Portland State University

PDXScholar

Dissertations and Theses

Dissertations and Theses

1973

Group experience with parents of preschool children with seizure disorders

George R. Jacobsen
Portland State University

Grant R. Kane
Portland State University

Joan Sacia
Portland State University

Follow this and additional works at: https://pdxscholar.library.pdx.edu/open_access_etds

Part of the [Disability and Equity in Education Commons](#), [Mental and Social Health Commons](#), and the [Social Work Commons](#)

Let us know how access to this document benefits you.

Recommended Citation

Jacobsen, George R.; Kane, Grant R.; and Sacia, Joan, "Group experience with parents of preschool children with seizure disorders" (1973). *Dissertations and Theses*. Paper 2932.
<https://doi.org/10.15760/etd.2892>

This Thesis is brought to you for free and open access. It has been accepted for inclusion in Dissertations and Theses by an authorized administrator of PDXScholar. Please contact us if we can make this document more accessible: pdxscholar@pdx.edu.

GROUP EXPERIENCE WITH PARENTS OF
PRESCHOOL CHILDREN WITH SEIZURE DISORDERS

by

George R. Jacobsen

Grant R. Kane

Joan Sacia

A Practicum
Submitted in Partial Fulfillment of the
Requirements for the Degree of

MASTER OF SOCIAL WORK

Portland State University

June 1973

APPROVED:

A large black rectangular redaction box covering the signature of the Research Advisor.

Mrs. June Dunn, Research Advisor

ACKNOWLEDGEMENTS

We wish to express appreciation to Dr. James R. Schimschock, Director of Good Samaritan Hospital and Medical Center Children's Clinic, for his encouragement, guidance and direction.

Gratitude is also expressed to Mrs. June Dunn, M.S.W., research advisor, and Quentin D. Clarkson, statistical consultant, at Portland State University, for their counsel; to Mrs. Betty Stokes, executive director of the Epilepsy League of Oregon, Inc., for her assistance in making this research possible; to Dr. Russell Jackson and Dr. Leif Terdal, for their efforts in managing the video-taping; and to the other members of the Children's Clinic for their time and patience.

Special appreciation goes to Jarvis M. Finley, Ph.D., Associate Professor of Sociology, Pacific University, for his suggestions on assembling the material and for his timely guidance during the final stages.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	iii
Chapter	Page
I. INTRODUCTION	1
Problem	2
Purpose	3
II. METHODOLOGY	4
Funding	4
Data Collection	4
Socio-Economic Inventory	5
Epilepsy Questionnaire	6
Handicap Problems Inventory	7
Brochure For Parents	7
Evaluation Questionnaire	8
Video-Taping	8
III. PARENT SEMINARS	10
Design	11
Group Membership	13
Unit of Study	14
Sequence of Events	17
Group Discussion Sesseion	17
IV. RESULTS	22
Handicap Problems Inventory	22
Evaluation Questionnaire	22
Epilepsy Questionnaire	25
Video-Taping	30
V. SUMMARY AND CONCLUSIONS	35
SELECTED BIBLIOGRAPHY	40
APPENDIX	55

CHAPTER I

INTRODUCTION

A project using parent seminars in aiding parents of children with seizure disorders was designed at the request of Dr. James R. Schimschock, pediatric neurologist and director of the Clinic for Neurologically Impaired Children, Good Samaritan Hospital and Medical Center. The clinic provides a diagnostic and educational therapy for neurologically impaired children. In addition to providing multidiscipline diagnostic evaluation, clinic services include operating classrooms for preschool and school-age children. The classrooms function for children with any type of neurologic impairment who are either excluded from school due to their delayed academic performance, their physical or developmental delay, emotional or behavior problems, or the severity of their condition. Having the classroom located in the Good Samaritan Hospital complex provides immediate access to medical assistance if it is required. Information derived from classroom observation is available to the child's physician. This information is valuable in the medical management of these children and is particularly useful with children having intractable seizure disorders.

The school age-program is directed by Mr. Pat Highhouse, M.S. in Special Education and Elementary Education, and currently has an enrollment of six. The preschool program is directed by Mrs. Jill West, M.S. in Special Education, which serves children between the

ages of one and one-half and five, and currently has an enrollment of 10 (includes one set of identical female twins). Miss Sandy Withrow, B.S. in Elementary Education, functions as administrative secretary and clinic coordinator of services. Several volunteers contribute their time and talents to the program. Referral sources include teachers, physicians, public health nurses, social workers, and parents. The clinic is currently funded by Good Samaritan Hospital, the federal Developmental Disabilities Services Act, Multnomah County, and Portland Public Schools.

Problem

Observations by local neurologists and the staff of the Epilepsy League of Oregon, Inc., indicated a need for expanded contact with parents of children with seizure disorders. These observations led to discussion of problems in identifying the major concerns and sensitive areas of these parents. Mrs. Betty Stokes, executive director of the Epilepsy League of Oregon, noted that there were no known programs designed to deal with this problem and suggested that the League might fund a study designed to investigate certain areas of concern, provide a supplementary learning experience, and set up a program to correlate these efforts.

As a preliminary project, parent group education was presented as one form of supplementary learning experience. The use of parent groups for various educational as well as therapeutic purposes has

been well documented. A number of authors have reported studies of groups of parents having children with epilepsy.¹

Purpose

A pilot study was designed by establishing a six-week series of parent group discussions. The purpose of this descriptive study was two-fold: (1) to observe and record parental knowledge of and attitudes toward seizure disorders by documenting their most prevalent questions and concerns about epilepsy, and (2) provide an opportunity for parents to deal with these specific areas in a constructive manner in order to alter parents' influence on their children.

