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A descriptive study of parental attitude toward institutionalization of their mentally retarded child.

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A DESCRIPTIVE STUDY OF PARENTAL ATTITUDES TOWARD INSTITUTIONALIZATION OF THEIR MENTALLY RETARDED CHILD

By

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CHAPTER I

INTRODUCTION

Mental retardation has been present in the world for many centuries. The retarded child has been a member of a family, and the family has handled their problem in whatever method they have had available. Frequently, the method has been to hide the child in a room away from people or to abandon him on a hillside. The relatives have felt stigmatized by the child and unwilling to acknowledge his presence. Society has ostracized not only the individual retarded person but also the whole family. They were ashamed and afraid to acknowledge that one of their members was mentally retarded. The most common belief in past years was that the retarded person was possessed by the devil and all contact with him should be avoided.

In order to prevent any knowledge of the stigma from leaking out, the families have often severed all ties with the retarded individual and tried to forget that he exists. For a long time retarded people were segregated from the population by placing them with the mentally disturbed. They often died at an early age because of the lack of care provided. More recently institutions have been built specifically for the mentally retarded. In some of these opportunities are
given for them to learn self-care and sometimes even to "graduate" from the institution. They have returned to the communities to function with their fellowman.

During the past fifteen years a dramatic change has begun to take place by publicizing all available information about mental retardation. This was begun and has continued because of the persistent efforts of parents of mentally retarded children. They have stirred up interest in the needs of the retarded in people from all walks of life. Legislature is more aware of the physical facilities available for the retarded; industry is more aware of their use and value; and medicine has taken great steps in discovering the causes and preventive measures of this disability. The field of social science has also taken renewed interest in developing the capabilities of these people and of making a place for them in cities, churches, schools, and homes.

At one state school for the mentally retarded there are many children and adults with varying degrees of retardation. Many of these are individuals who were placed by their families when they were young children and who are still institutionalized at the age of sixty or seventy. Other children are there only to attend classes and return home each afternoon. Some of these children appear to be more severely handicapped than those residing at the institution. They all need special training, and yet, as any child, they would benefit from living in a home atmosphere.
Statement of Problem

Why do some parents place their mentally retarded child in an institution and others keep them at home? What factors do parents recall as influencing them in their decision to keep their child at home or to place him in an institution? The parents' concept of the effects of the retarded child in their own situation and their ideas concerning institutional care of the mentally retarded are basic considerations as they make their decision about the type of care which they select for their child.

Importance of Problem

These considerations are important to the parents of mentally retarded children and should be of maximum concern to those working with these parents. It was hoped that the results of this study would be of value to professional people working with the parents of retarded children by making them more aware of the factors which influence parents in their decision to place their children. Knowledge of these factors, by persons working with retarded children, should help them develop a better understanding of the attitudes of parents toward their child. Consequently, the worker could better assess the needs of the individual child.

Much of the information given by these parents would be, at least in part, applicable also to parents of children with other handicaps. Even though most other handicaps are more acceptable in today's society, parents often react similarly
to them, particularly when they first learn of the handicap of their child. The acceptance and plan of care for their child with his handicap is a difficult matter. Parents frequently go from one doctor to another and from one city to another searching for a magic cure. With a greater understanding of their feelings, the worker may be better able to support them in their decision and have a greater appreciation of their situation.

The investigator hopes to be able to gain more insight into the feelings of parents of handicapped children in general, and specifically of parents of mentally retarded children. It is believed that the parents of handicapped children experience a unique problem, and that they are the only ones who will be able to fully appreciate the situation. However, it is felt that one of the best ways for others to acquire an understanding of their situation is by getting acquainted with them and talking with them about their problems.

Scope and Delimitation

This study considered the factors which parents of ten mentally retarded children recalled as influencing them in their decision of care for their child. All of these parents had some contact with the same state institution for mentally retarded children. Some had other and more extensive contacts with institutions. It was assumed that at least one of the parents of each of the children in this study recognized that their child was mentally retarded. All of the parents were
told that their child was retarded more than one year prior to this study. Thus, they had had time to think about their decision, and for several, it had been two years or longer since this decision was reached.

It is acknowledged that the intervening period probably altered to some extent the importance of the factors which influenced these parents. Too, they may have forgotten or repressed other factors. The fact that only ten children were in the sample limits the generalizations that can be made from the results. However, it is not the purpose of this study to include every factor which would affect every parent in a similar situation.

Definition of Terms

Mental retardation.--refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in one or more of the following: (1) maturation, (2) learning, and (3) social adjustment.¹

The developmental period ends at approximately sixteen years. More significant to this study, the rate of maturation refers to the rate of sequential development of self-help skills and is of prime importance in diagnosing mental retardation during the pre-school years.²

¹Rick Heber, A Manual on Terminology and Classification in Mental Retardation (Monograph Supplement to "American Journal of Mental Deficiency," Vol. LXIV; Willimantic, Conn.: The American Association of Mental Deficiency, 1959), p. 3.
²Ibid.
Institutionalization.--refers to the placement of a child for a prolonged period of time in an environment away from the family unit where he will be given total physical care.

Parental attitudes.--refers to those views which were stated by the parents concerning mental retardation and their feelings about their situation as it was affected by the presence of a mentally retarded child.

Resident child.--refers to that child, who at the time of the study, was living in an institution for the mentally retarded.

Community child.--refers to that child, who at the time of the study, was living in the home with his parents.

Preview of Methodology

This study was based on the feelings of twenty parents as they expressed them in an interview. Each parent was seen alone by the interviewer and asked a series of questions concerning mental retardation, institutionalization of the mentally retarded child, and their own situation as it relates to these subjects. The interviews took place in the homes of the parents, and notes were taken by the interviewer during the visit.
CHAPTER II

THEORETICAL FRAMEWORK OF THE STUDY

Review of Literature

The majority of the literature that has been written about mental retardation is based on personal opinions and experiences as opposed to actual research projects. In addition to the professional workers in mental retardation, many parents have written about their experiences. They frequently point out the problems they have had in making their decision of whether or not they should place their child in an institution. One of the best known is the book by the author, Pearl Buck.¹

Parents openly asked for help as indicated by what they have written and what they have published through their organization.² They presented ideas and opinions on how they would like to have been helped and what could be done for their child now.³ Paulette Hatrich advocates more concern and understanding of the parents' feelings and in this way gain a

²National Association for Retarded Children, Inc.
better understanding and relationship with the child.\footnote{Paulette Hatrich, "Parents and Nurses Work Together," \textit{Nursing Outlook}, IV (March, 1956), pp. 146-48.}

Six problems which have been listed as common to all families with a retarded child are: (1) acceptance of the fact that the child is retarded, (2) financial problems due to the extra cost of care for the retarded child, (3) emotional tension built up by carrying a burden which they cannot find it possible to satisfactorily share with their fellowmen, (4) theological conflicts when faced with such a heart-rending situation within their own personal lives, (5) problems in finding satisfactory life-time care for the child, and (6) professional advice which is inept, inaccurate, and ill-timed.\footnote{Mrs. Max A. Murray, "Needs of Parents of Mentally Retarded Children," \textit{American Journal of Mental Deficiency}, LXIII (May, 1959), pp. 1078-88.}

