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AN ABSTRACT OF THE THESIS OF Connie Finley, Kay Jernigan, Effrosini Rotous, Bonnie Hogan and Daryle Steffen for the Master of Social Work presented May 15, 1970.

Title: A Follow-up Study of Families with Children Labeled Retarded

APPROVED BY MEMBERS OF THE THESIS COMMITTEE:

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Crippled Children's Division

The research problem undertaken was to study how effective the University of Oregon Medical School-Crippled Children's Division Clinic is by determining how well patients followed through on Clinic recommendations. Three research hypotheses were posed for testing.

- (1) There is a difference between income and the following of Clinic recommendations.
- (2) There is a difference between educational levels of fathers and mothers and the following of Clinic recommendations.
- (3) There is a difference in the level of I.Q. of patients and the following of Clinic recommendations.

A random sample of 100 cases was selected from the patients who had been through the Clinic prior to January, 1968. Case records were abstracted from the files of the University of Oregon Medical School-Crippled Children's Division, prior to personal interviews in the homes with the families using a standard questionnaire. The X^2 was used in testing the hypotheses and the findings resulted in no statistical difference between the three variables and the criteria of following recommendations. Therefore the null hypotheses were accepted.

A FOLLOW-UP STUDY OF FAMILIES WITH
CHILDREN LABELED RETARDED

by

CONNIE FINLEY, KAY JERNIGAN, BONNIE HOGAN,
EFFROSINI ROTOUS AND DARYLE STEFFEN

A thesis submitted in partial fulfillment of the
requirements for the degree of

MASTER OF SOCIAL WORK

Portland State University
1970

TO THE OFFICE OF GRADUATE STUDIES:

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Connie Finley, Kay Jernigan, Bonnie Hogan, Effrosini Rotous and
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May 15, 1970

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CHAPTER I

MENTAL RETARDATION: AN INTRODUCTION

Mental retardation is a national social welfare concern. The United States Department of Health, Education and Welfare estimated in 1962 that there were five million mentally retarded individuals in the nation. It was also estimated that there will be six million mentally retarded individuals in the country by 1970, half of whom will be children. It is a significant social concern since institutions provide care for approximately only 4% of the nation's mentally retarded.¹

There is increased movement away from the use of institutional care for the mentally retarded because of the expense involved and because society is growing to recognize a responsibility for providing resources which will enable the retarded to become a productive, law-abiding member of society and as fully functioning a human being as his potential will allow.²

An increased awareness of the prevalence of mental retardation in the nation led to recognition of the fact that federal leadership and financing were vital if this social concern was to be dealt with effectively. Federal legislation has been enacted which allocated funds for

¹The Secretary's Committee on Mental Retardation, Mental Retardation Programs of the U.S. Department of Health, Education and Welfare (Washington, U.S. Department of Health, Education and Welfare, Feb., 1962), p. 11.

²Robert Sidney Justice, "Coping Patterns of Parents of Mentally Retarded Children" (unpublished doctoral dissertation, University of Southern California, June, 1968), p. 2.

the development of research centers, for the improvement of hospital programs, for demonstration and pilot projects, and for the education of professional personnel. Federal funds were made available to states in 1963 for the purpose of developing comprehensive coordinated plans to deal with mental retardation on a statewide basis.³

The Oregon Association for Retarded Children is a member of the National Association for Retarded Children. OARC is composed of local county units in the State of Oregon and is active in behalf of Oregon's mentally retarded. In Sestabrooke's "President's Yearly Report to the Membership" of OARC, 1969, it was found that the area of emphasis during the past year has not coincided with the NARC's emphasis upon residential care for the mentally retarded.⁴ During the past year Oregon Association for Retarded Children has been instrumental in obtaining Title VI funds totalling \$126,765.00 which has been allocated to a variety of programs for Oregon's mentally retarded. Also, according to the president's report, a federal grant through the Department of Mental Health to OARC will provide for a teacher training program on behavior modification. A pilot project for employing mentally retarded in government agencies has been successful for the past four years on a federal level, and the president of the Oregon Association is also working toward a strong OARC which could implement such a demonstration project in Oregon.

On a state level, the Oregon Association has also been very active

³Justice, loc. cit., p. 3.

⁴"The President's Yearly Report to the Membership", 1969 Annual State Convention, May 16, 1969, A. Lee Sestabrooke, President of OARC.

in encouraging progressive legislation for the mentally retarded. During the 1969-70 session, a total of eighty-eight bills were introduced in the legislature which related to mental retardation in some manner. Two major bills were enacted into law; House Bill 1217 relating to the trainable retarded, and House Bill 1253 relating to parental financial responsibility. House Bill 1217 provides for contracting with the public schools and public or private agencies for education for the trainable retarded and for counseling for parents or guardians. House Bill 1253 limits parental financial responsibility for institutionalized children. It provides for a fee scale to be determined by the court based on net receipt of income tax; parents are required to pay until their child is 21 or for a 10 year period, whichever occurs last.⁵

On a county level, the Multnomah Association for Retarded Children was organized as a parent's movement in 1953. It preceded the development of OARC and was known as the Portland Association for Retarded Children until 1967. It grew from a membership of 12 parents to over 600 parents and is financed by membership dues, contributions, and the Tri-County United Good Neighbors. According to MARC, there were an estimated 3,300 school-age mentally retarded children in the City of Portland alone in 1967.⁶ According to the same source, there were also 1,000 children and adults from Multnomah County served at Oregon Fairview Home in Salem, Oregon.⁷

⁵Ibid.

⁶Multnomah Association for Retarded Children (pamphlet), June, 1967.

⁷Ibid.

STATEMENT OF THE PROBLEM

Those clinics and institutions which are responsible for developing programs for the mentally retarded are concerned with providing the best possible services for the retarded and their families. However, there has been very little information gathered about how the recipients of these services perceived them and the degree to which they were able to utilize them. Therefore, the present study was undertaken for the purpose of exploring parental attitudes toward the services their children received as they were evaluated at the University of Oregon Medical School-Crippled Children's Division Clinic (UOMS-CCD). Particular interest has been directed toward the utilization of Clinic recommendations and the impact of the Clinic's services upon subsequent family life. Some of the variables which might have affected the utilization of recommendations are:

- a) the degree of retardation of the child,
- b) the level of parental education, and
- c) the level of family income.

However, in the process of this study other variables were discovered to have significant influence upon parental decisions about whether or not to follow through with Clinic recommendations.

It was felt that this study would provide significant information about how the consumers of the Clinic's services perceived them and the extent to which they were able to utilize them. Since parents, in most instances, are those most directly involved in the care and planning for the retarded child, it seemed most important in an evaluation of existing programs to determine how they viewed the strengths and weaknesses

of those services available to them. It is expected that the information collected in this study will be helpful in providing a basis for improving the services currently extended by the UOMS-CGD Clinic to retarded children and their families.

REVIEW OF PERTINENT LITERATURE

Review of the literature has been undertaken in the area of parents' evaluation of the clinical services. Studies in this area are relevant to the present study.

James Grant, MSW and Evelyn Smith, MSW⁸ in a study at the Child Development and Mental Retardation Center, investigated the parents' action on clinic recommendations for additional psychiatric or social work service. They mentioned there that "although mental retardation diagnostic clinics do make referrals for psychiatric or social work services, there are no studies published on factors related to continuance or discontinuance in treatment from such referrals."⁹

The above authors found a significant correlation between the father's education and the following of recommendations. However, education of the mother did not relate to continuance in treatment.

They also found that those parents who participated in church activities are more likely to continue than those who do not ($p < .05$). Another variable that they found to influence the following of recommendations was the clarity with which the recommendations were made. Sev-

⁸James Grant and Evelyn Smith, "After Diagnosis-What?" Child Development and Mental Retardation Center. University Hospital, University of Washington (unpublished pamphlet).

⁹Ibid., p. 2.

eral other authors have also pointed out the need for clarity. (Barclay et al.,¹⁰ Graliker,¹¹ McIntire¹²).

Some additional findings in this study are that parents of children under five years old were more likely to discontinue treatment than the parents of older children, although this was not statistically significant. Also parents of children diagnosed as mildly mentally retarded discontinued treatment or did not follow the recommendations.

Some of the variables used in the above study are also used in the study at the UOMS-CCD Clinic. These are: education of parents and IQ of children. Furthermore some of the other questions in the study by Grant and Smith are also explored in the present study.

Barclay and associates reported a study in which parents evaluated the clinical services provided to their retarded children. Purpose of this study was to help the staff in evaluating the adequacy of services and also to find out how services can become more effective. The findings suggested that careful consideration of the psychological implications of the total diagnostic and evaluative process can expand knowledge of the underlying attitudes of parents that determine how effectively services can be implemented.¹³

¹⁰A. Barclay, L.R. Goulet, M.M. Aoltgrewe, and A.R. Sharp, "Parental Evaluation of Clinical Services for Retarded Children," American Journal of Mental Deficiency, 67, No. 2, (Sept. 1962), 232-237.

¹¹B.V. Graliker, A.H. Parmalee, and R. Koch, "Attitude Study of Parents of Mentally Retarded Children: II. Initial Reactions and Concerns of Parents to a Diagnosis of Mental Retardation," Pediatrics, 24, (1959), 819-821.

¹²M.S. McIntire and T.C. Kiekhaefer, "Parental Reactions to a Clinic for the Evaluation of the Mentally Retarded," Nebraska Medical Journal, 48, (1963), 69-73.

¹³A. Barclay, et al., op.cit.

A similar study was conducted by Caldwell, et al., in which also clinical services were evaluated. A questionnaire was sent to both parents and representatives of the agency. The question was whether the clinic was fulfilling its objectives.¹⁴ In the analysis of the results for this study, there was no association between the degree of satisfaction and clinic variables or number of children in the family. There was a significant correlation between the higher level of intelligence and younger age of the child, with greater parental satisfaction with clinic services.¹⁵

Koch, et al., conducted a study in which the parents' attitudes toward previous medical care was investigated. He used a sample of one hundred and five families of which the children had been seen in a special clinic for the retardate. What parents were told and How parents were told about their child was investigated in the study. It was shown in the findings that the parents were looking for a diagnosis and more information about the nature of mental retardation. As a result of these findings senior medical students had now to put emphasis on the etiology of mental retardation as well as on parental counseling.¹⁶

¹⁴B. Caldwell, E. Manley, and Y. Nisson, "Reactions of Community Agencies and Parents to Services in a Clinic for Retarded Children," American Journal of Mental Deficiency, 65, No. 5, (March, 1961), 582-589.