¹See Appendix G for a review of the literature of these studies as well as related topics such as group approaches with parents of preschool children, relationships between social and emotional child behavior and seizures, primary parental reaction to a diagnosis of epilepsy.

CHAPTER II

METHODOLOGY

Under the guidance of James R. Schimschock, M.D., pediatric neurologist, Mrs. June Dunn, M.S.W., faculty advisor from Portland State University, and Quentin D. Clarkson, Ph.D., statistical consultant also on the P.S.U. faculty, various questionnaires were designed. All questionnaires were coded to establish an information retrieval system for future use in the clinic. Every mother involved in the project was individually video-taped in a 20-minute interaction with her child. In the case of the mother of twins the activity was taped with each child independently as well as with both children. The video-taping was done by Leif Terdal, Ph.D., and Russell Jackson, Ph.D., consulting clinical psychologists, in order to provide objective observation and recording of behavior.

Funding

A proposal in the form of request for a grant of \$1,700.00 was written and presented to the Epilepsy League of Oregon on May 22, 1972 (see Appendix A for the original proposal). The entire project was funded as submitted.

Data Collection

The multi-discipline approach of the Children's Clinic for

services to neurologically impaired children and their families presented problems in record keeping. Data collected on each child included neurological workup, psychological, social work, and educational evaluation. These data were collected on each patient and discussed at a staff conference. The confidentiality of each patient's record was carefully guarded.

Good Samaritan Hospital provided the impetus, structure, and consultation to assist the clinic staff in meeting the need for adequate records. Record keeping for diagnostic evaluation, however, remained strictly within the domain of the clinic staff.

Socio-Economic Inventory

The clinic's use of a multi-discipline team of consultants (neurology, psychology, social work, and special education) for diagnostic evaluation presented complexities in developing a uniform procedure in clinical recording. Representatives of each discipline assumed responsibility for establishing relevant criteria.

Social work members developed and used a formal procedure for collecting and recording data obtained during the clinical process of diagnostic evaluation. This procedure took the form of the Socio-Economic Inventory (Appendix I). Although the optimum condition of entirely objective and quantative data could not be fully achieved, a great deal of quantifiable information about each client was collected. Accessibility of this information for future use became the next obstacle. The clinic staff proposed that this

recorded information had potential to describe certain characteristics of the clinic population in addition to diagnostic evaluation of individual cases. For purposes of this project, the information was used to describe various socio-economic aspects of the participants.

Responses on the Socio-Economic Inventory were coded appropriately to facilitate storage of data on key-punch cards. When the diagnostic process and the record of each individual client was completed, coded responses on the Inventory were transferred to coding sheets and the key-punch cards processed.

Information stored on these cards represents a readily available source of diagnostic and demographic data on each clinic patient as well as the entire clinic population since July 1, 1972.

Epilepsy Questionnaire

A questionnaire that attempted to assess parental feelings toward, and knowledge of, epilepsy was constructed. Information from medical specialists on seizure disorders, the Epilepsy League of Oregon, and personal correspondence with Lydia Colon² was used in developing the Epilepsy Questionnaire (EQ). The final questionnaire presented to the parents consisted of 61 questions on epilepsy and attitudes, four questions on the position of the individual responding

² Social worker, Department of Medicine, Section of Neurology, University of Puerto Rico, Medical Sciences Campus, San Juan, Puerto Rico.

a list of available films, and a request for additional areas of interest (Appendix D). All responses were tallied and are reported in order that the information be available for use in planning future seminars. However, consulting professionals felt that 15 of the original 61 questions were nebulous or ambiguous. The Epilepsy Questionnaire was distributed to the parents included in the study prior to the seminars and again two months after the sixth session.

Handicap Problems Inventory

The Handicap Problems Inventory (HPI) consists of a check list of 280 problems attributable to physical disability. The Inventory was designed by C. N. Wright, Ph.D., program director for the National Epilepsy League, Inc., and H. H. Remmers, Ph.D., Professor of Psychology and Education at Purdue University (for a copy, detailed description, history and interpretation of the HPI, see Appendix E). In an attempt to discover the impact of their child's handicap on parental attitudes, this Inventory was administered prior to the series of parent seminars. The original HPI was designed for use with physically handicapped teenagers and adults. Instructions were adapted for use of parents of preschool children with seizure disorders.

Brochure For Parents

A Brochure For Parents was compiled, using materials from several sources. A bibliography was provided at the end of the Brochure. The Brochure attempted to provide information in commonly questioned areas

concerning seizure disorders (Appendix B). Information was included on causes of seizures, first aid, treatment of seizure disorders, kinds of seizures, etc. Each parent was provided with a copy of the Brochure as soon as he or she returned the completed EQ. All parents had received a copy prior to the third seminar.

Evaluation Questionnaire

A brief questionnaire was designed to evaluate the effectiveness of the parent seminars. The Evaluation Questionnaire consisted of 12 questions concerning the entire series of seminars (Appendix D). This final Evaluation Questionnaire was distributed two months after the series ended. This questionnaire was designed to provide assistance in establishing future parent seminars by noting areas of deficiency or confusion, pertinent material, and interest in the current series.

Video-Taping

During the six weeks the parents participated in the seminars, each mother was individually video-taped in a play interaction with her child. This tape was then viewed by both parents separately. Dr. Russell Jackson and Dr. Leif Terdal, University of Oregon Medical School, discussed with them the behaviors observed. This portion of the video-taping was part of a larger project currently in progress by Dr. Jackson and Dr. Terdal. The objectives of video-taping behavior were to record the kinds of behavior operating between mother and child and note tendencies toward disturbing or pathologic behavior

and to compare the behavior of this study population with others. The objectives were essentially an attempt to establish a point of reference for future study.

The children were taken to the Child Development and Rehabilitation Center by their mothers and a 20-minute mother-child interaction was video-taped. From the video-tape, two kinds of assessment were undertaken: (1) a coding of the mother-child interaction, along certain dimensions, and (2) a transcript and analysis of their report made while watching a video-tape playback of the interaction.

CHAPTER III

PARENT SEMINARS

As a result of the recognition that parents of children with seizure disorders frequently seemed anxious and had numerous child-rearing problems, often not directly associated with the child's seizure disorder, a series of parent seminars were initiated. The purpose was to help parents share concerns in regard to their children, to help them understand their child's seizures, to develop an awareness of work in the clinic and school, and attempt to prepare families for future events. Efforts were made to provide parents with pertinent information and afford them some relief from anxiety. Scherz discusses the role of parent-group sessions when dealing with families where the problem is a chronic or congenital handicap of one member.³ He feels the aim is to further understanding of the disablement, reduce guilt, and to improve role functioning and patterns of communication.

Alerting the clinic to any emergency problem which may require attention also was considered a possible result of parent-group interaction. Konopka points out how the social stigma of epilepsy

³Frances Scherz, "Multiple-Client Interviewing: Treatment Implications" Social Casework. 42 (March 1962), 120-125.

alone may drive people into isolation.⁴ The seminars were designed to provide parents with an interpretation of epilepsy which would be transmitted to the community. By increasing parental skills in meeting their child's handicap, it was hoped their talents might be used to help change attitudes in the community.

Design

The assumptions were that parents could explore some of their expectations, fears and fantasies, and check them against reality; look at their own emotional reactions and come to know and accept themselves better; and begin to think differently about things they can and want to do regarding their children. Anticipations in supplying guidance and information were that parents would learn at their own pace and focus on what was most significant for them.

The parent seminars were based primarily on the conception of the family as a "school for life" and on the development of interpersonal relationships using learning techniques. The group was assisted by three co-facilitators who were graduate student social workers and additional professional personnel as the need arose. The focus of attention was on the parent and parent-child relationships and on assisting them in using their own resources. A number of the principles and practices, discussed by Auerbach in Parents

⁴ Gisela Konopka, Social Group Work: A Helping Process (Englewood Cliffs, New Jersey: Prentice Hall, Inc., 1972), 201.

Learn Through Discussion, were incorporated into the program.⁵

These included: helping parents become familiar with basic concepts of child growth and development and parent-child interaction from a dynamic view, recognizing crisis points in different stages of the family cycle, and clarifying parental and other roles.

For greater clarity, contracts were drawn between parent and clinic. Such contracts enabled the facilitators to express their roles and expectations (see Appendix G for forms and initial correspondence between clinic and parents). Berne notes that such contractual arrangements often bring out actual realities in a situation which might have gone unnoticed.⁶

The decision was arbitrarily made to restrict the seminars to six weekly sessions. An evaluation and discussion meeting followed two months after the sixth session of the series. Each session was audio-taped for future review and evaluation. Free baby sitting was provided for each session. The seminars were scheduled for the early evening hours to make it easier for fathers to attend. In planning and organizing the parent discussion group, the original intention was that the primary topic of discussion would be the child's seizure disorder. This included exploring predominant family attitudes and

⁵Aline B. Auerbach, Parents Learn Through Discussion: Principles And Practices Of Parent Group Education, (New York: John Wiley and Sons, Inc., 1968).

⁶Eric Berne, Principles Of Group Treatment, (New York: Grove Press, 1966), p. 34.

behavior. Voeller and Rothenberg found that parental attitudes are of such importance in the therapeutic management of seizure disorders that much time and effort can be saved by expending more energy in this area.

In the course of interviewing and treating many children in seizure clinic, we have been impressed by the fact that the parents' and the child's attitudes about the illness may significantly influence the therapeutic course. We have seen that these attitudes arise again and again in predictable patterns and form a recurrent theme during the diagnostic and therapeutic phases of management.

Thousands of man-hours are expended in the treatment of seizure disorders, and it would appear that in the long run the initial investment of time devoted to exploring the family's attitudes and feelings regarding seizures results in a saving of time and better seizure control.⁷

Group Membership

This study originally was planned around the school-age population of the clinic. Because of staff changes and a delayed school-age program, a decision was made to work with parents of preschool children. Inclusion of the parents of school-age children with seizure disorders is left for consideration in future programs and studies. Considerable pressure and numerous questions from parents of preschool-age children also were influencing factors in establish-

⁷Kytja K. S. Voeller, and Michael B. Rothenberg, "Psychosocial Aspects of the Management of Seizures in Children," a 26-page paper written for the Albert Einstein College of Medicine, Bronx Municipal Hospital Center (no date), p. 1, 20-21.

ing the program with this particular age group.

Membership was limited to parents whose children were enrolled in the preschool program. One set of parents had identical female twins in the classroom. The severity and type of seizure disorders represented was variable. This group of children and parents had demonstrated need of the program and met the entrance requirements. These requirements were that the child have a neurological impairment and be between the age of one and six.

The group consisted of eight pairs of parents plus one single parent. Mean attendance was 83.5 percent including one father who never attended. A variety of ethnic and cultural backgrounds were represented.

Unit Of Study

The unit is this study was the child with a seizure disorder. Ten children were selected, five boys and five girls. Two of the girls were identical twins (N=10 for children, N=9 for families).

Childrens' Ages (n=10)

	Male		Female	
	yrs	mos	yrs	mos
Mean age males n=5	2	10	6	8*
2 yrs 11.4 mos	2	0	2	9
Mean age females n=4	4	1	2	9
3 yrs 11.8 mos	2	6	2	4
Mean age sample n=9	3	4	2	10
3 yrs 3.1 mos				

*This child was considered a preschool child because of her status in a preschool setting rather than in normal classes.

Birth Order Of Children (n=10)

	Male (n=5)	Female (n=5)
Only child	1	0
1st child	1	3**
2nd child	0	2**
3rd child	0	0
Adopted child	3*	0

*Of the three adopted children, one was adopted as the first child in the family, and the other two were adopted after the birth of natural children.

**Identical twins included

Composition Of Household (n=10)

	Children	
	Male	Female
Single-Parent Family	0	1
Two-Parent Family	5	4**
<hr/>		
No siblings	1	0
One biological sibling	1	2**
One adoptive sibling	1	1
One biological and one adoptive sibling	2	2
Three biological siblings	0	1

**Identical twins included

Seven children were living with their biological parents, six in two-parent households and one child in a one-parent household. Three adopted children were living in two-parent households which included four additional adopted children.

Parents' Ages (n=17)

Range of Fathers' ages	26 to 42 years of age
Mean age of Fathers	32.6 years of age
Range of Mothers' ages	25 to 41 years of age
Mean age of Mothers	30.9 years of age

Parents' Educational Attainment (n=17)

	Fathers (n=8)	Mothers (n=9)
High School Diploma	1	2
Some College, No Degree	2	3
College Degree	1	2
Advanced or Professional Degree	4	2

Employment Of Parents (n=17)

Clerical	0	1
Clerking	1	0
Architect	1	0
Physician	1	0
Supervisory	1	0
Sales	1	0
Attorney	2	0
Other (self-employed)	1	8

Annual Income Of Families (n=9)

\$3 - \$4,999	1
\$7 - \$8,999	1
\$9 - \$14,999	4
\$15 - \$19,999	3

Marital Status Of Parents (n=9)

Family intact, no separations or previous marriages by either parent	8
Family divided, father not at home, mother has custody of child	1

Sequence Of Events

Following the study design and funding, parents were given the Socio-Economic Inventory and a summary social evaluation was made at that time. A letter, detailed information, and authorization forms were mailed approximately one month prior to the first seminar. Upon receipt of the agreement to participate in the parent groups, the EQ and HPI were mailed to the parents. Those parents who returned the EQ and HPI prior to the first parent seminar were then given Parent Brochures. The rest of the parents received their Brochures following the first session after returning the EQ and HPI.

Group Discussion Sessions

The group began as rather apprehensive, anxious, and somewhat antagonistic. Parent involvement was low and facilitator input high. At the end of six weeks, facilitator input was reduced while parent involvement was very high, centering around additional sessions without facilitators. Because one of the goals of this study was to record parental concern, the majority of the questions asked in each session are presented in Appendix H. Major areas of concern expressed included etiology of seizures, future uncertainties, diagnostic confusion, medications, sibling involvement, labeling, percentage of adoptive children with seizure disorder, physiology of seizures, what to tell others, problems with the schools, and funding. Each item of concern was discussed by group members.

1. The first group session was an introductory and orientation meeting with 16 parents in attendance. Leif Terdal, Ph.D., clinical psychologist with the University of Oregon Crippled Children's Division, was present as a consultant. He explained the purpose of videotaping interaction of parent and child in a play setting. Re-scheduling of the preschool program, changes, and policies to adhere to state guidelines was briefly discussed. Two books were presented as reading material: Living With Children, and Parents Are Teachers. The EQ was discussed. Questions asked were primarily concerned with methods to be used in measuring their child's progress in the classroom, how additional information could be helpful to them as parents, EEG telemetry, the etiology of seizures, education advantages, and the social stigma attached to the word "epilepsy." A five minute film entitled "Benjamin" was shown. The meeting lasted for one and one-half hours.
2. The second session was a familiarity meeting with emphasis focused upon parent-group interaction. Specific questions were centered around agreements and disagreements with the Brochure For Parents. Each set of parents gave information regarding their child and his problems. Questions arose concerning heredity, obtaining precise scientific information, the relationship between seizure activity and developmental delay, and more understanding of various medications. A 23-minute film entitled "Not Without Hope" was shown and discussed.

There were 16 parents in attendance. The meeting lasted for two hours.

3. The third meeting was a continuation of the second where parents continued to exchange information about their children. Questions asked ranged from inquiry into EEG reliability, etiology of epilepsy, anticipated problems of the future in education, health and society, and treatment available. The question of the percentage of adopted children having a seizure was raised as a result of parent-group interaction. A 30-minute film entitled "Grand Mal Epilepsy: Diagnosis And Management" was shown and discussed. Fifteen parents attended. The meeting lasted for one and one-half hours.

4. The focus of the fourth meeting was in response to the desires of parents who wanted to receive some information from one of two reliable medical resources in the community. Dr. James R. Schimschock spoke to the group. A specific question and answer period centered around etiology, heredity, and anticipated problems. Descriptions, labeling, and classifications of definitions were discussed with suggestions for a more practical approach. Community education was a concern. Discussion ensued of involving other organizations for help in acquiring insurance, social acceptance and medical reference. During this session, some parents expressed hostility at not being told definitely that their child had epilepsy. Dr. Schimschock felt that they had failed to hear when they were being told. Wolfenberger refers to several authors who report parental hostility which is

directed toward professionals when the parents are experiencing difficulty in accepting their child's handicap.⁸ The meeting, lasting two hours, was attended by 17 parents.

5. Mrs. Pat Sawyer, a preschool special education teacher from the University of Oregon Crippled Children's Division, and Russell Jackson, Ph.D., clinical psychologist, attended the fifth meeting. Mrs. Pat Sawyer provided each parent with a list of Day Care, Kindergarten, and Nursery Schools in the metropolitan area. The speaker was James Watson, M.D., neurologist.

Community education was the major topic of the question and answer period with more specific questions centering around medication, seizures, and their effects upon the brain. The meeting lasted two hours and 17 parents attended.

6. The sixth session was a meeting to summarize and assess the group in terms of education. Mrs. June Dunn, M.S.W., research advisor from Portland State University, attended. The group discussed the topics covered during the previous five meetings, along with comparison of the speakers. Considerations of contacts with other parents and the possibilities of having more than one group were summarized in terms of future parent groups. Interest was shown in encouraging parents

⁸Wolf Wolfensberger, "Counseling The Parents Of The Retarded," in Alfred A. Baumeister (ed.) Mental Retardation (New York: Alpine Publishing Co., 1967), 366.

of other neurologically impaired children to become involved in future events. Legislative action was considered by the group to further their cause. A tentative date was established to meet the original membership in two months for the seventh and last time. The objectives of the seventh meeting were outlined. There were 16 parents in attendance and the meeting lasted for one and one-half hours.

CHAPTER IV

RESULTS

Fifteen of the original 17 parents responded to both the Evaluation Questionnaire and the Epilepsy Questionnaire on the first and second trials. One father did not participate and another was not available at the end of the project.

Handicap Problems Inventory (HPI)

Most of the parents expressed confusion and resentment toward the HPI. They felt that they could not answer the questions meaningfully because their children were too young. Although the Inventory was originally designed for the respondent to be the individual with the handicap, it has been used at the University of Oregon Medical School with parents of children with a handicap. Several parents refused to return the Inventory. On the basis of strong parental resentment, the HPI was eliminated as part of the project. This group of parents apparently were not ready to deal with many of the items included in the Inventory. For some of the parents whose children were only mildly handicapped such a confrontation might not be necessary and it appeared inappropriate at this time.

Evaluation Questionnaire

The final Evaluation Questionnaire provided pertinent and

helpful suggestions for future parent sessions (see Appendix D for detailed replies). Individuals were rather evenly divided on most "Yes" and "No" answers. All parents checked "Yes" on question 11, recommending this type of seminar to other parents of children with seizure disorders. This is consistent with conclusions drawn from a study in the state of Oregon by Dr. James J. Cereghino. He remarks on the need to avoid emotional and behavioral problems which may create difficulties in future interpersonal relations if they are based on prejudices and fallacies.⁹

Material which the parents felt was most interesting and informative involved speakers (especially physicians and educators), group discussion, and exchange of individual case histories. The out-dated movies presented (which were the only ones available on epilepsy) were unanimously felt to be of least interest and in some cases emotionally disturbing. One parent suggested that the next project be devoted to making a more adequate movie on seizure disorders!

⁹James J. Cereghino, Survey of Existing Services and Facilities for the Epileptic in the State of Oregon. Neurological and Sensory Disease Control Program, Division of Chronic Disease Programs, 4040 North Fairfax Drive, Arlington, Virginia 22203, p. 33.

A need to summarize information and specific responses to each question in the Epilepsy Questionnaire was pointed out. Problems of the adult with a seizure disorder, a study of the brain and its functions, testimonials from "successful" and "unsuccessful" epileptics were among a number of suggestions made by the parents. There was a strong response in favor of more speakers, participation, group discussion, information on convulsions, and that the seminar for parents should continue to be a requirement for school placement. This latter statement was a reversal of the resentment expressed at the beginning of the series.

Parents demonstrated considerable enthusiasm by their verbal and written comments. They also expressed a desire to continue to meet twice a month, without the assistance of facilitators, after the initial series of six seminars ended. A Sunday "potluck" social gathering was held which included the children as well as the parents.

One parent attended a meeting of an ad hoc committee of the Oregon State Legislature to assist in obtaining funds for the clinic, while two other parents involved themselves in the public school system in an effort to influence the public image of epilepsy. All such continuing efforts were initiated and performed without professional involvement.

Epilepsy Questionnaire

Specific questions in the Epilepsy Questionnaire attempted to elicit parental opinions and feelings in regard to their expectations, fears, overprotectiveness, and knowledge of epilepsy. Wolfensberger comments on these areas and others in a review of studies on the dynamic aspects of parent functioning.¹⁰ Overprotectiveness, for example, though not beneficial in all aspects, is considered adaptive and desirable rather than pathogenic. Instead of treating overprotectiveness as rejection, as many authors do, Wolfensberger portrays overprotectiveness as a result of parents' attempts to convince themselves that they enjoy responding to long-term infantile dependency needs. This, in turn, can result in a more infantile and dependent child, either aggressive or quite passive.

First trial replies on the Epilepsy Questionnaire to question 13 ("A child with epilepsy should not be punished for misbehaving if such punishment aggravates his seizures?") and question 19 ("I would trust an older epileptic child to handle his own medications.") showed a relatively large number of "Don't Know" replies. On the second trial, after the parents had been exposed to the six-week parent seminar series, the shift to more definitive answers of either "Agree" or "Disagree" appears to represent increasing

¹⁰Wolfensberger, 329-400.

confidence by parents in their own handling of the child and confidence in the child's abilities. There were only two "Don't Know" answers on each of these questions.

Responses of both professionals and parents to question 45 ("A child who has a seizure may die in one of his seizures.") are interesting. Although professionals could not reach a consensus between "Agree" and "Disagree", parent responses showed a definite shift to "Disagree". This shift may indicate an increasing confidence in both child rearing and child ability. A similar situation was noted in the dramatic shift in question 43 ("Epileptic children generally lead a long and healthy life.") from "Don't Know" to "Agree". There were six fewer "Don't Know" and five more "Agree" answers on the second trial. Concerns over the future of children with seizures were expressed a number of times in the parent seminars (see Appendix H for areas discussed).

Those parents whose children were more severely handicapped felt more confident in a more protective role, and those whose children did not need such concern were more aware of the child's greater abilities and their own overprotectiveness. Some of this confidence and awareness developed during the seminars, and some occurred during social gatherings when all the parents and children met one another. A number of parents commented that meeting the other children put their own child's condition in better perspective.

Question 59 ("A child with epilepsy should be trusted the same as any other child.") on the first trial elicited eight "Disagree" and three "Don't Know" answers. There was a change to 13 "Agree" answers on the second trial. Where possible, treating the child with a seizure disorder like other children is recommended by experts such as Henry Baird.¹¹ Much of the material presented to the parents contained this message, so that the shift in responses to question 59 is possibly a result of this effort. Discussions on the need to change the public image of epilepsy also were involved.

Questions 7, 14, 24, 40, and 60 attempted to approach the problem, common for children with a seizure disorder, of being "different," "weird," "possessed," etc. A slight shift from agreeing that the child should be treated as someone different was noted.

Questions dealing with medications (such as 17 and 18) show interesting responses. There was a shift from "Don't Know" answers to "Agree", a "wrong" answer in this case. Epilepsy is not cured through the use of medications, but controlled (question 17). Such medications are not generally habit forming (question 18) according

¹¹Henry Baird, The Child with Convulsions: A Guide for Parents, Teachers, Counselors, and Medical Personnel. New York: Greene and Stratton, 1972.

to authorities consulted. This information was presented to the parents and therefore there is some difficulty in interpreting their replies.

The majority of parent responses to question 34 on both trials (first trial, "Agree" 11; second trial, "Agree" 14) were in agreement that many people are afraid of an epileptic child. However, the professionals were divided between "Agree" and "Disagree". This discrepancy may have been related to the nature of the question, with parents responding more on a "feeling" level than the more "impersonal" professionals. Parent responses to question 44 ("It is difficult to plan for the future of an epileptic child.") changed from "Don't Know" with an increase in "Agree", whereas professionals, aware of the statistics and programs available, answered "Disagree". This material was presented to the parents during the seminars. Because the children were very young, parents might not have been ready for such areas as career planning at the time. This was observed in the number of "Don't Know" responses on both first and second trials to question 35 ("People with epilepsy generally have good work records."). Again, the excellent work records of many people with seizure disorders were discussed during the seminars.

Questions involving specific knowledge, such as driving cars, programs offered by the Epilepsy League of Oregon, medications, types of situations affecting seizure frequency, how to manage a

seizure, showed a definite change from "Don't Know". Question 56 ("Never put anything between a person's teeth during a seizure.") decreased from eight to two "Don't Know" responses. A change from seven "Agree" to 13 "Disagree" answers occurred for question 55 ("A child may swallow his tongue during a seizure.") Question 31 ("Epilepsy can cause heart trouble.") changed from nine "Don't Know" and one "Agree" answer to almost unanimous "Disagree". Other questions involving specific knowledge such as question 50 ("Screen doors have been known to trigger seizures."), question 52 ("Males have more violent seizures than females."), and question 46 ("The child with epilepsy suffers no pain during his seizures.") decreased in "Don't Know" responses between first and second trials. Some of the lack of change in response might be attributed to the parent's absence during the discussion session in which the particular material was presented.

In general, there was a decrease in the number of "Don't Know" responses by parents. The number of these responses was still substantially larger, however, than replies by professional consultants who gave a total of only three "Don't Know" answers. This large discrepancy can be attributed to difference in approach and to the way in which discussions were conducted. Parents were assumed to answer questions initially in terms of experiences with their children rather than from a more objective perspective. Each

question was not discussed separately but information designed to assist parents in finding their own answers was presented throughout the six weeks.

Several parents made critical comments about parts of the questionnaire and have agreed to assist in re-writing before it is used again. Pre-testing the questionnaire with non-handicapped persons or parents of non-handicapped persons or parents of non-handicapped children apparently did not indicate adequately the needs and information desired by parents of children with seizure disorders.

Video-Taping And Evaluation Of Parent-Child Interaction

1. Mother-child interaction. Each child was observed interacting with his mother. This was a standard situation divided into two parts: (1) a 15-minute period of free play, and (2) a command situation where requests were made of the child. The observations were recorded using an interaction matrix system.¹²

During the free play, the child's behavior was recorded in regard to whether he was responsive to the mother and whether the mother's behavior was facilitative of play. Whether the parent was aware of the child's level of development was noted. Special

¹²Eric J. Mash, Leif Terdal, and Kathryn Anderson, "The Response-Class Matrix: A Procedure for Recording Parent-Child Interaction," University of Oregon Medical School, Crippled Children's Division (In press).

interest was to see if this particular group of children followed a pattern which had been observed with other handicapped children and their parents. In addition, observations were recorded as to ability of these children at providing feedback to the parent, and whether the way the parents structured the task and their personal perception of the child affected the type of interaction in which they engaged. The latter point represented a major part of the study.

Following the free play session, each mother was asked to give the child three tasks. Since the tasks were geared to each child's developmental level, there was some variation of the specific tasks. For the child, attempts were made to observe and record the child's response to directives from his mother. The mother's pattern of structuring a task and her response to either compliance or non-compliance from her child were observed.

2. Video play back and unstructured interview. After the group sessions at Good Samaritan Hospital, the parents were invited to look at the video-tape. With one exception, all of the parents (husband and wife) chose to participate. The standard procedure was to inform the parents that they would have a chance to review the video-tape and to make any descriptive comments or give impressions and feelings which the tapes generated. In each case, the video was shown without interruption in its entirety. To ensure a standard situation, the tape was viewed in separate rooms concurrently by

husband and wife. Their comments, as well as questions, were recorded by audio-tape and transcriptions of the sessions are currently being made for further analysis. The role of Dr. Jackson and Dr. Terdal during the video playback was to support any comments and encourage them to continue to express themselves.

3. Joint discussion with husband and wife. Dr. Jackson and Dr. Terdal, after viewing the video-tape, answered questions from the parents. Perceptions of the interactions were discussed, sometimes in detail, involving the total family situation.

4. The data. Only the data relating to an initial analysis of the mother-child interaction of the ten children are given. Data are presented that was selected as sensitive to variations in parent-child interactions when a handicap is involved. A report will be made at a later date in which the data from the group will be compared with a normal control group and another handicapped group along the same dimensions.

The ten children were classified on the basis of ability to communicate. Four of the children had limited verbal skills and the data show that they differed from the six children who were more fluent in verbal skills and had normal or near normal intelligence. Under the heading "Play Session" is a column for "child reciprocates interaction" which shows the proportion of time that the children reciprocated or responded to the mother, following some action by her. The four children with limited verbal skills responded less often (.29 versus .73). The mothers of the children with limited

SOME DIMENSIONS OF MOTHER-CHILD INTERACTION

	<u>Play Session</u>			<u>Task Session</u>		
	<u>M's Dir*</u>	<u>MICP*</u>	<u>CRI*</u>	<u>M's Dir*</u>	<u>ICE*</u>	<u>LTCE*</u>
Total Group (N = 10)	.16	.44	.56	.41	.60	1.83
Children with Limited Verbalization (N = 4)	.14	.73	.29	.50	.43	.94
Children with Normal Verbalization (N = 6)	.16	.25	.73	.33	.70	2.41

*N's Dir = Mother's Directiveness

MICP = Mother's Interaction with Child's Independent Play

CRI = Child Reciprocates Interaction

ICE = Immediate Command Efficiency of Mother

LTCE = Long-Term Command Efficiency of Mother

verbal skills were not passive, however, as indicated by the high rate of responding to the children (.73 versus .25) while their children were engaged in independent activity. The column "mother's directiveness" gives the ratio of the mother's commands to the number of the total responses she gave during the play sessions. The ratio was similar for the two groupings.

In the "Task Session," the two groupings also differed from each other. When tasks were requested by the mothers, the mothers of the more verbally fluent group gave fewer commands (directive ratio of .33 versus .50), their children were more likely to show immediate compliance, immediate command efficiency of mother (.70 versus .43), and they stayed with tasks for longer time units per command (2.41 versus .70, a time unit of 1 = 10 seconds).

The data indicate that as far as interactions were concerned, the effect of limited verbal fluency was marked. The six children were more fluent verbally showed similar interaction patterns to a group of forty normal young children (data to be given the later report). This may indicate that programs for parents of children with seizure disorders should be based in part on the presence or absence of other significant handicapping conditions. The data for individual mother-child interactions was noted to reflect the overall competency of each individual mother.

CHAPTER V

SUMMARY AND CONCLUSIONS

Parents raising children with seizure disorders have an urgent need for more information about their child's disorder as well as emotional support. Comments in the literature, observations by professionals, and requests from parents attest to this need. This project was an effort to respond to this need by designing and facilitating a series of parent group seminars. It was our plan to describe parent need more clearly and evaluate the usefulness of the group process in meeting these needs. The type of groups developed attempted to reflect parent demands. No effort was made to separate group effect from educational and other experiences. Facilitator knowledge of available materials and speakers was used to deal with specific issues pertinent to a group whose members all were parents of preschool children with seizure disorders. The group focused on parent-child and parent-parent interaction, child-rearing techniques, and specific information on the disorder called "epilepsy." Included in the project was an attempt to objectively record happenings and a final assessment.

A major goal was the designing of a group program and methods of recording the activities of that group which the clinic could continue to use in the future. An effort also was made to develop enthusiasm in this initial group of parents to extend their knowledge

and experience to other parents, institutions, and community involvement.

Objective attendance records, examining replies to questionnaires, reviewing verbal comments, and noting the independent continuation of the sessions by the parents after the formal program had terminated. Parental expression of greater confidence in themselves, their child, and in their child's future was evidenced by changes in their response to the EQ developed for this study. A reduction in overprotectiveness and increased knowledge in specific areas were noted in the questionnaire replies. This was further demonstrated in increased social contacts between parents outside of the group setting and included reciprocal transportation, assistance, and sharing of other resources. In addition, several of the parents began providing volunteer assistance and materials to the clinic and participated more actively in the school program.

Revisions in several areas of this initial program became apparent. There appeared to be a greater demand for more speakers and more time for discussion in the groups. In some cases, certain parents had emotional problems which were detected in the videotaping of mother-child interaction and subsequent discussions with the psychologists. Some parents may have discovered new fears from additional knowledge and contact with parents of more severely handicapped children. Parents who expressed such concerns were referred to the appropriate counseling resources.

A certain inconsistency was evident between responses that requested more time for discussion and yet a more directive approach involving more speakers and greater structure in the program. Facilitator requests for more parental involvement and guidance in the group was met with resistance. Requests for more time for informal discussions were almost unanimous and not adequately met.

A critical issue that was not satisfactorily resolved was that of the definition of "epilepsy". Lack of national, regional, and local consensus in laws and definitions left the parents somewhat confused as to whether epilepsy is a "disease, a symptom or a disorder".

The parents have already taken on the project of assisting with the revision of the Epilepsy Questionnaire. Questions designated as "nebulous" by the professionals generally produced divided responses by the parents. Parents of children with a seizure disorder appear to have a different perspective and attitude than do professionals. As an attempt to discover parent "attitudes," the EQ was only partly successful. However, several of the questions dealing with "feelings" received different responses from the first to second trial.

No attempt has been made to generalize these findings for all parents of children with seizure disorders. This has been a pilot study with a specific group of parents, all of whom had children in a problem oriented setting designed to serve specific problems.

Unique features in the experience were the volume and variety of records (audio-tape, video-tape, questionnaires, slides, etc.) and the qualifications of the group leaders.

This group of parents benefited from the social work skills used in the project. Knowledge of group dynamics, interviewing techniques, research methods, family orientation, inter-personal communication, human development, and available services in the community contributed to the success of the group seminars.

A considerable amount of information on parent attitudes was obtained during this study and recorded for future use. Dr. Schim-schock is proposing a follow-up study on this group of parents and children in five years, after the children enter school. Dr. Terdal and Dr. Jackson are interested in using some of the data in a study of parental attitudes at the Crippled Children's Division of the University of Oregon Medical School.

Several unexplored aspects of this group need further study. The proportion of adopted children with seizure disorders (30%) appears high. The number of first or only children also appears relatively high. This latter case may be related to the age of the parents but is an interesting problem when one considers the hopes and expectations that parents often place on an oldest or only child. What happens to parent-child relationships when a child is found to be "imperfect" and unable to respond adequately to parental expectations? What is the parents' reaction to, and in, a group experience in relation to the severity of the child's seizure disorder?

Revision of the Epilepsy Questionnaire, using a parent's perspective, may have important implications for follow-up studies. Objective assessment of the parental perspective might influence both physiological and psychological treatment methods.

Comparison between males and females is another possibility for future study in attitude and attitude changes. Because the group was designed to involve fathers as well as mothers, including the evaluation of video-taping, an analysis of responses by sex might be of interest. All material is recorded and coded to make this feasible.

The Parent Brochure might be printed as a pamphlet for general distribution if there appears to be a demand for such material. It was assembled with parents of preschool and school-age children in mind.

This study has demonstrated the value, and feasibility of group experience for modifying parental attitudes toward their children and their children's seizure disorders. Adoption of parent seminars as a regular function of the Children's Clinic will enable refinement of methods of presenting information. Study of additional groups should provide data for continual evaluation of the effects of the program on relationships between parents and children and effects of these relationships on child learning and behavior.

SELECTED BIBLIOGRAPHY

- Amster, Fanny. "Collective Psychotherapy of Mothers of Emotionally Disturbed Children." American Journal of Orthopsychiatry. 14 (1944), 44-52.
- Andrews, Jean. "We Learned to Live with Epilepsy." In William G. Kvaraceus, and E. Nelson Hayes, If Your Child is Handicapped. Boston: F. Porter Sargeant, 1969.
- Appell, Melville V., Clarence Williams, and Kenneth N. Fishell. "Changes in Attitudes of Parents of Retarded Children Effected Through Group Counseling." American Journal of Mental Deficiency. 68:6 (May 1964), 807-812.
- Auerbach, Aline B. Parents Learn Through Discussion: Principles and Practices of Parent Group Education. New York: John Wiley and Sons, Inc., 1968.
- _____. "What Can Parents of Handicapped Children Gain from Group Experience." Helping Parents of Handicapped Children. Boston: Children's Hospital Medical Center and Child Study Association of America (October 1959).
- Bagley, Christopher. The Social Psychology of the Child with Epilepsy. London: Rutledge S. Kegan Paul, Ltd., 1971.
- Baird, Henry. The Child with Convulsions: A Guide for Parents, Teachers, Counselors, and Medical Personnel. New York: Greene and Stratton, 1972.
- Bakwin, Harry, and Ruth Morris Bakwin. Clinical Management of Behavior Disorders in Children. Philadelphia: W. B. Saunders Co., 1967.
- Bakwin, R. M., and Harry Bakwin. "Epilepsy." The Journal of Pediatrics. 39:4 (December 1951), 775-784.
- Barker, W. "Studies in Epilepsy: The Petit Mal Attack as a Response within the Central Nervous System to Distress in Organism-Environment Integration." Psychosomatic Medicine. 10 (1948), 73-94.
- Barnwell, John E. "Group Treatment of Older Adolescent Boys in a Family Agency." Social Casework. 41 (May 1960), 247-253.

- Barsch, Ray H. The Parent of the Handicapped Child. Springfield: Charles C. Thomas, 1968.
- Baus, Gaston J., L. LaVerne Letson, and Edith Russell. "Group Dynamics in the Treatment of Epilepsy." The Journal of Pediatrics. 52:3 (March 1958), 270-273.
- Beasley, J. "Social Aspects of Epilepsy in Childhood." Post-Graduate Medical Journal. 40:464 (June 1964), 344-345.
- Becker, Wesley C. