __att. tow. chld__ __freedom of child__

M F
__similarity of families__

OTHER _____

_____

Are there other things that are also important influences on your satisfaction with the placements? __yes __no

If yes, what are they? _____

How did the child respond to the foster family(s) when he/she first met them?

___positive ___negative ___unable to respond

Now I would like you to remember the first time you actually used the respite care service. How did child get to the home of the foster family? ___parents brought ___father broutht ___mother brought ___special transportation OTHER _____

If one or both parents brought the child there: When you brought child to the foster family's home for the first time to stay, what kinds of thoughts ran through your mind?

M F M F M F
__don't remember__ __nothing in particular__ __reluctance about FF__

M F M F M F
__reluctance about child__ __guilt__ __comfort__ OTHER _____

_____

Does child know when he goes on a respite stay? __yes __no

If yes, do you usually notice anything different or unusual that child does when he/she goes on a respite stay? __yes no__

If yes, what kind? __positive __negative __neutral

If someone brings child there, describe as best you can what the foster family(s) does (do) when you bring child there. _____

_____

_____

In general, are things different in the family while child is on a respite stay? F M F M
___yes___ ___no___

If yes, in what ways?

M F M F M F M F M
__more relaxed__ __more tense__ __vacation__ __hospital__ __entertain-
F M F M F M F
ing__ __more time alone__ __more time friends__ __more time spouse__
M F M F M F
__more time children__ __more time other relatives__ __go out more__

OTHER _____

Do you usually think a lot about child during the respite stay?

M F M F
__yes__ __no__

If yes what kinds of thoughts do you have?

M F M F M F M F
__worry__ __curious__ __guilty__ __glad not there__

Do your other children usually say anything about the respite stays?

__yes __no

If yes, what kinds of things do they say? _____

_____

Now I'd like to talk about your present ideas about respite care. Are your feelings or attitudes about the service or staff different now than they were at the beginning of your contacts? M F M F
__yes__ __no__

If yes, in what ways? _____

_____

If yes was there a specific time when these changes took place?
__yes __no If yes, when? _____

Do you think that your use of the service has helped child in any ways?

M F M F
__yes__ __no__

If yes, in what specific ways? _____

_____

Have you noticed any changes in child since you've used respite care?

M F M F
__yes__ __no__

If yes, what kinds? _____

Do you think that your feelings or attitudes about child have changed since your involvement with respite care?

M F M F
__yes__ __no__

If yes, in what ways? ___positive ___negative __neutral

Do you plan to use respite care again? ___yes ___no

If yes, do you know when _____

If not know when, about how soon _____

For any special reason? _____

Have you recommended the service to any other families? __yes __no

If no, would you, if you had the opportunity? __yes __no

Has your use of respite care prevented either short term or long term residential care? __yes __no

If yes, in what ways? _____

Do you have any suggestions about the respite care service that would make it more desirable, or a better experience for you? _____

_____

_____

MICHIGAN STATE UNIVERSITY

COLLEGE OF HUMAN ECOLOGY
DEPARTMENT OF FAMILY AND CHILD SCIENCES

EAST LANSING • MICHIGAN • 48824

April 19, 1976

I am a graduate student in the Department of Family and Child Sciences at Michigan State University. I am studying family experiences with the Lansing Respite Care Program, and would greatly appreciate your cooperation. I am conducting interviews with families who have used the Respite Care service, to discover their impressions and viewpoints of the service, and would like your family to participate. This would involve an interview with both of you, at your home, lasting approximately one and one-half hours.

I would like to emphasize that all information will remain strictly confidential and anonymous. The Respite Care staff is aware and has approved of the study. They will receive a report of the results, but no names will be identified. If you choose to participate, I will send you a summary of my findings. We believe that the results of the study will be useful in future development of the Respite Care Program. Your participation in the study will be important.

I will be in touch with you by telephone in the near future. Of course, you are in no way obliged to participate, and the Respite Care staff will not be informed as to who participates in the study.

I am looking forward to talking with you.

Sincerely,

Judith Simon

Judith Simon

Donald Melcer

Donald Melcer, Ph.D.
Faculty Supervisor

LIST OF REFERENCES

Boulding, K.E. General systems theory - the skeleton of a science pp. 3-10 in Buckley, W. (ed.) Modern systems research for the behavioral scientist, Chicago: Aldine Publishing Co., 1968.

Cummings, S.T., Bayley, H.C., and Rie, H.E. Effects of the child's deficiency on the mother: a study of mothers of mentally retarded,chronically ill, and neurotic children. American Journal of Orthopsychiatry, 1966, 36, (4), 595-608.

Farber, B. Effects of a severely mentally retarded child on family integration. Monographs of the Society for Research in Child Development, 1959, 24 (2).

Farber, B., Jeanne, W.C., and Toigo, R. Family crisis and the decision to institutionalize the retarded child. Council for Exceptional Children Monographs, 1960, series A, no. 1, Washington, D.C.

Farber, B. Perceptions of crisis and related variables in the impact of a retarded child on the mother. Journal of Health and Human Behavior, 1960(a), 1, (2), 108-118.

Holt, K.S. Home care of severely retarded children. Pediatrics, 1958, 22, 744-755.

Kantor, D. and Lehr, W. Inside the family, San Francisco: Jossey-Bass Inc, Publishers, 1975.

McAllister, R.J., Butler, E.W., and Lei, T.J. Patterns of social interaction among families of behaviorally retarded children. Journal of Marriage and the Family, 1973, 35, (1), 93-100.

Meyerowitz, J.H. and Farber, B. Family background of educable mentally retarded children. pp. 388-398 in Farber, B. (Ed.) Kinship and family organization, New York: John Wiley and Sons, 1966.

President's Committee on Mental Retardation. MR 69: Towards Progress: The Story of a Decade. Washington, D.C., 1969.

Ryckman, D.B. and Henderson, R.A. The meaning of a retarded child for his parents: a focus for counselors. Mental Retardation, 1965, 3, (4), 4-7.

Schild, S. The family of the retarded child, pp. 431-442 in Koch, R. and Dobson, J. (Eds.) The mentally retarded child in his family: A multidisciplinary handbook. New York: Brunner/Mazel Publishers, 1971.

Schonell, F.J., and Rorke, A. A second survey of the effects of a subnormal child on the family unit. American Journal of Mental Deficiency, 1956, 64, 862-868.

Schonell, F.J. and Watts, B.H. A first survey of the effects of a subnormal child on the family unit. American Journal of Mental Deficiency, 1956, 61, 210-219.

Tizard, J. and Grad, J. The mentally handicapped and their families: A social survey. London: Oxford University Press, 1961.

Wolfensberger, W. Counseling parents of the mentally retarded, pp. 329-400 in Baumeister, A.A. (Ed.) Mental Retardation: Appraisal, education, and rehabilitation. Chicago, Aldine Publishing Co. 1967.

General References

Goode, W.J. and Hatt, P.K. Methods in social research, New York: McGraw-Hill Book Co., Inc. 1952.

Kahn, R.L. and Cannell, C.F. The dynamics of interviewing, New York: John Wiley and Sons, Inc. 1963.