Parents complained consistently of the professional help and guidance which was given to them, or rather, lack of it. Their own ignorance of the nature of the disturbance of their child, and their resulting limited ability to plan effectively for the child were real problems for these parents.\footnote{Edmund W. Gordon and Montague Ullman, "Reactions of Parents to Problems of Mental Retardation in Children," \textit{American Journal of Mental Deficiency}, LXI (July, 1956), pp. 158-63.}

Laura Dittmann concentrated on the needs of the fami-
lies that had placed their child in an institution. She, also, noted that the purpose of the institutions was changing from a permanent to a temporary lodging with out-patient facilities. This is partially a reactivation of the original purpose of the institutions for the mentally retarded. A history of care for the mentally retarded points out that the early schools were organized to cure or overcome mental retardation by the application of physiological methods and improve the patient so much that he could return to the community.

The individuality of each situation is extremely important. The function of any institution must be clearly understood by all who have any contact with one. This would include those workers who guide parents in reaching a decision of care for their child.

Bernard Farber in his study of family organization and crisis indicated that institutionalization of the child does not, in itself, provide a solution for family problems, but may remove one impediment to this solution. Also, the results


of his study showed that when the retarded child was kept at
home the "normal sisters (but not brothers) are given parent-
substitute responsibilities and are seen by the mother to be
affected adversely." 10

One of the studies which examined the effect of placing
a child in an institution was based on the two extreme types
of care that may be given to a child there. The growth and
development of those children in an aseptic, impersonal atmos-
phere was delayed compared to the development of the children
in an institution where emphasis had been placed on mothering
the children and less effort was made toward cleanliness. 11

John Bowlby in his report for the World Health Organi-
zation stressed the importance of mother-love on the mental
health of the child. 12

Another study showed that following institutionaliza-
tion of their cerebral palsied, retarded child, parents ap-
peared hostile, suspicious, depressed, and generally uneasy.
This was interpreted from a questionnaire which was geared to
their remembered attitudes and reactions prior to the child's

10 Ibid., p. 90.

11 Rene A. Spitz, Hospitalism ("The Psychoanalytic Study

12 John Bowlby, Maternal Care and Mental Health (2d ed.
In general, the literature indicated that many factors were involved when deciding care for a mentally retarded child. In each case the decision of care for a retarded child is a difficult one for the parents. No matter what method of care the parents choose, there are likely to be adverse effects on either the child or on one or several family members.

Another point brought out by the superintendent of an institution for the mentally retarded when he was talking about the time a child should be placed was:

It is denied categorically that all subnormal children should be institutionalized. The decision to place a child in an institution should be based on the needs of the individual child and his family. It must be borne in mind that early institutionalization not only fails to relieve the stress but may intensify it. Early placement is likely to be interpreted by the troubled parents as a confirmation of their own guilt feelings and an irrevocable rejection of the child. Even a good institution is no substitute for the essential emotional interplay between parents and child.\(^{14}\)

Assumptions

It was assumed that the parents who were interviewed for this study were telling the interviewer how they really


felt about institutionalizing a mentally retarded child and not what they thought was expected of them. It was believed that parents who had made a move to care for their child in a special class or by placing the child in an institution had come to some realization that their child was mentally retarded. However, it was recognized that often both parents had not reached this realization before a decision was reached or initiated. Nevertheless, they were a part of this decision making and their feelings and opinions concerning the care were important factors to consider.
CHAPTER III

METHODOLOGY

Selection and Description of Sample

This study involved the parents of ten mentally retarded children. The children were selected with the stipulation that the parents would be accessible to the investigator for interviewing. All of the children were known to the investigator before the study was begun. This was primarily through a nursery clinic for mentally retarded children. The nursery clinic was located on the grounds of a large state institution for mentally retarded children. The clinic was started and operated by the Division of Mental Hygiene of the Massachusetts Department of Mental Health.

This particular clinic was begun for both children living at home and in the institution. The nursery clinic was designed to help the individual child in self-care and social adjustments. There were ten children attending the sessions; five of them lived at home with their families; the other five were residents of the institution.

The five resident children were selected to match the five community children as much as possible. The major factors considered in matching them were: diagnosis (that is, mongolism, brain damage, cerebral palsy), age, sex, and apparen-
ent intelligence.

It was planned that all ten children in the nursery clinic would be included in this study but this proved impossible because, of the five resident children selected, one was a ward of the state with parents inaccessible to interview, and another's family had moved from the state. In order to have five resident children included in the study, it was decided that two other institutional children would be used. These two had been considered likely candidates for the nursery clinic but had been eliminated because of their involvement in another education program in the institution.

**TABLE 1**

**SAMPLE**

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<thead>
<tr>
<th>Community Children</th>
<th>Resident Children</th>
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<tr>
<td><strong>Sex</strong></td>
<td><strong>Diagnosis</strong></td>
</tr>
<tr>
<td>M</td>
<td>Brain injury</td>
</tr>
<tr>
<td>M</td>
<td>Brain injury</td>
</tr>
<tr>
<td>M</td>
<td>Cerebral palsy</td>
</tr>
<tr>
<td>Fe</td>
<td>Mongolism</td>
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<tr>
<td>Fe</td>
<td>Mongolism</td>
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Apparent physical defects that the children were afflicted with included mongolism, cerebral palsy, bilateral cleft lip and palate, cleft palate, and deafness. As is shown in the above table, there were two with mongolism in each group. One community child had cerebral palsy, and another a repaired cleft palate. One of the resident children was deaf, and
another had a bilateral cleft lip and palate which had been partially repaired.

Time and Place of Study

Each parent was interviewed alone for approximately one hour, and then the husband and wife were seen together. It was the purpose of the first two interviews to discern any differences between the parents' views. In the last interview it was desired to have the parents talk about their situation together.

The mother of each child was contacted by mail informing her that a study concerning mentally retarded children was being done, and an appointment was made with her. She was informed that the interviewer was a graduate nurse, and that she had had some contact with her child at the institution.

On meeting the mother, the interviewer identified herself, and again requested her cooperation in the study. She explained that she was not employed by the institution and only had limited contact with the children there. It was also explained that this was part of a study regarding the institutionalization of mentally retarded children, and that the family would not be named in any reports of the study. The procedure that would be followed for the interviews was then given; that is, an interview with the mother, one with the father, and then with them together. Before leaving the mother, arrangements were made to meet with the father alone, and to follow this with a visit with the mother and father.
together. In several of the homes the father and mother greeted the interviewer. In these instances the above explanation was given, then the father was asked to leave the room while the mother was interviewed. Following the interview with her, the father was interviewed, and then both were seen together.