¹⁵Ibid., 590-594.

¹⁶R. Koch, B. Graliker, R. Sands, and A. Parmalee, "Attitude Study of Parents with Mentally Retarded Children: Evaluation of Parental Satisfaction with the Medical Care of a Retarded Child," Pediatrics, 23, No. 3, (March, 1959), 582-584.

STUDY QUESTIONS

The specific research questions posed for investigation in this study are:

1. Is higher income positively correlated with following Clinic recommendations?
2. Is the level of parental education affecting the following of Clinic recommendations?
3. Is the IQ of the patient related to the following of Clinic recommendations?

STUDY HYPOTHESES

Three hypotheses were developed in order to accomplish our purpose and answer the specific research questions which were posed.

1. H_0 There is no difference between income categories (above, below, median) and the following of Clinic recommendations.
 H_1 There is a difference between income categories (above, below, median) and the following of Clinic recommendations.
2. H_0 There is no difference between educational levels of father and mother and the following of Clinic recommendations.
 H_2 There is a difference between educational levels of father and mother and the following of Clinic recommendations.
3. H_0 There is no difference in the level of IQ of the child and the following of Clinic recommendations.
 H_3 There is a difference in the level of IQ of the child and the following of Clinic recommendations.

CHAPTER II

THE STUDY DESIGN

History and Operation of the University of Oregon Medical School- Crippled Children's Division

In 1963 a pilot program for mental retardation diagnostic services was established at the University of Oregon Medical School-Crippled Children's Division (UOMS-CCD). This program was the result of a dialogue between personnel from the Crippled Children's Division and the University of Oregon Special Education Department regarding mental retardation services for children. The philosophy of these concerned people can be best described in the following quote:

"Each child that is mentally retarded must be in as near a normal physical state as possible before he is able to learn to his maximum capacity."¹

In 1964 the staff's discussion culminated into a grant application from public health for a University affiliated center in mental retardation. The facility was to have a program focusing on diagnosis and clinic and teaching functions with the major emphasis on training professional persons to function in multiple discipline programs with the mentally retarded. The program was to emphasize the continual investigation of diagnosis and treatment procedures utilized in working with retarded

¹From information compiled by the UOMS-CCD Clinic and distributed in the form of a brochure.

children. A crucial aspect of the program was an examination of results in clinic processes, parent education training and follow-up activities.²

A planning grant was received from the Kennedy Foundation in 1964-65 to develop a training grant. Training support from the Children's Bureau was received in December, 1967. Presently, the center is being funded through a \$560,000.00 Children's Bureau grant. The center is a multi-discipline clinic where members of many different professions work together with both the child patient and the parents. It is staffed by people from the following professions: medicine, speech, dentistry, nursing, social work, psychology, audiology, occupational therapy, physical therapy, nutrition, special education, and genetics.³

Various kinds of services are provided by the UOMS-CCD. An active program of evaluation and limited treatment designed to help parents better understand and develop the child's abilities as much as possible are the primary services provided by the Clinic. Presently, the Clinic can only provide outpatient care. When the new building, which is currently under construction, is completed, inpatient services will be established at the facility. To keep the community abreast of activities and services of the Clinic, faculty members make presentations at institutes in the community for public welfare caseworkers, speech clinicians, physicians, and student nurses. Occasionally the Clinic has short educational programs for dietitians, dental hygienists, Licensed Practical Nurse volunteers, special education students, aids, and staff from the

²Ibid.

³Ibid.

state mental retardation residential facility, college and high school students.⁴

When a child is to be evaluated by the Clinic, the entire process is divided into two sections. During Phase 1, which is a six week program, the primary mission is outpatient diagnosis and treatment services. To accomplish this ten children are admitted to the program for a diagnosis. Five mornings for five weeks the children are functioning in a diagnostic classroom with the supervision of a special education teacher from 8:45 to 11:30 A.M. Throughout this time period students are taken individually and as needed by clinicians from the various disciplines for a specific diagnostic evaluation. The classroom educational activity is devoted to observation and task performance.

Also during Phase 1 parent-education services are provided both on a group and individual basis. During the first three weeks parent meetings are held to orient the parents to some of the procedures and test elements that the various disciplines use to evaluate the children. Mothers' and fathers' groups are organized to help parents work through some of their feelings and concerns about their child and the total family. During the sixth week, parents have two conferences with staff. One is with the staff concerned with the physical well-being of the child such as medicine, speech pathology, dentistry, and audiology. The other is with the staff concerned with the socio-psychological aspects of the child's functioning and includes psychology, social work, education and nursing. Other disciplines associated with the Clinic have had their summary conferences prior to the sixth week. However, during these

⁴Ibid.

last two conferences an integrated diagnosis and recommendation is given to the parents. After Phase 1 is completed there is a post-program parent conference to help parent integration of diagnostic findings. The parent group continues meeting once a week for three weeks in a group or individually after the completion of Phase 1.⁵

Phase 2 of the program involves assigning of families to social workers and psychologists when social and emotional problems exist within the family. Individual and group treatment programs are available to the parents if they so choose.⁶

These are the diagnostic services which the UOMS-CCD provides the mentally retarded child and its parents. This particular research group has done a follow-up study on 100 randomly selected families who have used the facility and its services to determine how effective and useful the Clinic has been to the consumer.

Description of the Community

The Area: Historically, the Oregon economy has been largely resource-oriented to forest and agricultural products. Early industries were fur trading, fishing, logging, and farming.⁷

The Portland area later grew to be a major distribution center for consumer goods and raw materials. However, in the past decade the economy of the area has been changing from primarily a distribution and ser-

⁵Ibid.

⁶Ibid.

⁷State of Oregon, Department of Commerce, Economic Development Division, The Oregon Economy and Outlook, 5th ed., March, 1968.

vice center to a growing manufacturing area, with impressive rates of growth in employment and output in manufacturing industries such as machinery, electronics, and fabricated metal products. Employment in these industries is increasing three and four times faster than the population growth in the area.⁸

Because of a well diversified economy, the well-being of the area is not wholly tied to any given industry. In order of importance it is impossible to rank Oregon's industries beyond the first three which are (1) forest products, (2) agriculture, and (3) tourism.⁹

Portland is Oregon's largest city, located on the Willamette River near its confluence with the Columbia River. It is 65 airline miles from the Pacific Ocean or 110 miles by deep-draft navigation by the Columbia River. It is the economic and financial center of the Metropolitan Portland region and is a major manufacturing and distribution center. The Portland urban area covers 436 square miles and the standard Metropolitan area covers 3,663 square miles. Industrial areas are heavily concentrated around the Columbia and Willamette Rivers in Portland. There was a 6.5% increase in total manufacturing employment in Metropolitan Portland during the summer of 1969, as compared with 2.6% in the nation.¹⁰ The total male and female employees in the labor force within the city limits was 149,796 of which 116,128 were private wage and salary workers, 13,060 were government workers, 14,690 were

⁸Ibid.

⁹Ibid.

¹⁰Portland, Oregon Industrial Location Facts File, Greater Portland Area, The Portland Chamber of Commerce, Jan., 1962.

self-employed workers, and 918 were unpaid family workers.¹¹

Within the city limits of Portland the population declined from 384,000 in 1967 to 377,800 in 1968 for a total decrease of 6,200 residents in Multnomah County just outside the city limits of Portland while the total population for the Metropolitan Portland area (which includes Multnomah Clackamas, and Washington Counties in Portland as well as Clark County in the State of Washington directly on the opposite side of the Columbia River from Portland) during this same period was increased by 26,945. The growth trend for Metropolitan Portland showed a population increase of 16.6% during the 1950-60 decade as compared with an increase of 21.1% during the 1958-68 decade.¹²

The median for the number of school years completed for this population was 12.0 (this median was the same for the whole of Multnomah County and nearly the same for the Metropolitan Portland area). Of the total population of 372,298 within the city limits, 351,379 were classified white (94.4%), 15,637 negro (4.2%) and 5,282 other (1.4%) (American Indians, Japanese, Chinese, Filipinos, Koreans, Asian Indians, and Malaysians).¹³

Resources: A full gamut of services is offered in the community. Major social services, both tax supported and privately supported, which serve the people of Clackamas, Multnomah and Washington Counties cover the following subjects: aged, alcoholism, child welfare, employment and

¹¹U.S. Bureau of the Census, U.S. Census of Population and Housing: 1960; Census Tracts, Final Report PHC (1)-121 (Portland), U.S.G.P.O., 1962.

¹²Ibid.

¹³U.S. Bureau of the Census, Op.Cit.

job training, family and personal problems, unmarried mother services, financial assistance, services for foreigners, handicapped, housing, inter-group services, legal advice, medical care, recreation and informal education, and veterans and armed forces. The Tri-County Community Council promotes the development, extension or modification of health, welfare and recreation services in accordance with community needs.¹⁴

To promote the general welfare of mentally retarded persons, there is the Multnomah Association for Retarded Children (MARC). It encourages development and expansion of services through public, private and religious organizations, sponsors and promotes programs for the retarded, and educates the public and parents of the retarded in better understanding of the problem through group meetings and special programs. It is a central resource of information regarding other programs for the mentally retarded in the community.¹⁵

Resources for retarded children within the city limits of Portland are varied, some of them encumbered with waiting lists and fees to parents, and heavily reliant upon private philanthropy. Some of the services offered are also limited in respect to the degree of retardation or its accompanying handicaps. Scholarship funds are sometimes available to parents through MARC or other private sources to help defray costs of services but such funds are limited.¹⁶

¹⁴"Where to Turn," a directory of health, welfare and recreation agencies, prepared by the Tri-County Community Council, 718 W. Burnside Street, Portland, Oregon, September, 1968.

