A Study of the Advice and Counsel given by Omaha Pediatricians and General Practitioners to the Parents of Retarded Children

Nancy Karen Kelly

University of Nebraska at Omaha

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A STUDY OF THE ADVICE AND COUNSEL GIVEN BY OMAHA
PEDIATRICIANS AND GENERAL PRACTITIONERS
TO THE PARENTS OF RETARDED CHILDREN

A Thesis
Presented to
the Faculty of the Graduate School
University of Nebraska at Omaha

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts

by
Nancy Karen Kelly
Accepted for the faculty of The Graduate College of the University of Nebraska at Omaha, in partial fulfillment of the requirements for the degree Master of Arts.

Graduate Committee

Name

Department

Chairman
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Chapter 1

BACKGROUND OF THE STUDY

PURPOSE OF CHAPTER 1

Chapter One presents the background of the study and a general description of the study. Included in this chapter are the following: (1) an introduction to the study, (2) the statement of the problem studied, (3) the hypotheses on which the research was based, (4) the significance of the study, (5) definitions of terms used in the study, (6) procedures used in collection of data, and (7) procedures used in the treatment of data. An overview of the organization of the remainder of the study will conclude Chapter One.

INTRODUCTION

Since the beginning of man, the human race has had the problem of dealing with those individuals who could not function and learn as well in society as could the great majority. The vast majority of them are best known by the label, retarded. In ancient times, they were persecuted, mistreated, and even left to die. The rise of Christianity had not significantly improved their lot, and it wasn't until the 19th century that men and women such as Itard, Sequin, Montessori, and Decroly began to investigate their potential. Despite considerable effort, many thousands
of retarded children and adults are still treated like sub-humans in institutions in every state. There are presently 200,000 retarded in state institutions, and another 20,000 in private ones. Thousands more are incorrectly residing in institutions for the mentally ill. Most were institutionalized on the advice of physicians.

In recent years, however, there has been a revolution concerning the care and education of the retarded. Normalization, a philosophy which was first put into practice in Sweden and Denmark, has been adopted by many American professionals and parents of the retarded. Normalization simply means that the retarded have a right to as normal a life as possible and a right to reach their potential in social and mental growth. Institutionalization is discouraged as it is not a normal environment, and community living is encouraged. The community services

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5 Wolf Wolfensberger and George Thomas, "Report on Community Services," The Report of the Nebraska Citizen's Study Committee on Mental Retardation, II (State of Nebraska, 1968), pp. 189-190.
in Omaha are outstanding examples of normalization ideas being put into practice. There are presently five developmental centers, four workshops, six hostels, one crisis assistance unit, one behavior shaping unit, and one developmental maximization unit in the metropolitan area. Because of these programs, many retarded individuals presently have a chance to lead full and productive lives instead of inactive ones in an institution.

Because the emphasis for care of the retarded has moved from the residential facility to community services, greater demands are put on the physicians who care for the retarded in the community. They must not only serve as counselors to the retarded and their families, but they must be a source of information and referral to appropriate community services. As the April 1964 Conference on Mental Retardation called by the American Medical Association concluded:

As society accepts more fully its responsibilities toward the retarded, their future will brighten. The health, happiness, and success of the individual retarded child, however, will always depend on the devotion, knowledge, and skills of the primary physician and his relationships with other professional groups and agencies in the community.

STATEMENT OF THE PROBLEM

Because the diagnosis of retardation is usually made by a physician,

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6 *Eastern Nebraska Community Office of Retardation* (Omaha, 1972), p. 2.

it is important that the physician be aware of services which are offered in the community and whether those services obviate the need to institutionalize the child. The physician involved would usually be a pediatrician or general practitioner. To investigate the problem, and the difference, if any, in advice offered between pediatricians or general practitioners, a four-fold study was initiated. The purposes of the study were:

a. To investigate the difference between pediatricians' and general practitioners' advice regarding institutionalization (to institutionalize or not to institutionalize).

b. To investigate the difference between pediatricians' and general practitioners' awareness (aware or not aware) of community services which serve the retarded (Greater Omaha Association for Retarded Children, the Eastern Nebraska Community Office of Retardation, Visiting Nurse Association, Meyer Children's Rehabilitation Institute, Nebraska Psychiatric Institute, Creighton Medical Center, and the University of Nebraska Medical Center).

c. To investigate the difference between pediatricians' and general practitioners' advice (recommend or not recommend) concerning community services (Greater Omaha Association for Retarded Children, the Eastern Nebraska Community Office of Retardation, Visiting Nurse Association, Meyer Children's Rehabilitation Institute, Nebraska Psychiatric Institute, Creighton Medical Center, and the University of Nebraska Medical Center).
d. To investigate parents' opinions concerning advice received from physicians (to institutionalize or to use community services).

e. To investigate parents' opinions regarding the general handling by the physician of their retarded child.

HYPOTHESIS

An investigation of the above problem tested the following hypotheses:

1. There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend institutionalization for all their patients who are profoundly or severely retarded.

2. There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend institutionalization for some of their patients who are profoundly or severely retarded.

3. There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend institutionalization for all their patients who are moderately retarded.

4. There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend institutionalization for some of their patients who are moderately retarded.

5. There is no significant relationship between the number of
pediatricians and the number of general practitioners who are aware of the services of the Greater Omaha Association for Retarded Children.

6. There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Greater Omaha Association for Retarded Children to parents of retarded children.

7. There is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Eastern Nebraska Community Office of Retardation.

8. There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Eastern Nebraska Community Office of Retardation to parents of retarded children.

9. There is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Visiting Nurse Association.

10. There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Visiting Nurse Association to parents of retarded children.

11. There is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Meyer Children's Rehabilitation Institute.

12. There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend
the Meyer Children's Rehabilitation Institute to parents of retarded children.

13. There is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Nebraska Psychiatric Institute.

14. There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Nebraska Psychiatric Institute to parents of retarded children.

15. There is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Creighton Medical Center.

16. There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Creighton Medical Center to parents of retarded children.

17. There is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the University of Nebraska Medical Center.

18. There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the University of Nebraska Medical Center to parents of retarded children.

19. General dissatisfaction with physicians' advice concerning their retarded child is widespread among parents of retarded children from the Omaha area.
SIGNIFICANCE OF THE STUDY

The information gathered and conclusions formed by this study were significant for several reasons. First, a search of various studies has shown that a study of this nature has never been done, and, therefore, new information has been made available to parents and those working the field of mental retardation.

Second, the information has proved useful to the service agencies, and several agencies are already working on plans for implementing better communication channels with Omaha physicians because of the information provided by the study.

Third, the study has made some physicians more aware of the needs of the retarded and services available to them. Several physicians have indicated that they needed more information on local services as a result of the study.

Fourth, the study and publicity about the study has generated interest among both professionals and laymen in improving the present counseling practices of physicians.

PROCEDURES FOR COLLECTION OF DATA

Both physicians and parents were surveyed in this study in order to draw more valid conclusions.

Questionnaires were sent to the thirty-seven general practitioners
and the twenty-three pediatricians in the Omaha area. Only those physicians who are in private practice were surveyed as they represented the type of doctor usually consulted by parents.

Questionnaires were also sent to the one hundred and eighty-nine sets of parents of children who are in the Eastern Nebraska Community Office of Retardation developmental centers. This group was chosen because they were a representative cross-section of the population as their geographical locations were so varied that parents of most of the socio-economic, racial, and ethnic groups were well represented and because the children in the centers were all profoundly, severely, or moderately retarded.

Dr. Frank Menolascino, vice-chairman of the National Association for Retarded Children, agreed to co-sign both cover letters which accompanied the questionnaires. It was felt that this procedure increased the chances of receiving physician and parent cooperation.

PROCEDURES FOR TREATMENT OF DATA

The doctors' questionnaire were sorted into two groups, those answered by pediatricians and those answered by general practitioners. The answers for each question were tabulated and converted into per-

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8 Appendix A

9 Appendix B
Inferential data analysis was then used to test the first eighteen hypotheses. The chi square test was used because more than one set of data was tested for significance. The answers to question 4a on the physicians' questionnaires were used to test the first and second hypotheses. The answers to question 4b were used to test the third and fourth hypotheses. The answers to question 6 were used to test the fifth through eighteenth hypotheses. The null hypotheses was rejected at the .05 level of significance.

The answers to the parents' questionnaire were also tabulated and converted into percentages. Tables showing number surveyed, number responding, and percentages responding to each question were included in the study. This procedure was not used for question 7 as it was open-ended. The answers to this question were categorized and summarized.

The answers to questions 3, 4 and 7 were analyzed to test the nineteen hypothesis. If a majority (more than fifty percent) responded that the physician was unsatisfactory (i.e., answers a or b to question three, c or d to question four, and opinions that revealed dissatisfaction with doctors' attitudes in question 7), then the nineteenth hypothesis was accepted as true.

The answers to some of the questions were not used to test the hypothesis. The data gathered from these questions was of use and interest in drawing conclusions and making recommendations.
ORGANIZATION OF REMAINDER OF THE STUDY

The remainder of the study is divided into four chapters. These are a review of the literature relating to physician counseling of the parents of retarded children, a detailed description of the procedures that were used for the collection and treatment of the data, the results of the study including a detailed analysis of the data, and a final chapter containing a summary, conclusions and recommendations.
Chapter 2

REVIEW OF RELATED LITERATURE

PURPOSE OF CHAPTER 2

The purpose of Chapter Two is to present a summary of previous research and the writings of various experts on the subject of physician counseling of parents of retarded children. A search of the research included an investigation of the following sources: (1) Cumulated Index Medicus, 1963-1971, (2) Education Research Information Center, 1967-1972, (3) Mental Retardation Abstracts, 1964-1972, (4) various bibliographies from articles on related subjects, and (5) books on the subject from libraries at the University of Nebraska at Omaha, Nebraska Psychiatric Institute, and the University of Nebraska Medical Center.

The review of related literature is presented in two parts. The first part contains a review of studies and articles on the subject of physician counseling of parents of retarded children. The second part contains a review of studies and articles on parents' attitudes and opinions of physician counseling.

RELATED LITERATURE

Physician Counseling

- Although many articles have been written concerning the importance
of physician-parent relationships, a literature search reveals very few studies made in the specific area of counseling regarding community services and institutionalization.

Some articles have been written on the subject of the importance of the physician in his role as counselor. According to Solomons and Menolascino

The "primary physician" (defined as the one who makes first contact with the retarded individual and his family) is probably the most important individual the family will meet. He sets the climate for the future, and to a great extent, influences the over-all prognosis of the child. Indeed, a successful initial assessment and intelligent management of family attitudes and problems may avoid institutionalization by default. 10

Many authorities stress the need for the consulting physicians to have a knowledge of community services and facilities. The American Medical Association has published a handbook on mental retardation which stresses the point that doctors should be aware of and use community facilities:

The retarded individual during his lifetime will need services from a wide range of professions and organizations. Research indicated the retarded individuals realize more of their potential when they can benefit from modern community facilities while receiving the stimulus, care, and encouragement of family living . . . . . . The increasing trend toward community based care places greater demands on the physicians' knowledge of local resources and on his skill in cooperation with allied disciplines and services. 11


11 American Medical Association Conference, xvi-xvii.
Other articles suggest the need of doctors to avoid long range prognostications, to tell parents of the retardation as soon as possible, to set realistic goals for the child, to give information relative to mental retardation to the parents, and to help the parents alleviate attitudes of denial and blame.

Several articles suggested ways physicians can keep informed about the facilities in their community. Murray, a parent of a retarded child, suggested more communication with local Associations for Retarded Children. The American Medical Association has proposed that physicians should take courses on mental retardation in medical school.

Most of the articles on physician counseling in mental retardation

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were not experimental studies. There are over one hundred and fifty publications dealing with this subject, yet very few experimental studies of any type have been conducted. Most of them just deal generally with the subject of the management of the family of the mentally retarded.

Several studies have been done, however, that have included direct questioning of physicians. The first of these studies was done in Cambridge, Massachusetts, under the direction of Olshansky, director of the Cambridge Service for Retarded Children. Olshansky and his associates actually did two studies, one of general practitioners and one of pediatricians. The primary purpose of the studies was to determine the attitudes of the two type of doctors toward mentally retarded children with special emphasis on their attitudes towards the early institutionalization of children. A secondary purpose was to determine the physicians' acquaintance with the local service for retarded children. Two major questions were asked: (1) "Would you comment on the view that retarded children, especially under 5-6, should be kept at home?" and (2) "Would you comment on the view that it is best for the mother to be immediately separated from the retarded child at time of delivery?"

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19 Solomons and Menolascino, p. 13.


Fifty-seven of the sixty-four general practitioners in the Cambridge area were interviewed. In response to the first question whether children should be kept at home until they are five or six years old, three-fourths of the doctors expressed some degree of approval while ten percent expressed some degree of disapproval to the idea.

In response to the second question on removing of the retarded baby from the mother immediately at birth, three-fifths of the general practitioners expressed some degree of disapproval while two-fifths favored immediate separation. Almost half of the doctors favored immediate separation of a Down's Syndrome baby from his mother.

When asked if they had heard of the Cambridge Service for Retarded Children, thirty of the fifty-seven general practitioners responded positively. Only eight doctors, however, could identify the location, sponsorship, or services of the agency.

The same study was done using a non-random sample of thirty pediatricians in the Cambridge area. Twenty-eight of the thirty responded with varying degrees of approval to the question on children remaining at home until the age of five or six. Twenty-seven expressed varying degrees of opposition to the question regarding the separation of a retarded child from his mother at his birth. Six felt that Down's Syndrome children should automatically be institutionalized. Only five of the thirty pediatricians felt that the decision to institutionalize belonged to the parents, and only four pediatricians noted that, regarding institutionalization,
each case should be considered on an individual basis.\textsuperscript{22} Data was not
given on the pediatricians' knowledge of local services for the retarded,
nor was any statistical study done.

The main conclusions of both studies were that many have not
accepted the "new views" that the retarded child is usually given a
better chance for growth and development in the home, that immediate
separation of the retarded baby from his mother at birth is usually un­
wise, and that institutionalization should be judged on an individual basis
and is the ultimate decision of the parent.

A similar and more recent study was done in 1968 in Michigan.\textsuperscript{23}
The purpose of the study was to identify the doctors in the state who had
an interest in and a need for information about the care of retarded child­
ren. A questionnaire, administered by interviewers, was given to a
random sample of general practitioners, doctors of osteopathy, and
general practitioners. The doctors' attitude towards early institution­
alization was analyzed by asking them the question, "What advice would
you give parents with a newborn Mongoloid baby about caring for the
child at home or putting him in an institution or foster home?" About
fifty percent of the general practitioners, forty-six percent of the doctors
of osteopathy, and twenty-four percent of the pediatricians favored early

\textsuperscript{22} Olshansky, "Attitudes of Some Pediatricians," 71.

\textsuperscript{23} Siegfried A. Centerwall, M. D., "The Mentally Retarded and
institutionalization of Down's Syndrome children.

Other results showed that seventeen percent of the pediatricians were concerned with trying to suit the solution to the particular family situation in contrast to only five percent of the doctors of osteopathy, eleven percent of general practitioners practicing in northern Michigan, and one of the general practitioners practicing in southern Michigan.

In response to the question asking if any of the doctors desired information about the care of retarded children, the various groups ranged from thirty-nine to forty-eight percent in responding that they did not want any information.

Only one to two percent of the general practitioners and twelve percent of the pediatricians expressed a special interest in mental retardation. 24

In contrast to the Olshansky study, no conclusions were made in the Michigan study except to recommend that continuing education be directed mainly to the needs of the pediatrician. Both studies indicated that a number of doctors (twenty-four to fifty percent) approve of early institutionalization, and that many doctors need information about community facilities for retarded children.

Parental Attitudes and Opinions of Physician Counseling

Experimental studies have also been done in the area regarding

24 Centerwall, 600-602.
parents's attitudes towards and opinions of the physician who treated their retarded child. Most of these studies were conducted ten years ago or more.