Methods Used to Collect Data

Prior to the home visits, basic data relevant to the family situation was obtained from the records of the institution and the Department of Mental Health which kept the records for the nursery clinic. This included such data as ages of the parents and siblings, family nationality; religion, education and occupation of parents. A copy of the form used for the basic data is given in Appendix A (p. 46).

At the beginning of the interview the mother was asked for any information that was not available on the records. She also confirmed or corrected the number and ages of the siblings and named anyone else living with the family.

A series of eight questions were designed to ask each of the parents. They were planned to cover the same subject matter, but the wording was altered for those questions put to parents of institutionalized children when appropriate. The list of questions for the parents is given in Appendix B and C (pp. 47,48). The questions begin with general information about institutions for the mentally retarded and become more specific to each individual family situation.
The ninth question, relating to the family's need for help, is the one question that was asked the parents when they were together. Brief notes were taken during the interviews, and at the first opportunity away from the family more detailed recordings of the visit were made.

The next chapter will deal mainly with the data collected from the interviews. The answers from each question will be presented together. In order to better assess the data collected, a short summary of the general characteristics of the families will begin the chapter.

Also, because it was felt that each of the families was unique in many ways which related to their retarded child, a description of each family will follow in Appendix D (p. 49).
CHAPTER IV

FINDINGS

Each of the parents was very cooperative with the interviewer. The families seemed to be of middle class socio-economic status, and all had other children living at home. All of the families except one, which was Protestant, were Roman Catholic.

Due to the similarity in the above characteristics, it was not possible to make any comparisons in these areas. However, it was noted that all of the community children were the youngest in their families and that their parents average age was 38.8 years. In contrast to this, the parents of the resident children had an average age of 29.5 years. Also, they each had at least one child younger than the one in the institution. This could denote that younger parents are less eager to burden themselves with a handicapped child and are more willing to "take a chance" on having other normal children than the older couples.

Three of the families from each group had three children; each of the other four families had four children. The ages of the siblings of the community children averaged twelve years. This may indicate, too, that parents whose youngest child is mentally retarded, or who are not burdened with small children in addition to the retarded child, are more reluctant
to place their child in an institution. Likewise, the mother would find it easier to care for only one small child and would be able to spend more time teaching this child if he was mentally retarded. However, these are only theories on the part of the investigator, as there was not conclusive evidence from the interviews to confirm either of these points.

Visits to Institutions

In reply to the questions, have you ever visited an institution for the mentally retarded, and what did you think of it; all of the parents of the resident children had had some contact with their child in the institution. However, most of their opinions were based on what they had seen on first bringing their child to the institution and on what they saw from the waiting rooms or yard. Only one couple mentioned that they had been on the wards of one building, and they were very upset that this was not permitted where their child was now. One other father had worked in another state institution and thought it was terrible that the children should be cared for in such an uncaring manner. He said: "There's no reason for them to run around naked."

They all stated that the children seemed happy when they saw them outside playing, and that the building their child was in was very clean looking.

Of the parents of the community children, two fathers and one mother had had no contact with institutions for the mentally retarded. Four of the mothers had been on the wards
of an institution and helped with the care of some of the children. Two fathers had had close contact with an institution for the retarded through their work. All of the mothers were quite amazed that so many older and "more capable" children were seen in the institution.

Institutionalizing the Retarded Child

When asked what they thought about institutionalizing a mentally retarded child, eight of the parents of the resident children thought it was a wonderful thing. Although each of the parents referred to their own situation, an answer which was fairly typical of all of these parents was: "I'm for it one hundred percent, if it's going to help the child, and most of the time it's going to help them, that is to learn. To learn just a little bit is good. It's a great chance for ______.

One father mentioned that it depended on the home environment and the mental stability of the parents as well as how retarded the child was. One extreme reaction of a parent was: "The best thing to do is put them in an institution, since you can't take them out and shoot them or put them in a gas chamber."

The parents of the children living at home were much more objective to this question. The majority of them qualified their answers according to the degree of severity of the retardation. Four of these parents mentioned that the physical appearance of the child would be an important considera-
tion. Each of them gave examples of a defect, which they felt they could not accept, for example, mongolism, cerebral palsy, or heart defect. They stated that they would have considered institutionalization if their child had any of these defects. The defect was always something other than that which afflicted their child.

Only one parent was completely against institutionalizing mentally retarded children. This parent had had his child in an institution for the first year of her life. He said that, when you put a retarded child in an institution it retards his progress even more, and that the contact with other retarded children does not allow for growth of those with ability.

Age a Child Should be Institutionalized

The parents of children in the institution consistently referred to their own child's age at the time of placement, when asked about the age a child should be institutionalized. Three of the parents said: "right away", as soon as you know for sure the child is retarded. Several considered the fact that it would be easier on the child in infancy since he would not know any different. Only one of these mothers remarked that the child needed the mother's love, and should be kept at home when it was a baby. One parent suggested placing the child when he was sixteen years old because by that time he would be trained and could care for himself. Another commented that his child was prepared for the institution by being
disciplined at home.

One of the mothers of a community child said that if you did not do it right away you could not do it. All of these parents agreed that the child should be taken home from the hospital and given a chance in the home. However, one mother said: "for the child it must be done in infancy, but for the parents' sake he should be taken home and given a try."

Differences of Institution Children

Only two parents of all those interviewed believed that there would not be any difference in a child brought up in an institution from one brought up at home. One had her child in the institution, the other had his child at home. However, most of the other parents could see advantages of both. Some said the child would be happier with his own kind, he would be disciplined, and taught to do many things in the institution which he would not be taught at home. The workers in the institution were trained in teaching these children and could do it better than the parent could in the home.

On the other hand, the parents pointed out that the children would miss home life and the love of the mother, if brought up in an institution. One mother stated that the child learned more at home because she had more time to spend with the child than the workers in the institution would have time to spend with any one child.

Another parent responded that there would definitely be a difference. "They wouldn't respond to any given situation
as a child in the home. . . . But you can't generalize--some of them would be better off in the home, but not necessarily would the home be better off. They would lack emotions when brought up in an institution."

Affect on Family

The reactions of each parent as to how their family was affected by their retarded child were quite varied. Only five parents said that their family was not affected, and not any of these were both parents in the same family.

Four of the parents stated that they now had a better understanding of the situation, and that their family was closer. There was more love in the family than there was previous to the recognition that they had a retarded child. One parent thought his oldest daughter (she was seven years old) had a better understanding of other children because of the retardation in the family. Counter to this was the parent who found it hard for the siblings to understand why their brother was slow and could not do the things that they did.

Several of the most common adverse effects were: they could not take the child out visiting or to a restaurant because of his hyperactivity and troublesome eating habits. Consequently, this had put a damper on family activities outside the home. Four of the parents stated they had to continually watch the child and were afraid to let him out to play without someone with him. Another parent said that they did not feel like celebrating or having a good time as they
were always thinking of their child and this made them very sad. One father said there was a general lack of harmony in the home until the child was put in the institution. Another admitted that he was jealous of his sister with eight normal children, and that his parents were ashamed of his child.