¹⁵Information gathered from pamphlet and discussion with representative at MARC office, Community Service Center, 718 W. Burnside Street, Portland, Oregon

¹⁶Information gathered from pamphlet and discussion with representative at MARC office, Community Service Center, 718 W. Burnside Street, Portland, Oregon

There are camping programs sponsored by various groups such as The Salvation Army, Kiwanis, Easter Seal Society, Bureau of Parks, and Oregon Association for Retarded Children. Neighborhood House, Inc. offers recreation activities for both physically and mentally handicapped children from the age of three years upward. The Bureau of Parks sponsors the Mr. Portland Program which provides a ten week summer program as well as daily recreation programs throughout the area during the entire year for retarded children. Sometimes they use public facilities but always provide their own personnel to conduct the programs.¹⁷

Among those private school programs for the trainable retarded are Timmy Educational Center which is under the auspices of the Model Cities Program; Roecker Day School under the auspices of Westminster Presbyterian Church which has a \$60.00 monthly fee; Pilot Educational Program with a monthly fee of \$35.00; Neighborhood House which has a fee of \$18.00 annually and provides an every day living course for retarded children twice per week (parents pay for the cost of supplies); and then the following schools which all charge a monthly fee of \$50.00: Portland Children's Center, Emily School for Retarded Children, Flavel Drive Day Nursery, Happy Hollow Children's Center, and Jewish Community Center (Pre-School) which serves only about 20 retarded children.¹⁸ The Portland Public Schools, District #1, provide special classes for the educable mentally retarded in twelve high schools and in thirty elemen-

¹⁷Information gathered from pamphlets available at MARC office and telephone discussions with representatives of Bureau of Parks and Neighborhood House.

¹⁸Information gathered from pamphlets and discussion with representative at MARC office.

tary schools within the city. Although they are considering the addition of trainable programs to the special class system, a trainable program was not available through the public schools at the time of this writing.¹⁹

Private residential facilities for the retarded include Happy Hollow Children's Center, Our Lady of Providence Child Center, Waverly Children's Home, and Albertina Kerr Nursery Home.²⁰

There is a half-way house for retarded young men and one for young women. MARC also maintains a current list of sheltered workshops in the area, some of which serve the retarded.²¹

Selection of the Sample

A random sample of 100 cases was selected from 232 patients who went through the UOMS-CCD prior to January, 1968 and whose parents were and are still residing in the Portland Metropolitan area. In selecting the random sample, the card file in the Clinic was utilized. Standards for random selection of the sample was followed.²² In counting the cards in the file, when a non-Portland resident or foster home situation appeared, it was treated as non-existing. Each of the five students were randomly assigned twenty cases for which they gathered data from the Clinic records and then conducted the semi-structured interviews.

¹⁹Information obtained from representative of Portland Public Schools, Child Service Bldg., 220 N.E. Beech Street, Portland.

²⁰Pamphlets containing this information available at the MARC office.

²¹Ibid.

²²Young and Veldman, Introductory Statistics for the Behavioral Sciences, 423.

Source of the Data

Two questionnaires were developed to elicit information that would be an aid in answering the specific research questions which were posed. Questionnaire A was designed to secure the information which would be abstracted from the Clinic records. This information included such items as the degree of retardation, the Clinic's recommendations, identifying information about the family such as race, religion, and referral source to the Clinic. This information was abstracted largely from the final summary in the Clinic records. Questionnaire A was completed prior to Questionnaire B. Both copies, A and B questionnaires can be found in Appendix A and B.

Questionnaire B was completed during the 20-30 minute semi-structured interview with either or both parents held in their residence. This questionnaire includes identifying items about the background of the family: age of parents and children, education and occupation of the parents, total income of the family. Questions regarding opinion and attitude toward the helpfulness of the clinic were an important part of this questionnaire. Examples of this were specific areas in which the clinic may or may not have been helpful such as in understanding medical questions about their child or in planning for the child's future. An important item on this questionnaire was the family's understanding and recall of Clinic recommendations and whether they could have been presented in a more helpful manner. Another item on this schedule was the family's ability or inability to follow through on the recommendations. Questionnaire B was designed to elicit responses on the part of the parents which would be evaluative of the Clinic's

effectiveness.

Procedures

A uniform procedure was followed in attempting to locate the study subjects. Information regarding the current address and telephone numbers of the families was taken from the card file of the UOMS-CCD Clinic. Telephone contact was made with each family during which a statement was read identifying the purpose of the study and an appointment scheduled for the family interview. If the families were no longer using the same telephone number, an attempt was made to locate a current address and telephone number through the 1969 Portland Metropolitan Directory. If this was not successful, attempts were made to locate a current telephone number through the information operator. If no new listing was available, the interviewers went to the family's address to determine if that was still their place of residence.

The original sample was composed of 100 families and 59 eventually proved to be accessible for the study. The 40 families that were inaccessible fell into the following categories:

- a) Cannot locate: 19
- b) Moved out of town: 7
- c) Outside of city limits: 7
- d) Refused interview: 4
- e) Clinic advised against contact: 2
- f) Moved to foster care: 1

The first category, "Cannot locate", was determined by following the procedures described above. Seven families fell into the category "Moved out of town", with information regarding five of the families

secured from neighbors. The Telephone Company gave information that one family had left the city and information regarding the last family was secured from the card catalogue at the Clinic.

Contact with the Study Families

Initial contact with the study families was made by telephone during which time the student identified himself and described the purpose of the study and the auspices under which it was being conducted. Emphasis was placed upon the fact that the students did not directly represent the UOMS-CCD and that confidentiality would be maintained if the family chose to participate in the study. The following introduction was stated to each family. (See Appendix B, first paragraph) During this telephone contact, an appointment was arranged with the parent in their home in order to complete Questionnaire B.

The semi-structured interview with the mother lasted approximately 20-30 minutes. When meeting the parent in their home, identification of interviewers, the purpose of the study, and the auspices under which it was being conducted was again repeated. The parent was informed that the interview would be structured and the questions to be read to the interviewee from the interview schedule. The final page of Questionnaire B was left unattached during the interview. It had been determined that the impression of the interviewer regarding the parent's degree of cooperativeness would be recorded following the interview. It had also been determined that the parent should have access to the questionnaire if they wished to read it during the interview. An attempt was made to keep the attention focused on responding to the questionnaire. If the parent asked questions regarding her child's current needs, a referral

was made to the UOMS-CCD. At the completion of the interview, gratitude was expressed for the cooperation in the study.

Definition of Terms and Concepts

Income. Total approximate income from all sources. Income was broken down into seven categories.

IQ. Profoundly retarded children were defined as having an intelligence quotient of less than 20, severely retarded as those with an IQ of 20-35, moderately retarded as those with an IQ of 36-52, mildly retarded as those with an IQ of 53-68 and borderline as those with an intelligence quotient of 69-83.²³

Clinic Recommendations. The recommendations given to the parents in a conference at the end of the six week evaluation period by the Clinic staff. The recommendations found in the records which the Clinic made about any particular child fell into the following eleven categories:

- 1) Special School
- 2) Counseling
- 3) Special Care
- 4) Recreational Therapy
- 5) Physical Therapy
- 6) Dental Care
- 7) Speech Training
- 8) Special Diet
- 9) Hearing

²³Helen Rick, "A Manual on Terminology and Classification in Mental Retardation," Monogr. Suppl. to American Journal of Mental Deficiency (2nd ed., 1961), 59.

- 10) Eye Care
- 11) Others (Medication, Behavior Control, Surgery, Neurological Clinic, Foot Care)

Recording and Analysis of the Data

The nature of this study, being a survey, was descriptive as well as exploratory. It was descriptive in the sense that it attempted to determine how helpful the Clinic had been to this sample of families. It was exploratory in that hypotheses were developed to test whether certain factors hinder or facilitate the following of recommendations on the part of the parents. Additional hypotheses derived from the data can be tested in future studies. Consequently the analysis of the data has taken two principle forms, descriptive and inferential.

Responses of the interviewees were recorded by the interviewers at the time of the interview. There was also space provided in the questionnaire for the open ended questions. Seventeen tables based on the recommendations were constructed and frequencies were tabulated by hand. Eighteen additional descriptive tables were constructed in which descriptive data was recorded. This demographic data, such as age, sex, marital status was then cross-tabulated with Clinic recommendation, and degree recommendations were followed.

To test for the relationship between the criterion and the different variables the chi square test of association was employed. The $\alpha = .05$ level of significance was set in advance of the collection of the data.

Study Limitations

Most of the data obtained in this study was sought retrospectively.

The interviewees had to mention recommendations given to them in the past, and recall feelings and difficulties they experienced in the past. Memory necessarily plays an important role. A number of them might have forgotten what happened in the past or might be unable to perceive things the same way at the present time. This presents a limitation in the study.

A second limitation is that the findings of this study apply only to families residing in the Portland Metropolitan area where this study was conducted. It is not known how families from other communities who have utilized the UOMS-CCD Clinic, respond to recommendations. Distance from the Clinic as well as availability of resources in those communities might be some additional factors to hinder or facilitate following of recommendations. Therefore, to generalize these findings to other communities would have to be done most cautiously.

Another limitation is the inaccessibility of a great number of people included in the sample. There were 19 cases we could not locate, 7 that had moved out of town, 7 which were outside city limits, 4 who refused to be interviewed, 2 which the clinic advised us not to contact, and 1 which had moved to foster home. The largest category was composed of families who could not be located at their former addresses.

A problem we faced during the collection of the data, was with regard to the incomplete and non-standardized records that the Clinic keeps, i.e., lack of social history, source of referral. It was attempted to complete this by obtaining the information during the interview.

CHAPTER III

ANALYSIS

General Description of Study Population

Summary

Analysis of Criterion and Variables

Discussion of Research Questions and Hypotheses

Other Findings

Chapter three will present the analysis of this study. The first part consists of an analysis of the descriptive tables followed by a profile of the typical child and his family seen at the clinic. Next an analysis of relationship between the criterion, following Clinic's recommendations, and the different variables is presented. A discussion of the research questions, hypotheses, and other findings will end the chapter.