One of the earliest studies was done by Zwerling, who conducted a study of eighty-five parents from twenty-three states and Canada to determine the circumstances of their first learning of the retardation of their child and their feelings on how the situation had been handled. Zwerling was attempting to show that the initial counseling of the parent is of critical importance in reducing parent anxiety and promoting the acceptance and understanding of the child. The study did not investigate a representative group of parents as he studied only middle-class families, nor did he do a statistical analysis of the results as he was interested only in finding common concerns of parents in regard to physicians. The study revealed the following:

1. Parents were very concerned with physician attitudes.
2. Parents desired additional information from the physician which he was unable or unwilling to provide.
3. Thirty-two of the eighty-five parents had been advised to institutionalize their child, but these parents had already made an adequate home adjustment.
4. All but one parent felt physicians should inform them immediately about retardation diagnosis.

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A similar study was done by the Maryland Society for Retarded Children in 1959. Fifty randomly selected parents from the middle-socio-economic class were sent questionnaires. Forty of these parents were also interviewed. Again, statistical methods were not used to analyze the data.

As in the study done by Zwerling, a large number (twenty-one of the forty parents interviewed) had been told to institutionalize their child, but in only one situation was the advice followed. They felt, as the parents in the previous study had, that professionals evaded the issue of retardation at first. Other findings of the study were that parents felt a need for frank diagnoses given with compassion and respect. Most of the parents felt that they had not received help from their physicians, so they searched elsewhere for advice and help.

A study conducted two years later came up with similar conclusions. This study, done by Bryant and Hurschberg, also concluded that parents are dissatisfied with the help that they had received from physicians because the physician had often given little advice nor had he made referrals to agencies or facilities which could benefit the retarded child or his family. The study also concluded that parents desire a physician who will not conceal his findings and one who would have a sympathetic and

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understanding attitude when explaining his findings. Again, no statistical data was presented.

A more extensive study that came to the same conclusion as the above studies, i.e., that parents feel a need for better professional service, was conducted in England.\(^2\)\(^8\) A lengthy study was done of 218 months in 1960. Again, the study found that a majority of the parents (89%) wanted the physician to inform them of their children's retardation, but only forty-two percent of the parents had actually been informed immediately when retardation was suspected by the physician. Other results of the study indicated that fifty-five percent of the parents felt that the diagnosis given to the parents had been poorly or unsatisfactorily handled by the physician. Forty-four percent of the parents felt that the medical advice and treatment given by the physician had some or many unsatisfactory features. The overall conclusion of the study was that many parents felt a need for better professional service from their physicians regarding their retarded child.\(^2\)\(^9\)

Another study was done in the United States in 1959 when one hundred and five families were surveyed in California.\(^3\)\(^0\) Fifty-three


\(^{29}\) Tizard, p. 148.

\(^{30}\) Koch and others, "Evaluation of Parental Dissatisfaction with the Medical Care of the Retarded Child, Pediatrics, XXIII (1959), 582-584,
percent of the parents whose child was cared for by a pediatrician were dissatisfied with the doctor's care of their child, while forty-five percent of the parents whose retarded child was under a general practitioner's care were similarly dissatisfied. Fifty percent of the general practitioners and pediatricians and sixty-four percent of the obstetricians had recommended immediate institutionalization. The authors concluded that the failure of the doctors may be due to a lack of adequate training in the field of mental retardation. 31

All of these studies indicate that many parents are dissatisfied with the counseling and care that they or their retarded child have received from their physicians.

Parents and professionals have also written numerous articles voicing the same dissatisfaction. Murray, a parent, wrote that the greatest problem most parents have to cope with is with "inept, inaccurate and ill-timed advice." 32

Patterson, another parent and one of the organizers of the National Association for Retarded Children, in an article, originally published seventeen years ago in Children, lists the following advice for professionals which she has gathered from professional workers and parents:

31 Koch, 583.

1. Tell the nature of the problem as soon as possible.

2. Always see both parents.

3. Use language parents can understand, but language that is not derogatory such as "vegetable."

4. Do not recommend institutionalization, but make parents aware that the child's welfare is their problem and such decisions must be made by them.

5. Help parents understand the problem by answering questions and recommending literature, agencies, and local associations.

6. Know local resources and services.

7. Remember that parents are normal people with a problem.

8. Do not let professional jealousies and feuds interfere with professional judgements.

9. A professional should show feelings of understanding and compassion.  

Professionals generally concur with Murray's views. Giannini, a physician, points out that the physician needs to "assist the parents in planning more meaningfully for the child's present and future care."  

Professionals have also written of the need of physicians to know the

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34 Margaret M. Giannini, "The Role of the Physician in Mental Retardation," Journal of the American Medical Women's Association, XXIV, 6 (1969), 491.
services available in the community for the retarded. Pearson is one of many professionals in the field who have stressed that it is the parent's decision to institutionalize, not the physician's. He said, "The physician's role must be that of counselor and guide. He cannot 'lift the burden of their guilt' by making the decision for them." Many other professionals have also written about the management of the family of the mentally retarded.

As stated earlier, the literature on the specific area of counseling on institutionalization or community services is quite scarce. None of the studies have yet investigated parental attitudes and physicians' attitudes within the same area. This study did so and used a statistical analysis approach in reporting the data. As a result, it adds new knowledge that is now not present in the literature.

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Chapter 3

PROCEDURES FOR COLLECTION AND TREATMENT OF THE DATA

PURPOSE OF CHAPTER 3

The purpose of Chapter Three is to present the procedures that was used to collect the data needed to investigate the advice given by physicians to parents of retarded children and the procedures that were used to analyze the data.

PROCEDURES FOR COLLECTION OF THE DATA

Although previous studies have surveyed either physicians or parents concerning the advice given to parents by physicians, this study surveyed both physicians and parents in the Omaha area.

Questionnaires were sent to the thirty-seven general practitioners and the twenty-three pediatricians in the Omaha area. Only those physicians who are in private practice were surveyed as they represent the type of doctor usually consulted initially by parents of retarded children. A minimum response of sixty percent was requested by the thesis committee before the data could be analyzed with validity. Since less than a sixty percent response was received, a second letter and question-

38 Appendix A.
naire was sent.

The questionnaire used was of the restricted or closed-form type. This type was primarily chosen because physicians are busy and would be more likely, therefore, to answer this type of questionnaire. It is also relatively objective and is fairly easy to tabulate and analyze. 39

Dr. Frank Menolascino, vice-chairman of the National Association for Retarded Children and a well known and respected leader in the field of retardation, agreed to co-sign the cover letter which accompanied the questionnaires. The letters were typed on National Association for Retarded Children stationery. Each letter had a personal inside address and salutation which gave a more personal touch to the letters. The survey was sponsored by the Greater Omaha Association for Retarded Children. The second signer of the cover letter was Karen Kelly, coordinator of parent-action committees for the Greater Omaha Association for Retarded Children. Doctors were not asked to identify themselves. All of these procedures probably produced a greater response than if the study had been conducted by an individual. 40

Questionnaires were also sent to the parents whose retarded children attend developmental centers of the Eastern Nebraska Community Office of Retardation (ENCOR). 41 ENCOR has eight centers in the Omaha


40 Best, p. 172.

41 Appendix B.
area. Six of these centers provide developmental and educational services five days a week for mentally retarded children under sixteen years of age who are not eligible for public school admission either because of their age or because of the extent of their handicap. Two of the centers are residential-educational units, the Behavior Shaping Unit, designed to serve a group of eight retarded children who possess extremely maladaptive behaviors, and the Developmental Maximation Unit, serving multiply handicapped, medically involved retarded children. From these centers, a total of one hundred and eighty-nine parents were surveyed. Random selection was not used as all parents who have children in the eight centers were sent questionnaires.

The above parent group was selected for several reasons. First, because the centers are geographically located throughout the city, and the children usually attend the center closest to their home, parents from most of the socio-economic, racial, and ethnic groups were well represented. Secondly, the children in the centers are profoundly, severely, or moderately retarded. The advice concerning such children was the subject of this study. Thirdly, the names and addresses of the parents of the children in the centers were available to the researcher through the ENCOR office.

Parents from the following centers were surveyed:

---

<table>
<thead>
<tr>
<th>Center</th>
<th>Location</th>
<th>Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Benson Developmental</td>
<td>6319 Maple Omaha, Nebraska</td>
<td>27</td>
</tr>
<tr>
<td>Center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Chance Developmental</td>
<td>1702 Grace Omaha, Nebraska</td>
<td>68</td>
</tr>
<tr>
<td>Center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Fremont Developmental</td>
<td>1515 N. Broad Street Fremont, Nebraska</td>
<td>15</td>
</tr>
<tr>
<td>Center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Sarpy Developmental</td>
<td>1910 Franklin Bellevue, Nebraska</td>
<td>21</td>
</tr>
<tr>
<td>Center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. South Omaha Developmental</td>
<td>4622 Monroe Omaha, Nebraska</td>
<td>21</td>
</tr>
<tr>
<td>Center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. West Developmental</td>
<td>9416 Pacific Omaha, Nebraska</td>
<td>25</td>
</tr>
<tr>
<td>Center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Behavior Shaping Unit</td>
<td>5016 California Omaha, Nebraska</td>
<td>4</td>
</tr>
<tr>
<td>8. Developmental Maximation Unit</td>
<td>Douglas County Hospital Omaha, Nebraska</td>
<td>8</td>
</tr>
</tbody>
</table>

Total ........................................ 189

The National Association for Retarded Children and the Greater Omaha Association for Retarded Children also sponsored the parent survey. Dr. Menolascino and Karen Kelly also co-signed this cover letter.

The questionnaire used was of the restricted or closed-form type except for one open-ended question. This type was chosen because it is easy to answer, fairly objective, and relatively easy to tabulate and analyze. It was further appropriate as it provided the necessary information needed for the study. The thesis committee requested a minimum
response of sixty percent before the data could be analyzed with validity. Since less than sixty percent was received, telephone interviews were conducted. The same questions that were on the questionnaire were asked.

The above procedures supplied the necessary data needed for the acceptance or rejection of the hypotheses of the study.

**PROCEDURES FOR TREATMENT OF THE DATA**

**Physicians' Questionnaire Data**

The first step in analyzing the data on the physician's questionnaires was to convert the answers into percentages. The questionnaires were sorted into two groups, those answered by pediatricians and those answered by general practitioners. By groups, tables showing the number surveyed, the number responding, and the percentages responding to each question were made to present data. In addition, the combined answers given by the two types of doctors were tabulated and converted into percentages. Tables were used to show these results.

Inferential data analysis was then used to test the first eighteen hypotheses. The chi square test was used because more than one set of data was tested for significance in accepting or rejecting these hypotheses. The answers to question 4a were used to test the first hypothesis. For example, the first hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who recommend institutionalization for all of their patients
who are profoundly or severely retarded children. This hypothesis was tested by using the answers to question number 4a. The question is as follows:

4. a. If a child is severely or profoundly retarded, do you recommend institutionalization?

_______ a. In all cases
_______ b. In some cases (approximate percentage ____?)
_______ c. In no cases

For the first hypothesis, the chi square test was used to discover if there was a significant difference between the answers given by pediatricians and the answers given by general practitioners to the above question. The chi square test was used because more than one set of data was tested for significance. This test provided a method for testing the difference between actual preferences and choices based upon a probability assumption. First, the theoretical or expected frequencies were computed from the distribution. The expected frequency was computed for each cell by the formula:

\[ f_e = \frac{(\Sigma f_{\text{columns}})(\Sigma f_{\text{rows}})}{\text{grand total}} \]

The chi square values for each cell was computed by the formula:

\[ X^2 = \sum \left[ \frac{(f_o - f_e)^2}{f_e} \right] \]

The null hypotheses was rejected at the . 05 level of significance.

The second hypothesis was tested in the same manner as it was identical to the first except it referred to recommendations for institution-
alization of only some severely or profoundly retarded children rather than all.

The pediatricians' and general practitioners' answers to question 4a supplied the necessary data for a chi square test. Hypotheses three and four were analyzed in the same manner except that answers to question 4b supplied the data for the chi square test.

The answers to question 6 were used to provide the data needed for the testing of the next fourteen hypotheses (hypotheses five through eighteen). In question 6, the physicians responded whether or not they were aware of local agencies which provide services to the retarded and their families and whether or not they recommended such services to parents. Each of the fourteen hypotheses were tested through the use of the chi square test using the pediatricians' and general practitioners' answers as the data. For example, the fifth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the Greater Omaha Association for Retarded Children. The pediatricians' and general practitioners' answers to question 6a provided the necessary data to do the chi square test for hypothesis five. Hypotheses six through eighteen were tested in the same manner. In this way, it was shown whether there was a significant relationship between the number of pediatricians who are aware of or who recommend each agency and the number of general practitioners who are aware of or who recommend each agency. The null hypotheses was rejected at the .05 level of significance.
A great deal of the data collected was not used to test the hypotheses but was part of the overall study. This data was analyzed to provide additional information which was relevant to the subject.

The data showed the percentages of pediatricians and general practitioners who gave printed material on the subject of retardation. Answers to question 2 showed when the physicians inform parents of their child's retardation. Information gathered from question 5 revealed under what circumstances physicians recommended institutionalization. All of this information was presented through tables, which showed the number surveyed, the number responding, and the percentage responding to the various questions.

Parents' Questionnaire Data

The first step in analyzing the data on the parents' questionnaires was to convert the answers into percentages. Tables, showing the number surveyed, the number responding, and the percentages responding to each question, were used to present this data. This procedure was not used for question 7 as it was open-ended. The answers to this question were categorized into three groups - those who seemed quite satisfied with their doctors, those who were fairly satisfied, but with reservations, and those who seemed unsatisfied. These three types of answers were also converted into percentages and presented in tabular form.

The answers to questions 3, 4 and 7 were analyzed to test the nineteenth hypothesis. If a majority (fifty-one percent or more) responded
that the physician was unsatisfactory (i.e., answers a or b to question 3, answers c or d to question 4, and opinions that revealed dissatisfaction with their doctor's attitude in response to question 7), then the nineteenth hypothesis was accepted as true. If the same majority of the parents' answers to any of the three questions showed satisfaction with their physician, then the hypotheses was not accepted as true.

As was true with the physicians' questionnaire, much of the data collected through the parent survey was not used to test a hypothesis. However, this data was also analyzed to provide additional information which was relevant to the subject of physician counseling of parents of retarded children. Question 1 provided information on how parents discovered their child was retarded. This information was presented by a table which showed the number and percentage of parents who were told of their child's retardation by a doctor or who learned of the condition through some other source.

The data from question 2 revealed the number and percentages of parents who were told to institutionalize their child. These percentages were compared through use of tables to the percentages of pediatricians and general practitioners who responded that they recommended or did not recommend institutionalization.

The data from question 5 showed the percentage of parents who did or did not receive material on retardation from their child's physician. Again, these percentages were compared with the percentages of physicians who responded that they did or did not give printed matter on
retardation to parents.

The data from question 6 showed the percentage of parents who were referred by their doctors to various social agencies, which serve the retarded. These percentages were compared to the percentages of doctors who said they referred parents to each agency. A table was used to show the above information for each agency.

The above procedures not only tested the nineteenth hypothesis but also provided additional information upon which conclusions and recommendations were made.
Chapter 4

RESULTS OF THE STUDY

PURPOSE OF CHAPTER 4

The results of this study are presented in four parts: (1) the results of the questionnaires sent to Omaha pediatricians and general practitioners, (2) the results of the questionnaires sent to the parents of retarded children who are in the Eastern Nebraska Community Office of Retardation educational centers, (3) the results of the testing of the nineteen hypotheses by means of inferential data analysis, and (4) the other results relevant to the study of physician counseling of parents of retarded children that are revealed by analysis of the data. Chapter Five presents conclusions and recommendations based on these results.

PHYSICIAN QUESTIONNAIRE DATA

Questionnaires were sent to all of the twenty-three pediatricians and the thirty-seven general practitioners in private practice in the Omaha area (Appendix A). Because only sixty-one percent of the pediatricians and fifty-one percent of the general practitioners responded to the first questionnaire, a second questionnaire was sent. Telephone calls were also made to each physician's office reminding him of the importance of the questionnaire and asking for his cooperation. These
procedures resulted in additional responses so that the end result was that seventeen pediatricians or seventy-four percent of the twenty-three surveyed and twenty-four general practitioners or sixty-five percent of the thirty-seven surveyed responded to the questionnaires.

Pediatrician Data

The first procedure was to tabulate the responses of the seventeen questionnaires sent by the pediatricians and to convert these numbers into percentages. The results were as follows:

**Question 2**

2. When you suspect a child is retarded, do you inform the parents:

   _____ a. Immediately
   _____ b. Wait for further developments
   _____ c. Wait for parents to discover it on their own
   _____ d. Other. Please specify.