Several couples agreed that they showed special favor toward their retarded child, and several others admitted that they had to spend extra time with their child. One couple spent two hours a day giving special exercises to their child. Only one mother mentioned the fact that an uncle and a friend had broken off all contacts with her since they learned of her daughter's condition.

As each of the answers were so individual it would be difficult to generalize on the affects. However, about half of the answers were based on the concepts of the parents, siblings, other relatives, and friends of the child; while the other replies were based on the actual time and effort involved in caring for the child.

Decision About Care

There were a total number of fifty-eight reasons given by the parents as factors, which they considered when deciding whether or not to place their child in an institution. Five parents of the community children stated that there was no decision for them to make—they had never considered placing their child in an institution. However, one of these parents was also advised by a doctor to take the child home and care
for him as any other child.

For the most part, the fifty-eight stated reasons could be grouped into several large categories. The investigator was aided by two other nurses in coding the given reasons into the various groups. The categories and some of the replies which they included were as follows:

1. Concern for the retarded child.--There were twenty-four replies in this area, all by parents of resident children. They included concern for the child's happiness, education and physical therapy facilities available for the retarded child in the institution, and concern that the retarded child was frustrated with others at home or abused by them. This also included four parents' desire to have the child cared for after their death.

2. Advice from doctor.--Seven parents stated that they were advised to place their child in an institution by a doctor. Four of the parents of children living at home mentioned that a doctor advised them to take their child home, but left the actual decision to the parents. One family had been advised by the doctor that delivered the infant to put her in an institution. But, he also called in a consultant who advised the parents not to place their child. The parents related how confused they were and wanted to believe the consultant, but because they had known the other doctor longer, they relied more on his judgement. This family made application for admission of their child to an institution. However,
they were unable to get her in immediately, so they had to take her home from the hospital. With her home, they found that many of their worries were unfounded and decided to keep her home when an opening in the institution was available.

3. Concern for mother's health.--Three of the fathers of resident children stated that care of their child at home was injuring their wife's health. In one situation, the three year old retarded child was not walking, and had to be lifted by the mother who was pregnant. Yet, one of the community children had been in an institution for the first year of her life, and both her mother and father reported how sick the mother was during this year. She stated that she was not sick after they brought the child home.

4. Concern for the normal siblings.--Five of the resident children's parents mentioned that they were neglecting their normal children when they had the retarded child at home. They stated they spent so much time caring for the child, they had little time for their other children. And, they could not take the other children places with the retarded child at home.

5. Difficulty caring for the retarded child.--Four parents stated that they actually could not manage their child at home. In these cases, the child was said to be hyperactive, or had to be constantly watched because he ran away from home, or was just too difficult to care for.

6. Other.--There were nine other replies which seemed
unique in themselves. Two of these were from the parents of the child, who attempted to place their child in an institution, and in the interim of waiting for an opening had to take her home, where they found caring for her was not such a problem. Three parents were concerned because the retarded child was hurting other children when playing with them. One parent considered the mental stability of the parents and the strain on them too much with the child at home. This person also disclosed that he was on the verge of a nervous breakdown at the time the decision was made to institutionalize their child. One other father answered the interviewer, "I think that way." He said the whole family had decided that it was the best way for all their sakes.

Of the fifty-eight reasons that the parents gave for making their decision to care for their retarded child, only eight of these were from parents whose child remained at home. This may be explained by the fact that the parents felt much more tension and ambivalence about placing their child in an institution, and each reason that they had was a psychological rationalization to confirm the acceptability of their decision and behavior.

The theory of Leon Festering on cognitive dissonance could be applied in this situation.\(^1\) The parents of mentally

---

retarded children have had to resolve in their own way a dissonance in society. This dissonance is based on the established rule that parents are responsible for raising and caring for their own children. This, also, could include the innate characteristic of parents to avoid the loss of one of their offspring. At the same time, the social pressure which is dissonant to this is one of rejection of evil and the deformed.

The parents of some of the children have been exposed to the acceptable method of rejecting their child by placing him in an institution by people whose opinions and judgments they respect, such as doctors and family members. This creates dissonance with their innate desire to retain the child. The fact that this desire is so strong makes it necessary for them to have a counteracting force that surpasses it. They, then begin collecting many reasons for giving up the child to overcome this natural inclination. Thus, the parents of institutionalized children have supported their decision with many other acceptable reasons for making it.

On the other hand, the parents of community children have either not been exposed to the idea of rejecting their child, or, at least, not by as strong a force and do not have the need to resolve any dissonance by forming supporting reasons for their decision. Another factor which must also be considered is that these parents have been exposed to the pressures of institutionalizing their child, but because of
a stronger force for keeping the child at home they have either rejected the person or persons causing them dissonance or avoided those things which may have led to it.

Reported Consultants
The preceding theory of resolving dissonance by the accumulation of positive forces to support the parents decision of care for their child was also apparent in the number of people with whom the parents stated they discussed their decision. These persons did not necessarily suggest or advise a particular method of care but only discussed the issue with the parent. The parents of the resident children talked over their decision with twenty-seven people, while the ten parents of community children only named twelve people. For a more specific appraisal of these figures they can be broken down into individual responses. Table 2 lists the number of consultants each parent mentioned.

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>REPORTED CONSULTANTS TO PARENTS</td>
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<tr>
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<td>4</td>
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<tr>
<td>Fathers:</td>
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<tr>
<td>Totals</td>
<td>27</td>
<td>12</td>
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The one mother of the community child, who listed five individuals that had talked with her, had considered placing her child in an institution and continued to contemplate this measure. The father of the resident child who said he did not talk about the decision with anyone, also considered himself unsympathetic with all children until they could converse with him on an adult level. He said he was disinterested in retarded children.

The average number of consultants listed by the mothers of resident children was 3.6, and 1.8 for the fathers. For the community parents the average number was 1.6 for the mothers, and 0.8 consultants for the fathers. It may be postulated that fathers, recognizing their authority in the home, are less likely to want to submit to the reasonings of others, and want to rely more on their own reflections to make their decisions. It can also be speculated that the force on the mother towards keeping her child is stronger than on the father, and for this reason it was necessary for mothers of the resident children to get support from more people.

The individuals who were named by the parents as having discussed with them their decision of care are listed in Table 3.

Help with Decision that Was Not Provided

Four parents implied that it would have been helpful if other parents of retarded children had talked with them at the time that they first learned that their child was retarded.
One mother kept repeating: "You feel so alone." Another mother said, if they would have given me an "explanation from the very beginning of how much they (retarded children) can do and what it's all about. But somebody would have to approach me, I couldn't ask anybody."

TABLE 3

NUMBER OF PARENTS LISTING REPORTED CONSULTANTS

<table>
<thead>
<tr>
<th>Consultant</th>
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<td>Doctor</td>
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<tr>
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<td>2</td>
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<tr>
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<tr>
<td>Total</td>
<td>39</td>
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One father said that he had to ask the doctor a few months after the baby was home what was the matter with it. "If they would have just told me right away." Another parent said: nobody can help you, you just have to accept within yourself the fact that your child is retarded.

Present Needs of Parents

The last visit with the mother and father of each of the children was very informal. They were led into a discussion of what they considered were their needs as they pertained to their retarded child at that time.

Many of the parents seemed unaware of the facilities that were available to them, such as, the association for retarded children and the association for the cerebral palsied.
at least in so far as these agencies could give them any guidance or help. They all wanted someone to approach them and seemed to have difficulty taking the initiative to go to an individual or agency. One mother told of how she had gotten a neighbor to make the phone call to get information about the nursery clinic because she was unable to do it.

The parents of children in the institution wanted to know more about what their child was doing, and how he was progressing while in the institution. One father said that when he picked up his daughter, if she was limping or had a bruise, he would ask about it. But the only response he would get was: "I don't know", and no effort would be made to find an answer or direct him to someone that would know.

Other parents wanted to know the schedule of their child in the institution, and what he was being taught so they could continue with this when they brought him home for a visit. Several complained that the short visiting periods, once a month, hardly gave them time to pick up the child and get him home before it was time to take him back. They said it was hard to plan on doing anything in this short time.

Two of these families complained of the bills which they received for their child's care. They stated that it was impossible for them to pay them and wanted to know how the rate was prorated. Apparently no one from the institution had talked with them about their financial circumstances, and this seemed to provoke them. Both of these families did admit to
having had "political pull" in getting their child in the institution.

One parent expressed ambivalent feelings toward attending the meetings sponsored by parents of the resident children. He said: "talking with other parents only upsets us more, yet we feel that we should go out to some of the events the . . . (parents' group) sponsors." The fact that he and his wife were unsure of the English language (they spoke Italian in the home) seemed to be an added deterrent from feeling at ease with the other parents.

The community families appeared to have found many of their worries solved or at least averted by the nursery clinic which their child was now attending. This had given the mothers a rest from the constant attention they had to give their children, they reported.

Several of the community mothers were very much concerned with finding a dentist for their child. One mother had been to three dentists and each in turn had said he could not handle her child. These mothers asked for a list of dentists in the communities who would care for retarded children. They, also, expressed interest in learning what school facilities were available for the children, but had no idea of where to get such information. An available list of schools with special classes was suggested by one parent.

One father said he was afraid to read the literature about mental retardation. He said that it was too general
and depressing as his daughter had far surpassed the predictions of the doctor and the literature he had read. He stated that nothing that he had read really applied to her. He and several other community parents noted that they had gotten most of their information from the encyclopedia.

Each of the mothers and fathers of the resident children talked more freely with each other when they were seen together than did the parents of the community children. Three of the community couples approached the subject of retardation hesitantly, and one parent usually predominated the conversation. They talked as though they had not discussed it very thoroughly at least not recently. However, one couple began talking with each other and completely disregarded the interviewer for approximately forty-five minutes. They spoke as though they had not talked about retardation together for a long time, and they were catching up on how each felt about it and their daughter.

One other father and mother disagreed quite heatedly on the way the mother did things for the child instead of allowing the child to do them. Besides this, they were very concerned with the behavior of their adolescent son and directed much of their conversation toward him.

As stated previously, the parents were very cooperative in answering the questions of the interviewer. Nevertheless, there were some problems which arose by having the interviews in the home. Two of the main interruptions were the telephone
and the children. In the two homes in which the fathers were home when the interviewer first visited, the fathers appeared adverse to the interviewer when they were asked to leave while she talked with their wives. This antagonism seemed to disappear during the interview with each of them.

The following chapter will summarize the findings presented in this chapter. Recommendations of activities for workers in the field of mental retardation which became apparent to the interviewer while talking with the parents are made; as well as, suggestions for future studies that developed while carrying out this study.
CHAPTER V

SUMMARY AND RECOMMENDATIONS

Today the families with mentally retarded children are very much aware of their child and his handicap. For the most part they want to keep him as a member of the family and help him to mature to his highest level.

The parents of the retarded child are very dissatisfied with the professional assistance which is provided for them. They feel that no one fully understands their situation or problem unless they have been faced with a retarded child of their own. These parents want guidance, but are unable to accept what is available to them either because of this feeling of lack of understanding or because no one has approached them.

The studies that have been done point out some of the adverse effects of keeping a retarded child in the home, as well as the harm that can be done by placing a child in an institution. The type of care that is prevalent in most institutions usually depresses the potentialities of the individual, regardless of the elaborate facilities, because of the lack of mother-love and emotional stimulation.

This study involved interviews with the mothers and fathers of ten mentally retarded children concerning their
feelings on institutionalization of the mentally retarded child. Five of these children were living in an institution, while the other five were living at home. Each of the parents was seen alone in their home by the investigator.

The families were aware of many of the advantages and disadvantages of bringing up a child in an institution. They felt that the child would be happier with others like himself. If placed in the institution in infancy the child would consider it his home without any traumatic separation. They also realized that the child would miss the emotional stimulation that usually permeates home life.

Either the mother or father in each family reported that their family had been changed since they learned that one of their children was retarded. These changes included such things as increased understanding of other people and of the handicapped; less family activities, especially outside the home; and greater amounts of time spent with the retarded child while he was living at home.

The parents of two of the children, living at home, said they had never considered placing their child in an institution. The rest of the parents gave a total of fifty-eight reasons for the decision that they had made.

The reasons listed were coded into the following categories: concern for the retarded child, advice from doctors, concern for the mother's health, concern for the normal siblings, difficulty caring for the retarded child in the home,
and others. Only eight of these reasons were given by parents of children living at home. The parents of resident children had also talked over their decision with more than twice as many people as did those parents of children living at home. This may indicate a need for parents to support their decision to institutionalize their child with many reasons and others' opinions to counteract the innate characteristic and social pressure on parents to raise their own child.

The parents wanted other parents of retarded children to talk with them when they first learned that their child was retarded. They mentioned that these parents or any agency or individual would have to approach them, that they could not go out looking or asking for help. They seemed unaware of the available services for them. The parents of the children in the institution wanted to know more about their child's activities there. Several questioned the rigid schedule that allowed them so little time with their child.

The community parents, although satisfied with the nursery clinic which their children were attending, were concerned with finding the special facilities that were in the communities for their children. This included, particularly, dentists who would work with the retarded child, as well as special classes toward which their child could progress.

The recommendations of this study are primarily based on the individual suggestions of the parents that were interviewed. Many of the suggestions are projects which could be
implemented through the parents' organizations provided there was sufficient professional guidance.

The following are recommendations for practice and further study in the field of mental retardation.

1. The approach and visiting of all parents of recently diagnosed retarded children by other parents of retarded children.

2. All pediatricians and obstetricians as well as nurses should be made aware of the capabilities of many retarded children and the function of the agencies they recommend.

3. When parents are confronted with making a decision for their child's care, they should be given an opportunity as well as be encouraged to visit the wards of the institution and the home of a family with a mentally retarded child.