FIGURE I

LOCATION OF FAMILIES IN STUDY

The location on a census tract of the families of retarded children used in this sample (Figure 1) shows distribution quite evenly throughout the general population, with more families located in the more densely populated area and fewer families located where the population was less. The population of this area covered a wide distribution of income and housing characteristics. For families both contacted and not contacted, the retarded population was equally scattered.

TABLE I
AGE BY SEX

Age	Male	%	Female	%	Total
5-7	5	55	4	44	9
8-11	15	79	4	21	19
12-15	15	45	16	52	31
	35		24		59

Table I compares the age and sex of the patients. This refers to age at the time of evaluation. It reveals that the largest portion of males and females in the study are adolescents. Males comprise a significantly higher portion of the latency age children than females.

TABLE II
AGE BY I.Q.

Age	Less 20	%	20-35	%	36-52	%	53-68	%	69-83	%	84- above	%	Unknown	%	Total
5-7	0		0		4	44	2	22	1	11	0		2	22	9
8-11	0		3	16	9	47	5	26	2	11	0		0		19
12-15	1	.03	2	7	11	34	10	38	5	14	1	.03	1	.03	31
	1		5		24		17		8		1		3		59

Table II compares the age and I.Q. of the patients at the time of evaluation. It reveals that the largest number of all age groups fall in the middle range of retardation; i.e., 36-68 I.Q. Only one patient was in the severely retarded range and only one in the dull normal range.

TABLE III
I.Q. BY RACE

I.Q.	White	%	Black	%	Total
Less 20	1	100		0	1
20-35	5	100		0	5
36-52	24	100		0	24
53-68	16	94	1	6	17
69-83	7	87	1	12	8
84 and above	1	100		0	1
Not Recorded	2	66	1	33	3
	56		3		59

Table III is a comparison of I.Q. and race. The ratio of blacks to whites in the Portland Metropolitan area is 1:37. This table shows that there has been a better than average representation of blacks in the program. This finding is supported by a recent study which found no differences between the total population and a clinic's sample for race.¹

¹R.S. Justice, D.S.W., M.M. Campbell, Ph.D., Gail O'Connor, M.A., Eugene Sabotta, M.A., A Look at the Population Served by a University Clinic for Retarded Children; Mental Retardation (in press).

TABLE IV
NUMBER OF CHILDREN IN FAMILY

Number of Children in Family	Sample Number of Families
1	1
2	11
3	19
4	13
5	5
6	5
7 or over*	5
	59

*Family of 15 children

TABLE V
PATIENTS RANK AMONG SIBLINGS IN FAMILY

Rank	Number in Sample
1st	12
2nd	2
Middle	10
2nd to Last	9
Last	26
	59

Tables IV & V describe the number of children in the study families and the rank of the patient among his siblings, respectively. The number of children per family occurring most frequently is "three". The largest number of patients in our study were composed of the last child born in the family. The next largest category of patients were middle children.

TABLE VI
FATHER'S AGE BY EDUCATION (YEARS)

Age	1-8	%	9-12	%	13-16	%	Over 16	%	Unknown*	%	Total
29-39	5	24	11	53	4	17	1	.05	0		21
40-49	2	9	7	33	9	43	3	14	0		21
50-59	2	14	6	42	5	36	1	7	0		14
60 & Above	0		1	100	0		0		0		1
Deceased	0		1	100	0		0		0		1
Unknown**	0		0		0		0		1	100	1
	9		26		18		5		1		59

*The "*Unknown" refers to those wives who did not know the level of their husband's education.

The category "*Unknown" refers to those wives who refused to discuss the issue because of a divorce from their spouse.

Table VI compares the age and education of the patients' fathers. Fathers in the middle-age range (40-59) tend to be in the higher educated bracket. The largest number of fathers in the study have had some high school and some college education.

Speculation on why the younger fathers have less education could be the lack of emphasis on higher education during this era. This is about the time 'dropouts' became increasingly high and there appears more flexibility on the need for education during the latter years than in the 50's.

TABLE VII
MOTHER'S AGE BY EDUCATION (YEARS)

Age	1-8	%	9-12	%	13-16	%	Over 16	%	Total
27-39	4	14	20	71	4	14	0	0	28
40-49	1	5	13	62	5	24	2	9	21
50-59	1	10	6	60	3	30	0	0	10
60-Above	0		0		0		0		0
	6		39		12		2		59

Table VII compares the age and education of the patients' mothers. The largest number of mothers in the study fall into the secondary education bracket. It also reveals that there are twice as many mothers who have had some college education as those who have had only elementary education.

TABLE VIII
OCCUPATION STATUS OF PARENTS

Occupation	Fathers	%	Mothers	%
Professional Managerial	22	37	2	3
Salesman Craftman Operatives	16	27	2	3
Private Household Service Workers	9	15	14	24
Laborers	7	12	1	2
Aid Unemployed Retired Housewife Student	3	5	40	68
Deceased Unknown	2	3	0	
	59		59	

Table VIII shows that 37% of the fathers in the studied population held positions in the professional or managerial area, whereas only 6% of the mothers of the studied population held positions in the same category. This would seem to be expected results. Sixty-eight percent of the mothers were unemployed and remain home as housewives.

TABLE IX
FAMILY INCOME

Income - Yearly	Families	%
(1) Under \$2,000	0	0
(2) \$2,000 - \$3,999	4	7
(3) \$4,000 - \$5,999	3	5
(4) \$6,000 - \$7,999	12	20
(5) \$8,000 - \$9,999	13	22
(6) \$10,000 - \$11,999	12	20
(7) \$12,000 & Over	15	25
	59	

Table IX shows that 45% of the families studied have incomes of \$10,000 or over. This would seem to follow with the high percentage of professional and managerial positions seen in Table VIII. The average income per worker per capita in the Portland area during 1969 period of time is \$4,000², indicating a large majority of families seen at the Clinic tend to be of about the same income bracket of that of the average Portlander. Only 7% fell in below average bracket.

²This date was obtained from the Portland Chamber of Commerce, Research Department. Income per worker per capita is found by dividing the population into the states personal income tax. The average family in the Portland area is 3.09.

TABLE X
I.Q. BY SOURCE OF REFERRAL

I.Q.	Physician	%	School	%	Friend	%	Others	%	Total
Less 20	0	0	0	0	0	0	1	100	1
20-35	4	80	1	20	0	0	0	0	5
36-52	8	33	4	17	3	12	9	37	24
53-68	8	47	7	41	0	0	2	12	17
69-83	5	62	2	25	0	0	1	12	8
83 & Above	0	0	1	100	0	0	0	0	1
Unknown	1	33	1	33	0	0	1	33	3
	26		16		3		14		59

Table X shows that of the cases referred most I.Q.'s fall into the 36-52 (Mild-Moderate) category. It also shows that few cases fall into the borderline or into the severely retarded category. The majority of referrals were made by physicians.

TABLE XI
SOURCE OF REFERRAL BY SEX

Source of Referral	Male	%	Female	%	Total
Physician	17	65	9	35	26
School	7	44	9	56	16
Friend	2	66	1	33	3
Others*	9	64	5	36	14
	35		24		59

*The category of "Others" includes self-referrals, social service agencies, specialty clinics or the Medical School.

Table XI compares the sex of the patient with the source of referral to the clinic. The largest number of males were referred by physicians. Of females referred, an equal number were referred by schools and physicians.

TABLE XII
SOURCE OF REFERRAL BY AGE

Source of Referral	5-7	%	8-11	%	12-14	%	15 & Over	%	Total
Physician	5	19	10	39	9	35	2	8	26
School	1	6	4	25	11	69	0	0	16
Friend	1	33	0	0	2	67	0	0	3
Others*	2	14	5	36	7	50	0	0	14
	9		19		29		2		59

*The category of "Others" includes specialist clinics or the Medical School, self-referrals, and social service agencies.

Table XII compares the age of the patient at the time of evaluation with the referral source. Physicians were the largest overall referral source to the Clinic. In early adolescence, the school became the largest referral source. Friends were a very small proportion of referrals.

TABLE XIII
SOURCE OF REFERRAL BY RESOURCES
FAMILIES CONTINUE TO
SEE CURRENTLY

Source of Referral*	Physician	%	School	%	Clinic	%	Others	%	Total
							No One7 Specialist3 Med. School Outpatient1		
Physician	14	40	5	14	11	31	5	14	35
School	9	37	4	17	7	29	4	17	24
Friend	2	40	1	20	1	20	1	20	5
Others*									
Self-referrals6									
Specialist Clinic5									
Social Service Agency ..2									
Unknown1	9	45	2	10	5	25	4	20	20
	34		12		24		14		84

*It should be noted that families tend to consult more than one source which accounts for the total of 84 instead of the expected 59.

Table XIII compares the source of referral and the resources the family currently sees for related problems. The largest number of study families were referred by physicians and continue to consult physicians for related problems.

TABLE XIV
NUMBER OF CLINIC'S RECOMMENDATIONS
BY SPECIFIC DIAGNOSIS*

Recommendations	Symptoms		Laboratory Tests		Physical Symptoms		Syndromes		Neurological Symptoms		Speech Symptoms		No Particular Diagnosis		Total
		%		%		%		%		%		%		%	
1	1	50	0	0	1	50	0	0	0	0	0	0	0	0	2
2	0	0	2	33	2	33	1	17	1	17	0	0	0	0	6
3	1	.06	2	11	9	50	3	17	2	11	0	0	1	.06	18
4	5	11	7	15	15	33	7	15	8	17	1	.02	3	.06	46
5	5	13	8	22	11	26	6	16	7	.19	1	.03	0	0	38
6 or more	4	15	5	19	8	31	3	12	5	19	1	.04	0	0	26
	16		24		46		20		23		3		4		136**

*See Appendix C for definition of each specific medical diagnosis.

**Many patients were given more than one specific medical diagnosis.

Table XIV is a comparison of the number of clinic's recommendations and specific medical diagnosis. As expected, those patients who presented more symptoms received more recommendations from the Clinic.

TABLE XV

I.Q. BY NUMBER OF RECOMMENDATIONS BY CLINIC

I.Q.	1		2		3		4		5		6 or More		Total
	%		%		%		%		%		%		
Less 20	0	0	0	0	0	0	0	0	1	100	0	0	1
20-35	0	0	0	0	1	20	1	20	2	40	1	20	5
36-52	1	4	0	0	6	25	8	29	6	25	3	12	24
53-68	0	0	2	12	3	18	7	41	1	6	4	23	17
69-83	1	12.5	0	0	1	12.5	4	50	1	12.5	1	12.5	8
84 or Above	0	0	0	0	0	0	1	100	0	0	0	0	1
Not Recorded	0	0	0	0	0	0	2	67	0	0	1	33	3
	2		2		11		23		11		10		59

Table XV shows that the large majority of patients that were seen at the Clinic had at least three or more recommendations. The average number of recommendations per patient is 4.1. Although the number is small there seems to be some trend toward the lower I.Q.'s (35 or below) receiving more recommendations. Recommendations given by the Clinic consisted of such categories as schooling, counseling, institutionalization, dental care, speech therapy, special diet, recreational therapy, hearing care, and eye care.

TABLE XVI
I.Q. BY NUMBER OF RECOMMENDATIONS

I.Q.	1-2	3	4	5	6	Total
0-35 Severe	0	1	1	3	1	6
36-52 Moderate	1	6	8	6	3	24
53 Mild	3	4	12	2	5	26
Total	4	11	21	11	9	56

Table XVI showed no statistical significance between I.Q. and number of recommendations made by the Clinic. More patients (26) were in the mildly retarded range with an average of 4 recommendations.

TABLE XVII
I.Q. BY SPECIFIC MEDICAL DIAGNOSIS**

I.Q.	Behavior Symptoms		Laboratory Tests		Physical Symptoms		Syndromes		Neurological Symptoms		Speech Symptoms		No Particular Diagnosis		Total
	%		%		%		%		%		%		%		
Less 20	0	0	1	25	1	25	1	25	1	25	0	0	0	0	4
20-35	1	10	1	10	3	30	3	30	2	20	0	0	0	0	10
36-52	6	11	9	16	20	36	8	14	11	20	1	2	0	0	55
53-68	5	12	10	24	13	32	3	7	8	20	1	2	1	2	41
69-83	2	10	3	16	7	37	3	16	1	5	1	5	2	10	19
84 or Above	0	0	0	0	0	0	0	0	0	0	0	0	1	100	1
Not Recorded	2	33	0	0	2	33	2	33	0	0	0	0	0	0	6
16		24		46		20		23		3		4		136*	

*Many patients were given more than one specific medical diagnosis.

**See Appendix C for specific medical diagnosis.

Table XVII indicates that more physical symptoms were diagnosed than any other category. "Physical Symptoms" refer to findings which involve eyes, mouth, ears, heart and bones. (See Appendix C for further information). Those patient presenting the largest number of physical symptoms were within the moderately retarded range; i.e., 36-52 I.Q.

PROFILE OF THE TYPICAL CHILD AND HIS FAMILY

This study reveals that the typical patient evaluated at the UOMS-CCD is a caucasian adolescent with an I.Q. in the moderate range; i.e., 36-52. The Clinic arrived at four recommendations concerning him. The study families were typically composed of three children and the patient's rank among his siblings was generally last. The child's mother has a high school education and is a homemaker. His father has had some college and holds a professional position. The family's income is approximately \$10,000 a year. The child was referred by a physician and his family continue to consult a physician for related problems.

TABLE XVIII

PATIENT'S AGE VS. FOLLOWING OF RECOMMENDATIONS

Age of Child	FOLLOW RECOMMENDATIONS			Total
	100%-75%	74%-26%	25%-0%	
(1) 5-7	3	3	3	9
(2) 8-11	4	7	8	19
(3) 12-15	4	14	13	31
Total	11	24	24	59

$$x^2 = 2.13 \quad df = 4 \quad x^2 \text{ not significant at } \alpha = .05$$

In Table XVIII the correlation between the ages of the patients and the following of recommendations was not statistically significant. A very small proportion of the parents whose child was 12-15 years old followed 75-100% of the recommendations.* Also there were more children in this age category who went through the Clinic.

*This finding is not supported in the literature.³

³James Grant & Evelyn Smith, "After Diagnosis - What?" Child Development and Mental Retardation Center, University Hospital, University of Washington. (Unpublished pamphlet)

TABLE XIX

I.Q. VS. FOLLOWING OF RECOMMENDATIONS

I.Q.	Follow Recommendations										Total
	100% - 75%		74% - 26%		25% - 0%						
	%	%	%	%	%	%	%	%	%		
(1) Profound- Less than 20	0		4	1	100		0				1
(2) Severe 20-35	0		12	3	60	8	2	40			5
(3) Moderate 36-52	36	4	17	50	12	50	33	8	33		24
(4) Mild 53-68	27	3	21	16	4	23	41	10	57		17
(5) Borderline 69-83	36	4	50	8	2	25	8	2	25		8
(6) Not Recorded*	0		8	2	66	4	1	33			3
(7) Above 83	0			0		9	1	100			1
Total	11		24		24		59				

*Not included in the analysis.

Table XIX shows most of the children seen at the Clinic were in the I.Q. range of moderate to mild retardation. Twenty-four of the children had I.Q.'s of 36-52 and seventeen were in the range of 53-68. Only one child was profoundly retarded. There is an indication that parents of those children falling in the 36-52 I.Q. range tended to follow through with Clinic recommendations more consistently than others. It is interesting to note that those in the mildly retarded category (44%) did not follow through as consistently as in the moderate category (67%). This is seen also in the study done by Grant and Smith.⁴ Reason for this can only be speculated upon. Possibly those parents of mildly retarded children more easily fit into the normal family roles as they are able to attend regular school and lead a more normal life in the family role. The disruption in the family is not as great as they are in the more retarded child. It also could indicate those of the moderate range are more obviously retarded requiring the need to follow recommendations more consistently.

⁴Op.Cit.

TABLE XX
FAMILY STRUCTURE VS. RECOMMENDATIONS FOLLOWED

Family Structure	Recommendations Followed						Total
	100%-75%	%	74%-26%	%	25%-0%	%	
(1) Married	8	15	21	40	24	45	53
(2) Other*	3		3		0	0	6
Total	11		24		24		59

*Other includes: Divorced 2
Stepfather 1
Deceased Father 1
Separated 2

Table XX shows 89% of the families studied were married at the time of the interview. Although the sample of "Others" is small, they tend to follow more of the Clinic's recommendations. A possible reason for this might be the mother trying to compensate for the lack of the real father in the home, thus placing more responsibility on the mother. Grant and Smith found that mothers in families who had less satisfying marriages followed recommendations for additional psychiatric or social work services better than mothers who rated their marriages as satisfying. Perhaps mothers are more motivated to follow Clinic recommendations when they have to assume the full burden.⁵

⁵Op.Cit.

TABLE XXI

FATHER'S AGE VS. FOLLOWING OF RECOMMENDATIONS

Father's Age	Follow Recommendation			Total
	100%-75%	74%-26%	25%-0%	
27-39	5	8	8	21
40-49	1	12	8	21
50-62	3	4	8	15
Total	9	24	24	57*

* $\chi^2 = 5.31$ $df = 4$ χ^2 not significant at $\alpha = .05$

TABLE XXII

MOTHER'S AGE VS. FOLLOWING OF RECOMMENDATIONS

Mother's Age	Follow Recommendation			Total
	100%-75%	74%-26%	25%-0%	
27-39	6	11	11	28
40-49	3	10	8	21
50-62	2	3	5	10
Total	11	24	24	59

$\chi^2 = 1.14$ $df = 4$ χ^2 not significant at $\alpha = .05$

Tables XXI and XXII show there is no statistically significant relationship between parents age and following through with recommendations. There is a trend toward fathers and mothers in the age range of 27-39 to follow through more consistently than older parents. As would be expected, the fathers ages are slightly older than the mothers ages, with 15 fathers in the age range of 50-62 and only 10 in the same age range for mothers.

TABLE XXIII

FATHER'S OCCUPATION VS. FOLLOWING OF RECOMMENDATIONS

Father's Occupation	100%-75%	Follow Recommendations				Total	
		%	74%-26%	%	25%-0%		%
1) Professional							
Managerial	3	14	11	50	8	36	22
Salesman							
2) Craftman							
Operatives	2	12	6	38	8	50	16
3) Private Household							
Service Workers	4	44	2	22	3	33	9
4) Laborer			3	43	4	57	7
Aid							
5) Unemployed							
Retired							
Housewife							
Student			2	67	1	33	3
6) Deceased and/or							
Unknown	2	100					2
Total	11		24		24		59

There appears to be a trend in Table XXIII of father's whose occupations are unskilled, retired, or unemployed, not to follow recommendations, as compared to those in the skilled, managerial, and professional occupations. Percentage wise, father's whose occupations are service workers, or private household skills tend to follow through with recommendations more consistently than those of higher status occupations. This can possibly be accounted for in viewing Farber's⁶ study in which he concluded that families of higher status have lower tolerance for deviance. Families of higher status place greater importance to assigned roles of family membership in the maintenance of the norms and values. In lower status families, there is greater tendency to emphasize the immediate wants and needs of the family members and less emphasis on status maintenance.

⁶Bernard Farber, "Effects of a Severely Retarded Child on Family Integration," Monograph of the Society for Research in Child Development, 24, No. 2, 1959 and Bernard Farber, "Family Organization and Crisis: Maintenance of Integration in Families with a Severely Mentally Retarded Child," Monograph of the Society for Research in Child Development, 25, No. 1, 1960.