Of the seventeen pediatricians who responded, fifty-three percent (9) informed parents immediately of the suspected retardation. Twenty-nine percent (5) responded that they waited for further developments, but none of the doctors indicated that they waited for parents to discover it on their own. Eighteen percent (3) gave other answers (i.e., (1) "Warn about possibility, diagnose when clear," (2) "depends on what the problem is -- may suggest possibility but do not inform until certain," and (3) "sometimes wait until next visit to verify.").
Table 1

Pediatricians' Responses to Question 2

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Immediately</td>
<td>9</td>
<td>52.9</td>
</tr>
<tr>
<td>b. Wait for further developments</td>
<td>5</td>
<td>29.4</td>
</tr>
<tr>
<td>c. Wait for parents to discover it on own</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>d. Other</td>
<td>3</td>
<td>17.7</td>
</tr>
<tr>
<td>Total</td>
<td>17</td>
<td>100</td>
</tr>
</tbody>
</table>

Total number surveyed . . . 23

Question 3

3. After diagnosing a child as retarded, do you give parents printed material on the subject of retardation?

_______ a. Never
_______ b. Seldom (1-25%)
_______ c. Sometimes (25-50%)
_______ d. Often (50-99%)
_______ e. Always
Of the sixteen pediatricians who responded to question three, nineteen percent (3) indicated that they never gave parents printed material on the subject of retardation, twenty-five percent (4) seldom did, nineteen percent (3) sometimes gave material, thirty-one percent (5) often did, and only six percent (1) of the pediatricians always gave such material to parents.

Table 2

Pediatricians' Responses to Question 3

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Never</td>
<td>3</td>
<td>18.8</td>
</tr>
<tr>
<td>b. Seldom (1-25%)</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td>c. Sometimes (25-50%)</td>
<td>3</td>
<td>18.8</td>
</tr>
<tr>
<td>d. Often (50-99%)</td>
<td>5</td>
<td>31.2</td>
</tr>
<tr>
<td>e. Always</td>
<td>1</td>
<td>6.2</td>
</tr>
<tr>
<td>Total . . . . . .</td>
<td>16</td>
<td>100</td>
</tr>
</tbody>
</table>

Total number surveyed . . . 23

Question 4a

4. a. If a child is severely or profoundly retarded, do you recommend institutionalization?
a. In all cases
b. In some cases (approximate percentage ___%)
c. In no cases

To the above question, of the sixteen pediatricians who responded, six percent (1) responded that they recommended institutionalization in all cases, eighty-one percent (13) recommended institutionalization in some cases, six percent (1) never recommended institutionalization, and six percent (1) stated that the decision was made by joint discussion with the parents. Of the thirteen pediatricians who responded that they recommended institutionalization some of the time, four did so twenty percent of the time or less, five did so fifty percent of the time or more, and four did not give percentages.

Table 3

Pediatricians' Responses to Question 4a

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. In all cases</td>
<td>1</td>
<td>6.25</td>
</tr>
<tr>
<td>b. In some cases</td>
<td>13</td>
<td>81.25</td>
</tr>
<tr>
<td>c. In no cases</td>
<td>1</td>
<td>6.25</td>
</tr>
<tr>
<td>d. Other</td>
<td>1</td>
<td>6.25</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>100</td>
</tr>
</tbody>
</table>
Total number surveyed . . . 23

**Question 4b**

4. b. If a child is moderately retarded, do you recommend institutionalization?

_____ a. In all cases

_____ b. In some cases (approximate percentage _____%)

_____ c. In no cases

To the above question, of the sixteen pediatricians who responded, none recommended institutionalization in all cases, forty-four percent (7) recommended institutionalization in some cases, fifty percent (8) never recommended institutionalization, and one pediatrician based his recommendation on a joint discussion with the parents. Of the seven pediatricians who responded that they recommended institutionalization some of the time, one did so fifty percent of the time, two did so ten percent of the time, and four did not give percentages.

**Table 4**

Pediatricians' Responses to Question 4b

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. In all cases</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
b. In some cases  
   | 7 | 44

c. In no cases  
   | 8 | 50

d. Other  
   | 1 |  6

Total . . . .  
   | 16| 100

Total number surveyed . . . 23

Question 5

5. If you ever recommend institutionalization, under what circumstances do you recommend it?

   ______ a. If the child is profoundly or severely retarded
   ______ b. If the family is unable to cope with child at home
   ______ c. If the child is multiply handicapped
   ______ d. If a parent will not accept the child as a member of the family
   ______ e. Other. Please specify.

Many of the pediatricians checked more than one answer. Of the fifteen who responded, sixty percent (9) recommended institutionalization if the child was profoundly or severely retarded, ninety-three percent (14) did so if the family was unable to cope with the child, twenty percent (3) made such a recommendation if the child was multiply handicapped, sixty percent (9) did so if the parent would not accept the child as a member of the family, and twenty percent (4) gave the following reasons for recommending institutionalization:

1. "Likely Hood (sic) of death in near future. Medical condition
unable to be managed by parents and O.P. care."

2. "Child is neglected."

3. "If caring for the handicapped child takes all time from other (usually younger) children, who also need attention."

4. "When long term care is needed." and/or "depending on associated anomalies."

In addition, the following comments were made by three other pediatricians:

1. "Total effect on family as a whole."

2. "Problems are complex and involve the whole family. I prefer direct counseling to printed material and urge joining groups where problems may be shared. I do not believe a whole family should be sacrificed in hopeless situations but try to gauge how they will stand the stress before recommending institutionalization."

3. "After joint discussion."

Table 5

Pediatricians' Responses to Question 5

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. If the child is profoundly or severely retarded</td>
<td>9</td>
<td>60</td>
</tr>
<tr>
<td>b. If the family is unable to cope with child at home</td>
<td>14</td>
<td>93</td>
</tr>
<tr>
<td>c. If the child is multiply handicapped</td>
<td>3</td>
<td>20</td>
</tr>
</tbody>
</table>
If a parent will not accept the child as a member of family

Other

Total number surveyed . . . 23
Total number responded . . . 15

Question 6

Of the fourteen pediatricians who responded to the question (page 45), fifty percent (7) were unfamiliar with the services of the Greater Omaha Association for Retarded Children (GOARC), twenty-one percent (3) were familiar with the agency but never recommended it, none of the pediatricians seldom recommended GOARC, fourteen percent (2) sometimes recommended the service, seven percent (1) often recommended it, and seven percent (1) always recommended GOARC to parents of retarded children.

In contrast, fourteen percent (2) were unfamiliar with the services of the Eastern Nebraska Community Office of Retardation (ENCOR), twenty-nine percent (4) were familiar with the agency but never recommended it, seven percent (1) seldom recommended ENCOR, twenty percent (4) sometimes recommended it, while fourteen percent (2) often recommended the agency, and seven percent (1) always recommended ENCOR.

A much greater percentage of pediatricians were familiar with and recommended the services of the Visiting Nurse Association (VNA) in
comparison with the two above agencies which serve the retarded. All pediatricians were familiar with the services of the VNA, and only fourteen percent (2) never recommended its services to parents of retarded children. Fourteen percent (2) seldom recommended the agency and twenty-one percent (3) sometimes recommended it.
6. Listed below are agencies which provide service to the retarded and their families. Check the appropriate space.

<table>
<thead>
<tr>
<th>Service Agency</th>
<th>Am unfamiliar with its services</th>
<th>Am familiar with but never recommend</th>
<th>Seldom Recommend (1-25%)</th>
<th>Sometimes Recommend (26-50%)</th>
<th>Often Recommend (50-99%)</th>
<th>Always Recommend</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Greater Omaha Association for Retarded Children(GOARC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Eastern Nebraska Community Office of Mental Retardation (ENCOR)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>c. Visiting Nurse Association</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Meyer Children's Rehabilitation Institute</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Nebraska Psychiatric Institute</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. Creighton Medical Center</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. University of Nebraska Medical Center</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. Family and Child Services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Jewish Federation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>j. United Catholic Social Services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>k. Lutheran Family and Social Services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Thirty-six percent (5) often recommended VNA, and fourteen percent (2) always recommended the agency.

Meyer Children's Rehabilitation Institute (MCRI) was recommended to parents by more pediatricians than any other agency. Only seven percent (1) were unfamiliar with its services and the same percentage was familiar with MCRI but never recommended it. Twenty-nine percent (4) seldom recommended the agency while none of the pediatricians responded that they sometimes recommended it. Forty-three percent (6) often recommend MCRI, and fourteen percent (2) always recommended the agency to parents.

Over seventy percent of the pediatricians seldom or never recommended the Nebraska Psychiatric Institute (NPI). Fourteen percent (2) were not familiar with NPI's services and twenty-one percent (3) were familiar with the services but never recommended it. The greatest number, thirty-six percent (5) of the pediatricians, seldom recommended the agency, while fourteen percent (2) sometimes recommended it. Only one doctor responded that he often recommended NPI and only seven percent (1) of the pediatricians always recommended the agency.

Although all of the pediatricians were familiar with the services of the Creighton Medical Center, thirty-eight percent (5) of them never recommended it to parents of retarded children, and thirty-one percent (4) seldom recommended its services. Only fifteen percent (2) of the pediatricians recommended the agency sometimes, while only seven percent (1) either often or always recommended Creighton Medical Center
to parents of retarded children.

The results for the University of Nebraska Medical Center were similar to those for Creighton's Center. Again, although all of the pediatricians were familiar with its services, forty-three percent (6) never recommended it. Twenty-one percent (3) seldom recommended the services of the medical center, and only fourteen percent (2) either sometimes recommended the facilities or often recommended them, while only seven percent (1) of the pediatricians always recommended the University of Nebraska Medical Center to parents of retarded children.

Of the social service agencies, of the fourteen pediatricians who responded, more recommended Family & Child Services than the other three agencies. Although fourteen percent (2) were not familiar with this agency and seven percent (1) never referred parents to it, thirty-six percent (5) of the doctors responded that they seldom recommended it, and twenty-nine percent (4) sometimes recommended the agency. Only fourteen percent (2) often recommended Family & Child Services, and no pediatrician always recommended it.

The responses to the questions referring to the Jewish Federation and Lutheran Family & Social Services were the same percentages. Of the fourteen pediatricians who responded, fifty percent (7) were unfamiliar with the services of the two agencies, while none who were familiar with the agencies never referred parents to them. Twenty-nine percent (4) seldom recommended the agencies, and twenty-one percent (3) of the
doctors sometimes recommended them. None of the pediatricians either often recommended or always recommended the Jewish or the Lutheran services.

The responses were also similar regarding the United Catholic Social Services. Thirty-six percent (5) of the pediatricians were unfamiliar with its services, and seven percent (1) of the doctors did not refer parents to the service though he was familiar with it. Thirty-six percent seldom recommended the agency, and twenty-one percent (3) sometimes recommended it. None of the pediatricians either often referred or always referred parents to the United Catholic Social Services.
Table 6

Pediatricians' Responses to Question 6

<table>
<thead>
<tr>
<th>Service Agency</th>
<th>Am unfamiliar with its services</th>
<th>Am familiar with but never recommend</th>
<th>Seldom Recommend (1-25%)</th>
<th>Sometimes Recommend (26-50%)</th>
<th>Often Recommend (50-99%)</th>
<th>Always Recommend</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>a. GOARC</td>
<td>7</td>
<td>50</td>
<td>3</td>
<td>21</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>b. ENCOR</td>
<td>2</td>
<td>14</td>
<td>4</td>
<td>29</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>c. VNA</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>14</td>
<td>2</td>
<td>14</td>
</tr>
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<td>d. MCRI</td>
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<td>7</td>
<td>4</td>
<td>29</td>
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<td>0</td>
</tr>
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<td>e. NPI</td>
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<td>21</td>
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<td>36</td>
</tr>
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<td>f. Creighton Medical Center</td>
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<td>0</td>
<td>5</td>
<td>38</td>
<td>4</td>
<td>31</td>
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<td>g. University of Nebraska Medical Center</td>
<td>6</td>
<td>43</td>
<td>3</td>
<td>21</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>h. Family &amp; Child Service</td>
<td>2</td>
<td>14</td>
<td>1</td>
<td>7</td>
<td>5</td>
<td>36</td>
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<td>i. Jewish Federation</td>
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<td>50</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>29</td>
</tr>
<tr>
<td>j. United Catholic Social Services</td>
<td>5</td>
<td>36</td>
<td>1</td>
<td>7</td>
<td>5</td>
<td>36</td>
</tr>
<tr>
<td>k. Lutheran Family &amp; Social Services</td>
<td>7</td>
<td>50</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>29</td>
</tr>
</tbody>
</table>

Total number surveyed . . . 24
Total number of pediatricians who responded . . . 14
Meyer Children's Rehabilitation Institute and Visiting Nurse Association were recommended by pediatricians to parents of retarded children more often than the other nine agencies. The Greater Omaha Association for Retarded Children and the social service agencies were recommended the least.

**General Practitioner Data**

Sixty-one percent (24) of the general practitioners responded to the questionnaire. Three did not answer the question as one said it did not apply. The first procedure was to tabulate the responses and convert these numbers into percentages. The results were as follows:

**Question 2**

2. When you suspect a child is retarded, do you inform the parents:

   ______ a. Immediately

   ______ b. Wait for further developments

   ______ c. Wait for parents to discover it on their own

   ______ d. Other. Please specify.

Of the twenty-four general practitioners who responded to question two, the majority, fifty-four percent (14), responded that they informed the parents immediately of the child's suspected retardation, most of the rest, forty-two percent (11), waited until further developments, none waited for parents to discover it on their own, and only one general practitioner specified that he waited until further evaluation was made before informing parents of suspected retardation.
Table 7

General Practitioners' Responses to Question 2

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Invid. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Immediately</td>
<td>14</td>
<td>54</td>
</tr>
<tr>
<td>b. Wait until further developments</td>
<td>11</td>
<td>42</td>
</tr>
<tr>
<td>c. Wait for parents to discover on own</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>d. Other</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>26</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Total number surveyed . . 37

**Question 3**

3. After diagnosing a child as retarded, do you give parents printed material on the subject of retardation?

   ______ a. Never
   ______ b. Seldom (1-25%)
   ______ c. Sometimes (25-50%)
   ______ d. Often (50-99%)
   ______ e. Always
Of the twenty-two general practitioners who responded, thirty-six percent (8) responded that they never gave parents material on retardation, while fourteen percent (3) said that they seldom did. Thirty-two percent (7) sometimes gave material, fourteen percent (3) often did, and one general practitioner always gave such material.

Table 8

General Practitioners' Responses to Question 3

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Never</td>
<td>8</td>
<td>36.4</td>
</tr>
<tr>
<td>b. Seldom (1-25%)</td>
<td>3</td>
<td>13.6</td>
</tr>
<tr>
<td>c. Sometimes (25-50%)</td>
<td>7</td>
<td>31.8</td>
</tr>
<tr>
<td>d. Often (50-99%)</td>
<td>3</td>
<td>13.6</td>
</tr>
<tr>
<td>e. Always</td>
<td>1</td>
<td>4.6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>22</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Total number surveyed . . . 37

**Question 4a**

4. a. If a child is severely or profoundly retarded, do you recommend institutionalization?

   a. In all cases
b. In some cases (approximate percentage ____%)

c. In no cases

A large number, fifteen or seventy-nine percent of the nineteen, general practitioners who responded, said that they recommended institutionalization for some severely or profoundly retarded children. Six indicated that they did so fifty to ninety percent of the time, two did so forty percent of the time or less, and seven gave no percentages. Eleven percent (2) indicated that they always recommended institutionalization for such children, and the same number indicated that they never made such recommendations.

Table 9

General Practitioners' Responses to Question 4a

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. In all cases</td>
<td>2</td>
<td>10.5</td>
</tr>
<tr>
<td>b. In some cases</td>
<td>15</td>
<td>79</td>
</tr>
<tr>
<td>c. In no cases</td>
<td>2</td>
<td>10.5</td>
</tr>
<tr>
<td>d. Other</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Total ........ 19 100

Total number surveyed . . . 37
Question 4b

4. b. If a child is moderately retarded, do you recommend institutionalization?

_______a. In all cases

_______b. In some cases (approximate percentage ___%)

_______c. In no cases

Again, a large number of the nineteen general practitioners who responded sixty-three percent (12), recommended institutionalization for some children. In contrast with the responses for severely or profoundly retarded children, none of the doctors recommended institutionalization in all cases for the moderately retarded, and thirty-seven percent (7) never recommended institutionalization for them.

Table 10

General Practitioners' Responses to Question 4b

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. In all cases</td>
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<td>0</td>
</tr>
<tr>
<td>b. In some cases</td>
<td>12</td>
<td>63</td>
</tr>
<tr>
<td>c. In no cases</td>
<td>7</td>
<td>37</td>
</tr>
<tr>
<td>d. Other</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Question 5

5. If you ever recommend institutionalization, under what circumstances do you recommend it?

_____ a. If the child is profoundly or severely retarded

_____ b. If the family is unable to cope with child at home

_____ c. If the child is multiply handicapped

_____ d. If a parent will not accept the child as a member of the family

_____ e. Other. Please specify.

Of the twenty general practitioners who responded, many checked more than one answer. Over half of them, fifty-five percent (11), responded that they recommended institutionalization if the child was profoundly or severely retarded, and almost all the doctors, ninety percent (18), did so if the family seemed unable to cope with the child. A few, fifteen percent (3), recommended institutionalization when the child was multiply handicapped, and seventy percent (14) did so when the parent would not accept the child as a family member. Although no one checked "e", the following comments were made:

1. "I do not recommend institutionalization, but if parents, for above reasons, desire to place the child in an institution I help them to make arrangements. The decision for home care or institutional care must be made by the parents without influence from me one way or the other."
2. "I usually obtain consultation and evaluation regarding the child in question. Appropriate literature and guidance then given by personnel with more expertise."

3. "I refer to pediatrician."

4. "Usually referred to appropriate agencies for proper evaluation and they in turn usually provide or refer to treating facilities. Usually refer to NPI, Creighton Clinic, or Nebraska Medical School."

5. "I really very rarely see this type of problem - an occasional mongoloid. If anything, I try to encourage the parent's caring for the child--I don't think this a problem for the state. In any event, I don't seek to engender guilt if they want to give it up."

Table 11

General Practitioners' Responses to Question 5

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. If the child is profoundly or severely retarded</td>
<td>11</td>
<td>55</td>
</tr>
<tr>
<td>b. If the family is unable to cope with child at home</td>
<td>18</td>
<td>90</td>
</tr>
<tr>
<td>c. If the child is multiply handicapped</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>d. If a parent will not accept child as member of family</td>
<td>14</td>
<td>70</td>
</tr>
<tr>
<td>e. Other</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Total number surveyed . . . 37

Total number responded . . . 20
Question 6

Of the eighteen who responded to question six (page 45), sixty-one percent (11) of the general practitioners were unfamiliar with the services of the Greater Omaha Association for Retarded Children (GOARC), eleven percent (2) were familiar with the agency but never recommended it, six percent (1) of the doctors seldom recommended its services, and eleven percent (2) sometimes recommended it. Only six percent (1) of the general practitioners often recommended GOARC, and only six percent (1) always did so.

The results were very similar concerning the Eastern Nebraska Community Office of Retardation (ENCOR). Fifty-six percent (10) of the general practitioners were not familiar with this agency, and of those who were, seventeen percent (3) never recommended it, six percent (1) seldom did, eleven percent (2) sometimes did, six percent (1) often did, and six percent (1) always referred parents of retarded children to ENCOR.

A much greater number of general practitioners referred parents to the Visiting Nurse Association (VNA) than to the above agencies, although eleven percent (2) were unfamiliar with its services, and eleven percent (2) were familiar with its services but never recommended the agency. Seventeen percent (3) of the doctors responded that they seldom recommended VNA, seventeen percent (3) sometimes refer parents to VNA, forty-one percent (7) indicated that they often do so, and six percent (1) said they always recommended the agency.
Although no general practitioners responded that they always recommended Meyer Children's Rehabilitation Institute (MCRI), forty-one percent (7) indicated that they often did, and twenty-four percent (4) sometimes recommend MCRI. None of the general practitioners responded that they seldom recommended the agency, and twelve percent (2) indicated that they were familiar with the facility but never referred parents to it. Twenty-four percent (4) were unfamiliar with the service offered.

No general practitioners indicated that they always recommended Nebraska Psychiatric Institute (NPI), but a large number, fifty percent (9), often referred parents of retarded children to the agency. Twenty-eight percent (5) sometimes referred parents to NPI, while six percent (1) responded that he seldom did so. One doctor or six percent indicated he never referred parents to the facility although he was aware of its services, and eleven percent (2) of the general practitioners were unfamiliar with the services of NPI.

The results referring to Omaha's two medical centers were similar. None of the general practitioners always referred parents either to the Creighton Medical Center or to the University of Nebraska Medical Center, and only sixteen percent (3) often or sometimes did so. Twenty-six percent (5) of the doctors seldom recommended Creighton Medical Center, while thirty-seven percent (7) seldom recommended the University of Nebraska Medical Center. Eleven percent (2) of the general practitioners never referred parents to Creighton Medical Center, and thirty-two per-
percent (6) were unaware of the services of the facility. Sixteen percent (3) never referred parents to the University of Nebraska Medical Center although they were aware of the facility, and sixteen percent (3) were not aware of its services.

Of the fourteen general practitioners who responded, over half fifty-seven percent (8), were unfamiliar with the services of Family & Child Services. Seven percent (1) of the doctors were aware of the service but never referred parents to it. While seven percent (1) of the doctors seldom recommended the agency, twenty-nine percent (4) indicated that they sometimes did. None of the general practitioners responded that they often or always referred parents of retarded children to Family & Child Services.

An even larger number of general practitioners, seventy-three percent (11), were unfamiliar with the services of the Jewish Federation. Of the four who were aware of the agency, thirteen percent (2) of those responding never recommended its services. Seven percent (1) seldom referred parents to the Jewish Federation, and seven percent sometimes did. None of the general practitioners responded that they often or always referred parents of retarded children to the agency.

Many general practitioners, fifty-seven percent (8) of those responding, were unfamiliar with the services of United Catholic Social Services. Seven percent (1) never recommended the agency, twenty-two percent (3) seldom did, and fourteen percent (2) sometimes did so. None of the general practitioners responded that they often or always referred
parents of retarded children to United Catholic Social Services.

Of the fifteen general practitioners who responded, forty-seven percent (7), were unfamiliar with the services of Lutheran Family & Social Services. Thirteen percent (2) never recommended the agency even though they were aware of its services, and twenty percent (3) seldom referred parents of retarded children to the agency. Twenty percent (3) of the general practitioners sometimes recommended the agency, and none of them often or always recommended Lutheran Family & Social Services to parents.

Similar to pediatricians, general practitioners referred parents of retarded children most often to Meyer Children's Rehabilitation Institute, Nebraska Psychiatric Institute, and the Visiting Nurse Association. The agencies that were recommended the least were the Greater Omaha Association for Retarded Children, the Eastern Nebraska Community Office of Retardation, and the four social service agencies.
Table 12

General Practitioners' Responses to Question 6

<table>
<thead>
<tr>
<th>Service Agency</th>
<th>Am unfamiliar with its services</th>
<th>Am familiar with but never recommend</th>
<th>Seldom Recommend (1-25%)</th>
<th>Sometimes Recommend (26-50%)</th>
<th>Often Recommend (50-99%)</th>
<th>Always Recommend</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N %</td>
<td>N %</td>
<td>N %</td>
<td>N %</td>
<td>N %</td>
<td>N %</td>
</tr>
<tr>
<td>a. GOARC</td>
<td>11 61</td>
<td>2 11</td>
<td>1 6</td>
<td>2 11</td>
<td>1 6</td>
<td>1 6</td>
</tr>
<tr>
<td>b. ENCOR</td>
<td>10 56</td>
<td>3 17</td>
<td>1 6</td>
<td>2 11</td>
<td>1 6</td>
<td>1 6</td>
</tr>
<tr>
<td>c. VNA</td>
<td>2 11</td>
<td>2 11</td>
<td>3 17</td>
<td>3 17</td>
<td>7 39</td>
<td>1 6</td>
</tr>
<tr>
<td>d. MGRI</td>
<td>4 24</td>
<td>2 12</td>
<td>0 0</td>
<td>4 24</td>
<td>7 41</td>
<td>0 0</td>
</tr>
<tr>
<td>e. NPI</td>
<td>2 11</td>
<td>1 6</td>
<td>1 6</td>
<td>5 28</td>
<td>9 50</td>
<td>0 0</td>
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<td>f. Creighton Medical Center</td>
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<td>2 11</td>
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<td>0 0</td>
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<td>g. University of Nebraska Medical Center</td>
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<td>3 16</td>
<td>7 37</td>
<td>3 16</td>
<td>3 16</td>
<td>0 0</td>
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<td>h. Family &amp; Child Service</td>
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<td>1 7</td>
<td>1 7</td>
<td>4 29</td>
<td>0 0</td>
<td>0 0</td>
</tr>
<tr>
<td>i. Jewish Federation</td>
<td>11 73</td>
<td>2 13</td>
<td>1 7</td>
<td>1 7</td>
<td>0 0</td>
<td>0 0</td>
</tr>
<tr>
<td>j. United Catholic Social Services</td>
<td>8 57</td>
<td>1 7</td>
<td>3 22</td>
<td>2 14</td>
<td>0 0</td>
<td>0 0</td>
</tr>
<tr>
<td>k. Lutheran Family &amp; Social Services</td>
<td>7 47</td>
<td>2 13</td>
<td>3 20</td>
<td>3 20</td>
<td>0 0</td>
<td>0 0</td>
</tr>
</tbody>
</table>

Total number surveyed . . . 37
Total number of general practitioners who responded . . . 18
Combined Responses of Pediatricians and General Practitioners

The responses of the seventeen pediatricians or seventy-four percent of the twenty-three surveyed and the responses of the twenty-three general practitioners or sixty-one percent of the thirty-seven surveyed were totaled and converted into percentages. The results are as follows:

Question 2

2. When you suspect a child is retarded, do you inform the parents:

_____ a. Immediately

_____ b. Wait until further developments

_____ c. Wait for parents to discover it on their own

_____ d. Other. Please specify.

Of the forty-three doctors who responded to the question, fifty-four percent (23) indicated that they inform parents of their child's retardation immediately, thirty-seven percent (16) waited until further developments, none waited for parents to discover it on their own, and ten percent (4) gave other reasons (cited previously),

Table 13

Combined Pediatricians' and General Practitioners'

Responses to Question 2

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv.</th>
<th>% of Total Responses</th>
</tr>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ped.</td>
<td>G.P.</td>
</tr>
<tr>
<td>--------------------------</td>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>a. Immediately</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>b. Wait until further</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>developments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Wait for parents to</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>discover on own</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Other</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>17</td>
<td>26</td>
</tr>
</tbody>
</table>

Number of pediatricians surveyed . . . 23
Number of general practitioners surveyed . . . 37
Total number surveyed . . . 60

Question 3

3. After diagnosing a child as retarded, do you give parents printed material on the subject of retardation?

    a. Never
    b. Seldom (1-25%)
    c. Sometimes (25-50%)
    d. Often (50-99%)
    e. Always

Of the thirty-eight responding to question three, twenty-nine percent (11) of the pediatricians and general practitioners never gave parents printed material on the subject of retardation. Eighteen percent (7) seldom did so, and twenty-six percent (10) sometimes did. Twenty-one
percent (8) often gave such material, and five percent (2) of the doctors always gave retardation material to parents of retarded children.

Table 14

Combined Pediatricians' and General Practitioners'
Responses to Question 3

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ped. G.P. Total</td>
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</tr>
<tr>
<td>a. Never</td>
<td>3 8 11</td>
<td>19       36.4 29</td>
</tr>
<tr>
<td>b. Seldom (1-25%)</td>
<td>4 3 7</td>
<td>25       13.6 18.4</td>
</tr>
<tr>
<td>c. Sometimes (25-50%)</td>
<td>3 7 10</td>
<td>19       31.8 26.3</td>
</tr>
<tr>
<td>d. Often (50-99%)</td>
<td>5 3 8</td>
<td>31       13.6 21</td>
</tr>
<tr>
<td>e. Always</td>
<td>1 1 2</td>
<td>6        4.6 5.3</td>
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<tr>
<td>Total . . .</td>
<td>16 22 38</td>
<td>100 100 100</td>
</tr>
</tbody>
</table>

Number of pediatricians surveyed . . . 23
Number of general practitioners surveyed . . . 37
Total number surveyed . . . 60

Question 4a

4. a. If a child is severely or profoundly retarded, do you recommend institutionalization?
a. In all cases
b. In some cases (approximate percentage ___%)
c. In no cases

Of the thirty-five pediatricians and general practitioners who responded to question 4a, nine percent (3) indicated that they recommend institutionalization in all cases if a child is severely or profoundly retarded. Eighty percent (28) did so in some cases. Of these, eleven did so fifty percent of the time or more, six did so forty percent of the time or less, and eleven gave no percentages. Nine percent (3) never recommended institutionalization and three percent (1) indicated that the decision was a joint one made with the parents.

Table 15

Combined Pediatricians' and General Practitioners' Responses to Question 4a

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
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<tbody>
<tr>
<td></td>
<td>Ped.</td>
<td>G.P.</td>
</tr>
<tr>
<td>a. In all cases</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>b. In some cases</td>
<td>13</td>
<td>15</td>
</tr>
<tr>
<td>c. In no cases</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
Question 4b

None of the thirty-five pediatricians and general practitioners who responded to question 4b, recommended institutionalization for moderately retarded children in all cases, but fifty-four percent (19) did so in some cases. Of these, two did so fifty percent of the time, six did so thirty percent of the time or less, and eleven did not give percentages. Forty-three percent (15) of the doctors never recommended institutionalization for such children, and three percent (1) indicated a joint decision was made with the parents.

Table 16

Combined Pediatricians' and General Practitioners' Responses to Question 4b

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ped. G.P. Total</td>
<td>Ped. G.P. Total</td>
<td></td>
</tr>
</tbody>
</table>
a. In all cases | 0 0 0 | 0 0 0 0
b. In some cases | 7 12 19 | 44 63 54
c. In no cases | 8 7 15 | 50 37 43
d. Other | 1 0 1 | 6 0 3
Total | 16 19 35 | 100 100 100

Number of pediatricians surveyed...23
Number of general practitioners surveyed...37
Total number surveyed...60

Question 5
5. If you ever recommend institutionalization, under what circumstances do you recommend it?

- a. If the child is profoundly or severely retarded
- b. If the family is unable to cope with child at home
- c. If the child is multiply handicapped
- d. If a parent will not accept the child as a member of the family
- e. Other. Please specify.

Many of the thirty-five general practitioners and pediatricians who responded to question five, checked more than one reason for recommending institutionalization. Fifty-seven percent (20) did so if the child was profoundly or severely retarded, and almost all of the doctors, ninety-one percent (32), did so if the family seemed unable to cope with the child at home. Seventeen percent (6) recommended institutionalization if the child
was multiply handicapped, and sixty-six percent (23) did so if a parent would not accept the child as a member of the family. Eleven percent (4) gave other reasons (cited previously).

Table 17

Combined Pediatricians' and General Practitioners'
Responses to Question 5

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ped. G.P. Total</td>
<td>Ped. G.P. Total</td>
</tr>
<tr>
<td>a. If the child is profoundly or severely retarded</td>
<td>9 11 20</td>
<td>60 55 57</td>
</tr>
<tr>
<td>b. If the family is unable to cope with child at home</td>
<td>14 18 32</td>
<td>93 90 91</td>
</tr>
<tr>
<td>c. If the child is multiply handicapped</td>
<td>3 3 6</td>
<td>20 15 17</td>
</tr>
<tr>
<td>d. If a parent will not accept the child</td>
<td>9 14 23</td>
<td>60 70 66</td>
</tr>
<tr>
<td>e. Other</td>
<td>4 0 4</td>
<td>27 0 11</td>
</tr>
</tbody>
</table>

Number of pediatricians surveyed . . . 23
Number of general practitioners surveyed . . . 37
Total number surveyed . . . 60
Question 6.

Of the thirty-two pediatricians and general practitioners who answered question six (see page 45), the greatest number, fifty-six percent (18), were unaware of the services of the Greater Omaha Association for Retarded Children (GOARC), and sixteen percent (5) never referred parents to the organization even though they were familiar with the services. Three percent (1) seldom recommended it, while thirteen percent (4) sometimes did. Only six percent (2) often recommended GOARC, and only six percent (2) always did.

Thirty-eight percent (12) of the doctors were unaware of the services of the Eastern Nebraska Community Office of Retardation (ENCOR), and twenty-two percent (7) never recommended the agency even though they were aware of its services. Six percent (2) of the doctors seldom referred parents to ENCOR, and nineteen percent (6) sometimes did. Nine percent (3) often recommended the agency, and only six percent (2) always did.

Only six percent (2) of the thirty-two pediatricians and general practitioners were unaware of the Visiting Nurse Association (VNA), and thirteen percent (4) never recommended it even though they were aware of its services. Sixteen percent (5) seldom referred parents to VNA, and nineteen percent (6) sometimes did. Thirty-eight percent (12) of the doctors often recommended the agency, and nine percent (3) always did so.

Sixteen percent (5) of the doctors responding were unaware of the services of Meyer Children's Rehabilitation Institute (MCRI), and ten percent (3) never referred parents to it even though they were aware of
its services. Thirteen percent (4) seldom referred parents to the agency, and thirteen percent (4) sometimes did. Forty-two percent (13) of the pediatricians and general practitioners often recommended MCRI, and six percent (2) always did.

Thirteen percent (4) of the pediatricians and general practitioners were unaware of the services of the Nebraska Psychiatric Institute (NPI), and thirteen percent (4) never referred parents of retarded children to it even though they were aware of its services. Nineteen percent (6) of the doctors seldom recommended the facility, and twenty-two percent (7) sometimes did. Thirty-one percent (10) often recommended NPI, and three percent (1) always did.

Of the thirty-two general practitioners and pediatricians who responded, nineteen percent (6) were unfamiliar with the services of Creighton Medical Center. Twenty-two percent (7) never referred parents to the facility though they were familiar with its services. Twenty-eight percent (9) seldom recommended the center, and sixteen percent (5) sometimes did. Thirteen percent (4) often referred parents to the center, and three percent (1) always did.

Nine percent (3) of the doctors responding were not familiar with the services of the University of Nebraska Medical Center, and twenty-seven percent (9) never referred parents there even though they were aware of its services. Thirty percent (10) of the doctors seldom recommended the center, and fifteen percent (5) sometimes did. Fifteen percent (5) often recommended the center, and three percent (1) always did.
The greatest number, thirty-six percent (10) of the pediatricians and general practitioners responding, were unfamiliar with the services of Family & Child Services. Seven percent (2) never referred parents to the agency even though they were familiar with the services, twenty-one percent (6) seldom recommended the agency, and twenty-nine percent (8) sometimes did. Seven percent (2) often recommended Family & Child Services, and none of the doctors always recommended it.

Sixty-two percent (18) of the doctors who responded were unfamiliar with the services of the Jewish Federation, and seven percent (2) never recommended the agency even though they were familiar with its services. Seventeen percent (5) seldom recommended the agency, and fourteen percent (4) sometimes did. None of the doctors either often or always referred parents to the Jewish Federation.

Forty-six percent (13) of the doctors were unfamiliar with the services of the United Catholic Social Services, and seven percent (2) never recommended the agency although they were familiar with its services. Twenty-nine percent (8) of the pediatricians and general practitioners seldom recommended the agency, and eighteen percent (5) sometimes did so. None of the doctors either often or always recommended United Catholic Social Services.

Almost half of the doctors, forty-eight percent (14), were unfamiliar with the services of Lutheran Family & Social Services, and seven percent (2) never recommended the agency though they were familiar with its services. Twenty-four percent (7) of the pediatricians and general
practitioners seldom referred parents to the agency, and twenty-one percent (6) sometimes did. None of the doctors either often or always referred parents to Lutheran Family & Social Services.

Pediatricians and general practitioners recommended Visiting Nurse Association and Meyer Children's Rehabilitation Institute more often than any of the other agencies. The Greater Omaha Association for Retarded Children, the Eastern Nebraska Community Office of Retardation, and the four social services agencies received the least referrals.
Table 18

Pediatricians' and General Practitioners' Responses to Question

<table>
<thead>
<tr>
<th>Service Agency</th>
<th>Am unfamiliar with its services</th>
<th>Am familiar with but never recommend</th>
<th>Seldom Recommend (1-25%)</th>
<th>Sometimes Recommend (26-50%)</th>
<th>Often Recommend (50-99%)</th>
<th>Always Recommend</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>a. GOARC</td>
<td>18</td>
<td>56</td>
<td>5</td>
<td>16</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>b. ENCOR</td>
<td>12</td>
<td>38</td>
<td>7</td>
<td>22</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>c. VNA</td>
<td>2</td>
<td>6</td>
<td>4</td>
<td>13</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>d. MCRI</td>
<td>5</td>
<td>16</td>
<td>3</td>
<td>10</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>e. NPI</td>
<td>4</td>
<td>13</td>
<td>4</td>
<td>13</td>
<td>6</td>
<td>19</td>
</tr>
<tr>
<td>f. Creighton Medical Center</td>
<td>6</td>
<td>19</td>
<td>7</td>
<td>22</td>
<td>9</td>
<td>28</td>
</tr>
<tr>
<td>g. University of Nebraska Medical Center</td>
<td>3</td>
<td>9</td>
<td>9</td>
<td>27</td>
<td>10</td>
<td>30</td>
</tr>
<tr>
<td>h. Family &amp; Child Service</td>
<td>10</td>
<td>36</td>
<td>2</td>
<td>7</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>i. Jewish Federation</td>
<td>18</td>
<td>62</td>
<td>2</td>
<td>7</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>j. United Catholic Social Services</td>
<td>13</td>
<td>46</td>
<td>2</td>
<td>7</td>
<td>8</td>
<td>29</td>
</tr>
<tr>
<td>k. Lutheran Family &amp; Social Services</td>
<td>14</td>
<td>48</td>
<td>2</td>
<td>7</td>
<td>7</td>
<td>24</td>
</tr>
</tbody>
</table>

Number of pediatrician surveyed . . . 23  Number of pediatricians responding . . . 14
Number of general practitioners surveyed . . . 37  Number of general practitioners responding . . . 18
Total number surveyed . . . 60  Total number responding . . . 32
PARENT QUESTIONNAIRE DATA

One hundred and eighty-nine letters and questionnaires were sent to the parents of children who were attending the various educational and developmental centers of the Eastern Nebraska Community Office of Retardation (Appendix B). Fourteen of these were returned by the post office as the addressee had moved and left no forwarding address. As only thirty-four percent returned the questionnaires, a second letter was sent to the parents from the Benson Developmental Center, parents were contacted personally whose children attended West Developmental Center, and most of the other parents were contacted by phone. The end result was that ninety-four questionnaires were returned by mail and thirty-one phone interviews were conducted to make a total of one hundred and twenty-five completed questionnaires or seventy-one percent of the parents surveyed. Because twenty-five percent (31) of the data was collected by phone in contrast to the seventy-five percent (94) which was sent by mail, there may be some question about the validity of the results as parents may not answer in the same way in an interview as they would when answering a written questionnaire. Thirteen of the parents surveyed did not answer the questions as they did not apply to their child because their child was attending the center for some reason other than retardation. The answers from the questionnaires were tabulated and these numbers were converted into percentages. The results were as follows:

Question 1
1. How did you discover your child was retarded?

a. Told by family doctor or pediatrician when he first suspected condition

b. Told by family doctor or pediatrician when diagnosis of retardation was certain

c. Told by family doctor or pediatrician sometime after doctor knew child was retarded

d. Suspected by parent first, later confirmed by family doctor or pediatrician

e. Other. (Please identify)

Of the one hundred and twelve parents who answered question one, twenty percent (22) of the parents responded that they had been told of their child's retardation when the doctor first suspected the condition, but fifteen percent (17) had been told when the diagnosis of retardation was certain. Only five percent (5) of the parents had been informed of the retardation sometime after the doctor knew of it. The greatest number, forty-six percent (51) of the parents, had suspected the retardation first and later had it confirmed by a doctor. Fifteen percent (17) of the parents responded that they had learned of the retardation in the following ways:

1. Relatives (2)

2. Overheard doctor tell students

3. Neurologist (2)

4. Foster child, so already knew (2)

5. Nebraska Psychiatric Institute (NPI) (3)
6. Mayo Clinic
7. Meyer Children's Rehabilitation Institute (MCRI) (2)
8. Clinic
9. Children's Hospital
10. Overheard doctor at University Clinic
11. Chance Developmental Center

Table 19

Parents' Responses to Question 1

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Told by family doctor or pediatrician when he first suspected condition</td>
<td>22</td>
<td>19.6</td>
</tr>
<tr>
<td>b. Told by family doctor or pediatrician when diagnosis of retardation was certain</td>
<td>17</td>
<td>15.2</td>
</tr>
<tr>
<td>c. Told by family doctor or pediatrician sometime after doctor knew child was retarded</td>
<td>5</td>
<td>4.5</td>
</tr>
<tr>
<td>d. Suspected by parent first, later confirmed by family doctor or pediatrician</td>
<td>51</td>
<td>45.5</td>
</tr>
<tr>
<td>e. Other</td>
<td>17</td>
<td>15.2</td>
</tr>
<tr>
<td>Total</td>
<td>112</td>
<td>100</td>
</tr>
</tbody>
</table>
Total number surveyed . . . 175

Question 2

2. a. Did your family doctor or pediatrician recommend institutionalization?
   __Yes  __No

   b. If yes, when was institutionalization recommended?
      __a. Immediately at diagnosis
      __b. Within a year after diagnosis
      __c. Over a year after diagnosis

Of the one hundred and eight parents who answered question two, forty percent (43) responded that their doctor had recommended institutionalization for their child, and sixty percent (65) of the parents answered that their doctor had not recommended such a step. Of the parents who had been told to institutionalize their child, sixty-two percent (26) had been advised to do so immediately, twenty-four percent (10) had been advised to do so within a year after diagnosis and fourteen percent (6) of the parents had been so advised a year or more after the diagnosis of their child's retardation.

Table 20

Parents Response to Question 2a

<table>
<thead>
<tr>
<th>Response</th>
<th>N Responded</th>
<th>% Responded</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Parents' Responses to Question 2b

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Immediately at diagnosis</td>
<td>26</td>
<td>62</td>
</tr>
<tr>
<td>b. Within a year after diagnosis</td>
<td>10</td>
<td>24</td>
</tr>
<tr>
<td>c. Over a year after diagnosis</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>42</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Total number surveyed ... 175

Question 3

3. Which term best describes your family doctor's or pediatrician's handling of his telling you of your child's retardation?
   
   _____ a. Very poorly handled
   
   _____ b. Unsatisfactory
   
   _____ c. Satisfactory
Of the one hundred and three parents who responded, twenty-six percent (27) felt that their doctor's handling of his telling them of their child's retardation had been very poor, while eighteen percent (19) of the parents responded that it had been unsatisfactory. The greatest number, thirty-two percent (33) of the parents, felt the situation had been handled satisfactorily, and twenty-three percent (24) felt it had been well-handled.

Table 22

Parents' Responses to Question 3

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Very poorly handled</td>
<td>27</td>
<td>26.2</td>
</tr>
<tr>
<td>b. Unsatisfactory</td>
<td>19</td>
<td>18.5</td>
</tr>
<tr>
<td>c. Satisfactory</td>
<td>33</td>
<td>32</td>
</tr>
<tr>
<td>d. Well-handled</td>
<td>24</td>
<td>23.3</td>
</tr>
<tr>
<td>Total . . . .</td>
<td>103</td>
<td>100</td>
</tr>
</tbody>
</table>

Total number surveyed . . . 175

Question 4

4. Check which term best describes how you feel about medical advice
and treatment given by your family doctor or pediatrician for your child:

_____ a. Good

_____ b. Satisfactory

_____ c. Unsatisfactory

_____ d. Very poor

Of the ninety-four parents who responded to the question, thirty-one percent (29) felt that their doctor's medical advice and treatment for their retarded child had been good. Thirty-seven percent (35) felt that the advice and treatment had been satisfactory, but seventeen percent (16) felt it had been unsatisfactory. Fourteen percent (14) of the parents felt that such advice and treatment had been very poor.

Table 23

Parents' Responses to Question 4

<table>
<thead>
<tr>
<th>Answers</th>
<th>N of Indiv. Responses</th>
<th>% of Total Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Good</td>
<td>29</td>
<td>31</td>
</tr>
<tr>
<td>b. Satisfactory</td>
<td>35</td>
<td>37</td>
</tr>
<tr>
<td>c. Unsatisfactory</td>
<td>16</td>
<td>17</td>
</tr>
<tr>
<td>d. Very poor</td>
<td>14</td>
<td>15</td>
</tr>
<tr>
<td>Total</td>
<td>94</td>
<td>100</td>
</tr>
</tbody>
</table>
Total number surveyed . . . 175

**Question 5**

5. a. Did your family doctor or pediatrician give you printed material on retardation?

   ___Yes  ___No

   b. If so, did you find it helpful?

   ___Yes  ___No.

Of the one hundred and one parents who responded, ten percent (10) had received printed material on retardation from their doctor, but ninety percent (91) had not. Of the ten who had received material, sixty percent (6) of the parents found the material helpful, but forty percent (4) had not.

Table 24

*Parents' Responses to Question 5*

<table>
<thead>
<tr>
<th>Response</th>
<th>N Responded</th>
<th>% Responded</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Yes</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>No</td>
<td>91</td>
<td>90</td>
</tr>
<tr>
<td>Total</td>
<td>101</td>
<td>100</td>
</tr>
<tr>
<td>b. Yes</td>
<td>6</td>
<td>60</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
<td>40</td>
</tr>
</tbody>
</table>
Total number surveyed . . . 175

Question 6

6. Check agencies recommended by your family doctor or pediatrician.

   a. Eastern Nebraska Community Office of Retardation (ENCOR)
   b. Greater Omaha Association for Retarded Children (GOARC)
   c. Visiting Nurses' Association (VNA)
   d. Meyer Children's Rehabilitation Institute (MCRI)
   e. Nebraska Psychiatric Institute (NPI) (Genetic Counseling)
   f. Family & Child Services
   g. Jewish Federation
   h. United Catholic Social Services
   i. Lutheran Family and Social Services
   j. Other (please specify)
   k. None at all

A few parents checked more than one agency. Of the one hundred and three parents who responded, eleven percent (11) had been referred to the Eastern Nebraska Community Office of Retardation, but only three percent (3) had been referred to the Greater Omaha Association for Retarded Children by their doctor. The same number, three percent, had been referred to the Visiting Nurses' Association. The greatest number of those who had received referrals, twenty percent (21) of the parents, had been referred to Meyer Childrens' Rehabilitation Institute. Nebraska
Psychiatric Institute had been recommended to eighteen percent (18) of the parents but no doctors had recommended the four social services (Family & Child Services, Jewish Federation, United Catholic Social Services, and Lutheran Family and Social Services). Eight parents responded that they had been referred to the following non-listed agencies: (1) Epilepsy League, (2) HELP School, (3) University of Nebraska Medical Center, (4) Crippled Children Association, (5) J. P. Lord School, and (6) Bluebird Clinic, Houston, Texas. The majority of the parents, fifty-one percent, had not had any agencies recommended to them by their doctor.

Table 25

Parents' Responses to Question 6

<table>
<thead>
<tr>
<th>Response</th>
<th>N Responded</th>
<th>% Responded</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Eastern Nebraska Community Office of Mental Retardation</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>b. Greater Omaha Association for Retarded Children</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>c. Visiting Nurses' Association</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>d. Meyer Children's Rehabilitation Institute</td>
<td>21</td>
<td>20</td>
</tr>
<tr>
<td>e. Nebraska Psychiatric Institute</td>
<td>18</td>
<td>18</td>
</tr>
</tbody>
</table>
f. Family & Child Services 0 0
g. Jewish Federation 0 0
h. United Catholic Social Services 0 0
i. Lutheran Family and Social Services 0 0
j. Other 8 8
k. None at all 52 51

Number of total Responses . . . 103
Number surveyed . . . 175

Question 7

7. In a brief paragraph, give your opinion of your family doctor's or pediatrician's attitude towards your child.

The one hundred and five responses were sorted into three categories: (1) responses which indicate satisfaction with the doctor's attitude towards the retarded child, (2) responses which indicate that the parents felt that the doctor's attitude was only fair towards the child, and (3) responses which indicate dissatisfaction with the doctor's attitude.

Although one hundred and five parents answered question seven, there were one hundred and sixteen responses as eleven parents commented on two different doctors. Forty-three percent (50) of the parents indicated that their doctor's attitude towards their retarded child had been satis-
factory. Forty-five percent (52) indicated that the attitude of the doctor had been unsatisfactory, and twelve percent (14) of the parents judged the doctor's attitude as fair. Sixteen percent (17) indicated that the first doctor had been unsatisfactory, and they had either changed doctors or their original doctor had changed his attitude.

Table 26

Parents' Responses to Question 7

<table>
<thead>
<tr>
<th>Response</th>
<th>N Responded</th>
<th>% Responded</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Satisfactory attitude</td>
<td>50</td>
<td>43</td>
</tr>
<tr>
<td>2. Unsatisfactory attitude</td>
<td>52</td>
<td>45</td>
</tr>
<tr>
<td>3. Fair attitude</td>
<td>14</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>116</td>
<td>100</td>
</tr>
</tbody>
</table>

Total number surveyed... 175

Question 8

8. Type of doctor to whom above questions refer.

_____ General Practitioner

_____ Obstetrician

_____ Pediatrician

_____ Other Specialist
Of the one hundred and eleven parents who responded to question eight, nineteen percent (21) referred to general practitioners, sixty-eight percent (75) referred to pediatricians, and thirteen percent (14) referred to other specialists. Only one percent (1) referred to an obstetrician.

Table 27

Parents' Responses to Question 8

<table>
<thead>
<tr>
<th>Response</th>
<th>N Responded</th>
<th>% Responded</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. General Practitioner</td>
<td>21</td>
<td>19</td>
</tr>
<tr>
<td>2. Pediatrician</td>
<td>75</td>
<td>68</td>
</tr>
<tr>
<td>3. Obstetrician</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>4. Other Specialist</td>
<td>14</td>
<td>13</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>111</strong></td>
<td><strong>101</strong></td>
</tr>
</tbody>
</table>

Total number surveyed ... 175

ANALYSIS OF HYPOTHESES

After the data had been collected, the answers were tabulated. Inferential data analysis was used to test the first eighteen hypotheses. The chi square test was used because more than one set of data was tested for significance in proving or disproving each hypothesis. The hypotheses were rejected at the .05 level of significance. The last hypothesis
was tested by converting the responses to the relevant questions into percentages. If any of the responses indicated that over fifty percent of the parents were satisfied with their doctor, the hypothesis was rejected.

The results were as follows:

**Hypothesis 1**

The first hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who recommend institutionalization for all their patients who are profoundly or severely retarded children. The pediatricians' and general practitioners' responses to the following question provided the necessary data for a chi square test for significance:

4. a. If a child is severely or profoundly retarded, do you recommend institutionalization?

   _____ a. In all cases

   _____ b. In some cases (approximate percentage ____%)

   _____ c. In no cases

**Table 28**

<table>
<thead>
<tr>
<th></th>
<th>a.</th>
<th>b.</th>
<th>c.</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ped.</td>
<td>1 (1.37)</td>
<td>13 (12.8)</td>
<td>1 (1.37)</td>
<td>1 (.46)</td>
<td>16</td>
</tr>
<tr>
<td>G. P.</td>
<td>2 (1.63)</td>
<td>15 (15.2)</td>
<td>2 (1.63)</td>
<td>0 (.54)</td>
<td>19</td>
</tr>
</tbody>
</table>
\[ X^2 = 1.5572 \quad \text{The } X^2 \text{ Table Value @ 3 DF} = 7.815 \]

Since the calculated chi square value of 1.5572 is less than 7.815, the null hypotheses may be accepted at the .05 level of significance. There appears to be no evidence at the .05 level that there is a significant relationship between the number of pediatricians and the number of general practitioners who recommend institutionalization for all their patients who are profoundly or severely retarded.

Hypothesis 2

The second hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who recommend institutionalization for some patients who are profoundly or severely retarded. The pediatricians’ and general practitioners’ responses to the question 4a (above) provided the necessary data for a chi square test for significance.

<table>
<thead>
<tr>
<th>Ped.</th>
<th>a.</th>
<th>b.</th>
<th>c.</th>
<th>d.</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 (1.37)</td>
<td>13 (12.8)</td>
<td>1 (1.37)</td>
<td>1 (0.46)</td>
<td>16</td>
</tr>
</tbody>
</table>
Hypothesis 3

According to the third hypothesis, there is no significance relationship between the number of pediatricians and the number of general practitioners who recommend institutionalization for all their patients who are moderately retarded. The pediatricians' and general practitioners' responses to the following question provided the necessary data for a chi square test for significance:

4. b. If a child is moderately retarded, do you recommend institutionalization?

_______ a. In all cases

_______ b. In some cases (approximate percentage ____%)

_______ c. In no cases

Table 30

Chi Square Test of Hypothesis 3

<table>
<thead>
<tr>
<th></th>
<th>a.</th>
<th>b.</th>
<th>c.</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>G. P.</td>
<td>2</td>
<td>15</td>
<td>2</td>
<td>0</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
<td>28</td>
<td>3</td>
<td>1</td>
<td>35</td>
</tr>
</tbody>
</table>

$X^2 = 1.5572$  The $X^2$ Table Value @ 3 DF = 7.815

Since the calculated chi square value of 1.5572 is less than 7.815, the null hypothesis may be accepted at the .05 level of significance.
The fourth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who recommend institutionalization for some of their patients who are moderately retarded. The pediatricians' and general practitioners' responses to question 4b (above) provided the necessary data for a chi square test for significance.

Table 31

Chi Square Test of Hypothesis 4

<table>
<thead>
<tr>
<th>a.</th>
<th>b.</th>
<th>c.</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ped.</td>
<td>0 (0)</td>
<td>7 (8.7)</td>
<td>8 (6.86)</td>
<td>1 (.46)</td>
</tr>
<tr>
<td>G. P.</td>
<td>0 (0)</td>
<td>12 (10.31)</td>
<td>7 (8.14)</td>
<td>0 (.54)</td>
</tr>
<tr>
<td>Total</td>
<td>0</td>
<td>19</td>
<td>15</td>
<td>1</td>
</tr>
</tbody>
</table>

\[ X^2 = 2.13 \] The \( X^2 \) Table Value @ 3 DF = 7.815

Since the calculated chi square value of 2.13 is less than 7.815, the null hypothesis may be accepted at the .05 level of significance.

There, therefore, appears to be no significant relationship between the number of pediatricians and the number of general practitioners who recommend institutionalization for all their patients who are moderately retarded children.

Hypothesis 4
Hypothesis 5

The fifth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Greater Omaha Association for Retarded Children (GOARC). The pediatricians' and general practitioners' responses to question 6 (page 45) will provide the data for a chi square test for significance for the fifth through the eighteenth hypothesis.

Table 32

<table>
<thead>
<tr>
<th></th>
<th>Ped.</th>
<th></th>
<th></th>
<th>G. P.</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 (0)</td>
<td>7 (8.7)</td>
<td>8 (6.86)</td>
<td>0 (0)</td>
<td>12 (10.31)</td>
<td>7 (8.14)</td>
</tr>
<tr>
<td>Total</td>
<td>0</td>
<td>19</td>
<td>15</td>
<td>1</td>
<td>35</td>
<td>7.815</td>
</tr>
</tbody>
</table>

\[ X^2 = 2.13 \] The \( X^2 \) Table Value @ 3 DF = 7.815

Since the calculated chi square value of 2.13 is less than 7.815, the null hypothesis may be accepted at the .05 level of significance. There appears to be no evidence at the .05 level that there is a significant relationship between the number of pediatricians and the number of general practitioners who recommend institutionalization for some of their patients who are moderately retarded.
Unaware of Services | Aware of Services | Total
---|---|---
Ped. | **7 (7.88)** | **7 (6.12)** | **14**
G. P. | **11 (10.13)** | **7 (7.88)** | **18**
Total | **18** | **14** | **32**

\[ X^2 = 0.3976 \] The \( X^2 \) Table Value @ 1 DF = 3.841

Because the calculated chi square value of 0.3976 is less than 3.841, the null hypothesis may be accepted at 0.05 level of significance. There appears to be no significant relationship between the number of pediatricians and the number of general practitioners who are aware of GOARC.

**Hypothesis 6**

The sixth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Greater Omaha Association for Retarded Children to the parents of retarded children. As stated above, question six provided the data for a chi square test for significance.

Table 33

Chi Square Test of Hypothesis 6
Because the calculated chi square value of 1.2 is less than 9.4888, the null hypothesis may be accepted at the .05 level of significance. There seems to be no evidence at the .05 level that there is a significant relationship between the number of pediatricians and the number of general practitioners who recommend GOARC.

**Hypothesis 7**

The seventh hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Eastern Nebraska Community Office of Retardation (ENCOR). Again, the responses to question six were used as data for a chi square test for significance.
Unaware of Services | Aware of Services | Total
--- | --- | ---
Ped. | 2 (5.25) | 12 (8.75) | 14
G. P. | 10 (6.75) | 8 (11.25) | 18
Total | 12 | 20 | 32

$X^2 = 5.723$ The $X^2$ Table Value @ 1 DF = 3.841

Because the calculated chi square value of 5.723 is greater than 3.841, the null hypothesis may be rejected at .05 level of significance. There is a significant relationship at the .05 level between the number of pediatricians and the number of general practitioners who are aware of ENCOR.

Hypothesis 8

The eighth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Eastern Nebraska Community Office of Retardation to the parents of retarded children. Using the data from question six, the chi square test for significance is as follows:

Table 35

Chi Square Test of Hypothesis 8
Because the calculated chi square value of .3565 is less than 9.4888, the null hypothesis may be accepted at the .05 level of significance. There appears to be no evidence at the .05 level that there is a significant relationship between the number of pediatricians and the number of general practitioners who recommend ENCOR.

Hypothesis 9

The ninth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Visiting Nurse Association. Using the data from question 6, the chi square test for significance is as follows:

Table 36

Chi Square Test of Hypothesis 9
Unaware of Services | Aware of Services | Total
---|---|---
Pcd. | 0 (.88) | 14 (13.13) | 14
G. P. | 2 (1.13) | 16 (16.88) | 18
Total | 2 | 30 | 32

$X^2 = 1.6536$  The $X^2$ Table Value @ 1 DF = 3.841

Since the calculated chi square value of 1.6536 is less than 3.841, the null hypothesis may be accepted at .05 level of significance. There is no relationship between the number of pediatricians and the number of general practitioners who are aware of the Visiting Nurse Association.

**Hypothesis 10**

The tenth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Visiting Nurse Association to the parents of retarded children. Again, data from question six was used for a chi square test for significance.

Table 37

Chi Square Test of Hypothesis 10
Since the calculated chi square value of .7335 is less than 9.4888, the null hypothesis may be accepted at the .05 level of significance. There, therefore, seems to be no evidence at the .05 level that there is a significance relationship between the number of pediatricians and the number of general practitioners who recommend the Visiting Nurse Association to parents of retarded children.

Hypothesis 11

The eleventh hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Meyer Children's Rehabilitation Institute (MCRI). The chi square test results were as follows:

Table 38

Chi Square Test of Hypothesis 11
Unaware of Services | Aware of Services | Total
--- | --- | ---
Pcd. | 1 (2.26) | 13 (11.74) | 14
G. P. | 4 (2.74) | 13 (14.26) | 17
Total | 5 | 26 | 31

$X^2 = .8552$ The $X^2$ Table Value @ 1 DF = 3.841

Because the calculated chi square value of .8552 is less than 3.841, the null hypothesis may be accepted at .05 level of significance. Therefore, there is no relationship between the number of pediatricians and the number of general practitioners who are aware of the services of MCRI.

**Hypothesis 12**

The twelfth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Meyer Children's Rehabilitation Institute to the parents of retarded children. The chi square test results were as follows:

Table 39

Chi Square Test of Hypothesis 12
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ped.</td>
<td>1 (1.5)</td>
<td>4 (2)</td>
<td>0 (2)</td>
<td>6 (6.5)</td>
<td>2 (1)</td>
<td>13</td>
</tr>
<tr>
<td>G. P.</td>
<td>2 (1.5)</td>
<td>0 (2)</td>
<td>4 (2)</td>
<td>7 (6.5)</td>
<td>0 (1)</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>13</td>
<td>2</td>
<td>26</td>
</tr>
</tbody>
</table>

\[ X^2 = 10.9138 \]  The \( \chi^2 \) Table Value @ 4 DF = 9.4888

Since the calculated chi square value of 10.9138 is more than 9.488, the null hypothesis may be rejected at the .05 level of significance; and, therefore, there is a significant relationship between the number of pediatricians and the number of general practitioners who recommend MCRI to parents of retarded children.

**Hypothesis 13**

The thirteenth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Nebraska Psychiatric Institute. The chi square test results were as follows:

Table 40

Chi Square Test of Hypothesis 13
<table>
<thead>
<tr>
<th></th>
<th>Unaware of Services</th>
<th>Aware of Services</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ped.</td>
<td>2 (1.75)</td>
<td>12 (12.25)</td>
<td>14</td>
</tr>
<tr>
<td>G. P.</td>
<td>2 (2.25)</td>
<td>16 (15.75)</td>
<td>18</td>
</tr>
<tr>
<td>Total</td>
<td>4</td>
<td>28</td>
<td>32</td>
</tr>
</tbody>
</table>

\[ X^2 = 0.0724 \]  The \( X^2 \) Table Value @ 1 DF = 3.841

Because the calculated chi square value of 0.0724 is less than 3.841, the null hypothesis may be accepted at the .05 level of significance; and, therefore, there appears to be no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Nebraska Psychiatric Institute.

**Hypothesis 14**

The fourteenth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Nebraska Psychiatric Institute to the parents of retarded children. Using the data from question 6, the chi square test results were as follows:

Table 41

Chi Square Test of Hypothesis 14
Never Seldom Sometimes Often Always Total

Ped. 3 (1.71) 5 (2.57) 2 (3) 1 (4.29) 1 (.429) 12
G. P. 1 (2.29) 1 (3.429) 5 (4) 9 (5.71) 0 (.57) 16
Total 4 6 7 10 1 28

X^2 = 12.0411  The X^2 Table Value @ 4 DF = 9.4888

Because the calculated chi square value of 12.0411 is greater than 9.4888, the null hypothesis may be rejected at the .05 level of significance.

There is a significant relationship at the .05 level between the number of pediatricians and the number of general practitioners who recommend the services of Nebraska Psychiatric Institute to the parents of retarded children.

Hypothesis 15

The fifteenth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Creighton Medical Center. The chi square test results are as follows:

Table 42

Chi Square Test of Hypothesis 15
Since the calculated chi square value of 5.0615 is greater than 3.841, the null hypothesis may be rejected at the .05 level of significance; therefore, there is a significant relationship at the .05 level between the number of pediatricians and the number of general practitioners who are aware of the services of the Creighton Medical Center.

Hypothesis 16

The sixteenth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Creighton Medical Center to the parents of retarded children. Using the data from question six, the chi square test produced the following results:

Table 43

Chi Square Test of Hypothesis 16
X^2 = 3.5966  The X^2 Table Value @ 4 DF = 9.4888

Since the calculated chi square value of 3.5966 is less than 9.4888, the null hypothesis may be accepted at the .05 level of significance; therefore, there is no significant relationship at the .05 level between the number of pediatricians and the number of general practitioners who recommend the services of Creighton Medical Center to the parents of retarded children.

Hypothesis 17

The seventeenth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the University of Nebraska Medical Center. The chi square test results are as follows:

Table 44

Chi Square Test of Hypothesis 18
<table>
<thead>
<tr>
<th></th>
<th>Unaware of Services</th>
<th>Aware of Services</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ped.</td>
<td>0 (1.27)</td>
<td>14 (12.73)</td>
<td>14</td>
</tr>
<tr>
<td>G. P.</td>
<td>3 (1.73)</td>
<td>16 (17.27)</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
<td>30</td>
<td>33</td>
</tr>
</tbody>
</table>

\[ X^2 = 2.4223 \] The \( X^2 \) Table Value @ 1 DF = 3.841

As the calculated chi square value of 2.4223 is less than 3.841, the null hypothesis may be accepted at .05 level of significance. There is, therefore, no relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the University of Nebraska Medical Center.

**Hypothesis 18**

The eighteenth hypothesis states that there is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the University of Nebraska Medical Center to the parents of retarded children. The responses from question six provided the data to use in the following chi square test for significance:

**Table 45**

Chi Square Test of Hypothesis 18
Because the calculated chi square value of 3.5966 is less than 9.4888, the null hypothesis may be accepted at the .05 level of significance; and, therefore, there is no significant relationship at the .05 level between the number of pediatricians and the number of general practitioners who recommend the services of the University of Nebraska Medical Center.

Hypothesis 19

The nineteenth hypothesis states that general dissatisfaction with physicians' advice concerning their retarded child is widespread among parents of retarded children from the Omaha area. The parents' responses to questions three, four, and seven were analyzed to test this hypothesis. (Appendix B). If a majority (fifty-one percent or more) of the responses to each question indicated that parents were dissatisfied with their doctors' attitudes, then the hypothesis would be accepted. The results were as follows:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Pcd.</td>
<td>6 (4.2)</td>
<td>3 (4.67)</td>
<td>2 (2.33)</td>
<td>2 (2.33)</td>
<td>1 (.467)</td>
<td>14</td>
</tr>
<tr>
<td>G. P.</td>
<td>3 (4.8)</td>
<td>7 (5.33)</td>
<td>3 (2.67)</td>
<td>3 (2.67)</td>
<td>0 (.533)</td>
<td>16</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
<td>10</td>
<td>5</td>
<td>5</td>
<td>1</td>
<td>30</td>
</tr>
</tbody>
</table>

$X^2 = 3.8824 \quad \text{The } X^2 \text{ Table Value} @ 4 \text{ DF} = 9.4888$

Table 46
Percentage Results of Questions 3, 5 and 7

<table>
<thead>
<tr>
<th>Question</th>
<th>Satisfactory</th>
<th>Unsatisfactory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 3</td>
<td>55%</td>
<td>44%</td>
</tr>
<tr>
<td>Question 4</td>
<td>68%</td>
<td>31%</td>
</tr>
<tr>
<td>Question 7</td>
<td>43%</td>
<td>45%</td>
</tr>
</tbody>
</table>

Because fifty-five percent of the parents who responded to question three indicated that they felt that their doctors' handling of his telling them of their child's retardation was satisfactorily or well-handled, and because sixty-eight percent of the parents, responding to question four, felt that their doctor's medical advice and treatment had been either good or satisfactory, the nineteenth hypothesis must be rejected. In addition, less than fifty-one percent of the parents, in responding to question seven, felt that their doctor's attitude was unsatisfactory. Thus, one cannot accept the hypothesis that general dissatisfaction with physicians' advice concerning their retarded child is widespread among parents of retarded children from the Omaha area.

Conclusion

An inferential data analysis of the first eighteen hypotheses found that only the following four hypotheses were rejected at the .05 level of significance:

1. Hypothesis 7: There is no significant relationship between the
number of pediatricians and the number of general practitioners who are aware of the services of the Eastern Nebraska Community Office of Retardation.

2. Hypothesis 12: There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Meyer Children's Rehabilitation Institute to the parents of retarded children.

3. Hypothesis 14: There is no significant relationship between the number of pediatricians and the number of general practitioners who recommend the Nebraska Psychiatric Institute to the parents of retarded children.

4. Hypothesis 15: There is no significant relationship between the number of pediatricians and the number of general practitioners who are aware of the services of the Creighton Medical Center.

The other fourteen hypotheses were accepted at the .05 level of significance. The nineteenth hypothesis was rejected as less than fifty percent of the parents responding were dissatisfied with their doctors' advice concerning their retarded child; therefore, general dissatisfaction with physicians' advice concerning their retarded child is not widespread among parents of retarded children in the Omaha area.

OTHER RELEVANT RESULTS

Some of the questions on the physicians' questionnaire were identical or nearly the same as some on the parents' questionnaire. A comparison
between the doctors' and the parents' responses follows:

**Institutionalization**

Question four asked the doctors if they recommended institutionalization for profoundly, severely, or moderately retarded children, and question two on the parents' questionnaire asked the parents if their physician had recommended institutionalization. Of the thirty-five doctors who responded, eighty-nine percent recommended institutionalization for all or some severely or profoundly retarded children, and fifty-four percent made such recommendations for all or some moderately retarded children. In contrast, of the one hundred and eight parents who responded to the question on institutionalization, thirty-nine percent said that their doctor had recommended institutionalization.

**Table 47**

A Comparison of Physicians' and Parents' Responses to Questions Referring to Institutionalization

<table>
<thead>
<tr>
<th></th>
<th>Physicians</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Prof. or Sev.</td>
<td>Mod. Retarded</td>
</tr>
<tr>
<td>Recommend</td>
<td>80%</td>
<td>54%</td>
</tr>
<tr>
<td>Institutionalization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not recommend</td>
<td>20%</td>
<td>46%</td>
</tr>
<tr>
<td>Institutionalization</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Because the number of parents who had been told to institutionalize their child cannot be broken down into those that refer to profoundly or severely retarded and those that refer to moderately retarded, an inferential analysis cannot be done on this data.

**Written Material on Retardation**

Question three asked the doctors if and how often they gave printed material on the subject of retardation to parents, and question five on the parents' questionnaire asked parents if their doctor had given them such material. Of the thirty-eight doctors who responded, twenty-nine percent never gave material, eighteen percent seldom did, twenty-six percent sometimes did, twenty-one percent often did so, and five percent always gave parents material. In contrast, of the one hundred and one parents who responded to question five, ninety percent said that they had not been given material on the subject of retardation.

**Physician Referrals to Agencies**

Physicians were asked to check agencies which they did or did not recommend to parents of retarded children (Appendix A, question b). Parents were asked to check the agencies that had been recommended by their doctors (Appendix B, question 6). A comparison of the doctors' and parents' responses revealed the following:

**Greater Omaha Association for Retarded Children (GOARC)** Of the thirty-two pediatricians and general practitioners who responded, sixteen percent either seldom or sometimes recommended GOARC, while twelve
percent either often or always did. However, of the one hundred and three parents who responded, only three percent indicated that the agency had been recommended by their doctor.

**Eastern Nebraska Community Office of Retardation (ENCOR)**

Twenty-five percent of the thirty-two doctors responded that they either seldom or sometimes recommended ENCOR, and fifteen percent often or always referred parents to the agency. In contrast, only eleven percent of the one hundred and three parents indicated that they had been referred to the agency by their doctor.

**Visiting Nurses' Association (VNA)**

There was even more discrepancy between what doctors said about their recommendation of Visiting Nurse Association and what parents said. Of the thirty-two doctors who responded, thirty-five percent said that they either seldom or sometimes recommended VNA, and forty-seven percent indicated that they often or always referred parents to the agency but only three percent of the one hundred and three parents responding said that they had been referred to the VNA by their physician.

**Meyer Children's Rehabilitation Institute (MCRI)**

As was true with the VNA, a much larger percentage of doctors indicated that they recommended the Meyer Children's Rehabilitation Institute than the percentage of parents who responded that their doctors had recommended the agency. Twenty-six percent of the thirty-two doctors responding recommended MCRI either seldom or sometimes, while forty-eight percent recommended the agency either often or always. In contrast, only twenty percent of the
one hundred and three parents responded that they had been referred to MCRI by their physician.

**Nebraska Psychiatric Institute (NPI)** Although forty-one percent of the doctors seldom or sometimes referred parents of retarded children to NPI, and thirty-four percent either often or always recommended the agency, only eighteen percent of the one hundred and three parents responded that their doctor had referred them to NPI.

**Family & Child Services** Again, there was a great difference between the number of doctors who said they referred parents to Family & Child Services and the number of parents who indicated that they were referred to the service. While forty percent of the twenty-eight doctors said that they referred parents either seldom or sometimes to the Family & Child Services and seven percent indicated that they often or always did, none of the one hundred and three parents responded that they had been referred to the agency by their doctor.

**Jewish Federation** As for the above agency, none of the parents responded that they had been referred to the Jewish Federation by their doctor, but forty-one percent of the twenty-nine doctors responded that they seldom or sometimes referred parents of retarded children to it.

**United Catholic Social Services** Again, none of the one hundred and three parents responded that they had been referred to the United Catholic Social Services, but forty-seven percent of the twenty-seven doctors said they either seldom or sometimes recommended the agency.

**Lutheran Family & Social Services** Although forty-five percent of
the twenty-nine doctors seldom or sometimes recommended Lutheran Family & Social Services, none of the one hundred and three parents indicated that they had been referred to the agency by a doctor.

Table 48

Comparison of Physicians' and Parents' Responses to Questions Referring to Recommendations of Agencies

<table>
<thead>
<tr>
<th>Physicians</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seldom or Sometimes Recommend</td>
<td>Often Or Always Recommend</td>
</tr>
<tr>
<td>1. GOARC</td>
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The above results, although not analyzed statistically, show the
similarities or differences between what doctors say they do regarding the counseling of parents and what parents say doctors do in regard to counseling.
Chapter 5

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

PURPOSE OF CHAPTER 5

The purposes of Chapter Five are: (1) to summarize the study of physician counseling of parents of retarded children, (2) to summarize the significant results of the study, (3) to present conclusions based on the results of the study, and (4) to make recommendations for future studies.

SUMMARY OF STUDY

Because the emphasis for care of the retarded has moved from the residential facility to community services, especially in the Omaha area, greater demands are put on the physicians who care for the retarded in the community. Because a parent usually first learns that his child is retarded from a pediatrician or a general practitioner, it is important that these physicians not only serve as counselors to the retarded and his family, but they must also be a source of information and referral to appropriate community services. They, therefore, should be aware if services are offered within the community and whether those services obviate the need to institutionalize the child. To investigate the problem, and the difference, if any, in advice offered between pediatricians or gen-
eral practitioner, the following study was done. The purposes were:

a. To investigate the difference between pediatricians' and general practitioners' advice regarding institutionalization (to institutionalize or not to institutionalize).

b. To investigate the difference between pediatricians' and general practitioners' awareness of community services (aware or not aware) and the advice offered concerning them (recommend or not recommend).

c. To investigate parents' opinions concerning advice received from physicians (to institutionalize or to use community services).

d. To investigate parents' opinions regarding the general handling by the physician of their retarded child.

To collect data for the investigation of the above, questionnaires were sent to the thirty-seven general practitioners and the twenty-three pediatricians in the Omaha area (Appendix A). Questionnaires were also sent to the one hundred and eighty-nine sets of parents of children who are in the Eastern Nebraska Community Office of Retardation developmental centers (Appendix B). Seventy-four percent (17) of the pediatricians and sixty-one percent (23) of the general practitioners responded to the physician questionnaire, and seventy-one percent (125) of the parents responded.

SUMMARY OF RESULTS

An analysis of the data collected by the questionnaires revealed results that can be categorized under five basic headings: (1) pediatricians' and general practitioners' advice regarding institutionalization, (2) ped-
Pediatricians' and general practitioners' awareness of community services and the advice offered concerning them, (3) the giving of written materials on retardation by the physician, (4) parents' opinions regarding the general handling by the physician of their retarded child, and (5) results referring to diagnosis of retardation by the physician.

**Pediatricians' and General Practitioners' Advice Regarding Institutionalization**

A statistical analysis, using the chi square test, revealed that there was no significant difference between the number of pediatricians and the number of general practitioners who recommended institutionalization for all or some of their patients who are profoundly, severely, or moderately retarded. Therefore, the first four hypotheses were accepted at the .05 level of significance.

The results also showed that a large majority of both groups, eighty-one percent of the sixteen pediatricians and seventy-nine percent of the nineteen general practitioners, recommended institutionalization for some of their patients who are profoundly or severely retarded. For moderately retarded children only forty-four percent of the pediatricians and sixty-three percent of the general practitioners sometimes recommended institutionalization while fifty percent of the pediatricians and thirty-seven percent of the general practitioners never recommended it.

The results of the parents' questionnaires revealed that forty percent of the one hundred and eight who responded had been advised by their physician to institutionalize their child. Eighty-six percent of these had
been advised to do so immediately or within one year after diagnosis.

**Pediatricians' and General Practitioners' Awareness of Community Services and the Advice Offered Concerning Them**

A statistical analysis, using the chi square test, revealed that there was no significant difference between the number of pediatricians and the number of general practitioners who were aware of the services of the following five agencies: (1) Greater Omaha Association for Retarded Children (GOARC), (2) Visiting Nurse Association (VNA), (3) Meyer Children's Rehabilitation Institute (MCRI), (4) Nebraska Psychiatric Institute (NPI), and (5) University of Nebraska Medical Center. There was a significant difference, however, between the two groups' awareness of the services of the Eastern Nebraska Community Office of Retardation (ENCOR) and the Creighton Medical Center.

Other significant results revealed that of the major agencies serving the handicapped, the two agencies which exclusively serve the retarded were the least familiar to the physicians who responded. Over half of the doctors, fifty-six percent, were unaware of the services of the Greater Omaha Association for Retarded Children, a volunteer organization of parents, concerned citizens, and professionals who serve the retarded; and thirty-eight percent were unfamiliar with the Eastern Nebraska Community Office of Retardation, an agency which provides a wide range of services for the retarded and their families.

A statistical analysis of the responses concerning physician referral to community services revealed through use of the chi square test that there
is no significant relationship at the .05 level between the number of pediatricians and the number of general practitioners who recommend the following five agencies: (1) Greater Omaha Association for Retarded Children, (2) Eastern Nebraska Office of Retardation (ENCOR), (3) Visiting Nurse Association (VNA), (4) Creighton Medical Center, and (5) the University of Nebraska Medical Center. There was a significant difference, however, between the two groups' recommendations of Meyer Children's Rehabilitation Institute and the Nebraska Psychiatric Institute.

Not only were GOARC and ENCOR the least known by the physicians, but these two agencies were also the least recommended to parents. Only twelve percent of the doctors recommended GOARC to fifty percent or more of the parents of their retarded patients, and only fifteen percent recommended ENCOR. In contrast to these percentages, forty-seven percent recommended VNA, forty-eight percent recommended MCRI, and thirty-four percent referred parents to NPI at least fifty percent of the time.

Although all of the agencies, according to the physicians' responses, were recommended to parents at least some of the time, an analysis of the parents' responses revealed that fifty-one percent had never received any referral to any agency by their doctor. For example, eighty-two percent of the doctors responded that they referred some or all parents to VNA, but only three percent of the parents said that they had been referred to that service by their physician. Similar differences were observed between the parents' and doctors' responses for the other agencies.
Although most of the doctors, seventy-one percent of the thirty-eight who responded, answered that they gave material about retardation to some or all of the parents of their retarded patients, only ten percent of the one hundred and one parents responding said they received such material from their physician.

An analysis of the parents' responses to the three questions asking their opinions of their physicians' treatment of and attitude towards their retarded child showed that more than half of the parents were satisfied with their physician. However, while sixty-eight percent of the parents were satisfied with the medical advice and treatment given by the doctor, only forty-three percent of the parents were satisfied with their doctor's attitude towards their child.

An analysis of the data revealed that fifty-three percent of the doctors informed the parents immediately when they suspected a child was retarded, and thirty-seven percent waited until further developments.

Eighty-five percent of the parents surveyed had been informed of their child's retardation by their doctor, but forty-six percent had suspected the
retardation before it had been confirmed by a physician.

CONCLUSIONS

The following conclusions were drawn from the results of the questionnaires: (1) Some physicians are unaware of the local agencies which serve the retarded, (2) communication channels are inadequate between physicians and agencies which serve the retarded, (3) communication channels are inadequate between parents of retarded children and physicians, (4) many physicians feel that the institution is the place for some retarded children, and (5) many parents are more dissatisfied with the physicians attitude toward their retarded child than they are with the medical treatment he receives.