4. Parents should be given support in the decision they have made. The families should be contacted periodically by an individual from either the institution where their child is living or a community agency, if their child is at home. This would allow the parents to ask questions they may have, together with maintaining contact with those agencies which are interested in the care of the mentally retarded.

5. Parents with recent foreign background should be acquainted with others of similar background so that they would have an understanding person with whom to discuss their problems.
6. It is recommended that other studies be done on the ages of parents of retarded children in institutions compared with the ages of parents of children in the home, and too, compare the ages of the siblings of retarded children in these two groups.

7. A study concerning parents visiting habits in institutions and the reasons for them might be very enlightening.

8. A study of resident children's home visits with and without help toward the parents' and child's adjustments may produce very beneficial material.

9. A study of the care selected by parents for their mentally retarded child with and without physical disabilities may also be helpful.

10. Studies reproducing this one with parents who are in the process of applying for admission of their child to an institution would be more accurate in determining the reasons parents have for placing their child.

This study has indicated the many differences of each family situation and that the individuality of the family must always be considered. Because of this, it is even more important that those people working with the families of the mentally retarded and handicapped must have an awareness for the vast number of circumstances which can alter the families' attitude toward the disability and toward their child.
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Hillsman, Gladys M. "Now I Am a Person!" Nursing Outlook, XI (March, 1963), 172-74.


## APPENDIX A

### BASIC DATA

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APPENDIX B

INTERVIEW QUESTIONS FOR PARENTS
OF COMMUNITY CHILDREN

1. Have you ever visited an institution for the mentally retarded? What did you think of it?

2. What do you think about institutionalizing a mentally retarded child?

3. What do you feel is the best age to place a mentally retarded child in an institution? Why?

4. Do you think a child is any different when brought up in an institution? How?

5. How has your family been affected by the fact that your child is mentally retarded?

6. Can you recall how you were helped in your decision to care for your child at home?

7. Do you remember who helped you make this decision to keep your child at home?

8. What help do you think could have been given you which would have helped you make your decision?

9. Is there any particular kind of help which you feel you need or could use at this time?
APPENDIX C

INTERVIEW QUESTIONS FOR PARENTS
OF RESIDENT CHILDREN

1. Have you ever visited an institution for the mentally retarded? What did you think of it?

2. What do you think about institutionalizing a mentally retarded child—in general?

3. What do you feel is the best age to place a mentally retarded child in an institution? Why?

4. Do you think a child is any different when brought up in an institution? How?

5. How has your family been affected by the fact that your child is mentally retarded?

6. Can you recall how you were helped in your decision to put your child in an institution?

7. Do you remember who helped you make this decision?

8. What help do you think could have been given you which would have helped you make your decision?

9. Is there any particular kind of help which you feel you need or could use at this time?
APPENDIX D

Family A

Mr. and Mrs. A. had lived in the area most of their lives. They were living in another state, however, when John, their retarded child, was born. Mr. A. was thirty-eight years old and worked at least six days a week. He had a full-time job as a drug salesman, and worked part-time in several drug stores each week. Therefore, he was not home very often and participated only infrequently in family activities.

Mrs. A. was thirty-six years old. She seemed very tense over the condition of their retarded child. The family consisted of one girl, twelve years old; two boys, fourteen and ten; and John, six years old. John was a handsome blond boy who was diagnosed as mentally retarded following hospitalization for epileptic seizures when he was three years old.

Mrs. A. expressed great fear of the seizures that affected her son. She talked about the multiple factors which could have caused his retardation and epilepsy. She had been told that the two were not associated but could not be sure of this. Mrs. A. was with a relative when she learned that John was retarded and was the one that told her husband. At that time, he said "he's not", and she intimated

1All names are fictitious.
that they had only discussed this briefly. Mr. A. never went with her when Mrs. A. took John to the doctors.

Mr. A. appeared to accept the fact that John was slow at the time of the interview. When the original diagnosis was made, they were told that John was two years behind in his mental development. Therefore, Mr. A. said that he felt John would reach maturity two years later than normal, but that he would reach adulthood.

Mrs. A. cried a great deal and told of crying when seeing a new baby because it reminded her so much of John as a baby. She had many fears of leaving him anywhere, and was very apprehensive about leaving him in school. Mr. and Mrs. A. both said they had never considered placing John in an institution. Mrs. A. said that because he was handicapped, she loved him more and seemed to want approval of this.

His sister often played with him, but the mother said that the children could not understand why he was slow and could not do the things they did.

Mr. and Mrs. A. had looked in the encyclopedia for information about epilepsy and mental retardation. Mrs. A. had to have a neighbor call for information concerning the nursery clinic program because she said she could not get herself to do it. She answered the interview questions very hesitantly, while Mr. A. gave quick brief answers. He did not bring in his own family situation until the questions were specific to this, and then indicated that they did not have
any problems as their child did not fit into the category with other mentally retarded children.
Family B

Bruce B. was a six year old normal looking child with a cleft palate and very retarded speech. Bruce had a brother fourteen years old and a sister nine years old. He was often given special consideration in the home because of his slowness.

Mr. and Mrs. B. appeared to be a very happy couple who spent a great deal of time in family activities. They told the interviewer that they had not been out together without the children. However, each one of them had activities which he or she participated in outside the home each week; e.g. bowling, card games, creative classes, etc.

Mr. B. was forty years old, and had a job as warehouse manager. When asked about the care of Bruce in the home he directed the interviewer to his wife saying the child was mainly the mother's responsibility, and the man was primarily concerned with the livelihood for the family. He referred to his son as being slow, but did not call him retarded, also saying: "He'll catch up later on."

Mr. B. read to Bruce every evening as was suggested by a speech therapist. Although he said he was not embarrassed when Bruce was not able to talk with visitors, he seemed upset by this. He implied that the child's mental slowness was due to his lack of speech, and that this was due to the cleft
palate.

Mrs. B. was a very outgoing, cheerful woman, thirty-seven years old. She seemed to have a realistic attitude toward her child's handicap. Yet, during the final interview she and her husband disagreed quite avidly because she would do things for Bruce rather than waiting for him to do them. She also seemed to have difficulty setting limits for him and enforcing those she did set.

At the time of the interviews they were preparing to enroll Bruce in special classes in a nearby school. Mr. B. at one time referred to the two classes of mentally retarded as "trainable and eligible" but only that Bruce was slow.

Neither parent had ever considered placing their child in an institution. They found out that Bruce was retarded when he was about three years old. Up to that time they had been involved with corrective procedures for his cleft palate. The chief concern during the last interview was the behavior of their adolescent son. Mrs. B., also, mentioned that her daughter was suddenly doing poorly in school, and considered the fact that it may have been caused by herself devoting too much time and attention on Bruce.
Family C

Family C seemed to be a very active family. Mr. and Mrs. C. were in their early forties, but acted and looked much younger. They had four daughters, ages fifteen, thirteen, eleven, and four and one-half. Ann was the youngest and was afflicted with mongolism. She was diagnosed at birth and placed in an institution at that time. She remained there for one year during which time her parents reported they visited every week, and contemplated buying a house next to the institution to be near her. Mrs. C. recalled having chest pain continuously during that year, and said she was sick all the time, but recovered immediately after bringing the child home. At the end of the year they brought Ann home for a visit and decided to keep her home and see how she did. They recalled that within a month she began sitting up and her color improved. They discovered that she was not sick all the time contrary to their expectations.