TABLE XXIV

MOTHER'S OCCUPATION VS. FOLLOWING OF RECOMMENDATIONS

Mother's Occupation	Follow Recommendations					Total
	100%-75%	% 74%-26%	% 25%-0%	%		
1) Professional Managerial	0	0	0	0	2	2
2) Salesman Craftman Operatives	0	0	1	50	1	2
3) Private Household Service Workers	2	14	3	21	9	14
4) Laborers	0	0	1	100	0	1
5) Aid Unemployed Retired Housewife Student	9	22	19	47	12	40
Total	11	24	24			59

Table XXIV indicates that most of the mothers in the studied families are in the housewife category. There seems to be a trend toward the unemployed mothers following through with more of the Clinic's recommendations in comparison to working mothers, although it is not statistical. Note that the two mothers in the professional category did not follow through with even 0 to 25% of the Clinic's recommendations.

TABLE XXV
INCOME VS. FOLLOWING OF RECOMMENDATIONS

Income Categories	Follow Recommendations						Total
	100%-75%	%	74%-26%	%	25%-0%	%	
1) 0-5,999	1	14	3	43	3	43	7
2) 6,000-9,999	5	20	11	44	9	36	25
3) 10,000-12,000 & Above	5	19	10	36	12	44	27
Total	11		24		24		59

$$x^2 = .496 \quad df = 4 \quad x^2 \text{ not significant at } \alpha = .05$$

Table XXV compares income categories and following of recommendations. The seven different categories in the questionnaire were combined into three categories and x^2 was applied. No statistical significance was found in the following of recommendations by families with either higher or lower income. See Table IX for frequency distributions.

TABLE XXVI
HOME OWNERSHIP VS. FOLLOWING RECOMMENDATIONS

Home	Follow Recommendations						Total	
	100%-75%	%	74%-26%	%	25%-0%	%		
1) Renting	1	14	3	43	3	43	7	12
2) Purchasing	6	17	13	36	17	47	36	61
3) Own	4	25	8	50	4	25	16	27
Total	11		24		24		59	

Eighty-eight percent of the families studied either owned their homes or were in the process of purchasing one. Twenty-seven percent of the families had paid up mortgages. This seems to be a rather high percentage but does go along in conjunction with Table IX and high income. There appears to be a trend of those who own their homes tended to follow recommendations more consistently than those renting or purchasing.

TABLE XXVII
EDUCATION VS. FOLLOWING OF RECOMMENDATIONS

Father's Education	Follow Recommendations			Total
	100% - 75%	74% - 26%	25% - 0%	
(1) Under 8th Grade	0	3	5	8
(2) H.S. Completed Grades 9-12	6	10	9	25
(3) College Graduates 13-16				
(4) Over 16	4	11	10	25
(5) Unknown	1	0	0	1
Total	11	24	24	59

$\chi^2 = 3.196$ $df = 4$ χ^2 not significant at $\alpha = .05$

Mother's Education	Follow Recommendations			Total
	100% - 75%	74% - 26%	25% - 0%	
(1) Under 8th Grade	0	2	4	6
(2) H.S. Completed Grades 9-12	8	15	14	37
(3) College Graduates 13-16				
(4) Over 16	3	7	6	16
Total	11	24	24	59

$\chi^2 = 2.521$ $df = 4$ χ^2 not significant at $\alpha = .05$

With regard to father's education and the following of recommendations Table XXVII shows there is no statistical significance. The same is true in regard to the mother's education and the following of recommendations as seen in Table XXVII. In the statistical analysis of the data, categories 3 and 4 (college education) were combined and the "Unknown" category was not included in the analysis. There does seem to be a trend of both parents with below 8th grade education of not following recommendations. Also 50% of the fathers with over 16 years of education did not follow recommendations as consistent as high school or college graduates. This same tendency holds true with regard to the mother's education. One of the explanations for this phenomenon might be that parents with higher education appeared to be more sophisticated and had already researched most of the resources in the area of mental retardation. On the other hand, for parents with lower education, following recommendations for their retarded child might not have been a top priority problem nor may it have presented the stigma to the family.

TABLE XXVIII
SOURCE OF REFERRAL VS. FOLLOWING OF RECOMMENDATIONS

Source of Referral	%	F o l l o w R e c o m m e n d a t i o n s								Total	
		100%-75%	%	%	74%-26%	%	%	25%-0%	%		
(1) Physician	36	4	18	21	5	23	54	13	59	22	
(2) School	18	2	12	29	7	43	29	7	43	16	
(3) Friends	9	1	12	25	6	75	4	1	12	8	
(4) Other											
Self-Ref.	6										
Soc. Agency	2										
Spec.Clinic	5	36	4	30	25	6	46	13	3	23	13
Total		11			24			24		59	

Table XXVIII shows the relationship between source of referrals and the following of recommendations. The category of "Others" includes 6 self-referrals, 2 social service agencies, and 5 specialist clinic referrals. There appears to be a tendency for those in the "Others" category to follow the recommendations more consistently than those referred by physicians or schools. This could be because the families in the "Others" category were more motivated as they had initiated some action or were involved in seeking some kind of help on their own. More patients were referred by physicians, followed by school referrals. Fifty percent of the physicians referrals followed only 0-25% of the recommendations made.

TABLE XXIX

USEABILITY OF CLINIC RECOMMENDATIONS VS.
FOLLOWING RECOMMENDATIONS

		Follow Recommendations							
		100-75%	%	74-26%	%	25-0%	%	Total	%
(1)	Yes	8	17	22	48	16	35	46	78
(2)	No	3	23	2	15	8	61	13	22
Total		11		24		24		59	

In Table XXIX, seventy-eight percent of the families in the study stated they were able to use the Clinic's recommendations. It is interesting to note that although this high percentage stated they were able to use the recommendation, thirty-five percent of them followed through with only 0-25% of recommendations offered. Perhaps this could be a lack of motivation on the part of the parents. Three families stated they were not able to use the Clinic's recommendation but were able to follow through with 75% or more of the ones given. This could be a misinterpretation of the question - meaning able to follow through with all recommendations. Some of the reasons given for not being able to make use of Clinic recommendations were lack of money, unable to place child in suggested school, unwillingness on the part of the parent to put child in recommended placement, and inability to recall or understand Clinic's recommendations.

TABLE XXX

PRESENTATION OF RECOMMENDATIONS VS.
FOLLOWING RECOMMENDATIONS

Could Recomm. Have Been Presented in a Better Way?	Follow Recommendations									
	%	100-75%	%	%	74-26%	%	%	25-0%	%	Total
(1) Yes - Dissatisfied	10	1	10	17	4	37	25	6	54	11
(2) No - Satisfied	90	10	21	83	20	42	75	18	37	48
Total		11			24			24		59

Table XXX compares the way recommendations were presented and the following of recommendations. This table shows that 48 families were satisfied with the way recommendations were presented. It also shows that those who were satisfied tended to follow more recommendations.

Some of the suggestions dissatisfied parents made were:

- a) Seven parents said that more clarified permanent reports were necessary.
- b) Two asked for more information with regard to resources in the community and follow-up appointments.
- c) One complained about the staff's approach as needing to be changed.

TABLE XXXI

AREAS WHICH CLINIC WAS HELPFUL VS. FOLLOWING RECOMMENDATIONS

A. Medical Questions Vs. Following Recommendations

	Following Recommendations			Total
	100%-75%	74%-26%	25%-0%	
Yes	8	16	13	37
No	3	8	11	22
Total	11	24	24	59

$$x^2 = 1.38 \quad df=2 \quad NS$$

B. Planning for Child Vs. Following Recommendations

	Following Recommendations			Total
	100%-75%	74%-26%	25%-0%	
Yes	5	15	9	29
No	6	9	15	30
Total	11	24	24	59

$$x^2 = 3.07 \quad df=2 \quad NS$$

C. Caring for Physical Need Vs. Following Recommendations

	Following Recommendations			Total
	100%-75%	74%-26%	25%-0%	
Yes	8	16	6	30
No	3	8	18	29
Total	11	24	24	59

$$x^2 = 10.92 \quad df=2 \quad P < .01$$

D. Caring for Emotional Needs Vs. Following Recommendations

	Following Recommendations			Total
	100%-75%	74%-26%	25%-0%	
Yes	8	12	9	29
No	3	12	15	30
Total	11	24	24	59

$$x^2 = 3.76 \quad df=2 \quad NS$$

TABLE XXXI - Continued

E. Other Vs. Following Recommendations				
	Following Recommendations			
	100%-75%	74%-26%	25%-0%	Total
Yes	2	2	5	9
No	9	22	19	50
Total	11	24	24	59

Table XXXI shows there was no statistical significance between the Clinic's helpfulness in the areas of medical questions, future planning, emotional needs and the following of recommendations. There does seem to be a trend toward not following the recommendations in areas where the parents felt the Clinic had not been helpful. In the area of caring for physical needs and the following of Clinic recommendations a statistical significance of $P < .01$ is seen. This could happen just by chance. The category which seems to be of most help to the parents was helping to understand the medical questions. The category of "Others" allowed parents to relate their individual opinions on where they felt the Clinic had helped them. This category was not included in the statistical analysis. Some of the responses to this category were: helped parents to better understand their child's problem, specific help by Clinic in speech, dental care, and school placements.

TABLE XXXII

DISSATISFACTION OF CLINIC'S PROGRAM BY PARENTS
VS. FOLLOWING RECOMMENDATIONS

Aspects of Clinic's Program Parents Disliked							
		Follow Recommendations					
A. Way they were treated by staff	100-75%	%	74-26%	%	25-0%	%	Total
1) Yes	0	0	0	0	0	0	0
2) No	11	19	24	41	24	41	59
B. Way child was treated							
1) Yes	0	0	1	100	0	0	1
2) No	11	19	23	39	24	41	<u>58</u> 59
C. Quality of care child received							
1) Yes	0	0	0	0	0	0	0
2) No	11	19	24	41	24	41	59
D. Scheduling of sessions							
1) Yes	0	0	1	50	1	50	2
2) No	11	19	23	39	23	39	<u>27</u> 59
E. Others:							
1. Clinic lacks understanding of child...5							
2. Inappropriate or wrong diagnosis..5							
3. Clinic needs further follow-up care & clarification.....7							
4. Personal complaints - no coffee - transportation difficulties...2							
1) Yes	4	23	8	47	5	29	17
2) No	7	17	16	38	19	45	42
Total	11		24		24		59

Table XXXII indicates that most of the families studied were satisfied with the Clinic's program in regard to how the staff treated the family, as well as the care and consideration given to both family and child. There were a few areas which some of the families felt the Clinic could be improved. These included better understanding of the child by the Clinic, more appropriate diagnosis, need for follow-up care and clearer interpretation of the problem. This, in itself, did not have any statistical significance whether recommendations were or were not followed.