Physician Unawareness of Local Agencies

Because of the rapid growth of community services for the retarded in the Omaha area, it is important to determine if physicians are aware of such services. The results clearly showed that some doctors are unfamiliar with some of the local agencies which serve the retarded. Even more significant, the Eastern Nebraska Community Office of Retardation and the Greater Omaha Association for Retarded Children, the two agencies which exclusively serve the retarded, were the least known of all the local agencies, even though mental retardation, in terms of magnitude, is the most handicapping of all childhood disorders. 43

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43 American Medical Association Conference, xi.
The physicians' lack of knowledge of local services can cause them to do a serious disservice to the retarded and their family because the physician is often their primary counselor and advisor. A search of the literature revealed that both professionals and parents felt that it was the physicians' responsibility to act as an informed counselor and a source of information and referral to appropriate community services. Obviously, a physician can only do this if he has a knowledge of what services are available in his area.

Inadequate Communication Between Physicians and Agencies

The preceding conclusion points to a second one: communication channels are inadequate between physicians and agencies which serve the retarded.

The lack of communication between the two groups may be partly due to the fact that agencies are not communicating adequately with local physicians. All of the agencies may not have provided doctors with information about their services or the information provided may have been inadequate or poorly presented.

The physicians may not have made a real effort to communicate with local agencies in order to discover what services are available in the community for the retarded. Doctors may not read material sent to them either from lack of time or interest. Although some agencies have made

their services known through the news media, this method has not been successful in informing all doctors of their services. Again, this failure may be due to the doctors' lack of time or a lack of interest in such information.

Because some agencies may have failed completely to communicate with physicians, the doctor may have to learn about them through his own efforts. Murray has stated that it is the doctors' responsibility to do so and that the "plea of ignorance or of not knowing what to do is no longer a valid one. Those who fail in this respect today could more accurately be charged with indifference than with ignorance."45

These factors, the agencies' lack of or inadequate communication with doctors and the lack of interest by the doctors in developing their communication with the agencies, probably are responsible for the present unawareness that some physicians have of these agencies.

Inadequate Communication Between Parents and Physicians.

A study of the results indicated that there is also a need for better communication between parents and the doctor of their retarded child. Large discrepancies between parents' and physicians' responses to similar questions indicated that the present communication between the two groups is inadequate. While some of the differences between the two

groups' responses may be due to the sample and some of the parents or physicians may not have remembered what advice they had received or given, the discrepancies were so large in some cases that inadequate communication between the two must be considered as a major concern.

The cause for some of the discrepancies may be due to the fact that the doctor is not giving the information to the parents or the parents do not understand the information given by him. In either case, better communication between the two is needed.

Further evidence of poor communication between doctors and parents was given by the parents' responses to question six which asked which agencies had been recommended by their physician. Although all of the parents had a child being served by a community service, less than half of the parents had been referred to any local agency by their doctor. Again, though some of the parents may have forgotten that their doctor had recommended some local services, communication between the doctor and the parents of a retarded child is inadequate when some doctors do not advise parents about the services available in the community for them and their retarded child.

It is also possible that parents may not be adequately communicating their needs to the doctor. Many of the parents who responded may not have asked their doctor about services available for their child. Although a search of the literature revealed that both professionals and parents felt that it was the doctors' responsibility to act as a source of information about community services, perhaps parents should also take some respon-
sibility for communicating their needs to doctors. In any case, the need for better communication between the two was indicated by the results of the study.

The parents' responses to question seven which asked their opinion of their doctor's attitude towards their child also revealed further evidence of this need. Of the parents who were not satisfied with their doctor's attitude, many indicated a desire for more information from their doctor concerning the care and treatment for their retarded child. In contrast, the comments made by the parents who were satisfied with their doctor's attitude often included comments about the doctor's willingness to discuss their child's problems and progress. It seems that, based on these results, parents want doctors to communicate with them, and dissatisfaction with doctors is partly caused by doctors' unwillingness or inability to talk to parents about their child.

From the above results, one can conclude that the present communication channels between parents and physicians are inadequate.

Physicians and Institutionalization

The physicians' responses to the questionnaire revealed that many doctors feel that the institution is still the place for some retarded children despite the rapid increase in community services in the last few years.

One of the reasons why such a large number of doctors recommended institutionalization may be due to the fact that the results showed that many doctors were unaware of the community services offered for the retarded.
Perhaps even some of those doctors who are aware of the local agencies are not fully familiar with the various alternatives offered by such agencies to institutional care.

Some doctors may recommend institutionalization even though they are aware of local services if they feel that the services are inadequate and would not meet the needs of a particular child or his family as well as an institution would.

The results revealed that most doctors recommended institutionalization when they felt that the family was unable to cope with the child at home, and many made such a recommendation when the family would not accept the child as a member of the family. These results suggest that many physicians recommend institutionalization when they feel that the family situation indicates that the retarded child should or could not remain at home. However, one cannot determine from the results if the doctors who recommended institutionalization for such children knew of the residential facilities for the retarded in the community or if the family was unable to cope with the child or accept him because they were receiving no help from community services.

It is also significant to note that a search of the literature revealed that professionals advise that physicians should not recommend institutionalization, but, instead, should discuss all the alternatives with the parents, but the decision for the care of the retarded child should always be made by the parents. In contrast to this procedure, the local physicians, with one exception, seem to feel that it is their responsibility to recommend
institutionalization for some of their patients.

Because many physicians are still recommending institutionalization for some retarded children, it would appear that they have not fully accepted the philosophy of most of the other professionals in the field who are advocating that all retarded should stay in the community if at all possible.

Parents' Opinions of Physicians

The parents' responses to several of the questions pointed to the conclusion that parents are more dissatisfied with doctors' attitudes toward their retarded child than they are with the medical treatment given. There are probably several reasons for this difference. One of the reasons may be due to the lack of good communication between parent and doctor which was discussed earlier. Another reason might be the over-sensitivity of parents to others' behavior towards their child. Parents may be sensitive to what they feel are criticisms of themselves or their child and react with hostility and resentment. The family doctor can become a target for such feelings.

A third reason for the difference between the parents' opinions concerning the medical treatment of their child and their opinions of their doctor's attitude toward him may be that some of the doctors, although capable medically, have a poor attitude towards retarded children. "The

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physician with little empathy for or experience in the field of mental retardation cannot avoid revealing both his disinterest and his uncertainty in his discussion of diagnostic findings and the resultant recommendations."

47 The physician may also have feelings of frustration when dealing with the retarded because retardation cannot be cured, and the treatment for the retarded is more educational in nature than medical. These feelings of the physician could be a contributing factor to poor relations with the parents of a retarded child.

The above three factors, poor communication between doctors and parents, parents' over-sensitivity, and doctors' attitudes towards retarded children, probably explain why parents are more dissatisfied with physicians' attitudes towards their retarded children than they are with the medical treatment given by the physicians.

RECOMMENDATIONS

The results and conclusions of the study indicated the need for two types of recommendations: proposals for immediate action by parents, physicians, and community agencies; and recommendations for further research.

Proposals for Immediate Action

Because many physicians are unaware of the services of the community agencies, the local agencies should take immediate steps to inform

47 Solomons and Menolascino, p. 11.
doctors of their services. If mailings have proved inadequate, other avenues of communication should be explored. Personal contacts could be made with each physician by one individual representing all the major agencies with the purpose of explaining services, answering questions, and settling misunderstandings if they exist.

Physicians also must take some responsibility to become more knowledgeable in the field of mental retardation. One solution to this problem would be for physicians to attend workshops on mental retardation. One is offered by the Nebraska Psychiatric Institute in Omaha so it would be convenient for doctors to attend such a seminar. This particular workshop includes a tour of community services, which would provide physicians with a first hand knowledge of alternatives to institutional care.

Another method of increasing physicians' knowledge and understanding of mental retardation would be to include more courses on the subject in medical school. At the present time, most medical schools do not teach mental retardation in the undergraduate medical curriculum. Another possibility would be for medical schools to provide training so that a physician could become a specialist in this field.

Recommendations for Further Research

Many questions concerning physician counseling of parents of retarded children were not answered by the study, and, moreover, the

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One of the questions raised by the study was whether or not physicians feel an obligation to be familiar with community services that serve the retarded. Although a research of the literature revealed that both professionals and parents felt that doctors had an obligation to be aware of local resources and that they should refer such services to parents of the retarded, there apparently has been no study to discover if the physicians feel such an obligation.

A study also needs to be done to determine if doctors who recommend community services actually know what specific services each agency offers. Olshansky discovered that only twenty-seven percent of the general practitioners who were familiar with the local service for the retarded could identify either the location, sponsorship, or services of the agency. 49

It would also be valuable to know if doctors who are familiar with community services are less likely to recommend institutionalization. A study of this subject could also investigate if doctors who are familiar with community services but continue to recommend institutionalization feel that local services are inadequate.

An investigation of the effects of age, training, and years in medical practice on physicians' attitudes towards the care and treatment of the retarded would add new knowledge to the area of physician counseling of

parents of retarded children.

Although there have been some studies of parents regarding the counseling that they received from their physician, a research of the literature revealed that much research needs to be done in this area. Although studies have shown that parents are often dissatisfied with the counseling they received from the doctor of their retarded child, a study should be done to determine if there is any difference between the opinions of parents of retarded children and the opinions of parents of normal children regarding the physicians' handling of their child.

A study also needs to be done to determine if parents follow the advice given by physicians regarding community services and institutionalization. Several early studies indicated that most parents did not follow their physicians' advice to institutionalize their child. It would be important to know how much impact physicians' advice on institutionalization and community services has on parents.

An investigation should also be done on the importance of printed material on retardation given to parents by their doctor. A determination should be made if parents find such material of value, and if so, what material is most helpful to parents.

Because of the recent increase in community services for the retarded, research should be done to determine if there has been a significant decrease in doctor's recommendations for institutionalization. Because

50 Zwerling, 319-329; Waskowitz, 469-479.
of the present alternatives to residential care away from the community, one would suspect that physicians' recommendations for institutionalization would have decreased, but this may not be true.

The problems in the area of physician counseling of parents of retarded children are complex and many. It is hoped that this study has helped answer some questions and will encourage constructive action on the part of agencies, physicians, and parents to improve future relations between doctors and the parents of their retarded patients. With such action and further research, the needs of the retarded will be more adequately met.
BIBLIOGRAPHY
BIBLIOGRAPHY


Giannini, Margaret M. "The Role of the Physician in Mental Retardation, "Journal of the American Medical Women's Association, XXIV, 6 (1969), 488-496.


APPENDIX A
Dear [Physician's Name]

In order to promote better parent-physician relations, the National Association for Retarded Children is asking all Omaha pediatricians, obstetricians and general practitioners to answer the enclosed questionnaire concerning your present counseling practices with parents of the mentally retarded.

The physician is of the utmost importance in treating the retarded, so we are asking you for a few minutes to answer the questionnaire, as the study will be of no value without your cooperation. We feel that the information gathered from this project will help us understand the present procedures used by physicians in their counseling with parents of retarded children. We are not asking physicians to identify themselves.

An addressed, stamped envelope is enclosed for your convenience. If you have any questions or objections concerning the questionnaire, please feel free to contact me (N. K. K.) at the above address or call directly (551-3267).

Very truly yours,

F. J. Menolascino, M. D.
Vice President
North Central Region

N. Karen Kelly
Coordinator of Parent Action Groups
Greater Omaha Association for Retarded Children

NKK/js
Enclosure

Twenty-Fourth Annual Meeting
Anaheim, California October 31 - November 3, 1973
December 20, 1972

Dear Physician,

I am sorry to bother you again but so few doctors responded to the questionnaire pertaining to parent-physician counseling regarding the care of retarded children, that I'm hoping this letter will bring better results. If you have already answered the questionnaire, please disregard this letter. Unless more physicians respond, no valid study can be made.

Perhaps the questionnaire did not apply to your practice. If not, would you please indicate this and return it to me anyway.

I am counting on your cooperation. If you would like to have a copy of the results of the study, I would be glad to send you one when completed.

Sincerely,

Karen Kelly

Karen Kelly, Coordinator
Parent Action Groups
Greater Omaha Association
for Retarded Children
Physician Questionnaire

Please check the appropriate answers. Feel free to add your comments on any of the questions:

1. I am a
   □ General practitioner □ Pediatrician □ Obstetrician □ Other Specialist

2. When you suspect a child is retarded, do you inform the parents:
   ___________ a. Immediately
   ___________ b. Wait until further developments
   ___________ c. Wait for parents to discover it on their own
   ___________ d. Other. Please specify.

Comment:

3. After diagnosing a child as retarded, do you give parents printed material on the subject of retardation?
   ___________ a. Never
   ___________ b. Seldom (1-25%)
   ___________ c. Sometimes (25-50%)
   ___________ d. Often (50-99%)
   ___________ e. Always

Comment:

4. a. If a child is severely or profoundly retarded, do you recommend institutionalization?
   ___________ a. In all cases
   ___________ b. In some cases (approximate percentage ___%)
   ___________ c. In no cases

Comment:

b. If a child is moderately retarded, do you recommend institutionalization?
   ___________ a. In all cases
   ___________ b. In some cases (approximate percentage ___%)
   ___________ c. In no cases
5. If you ever recommend institutionalization, under what circumstances do you recommend it?

___________a. If the child is profoundly or severely retarded
___________b. If the family is unable to cope with child at home
___________c. If the child is multiply handicapped
___________d. If a parent will not accept the child as a member of the family
___________e. Other. Please specify.

Comment:
6. Listed below are agencies which provide service to the retarded and their families. Check the appropriate space.

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APPENDIX B
Dear Parents:

The National Association for Retarded Children is conducting a study of present and past attitudes of Omaha physicians regarding the treatment and potential of retarded children. The results of this study will give us a clearer picture of what advice and counsel doctors give to parents of the retarded.

Would you please answer the enclosed questionnaire as honestly as possible. Please do not identify yourself. An addressed, stamped envelope is enclosed for your convenience.

This study can only be significant and valid if we get an adequate response from parents. As the study may lead to improved parent-physician relationships, it would be to your and your child's benefit to send us the completed questionnaire as soon as possible.

Very truly yours,

N. Karen Kelly
Coordinator of Parent Action Groups
Greater Omaha Association for Retarded Children

F. J. Menolascino, M. D.
Vice President
North Central Region

Barbra Streisand
National Honorary Chairman

November 21, 1972

Twenty-Fourth Annual Meeting
Anaheim, California
October 31 - November 3, 1973
Parent Questionnaire

Directions: Please check the appropriate answers. Feel free to comment on any of the questions.

1. How did you discover your child was retarded?
   - a. Told by family doctor or pediatrician when he first suspected condition.
   - b. Told by family doctor or pediatrician when diagnosis of retardation was certain.
   - c. Told by family doctor or pediatrician sometime after doctor knew child was retarded.
   - d. Suspected by parent first, later confirmed by family doctor or pediatrician.
   - e. Other (Please identify).

2. Did your family doctor or pediatrician recommend institutionalization?
   - Yes
   - No

   If yes, when was institutionalization recommended?
   - a. Immediately at diagnosis.
   - b. Within a year after diagnosis.
   - c. Over a year after diagnosis.

3. Which term best describes your family doctor's or pediatrician's handling of his telling you of your child's retardation?
   - a. Very poorly handled.
   - b. Unsatisfactory.
   - c. Satisfactory.
   - d. Well-handled.

   Comments:

4. Check which term best describes how you feel about medical advice and treatment given by your family doctor or pediatrician for your child:
   - a. Good.
   - b. Satisfactory.
   - c. Unsatisfactory.
   - d. Very poor.

   Comments:

5. Did your family doctor or pediatrician give you printed matter on retardation?
   - Yes
   - No

   If so, did you find it helpful?
   - Yes
   - No
6. Check agencies recommended by your family doctor or pediatrician.

   _______a. Eastern Nebraska Community Office of Mental Retardation (ENCOR)
   _______b. Greater Omaha Association for Retarded Children (GOARC)
   _______c. Visiting Nurses' Association
   _______d. Meyer Children's Rehabilitation Institute (MCRI)
   _______e. Nebraska Psychiatric Institute (Genetic Counseling)
   _______f. Family & Child Services
   _______g. Jewish Federation
   _______h. United Catholic Social Services
   _______i. Lutheran Family and Social Services
   _______j. Other (please specify) __________________________________________
   _______k. None at all

Comments:

7. In a brief paragraph, give your opinion of your family doctor's or pediatrician's attitude towards your child.

8. Type of doctor to whom above questions refer.

   □ General Practitioner   □ Pediatrician   □ Obstetrician   □ Other Specialist