Mrs. C. said: "I couldn't talk with anybody about it for a long time. I cried a lot. Even after I brought her home I couldn't talk about it, but now I can. She is so close to being like the others." They reported that they had not talked with anyone about bringing her home but just decided to do it.

Mr. C. recalled: "In the institution she seemed lost
and didn't seem to have any emotions, but she developed so much when we had her home. She seemed confused. I guess she just had a need for love." Mr. C. felt that placing a retarded child in an institution retarded his progress even more, and that contact with other retarded persons does not allow for growth of the individual. He mentioned that he was making provisions for her care after he and his wife died. He also expressed concern for her safety when she got older. He had been given many warnings about how much trouble she would be when she got older by a doctor at the institution. He followed this by saying that they had found that most of the problems were in their mind and they all ironed out eventually.

Mr. C. described the literature he had read about mongolism as too general and depressing. They both said that they had gotten most of their information from the encyclopedia. Mrs. C. stated: "If only we had been given an explanation in the very beginning of how much they (children with mongolism) could do and what it was all about. But somebody would have had to approach me as I couldn't ask anybody."

Mr. and Mrs. C. discussed their child and mongolism in general for about forty-five minutes and were practically unaware of the interviewer sitting with them. They talked as though it had been a long time since they had talked freely about the subject and kept asking each other what they thought about various aspects.
Family D

Kay who had mongolism, was the daughter of parents who were in their mid-thirties. She had a brother sixteen years old and a sister nine years old. She was three and one-half years old and was very passive in her appearance and activities.

Both Mr. and Mrs. D. were interested in the retarded child. Mrs. D. was an active member in the local association for the retarded, and Mr. D. attended when the meetings did not interfere with his work.

Mr. D. had worked in an institution with retarded adults when he was in high school and had vivid memories of the environment. He commented that he thought they probably had changed a lot since then. He seemed proud of his family and very close to his youngest daughter. He expressed much concern over his daughter being harmed by others when she got older. He stated that their doctor recommended placing her in an institution when she was born. Therefore, they made application for admission at that time. When an opening was available a year later they had decided to keep her at home for a while longer, as they found that it was not so difficult to care for her. He stated that if they would have had good information in the beginning they would not even have applied. He felt it was the place of the doctors and the hospitals to
have information for the parents as they had no idea where to get it. He said that they never did get any information.

Mrs. D. was teary through most of the interview with her. She talked freely about retardation, though not too much about how she felt about it. She expressed guilt in not doing more with the children who were in the institution. She said she felt she was being selfish for wanting to get away from all of it when Kay was in school. Mrs. D. pointed out several physical deformities which were very repulsive to her and stated that these children should be put in an institution. "Any who are a burden to care for should be placed, but she (her daughter) really isn't that bad. . . . But I'm not saying I'll never put her in an institution."

Mrs. D. mentioned that her son had run away from home several weeks before. She did not talk about it any further than to say it was the only time she had seen her husband cry other than when he told her about the baby.

She told of a friend and an uncle who had broken all contact with her since Kay was born, and said she was certain it was because of Kay. She said: "My uncle has never been here since she was born. Oh, he's terrible. He can't accept her at all. He thinks we should put her in a place." She also expressed great fear of letting her out alone because she would not defend herself and would be hurt by the other children or run away.
Family E

Mr. and Mrs. E. had three children; two girls fourteen and six years old, and Timmy four years old. The parents were each thirty-nine years old and had lived in the area all their lives. Also, living with this family were the mother's father and her uncle. Both men were in their late seventies, and though they were not helpless, they did require extra attention from Mrs. E.

Timmy was a very small boy with borderline cerebral palsy. His muscles were very flacid, but had been built up somewhat by constant exercises. Since he was about seven months old, the parents had spent about two hours every day with him in activities specific to developing the muscles. Mrs. E. pointed out that this probably could not have been done had he been in an institution.

Mrs. E. felt that there was more love in the family and that they were much closer because of Timmy's condition. When the parents were told about Timmy's retardation, he was seven months old. On the second visit to the diagnostic clinic, Mrs. E. recalled that the doctor said that he qualified for institutional care, but he strongly advised against it. She also said: "Friends asked us when we were going to put him in an institution, but we didn't really consider it."

Mrs. E. seemed to derive much support from her relig-
She continually spoke of the progress Timmy had made since he had been in school.

Mr. E. had frequent contact with the institution for retarded children in the area in his work. He felt that "only as a last resort should a child be placed in an institution. He should be kept at home until he or she is completely out of hand."

At the time of the final interview, Mrs. E. had just had a third dentist refuse to care for her child. She was very upset by this and did not know where to go for help. The only contacts with persons concerned with her child that they had were the family doctor and the nursery clinic. She had originally gone to the dentist suggested by the doctor, and the other two dentists had each been suggested by the previous one contacted.
Family F

Tony was a four year old with mongolism. He had two brothers; one seven years, and one five years old; and a sister eighteen months. Tony was placed in the institution five months before the interviews with the parents. His mother freely admitted that her husband did not want to put him in an institution, but that she had wanted to because she just could not give each of the children proper care when Tony required so much time. She explained that she had three children under three and one-half years when he was born and three years later another baby.

Mr. and Mrs. F. were a very friendly couple both in their late thirties. Mr. F. had worked for a large mental hospital for several years, and during this time encountered some retarded persons. He had grown up near the institution where Tony was now living and had often played on the grounds as a youngster. He said he was very disturbed by the care provided for the patients in the institutions and emphasized how he had fought to keep his child at home. He said: "It was a battle all the way for me. I don't really think a child should be there except when necessary, as in our case. I really didn't want to put him in there. Of course, for my wife and the children we had to."

Mr. F. stated that he thought a child should be placed
in an institution when they are a teenager because they would be able to care for themselves and be more independent by then. However, he followed this by saying they had to place Tony because the other children were suffering.

Mrs. F. said that she felt all along they would have to place Tony in an institution. She praised the facilities of the institution, but said that since he, Tony, had mongolism, he probably couldn't learn too much, explaining, "he isn't able to progress very much despite the fine facilities." She reported that the other children often asked about him and enjoyed being with him when he came home to visit. She expressed wonder because on these visits he was not talking as much or doing as many things as he had done prior to his placement.

She said that the doctor and a priest had advised them to place the child in an institution. She recalled giving up all attempts to train him when their daughter arrived.

Mrs. F. described how panicky she was when Tony was between six and twelve months old, and that looking back she thought she needed reassurance from someone else who had a child like her son, especially during this period. Mr. and Mrs. F. talked at length about the home visiting periods at the institution, and felt they could help their son more by knowing what he was being taught at the time they brought him home.
Family G

Mr. and Mrs. G. were in their late twenties and had four children. Their oldest daughter, age seven, was very close to Linda, their six year old retarded daughter. They also had two boys; one four years old and another, one and one-half years. Linda had a bilateral cleft lip and cleft palate which had been partially repaired. She had four operations on her lip and palate before the surgeon learned that she was retarded. Mrs. G. recalled that he then interrupted his treatment, saying: "There's no rush as they don't care how they look." Linda had been in the institution for three years and nothing since then had been done to further improve her physical appearance. Linda was, however, getting physical therapy for a slight paralysis of the right side which was due to brain injury. Mrs. G. pointed this out as one of the advantages of having her in the institution, as she could not give her physical therapy every day at home. Mrs. G. felt it would have been "selfish" and "cruel" to keep her at home. She said she was happy there with her own kind, and not frustrated as she had been at home trying to keep up with her sister.

Before placing her, they had her evaluated in three different places and agreed on what was best for her, not what was best for themselves. Mrs. G. pointed out that she
felt that the children should stay at home when they are babies because they need the mother's love, and then after infancy the child should be placed in an institution.

Mr. G. was sure of the advantages of the institution for his child, but emphasized that the husband and wife must agree on the decision of care for their child, and that it must be their decision. He praised the doctor that first told them of their daughter's handicap saying the biggest impression was made then, and that that doctor helped them the most. Mr. G. felt that the parents gave their retarded child "half-a-chance" by placing them in an institution, and giving them all the love in the world would not help them learn anything.

Mr. G. felt that his other daughter was more helpful and understanding of others because of Linda's disability, and he said that she was very proud of Linda.

Linda came home each weekend for a visit, and at the time of the first interview she was on a two week home visit. Mrs. G. had given more thought to bringing her home permanently since Linda had been transferred to a new building where the rules were much stricter concerning parent-child visiting privileges. Mr. G. reported what a difficult time he had picking her up, and that he had to return her to the institution in five to six hours. They told the interviewer how much friendlier Linda was with strangers since she had been in the institution, and that now they often took her visiting when she was home.
Family H

Mr. and Mrs. H. were a young couple with two small children at home. Mark was three and one-half years old, and had been placed in the institution one year prior to the interviews. His parents were in their mid twenties, and he had a brother two years old and a sister five months old.

Mrs. H. seemed unsure of the righteousness of placing him in the institution and seemed to be relying mainly on her husband's decision. She told how her father was against placing the child in the institution, but she said that as long as she knew the child was happy she felt she had done the right thing. To confirm his happiness, she said; "He never whines when we take him back." Later she told the interviewer Mark had only been home once since they had taken him out to the institution. It seemed that that had been within the last month because they had been called to have his hearing tested by a doctor at a nearby hospital. It was discovered at the institution that he was hard of hearing.

Mr. H. seemed to be indifferent, yet almost antagonistic toward the interviewer from the beginning. He had been asked to leave the room while she spoke to his wife. When he returned one of the first statements he made was: "I don't have much interest in children until you can carry on a conversation with them. I'm disinterested in retarded children,
not sympathetic toward them." His answers were very brief, and he showed no feeling for his child.

Mr. H. said that he felt a child who is retarded should be placed in an institution as soon as you find out they are retarded "just to get rid of them." He spoke of the bills which they got each month for Mark's care and said he could not pay them. He said he could not see depriving everybody to pay the bills and was told by a friend not to worry about them.

Mr. H. reported that it was very easy to accept the fact that his child was retarded. The only problem was to get the child into an institution.
Family I

Karen was the oldest of three girls in her family. She was six years old, her sisters were two and three years old. She had been placed in the institution six months prior to the interviews. Her mother was twenty-nine years old, and worked on weekends as a technician in a hospital. Her father was thirty-one and seemed to change jobs frequently.

Both her parents were home at the time the interviewer visited. Mrs. I. became upset during the interview and got teary-eyed when she was talking. Both of them related all of the questions to their own situation. They each told how hyperactive Karen was when she was living at home and pointed out several instances which had caused them much concern e.g. she frequently ran away to the downtown district and was returned by the police.

Mrs. I. reported that a doctor had accused them of spoiling Karen, and she was quite indignant at this. She said that Karen had so much energy she could not keep her from being bored. She described the mother that kept her retarded child at home as having to be exceptional, and that the people in the institution were trained so that it would be easier for them to care for a child like Karen.

Karen also often had seizures when she was home which both parents mentioned as affecting them very much. Mrs. I.
recalled that when she heard a neighbor abusing Karen she could not stand it any longer, and then began considering placing her in an institution.

Mr. and Mrs. I. reported how much help and support they received from the director of the association for retarded children in their area. They said he also had a child in an institution and was very understanding.

Mr. I. told that when Karen was home, they were unable to have company when she was up, and they couldn't take her anywhere with them. He confided that his parents were ashamed of her, and that he was jealous of his sister who had eight normal children. Mr. I. also said that they decided to place Karen in the institution when he came home from a trip and found his wife very upset with her, and just unable to take care of her anymore. He said that at the time, he was having a serious drinking problem and "on the verge of a nervous break-down."

Mr. I. stated that he would like to talk with the doctor and the teacher that were working with Karen now, and find out how she was doing. Karen had been transferred to another building and the parents were advised not to see her for at least six weeks. Mrs. I. said that she had not been able to visit Karen since they had placed her in the institution, but that her husband had visited her several times.
Family J

Mr. and Mrs. J. were a young couple in their mid-twenties with three children. They had a daughter five years old; and two boys, one three months old, and Joe who was four years old, and had mongolism. Mr. and Mrs. J. spoke Italian in the home, but were able to talk with the interviewer without an interpreter. Joe had been placed in the institution when he was two and one-half years old, after several doctors had advised the parents that they should institutionalize their child.

Mrs. J. said they visited Joe every week, and she felt that he was better off there because she could not spend all her time with him. The personnel of the institution could teach the child many things which she could not, e.g. how to walk, and to feed himself. She said he was much friendlier and got along with more people than he did before he went to the institution.

Mr. J. thought it was wonderful for the children, and that the institution had helped Joe. He said that Joe cried now, something he never did before. Mr. J. described how he had to ask the doctors what was the matter with Joe when he noticed that he did not do things like his other child had done. He also said the doctor told him to have him tested at the hospital. The doctors there said he could not be helped
and should be put in an institution.

Mr. J. thought that the children in the institution seemed to be better than those he had seen who were living at home. He pointed out several examples of retarded children he had seen who were being made fun of by other children.

Mr. J. said that they went out and took him places when he was living at home, but now they were so sad and always thinking about him they did not feel like having a good time. He also considered the fact that Joe would be cared for if something happened to him, whereas, if he was living at home it would leave his care to his wife and the rest of the family which he did not want to happen.