TABLE XXXIII

DEGREE CLINIC HELPED PARENTS TO UNDERSTAND CHILD
VS. FOLLOWING OF RECOMMENDATIONS

Degree that Clinic Helped Parents to Understand Child	Follow Recommendations			Total
	100%-75%	74%-26%	25%-0%	
(1) Much	9	12	17	38
(2) Some	0	8	4	12
(3) Little	2	4	3	10
Total	11	24	24	59

$$\chi^2 = 6.05 \quad df = 4 \quad \chi^2 \text{ not significant at } \alpha = .05$$

In Table XXXIII the degree to which the Clinic helped parents to understand their child--on a scale from "Much" to "Little"-- there was no statistical significance between the parents perception of the degree they were helped vs. the following of recommendations. Of 38 parents who indicated that the Clinic helped them much, 17 of these same parents did not follow any recommendations. This may have been due to parents disagreeing with the diagnosis or not finding resources available to follow recommendations. Of those who indicated that they were not helped, they complained that the diagnosis was either wrong or unspecific; they did not understand the Clinic; or the program offered no help or alternatives for help.

TABLE XXXIV

CHANGES IN CHILD AND FAMILY LIFE VS. FOLLOWING RECOMMENDATIONS

		Follow Recommendations									
Changes in Family Life Since Child Seen at the Clinic	%	100-75%	%	%	74-26%	%	%	25-0%	%	Total	%
1) Yes - There were changes	63	7	25	46	11	39	42	10	36	28	47
2) No - There were not changes	36	4	13	54	13	42	58	14	45	31	53
Total		11			24			24		59	

$$\chi^2 = 1.50 \quad df = 2 \quad \chi^2 \text{ not significant at } \alpha = .05$$

In Table XXXIV, there was no statistically significant correlation between changes in family life since the child was seen at the Clinic and following recommendations of the Clinic. There were 28 families who felt their family life had changed since they have been to the Clinic. Some of the changes the family experienced were in the areas of 1) family understanding of the patient's emotional and physical problems, 2) better acceptance of the child with his limitations, 3) an awareness of the child's needs such as speech therapy, special schools, and medication. Of those parents who followed 75-100% of the Clinic's recommendations, 63.6% indicated that there were changes in family life since the Clinic had seen them.

STUDY QUESTIONS

- I. Is higher income correlated with the following of recommendations?
- II. Is the I.Q. of the patient related to the following of Clinic recommendations?
- III. Is the level of parental education affecting the following of Clinic recommendations?

I. From the data gathered it was determined that there is no statistical significance between higher income and the following of recommendations. This appears to be so even though 50% of the families have incomes of \$10,000.00 or more. Although 27% owned their homes, there again is no statistical significance to home ownership and the following of recommendations. However, there appears to be a trend indicating that individuals from the unskilled and professional levels follow recommendations less than those individuals who fall in the middle employment brackets -- skilled or managerial positions.

Most of the patients' mothers are housewives. The data seems to indicate that families having housewives as mothers tend to follow recommendations more than families with working mothers. The study shows that two of the professional mothers did not follow even 25% of the recommendations. (Refer to Farber's study -- Table XXIV)

II. Results of the survey of the families indicates that if the parents' level of education was at either extreme of the educational continuum the families did not follow through on recommendations. This tendency is supported by occupational trend. (Refer to Tables XXIII and XXIV)

III. The data shows that there is no statistical significance between I.Q. and the following of Clinic recommendations. Even though there was a small number of patients in the severely retarded category or lower, there appears to be a trend indicating that this group of parents do not follow through on recommendations. The majority of the patients who went through the Clinic are moderately retarded (36-58).

HYPOTHESES

Relationship of Following Clinic Recommendations
to the Income of the Parents

H_1 : There is a difference between income categories (above, below, median) and the following of Clinic recommendations.

To test this hypothesis, income was defined as the total approximate income from all sources. The seven income categories of the questionnaire were combined into three following: a) 0-5,999 per year; b) 6,000-9,999 per year; c) 10,000-12,000 and above per year. A three by three table was set up with income categories by following of recommendations. The results show no significant difference between income categories and following of recommendations. Therefore, the null hypothesis is accepted.

TABLE XXXV

RELATIONSHIP OF FOLLOWING CLINIC RECOMMENDATIONS
TO THE INCOME OF THE PARENTS

Income Categories	Follow Recommendations			Total
	100%-75%	74%-26%	25%-0%	
0 - 5,999	1	3	3	7
6,000-9,999	5	11	9	25
10,000-12,000 and above	5	10	12	27
Total	11	24	24	59

$\chi^2 = .496$ $df = 4$ χ^2 not significant at $\alpha = .05$

Relationship of Following of Clinic Recommendations
to the Father's and Mother's Education

H₂: There is a difference between educational levels of fathers and mothers and the following of Clinic recommendations.

To test this hypothesis, the following categories with regard to parents' education were established. 1) Under 8th grade; 2) H.S. completed, grades 9-12; 3) College graduates, 13-16; 4) Over 16; 5) Unknown. Categories (3) and (4) were combined together in the analysis of the data and category (5) was not included in the analysis. A chi square test was used to test whether the parents' education was affecting the following of recommendations. The results as seen in Table XXXVI A and XXXVI B show that (2) with regard to father's education and with regard to mother's education that neither of these is significant at the .05 level of significance. Therefore, the null hypothesis can be accepted.

TABLE XXXVI A

RELATIONSHIP OF FOLLOWING OF CLINIC RECOMMENDATIONS
TO THE FATHER'S AND MOTHER'S EDUCATION

Father's Education	Follow Recommendations			Total
	100%-75%	74%-26%	25%-0%	
Under 8th Grade	0	3	5	8
H.S. Completed Grades 9-12	6	10	9	25
College Graduates 13-16 & Above	4	11	10	25
Unknown*	1	0	0	1
Total	11	24	24	59

*Not included in the analysis

$\chi^2 = 3.196$ $df = 4$ χ^2 not significant at $\alpha = .05$

TABLE XXXVI B

RELATIONSHIP OF FOLLOWING OF CLINIC RECOMMENDATIONS
TO THE FATHER'S AND MOTHER'S EDUCATION

Mother's Education	Follow Recommendations			Total
	100%-75%	74%-26%	25%-0%	
Under 8th Grade	0	2	4	6
H.S. Completed Grades 9-12	8	15	14	37
College Graduate 13-16 & Above	3	7	6	16
Total	11	24	24	59

$\chi^2 = 2.521$ $df = 4$ χ^2 not significant at $\alpha = .05$

Relationship of Following Clinic Recommendations
to the I.Q. of the Patients

H₃: There is a difference in the level of I.Q. of the child and the following of Clinic recommendations.

To test this hypothesis, recommendations were defined as those recommendations given by the staff of the UOMS-CCD to the parents of the retardates. A three by three contingency table (see Table XIX) was constructed with three categories of the following: 100-75%, 74-26%, or 25-0% of the recommendations, by six I.Q. categories, combined into three (see Table II) for frequency distributions. The results show that χ^2 6.515 was not significant at the .05 level. Thus, the null hypothesis was accepted and the research hypothesis rejected.

TABLE XXXVII

RELATIONSHIP OF FOLLOWING CLINIC RECOMMENDATIONS
TO THE I.Q. OF THE PATIENTS

I.Q.		Follow Recommendations			Total
		100-75%	74-26%	25-0%	
1-2	Profound & Severe 20-35	0	4	2	6
3	Moderate 36-52	4	12	8	24
4-5-7	Mild-Borderline & Above 83	7	6	13	26
Total		11	22	23	56

$\chi^2 = 6.515$ $df = 4$ χ^2 is not significant at $\alpha = .05$

Other Findings

A finding of significant interest in the study is the fact that the majority of families whose children were evaluated at the UOMS-CCD were satisfied with the way in which the recommendations were presented to them. Those who were satisfied with the way in which recommendations were presented by staff also tended to follow through on them. Those families who felt that the recommendations could have been presented in a better or more helpful manner did not tend to follow through on them. These are findings indicated in Table XXX.

Table XXXII indicates that most of the families whose children were evaluated at the Clinic were satisfied with the way in which they were treated by the staff. It shows that most families were satisfied with the care and consideration given both the child and the family. Although this is a finding of the study, it was not statistically significant for the following of recommendations by the families.

Table XXXIV indicates another significant finding of the study which did not seem to have statistical significance for the following of Clinic recommendations. This table reveals that 47% of the families in the study felt that there have been changes within their family life following their child's evaluation at the UOMS-CCD. Also, on a scale of "Much to None" in Table XXXIII, over half of the study families indicated that the Clinic helped them "much". Again, this does not have statistical significance for the following of recommendations by those families.

Other significant findings of the study related to the source of referral to the UOMS-CCD. Physicians comprised the largest single

referral source. Table XI indicates that among females referred, an equal number were referred by physicians and schools. However, among males referred, the largest referral source was physicians. The study also reveals that as children reach adolescence, the school as well as the physician becomes a significant referral source to the Clinic. An additional finding of the study is that only 29% of the families continue to consult the Clinic for related problems; most families return to their physician for related problems.

In regard to the distribution of retarded children in the population according to the census tract, this sample did not show a significantly high concentration of retarded children from any particular location or socio-economic group in the Portland area.

CHAPTER IV

SUMMARY AND IMPLICATIONS

The first section of this chapter deals with the summary of the study, followed by the implications resulting.

Purpose: The purpose of this study was to determine how effective the UOMS-CCD was from the standpoint of the users of the services. One criterion upon which to base a judgment of effectiveness of the Clinic was to see if the studied families were able to follow the recommendations suggested by the Clinic.

Sample: A random sample of 100 cases was selected from the 232 patients who had been through the Clinic prior to January, 1968. This sample was geographically restricted to children whose parents had a Portland address. Out of the 100 sample selected, 59 were available for interviewing. The others could not be located, moved from the city or refused the interview.

Hypotheses: The following three research hypotheses were posed for testing.

- (1) There is a difference between income categories (above, below, median) and the following of Clinic recommendations.
- (2) There is a difference between educational levels of fathers and mothers and the following of Clinic recommendations.
- (3) There is a difference in the level of I.Q. of the patient and the following of Clinic recommendations.

The χ^2 was used in testing the hypotheses and the findings resulted in no

statistical difference between the three variables and the criteria of following recommendations. Therefore, the null hypotheses were accepted.

Although these were not statistically significant, some trends were indicated. In regard to education and the following of recommendations, it is noted that parents of both the lower and high education continuum tend not to follow recommendations as consistently as those of average education. There was a trend indicated in regard to I.Q. and following recommendations in that most parents whose children fell within the moderate range of ability, follow recommendations more consistently than others.

Other findings revealed that the majority of the study population were satisfied with the treatment they received from the Clinic. Also, most were satisfied with the way the recommendations were presented. Forty-seven percent felt there had been changes in their family life since being seen at the Clinic.

Physicians were the largest single referral source to the Clinic and most families continued to consult the physician for related problems while only 29% of the families continued to consult the Clinic. The number of blacks seen at the Clinic was in proportion to the population of the Portland area.

Implications of the Study

Some significant implications of this study relate to the ability of the study families to utilize the recommendations of the UOMS-CCD. Table XXIX suggests several implications regarding Clinic recommendations. One important finding is that study families felt that recommendations should have been more clearly defined for their understanding. Table XXIX also indicates that 35% of the study families said they could use the Clinic's recommendations but then did not do so. It is possible to speculate that additional counseling services may have helped motivate families to follow through on recommendations where resources were available in the community. Another speculation is that a family's lack of financial resources may have interfered with following the Clinic's recommendations. In such cases, perhaps the Clinic could make more realistic recommendations in accord with the family's income.

Table XXX describes the families' responses to the way in which recommendations were presented to them. Most families (48) were satisfied with the way recommendations were presented but for those families who were dissatisfied, seven said that clearer, written evaluations were necessary; two said that more information and encouragement to follow through on available resources was necessary, and only one felt that the approach of the professional staff should be changed.

Table XXXII describes aspects of the Clinic's program which the study families disliked. It should be noted, first, that the general reaction of study families to the services provided by the Clinic was one of satisfaction. Among those who expressed some dissatisfaction, five families felt that the Clinic did not individualize each child

enough. An additional five families expressed dissatisfaction with the nature of the diagnosis of their child received; they later found it to be unsubstantiated. Significantly, seven families again stated that they required a clearer interpretation of the child's problems and also felt that more follow-up contact by the Clinic would have been helpful.

Further implications of the study are suggested by Descriptive Table XXXI. An open-ended question designed to discover in which areas the Clinic was most helpful, revealed that study families felt the Clinic was generally helpful in better understanding their child's problems. It also revealed that study families felt the Clinic to be very helpful in such specific areas as speech, dental care, school placement, and counseling for behavioral adjustment.

Table XXVIII reveals that those families who were self-referred or referred by social agencies tended to follow through on recommendations more readily than those referred by physicians or schools. The reason for this might be that those self-referred families were more highly motivated and that those referred by social agencies received preparation and follow-up which contributed to following of recommendations.

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APPENDIX A

RECORD DATA

I. FAMILY

a. Name:

Father _____

Mother _____

Mother's Address _____

Phone _____

b. Family Structure:

Married _____ Stepfather _____ Deceased Father _____

Divorced _____ Stepmother _____ Deceased Mother _____

c. Race:

White _____ Black _____ Other _____

d. Religion:

Protestant _____ Church _____

Catholic _____

Jewish _____

Other _____

II. PATIENT

a. Name: _____ Age: _____

b. Sex: Male _____ Female _____

c. I.Q.: Profound Less than 20 _____
Severe 20 - 35 _____
Moderate 36 - 52 _____
Mild 53 - 68 _____
Borderline 69 - 83 _____

d. Date of Evaluation: _____

e. Source of Referral: Physician _____
School _____
Friend _____
Family _____
Other _____

f. Specific Medical Diagnosis: (List from Medical Report)

g. Recommendations: (Check)

_____	1. Special School	Trainable _____	Educable _____
_____	2. Counseling		
_____	3. Special Care (Inst.)		
_____	4. Recreational Therapy		
_____	5. Physical Therapy		
_____	6. Dental Care		
_____	7. Speech Training		
_____	8. Special Diet		
_____	9. Hearing		
_____	10. Eye Care		
_____	11. Others (List)		

APPENDIX B

SEMI-STRUCTURED INTERVIEW WITH MOTHER

I am a graduate student at the School of Social Work involved in a research project with the Crippled Children's Clinic to determine how effective and helpful the Clinic is. You could be helpful by answering some questions for us. We are interested in knowing how useful the Clinic was in regard to your family. All of the information is confidential and names will not be used in the project.

I. First I would like to check our information regarding family background.

A. Age: Father _____ Children _____
Mother _____

B. Highest grade completed:

Father _____ Never Attended: Father _____
Mother _____ Mother _____

C. Occupation: Father # _____ Mother # _____

1. Professional, technical and kindred workers
2. Manager, officials and proprietors, except farm
3. Sales workers
4. Craftsman, foremen and kindred workers
5. Operatives and kindred workers
6. Private household workers
7. Service workers, except private household
8. Farm owners, managers, foremen and laborers
9. Laborers, except farm and mine
10. Living on aid
11. Unemployed (not retired, includes housewives head of household, not employed and not on aid)
12. Retired (no prior occupation given)
13. Housewife (not head of household and not working)

D. Total approximate income of family from all sources: # _____

1. Under \$2,000
2. 2,000 - 3,999
3. 4,000 - 5,999
4. 6,000 - 7,999
5. 8,000 - 9,999
6. 10,000 - 11,999
7. 12,000 and over

E. Home

Renting _____ Purchasing _____ Own _____ Other _____

II. How did you hear about the Clinic?

A. Physician _____	C. Friends _____
B. School _____	D. Other _____

III. Who referred you to the Clinic?

A. Physician _____	C. Friends _____
B. School _____	D. Other _____

IV. In which of these areas was the Clinic helpful to you?

A. Understanding medical questions about your child	_____
B. Planning for your child's future	_____
C. Caring for your child's physical needs	_____
D. Caring for your child's emotional needs	_____
E. Other	_____

V. Was there any aspect of the Clinic's program you didn't like?

A. Way you were treated by staff?	_____
B. Way your child was treated by staff?	_____
C. Quality of care your child received?	_____
D. Scheduling of the Clinic sessions?	_____
E. Other?	_____

VI. Do you feel the Clinic has better helped you understand your child?

A. Much _____	C. Little _____
B. Some _____	D. None _____

E. If none, what would have been more helpful?

VII. Did your family life change after the birth of your child?

A. Much _____ C. Little _____

B. Some _____ D. None _____

E. In what way did it change? _____

VIII. Have there been any changes in your family life since your child has been seen at the Clinic?

A. Yes _____ In what way?

B. No _____

IX. Can you tell me what the Clinic's recommendations were?

A. Yes _____ List:

B. No _____

X. Were you able to use the Clinic's recommendations?

A. Yes _____

B. No _____ List why not:

XI. Could the recommendations have been presented to you in a better way?

A. Yes _____ List:

B. No _____

XII. Who do you see now when you have questions concerning your child?

A. Public Health Nurse _____ C. Clinic _____

B. Physician _____ D. School _____

E. Other _____ List:

XIII. Social work impressions to be filled out following the interview:

A. Quality of the mother-child relationship:

1. Accepting _____	3. Rigid _____
2. Rejecting _____	4. Flexible _____

B. Mother's self-esteem:

1. Excellent _____	3. Fair _____
2. Good _____	4. Poor _____

C. Mother's attitude toward interview:

1. Cooperative _____	2. Uncooperative _____

D. Would you describe mother as any of the following?

1. Hostile _____	3. Depressed _____
2. Dependent _____	4. Aggressive _____
5. Passive _____	

E. Quality of family relationships:

1. Excellent _____	3. Fair _____
2. Good _____	4. Poor _____

APPENDIX C

I. Behavior Symptoms

- 1. Hyperactive
- 2. Short Attention Span

II. Miscellaenous Lab Tests

- 1. Urinalysis
- 2.
- 3. Pinworm
- 4. Densities

III. Miscellaneous Physical Findings

- a) Eye
 - 5. Astigmatism
 - 10. Hyperopia
 - 21. Esotropia
- b) Ear
 - 24. Bilateral Hearing Loss
- c) Palate
 - 13. High Arch
- d) Nose
 - 19. Epistaxis (nosebleed)
- e) Mouth Breather
 - 22-27. Chronic Gingivitis
 - 6. Active Dental Curves
- f) Heart
 - 14. Pansystolic Murmur
 - 26. Enlarged Cardiac Silhouette
 - 28. Ductus
- g) Skull
 - 8. Microcephaly
- h) Abdomen
 - 15. Diastasis Recti (spread of rectus muscles)
- i) Bone
 - 11. Bone Retardation
- j) Obesity
- k) Scoliosis

IV. Syndrome

- 4. Down's
- 9. Spastic Dysplegia (cerebral palsy)

V. Neurological Findings

a) Physical Findings

- 9. Spastic Dysplegia
- 16. Abnormal gait
- 18. Bilateral Clonus
- 17. Babinski

b) Lab

- 3. EEG Abnormal

c) Seizure Disorder

d) Behavior as I

e) Physical Findings - Skull, Eye, Ear in III

VI. Speech

- 12. Echoic

- 20. Expressive Aphasia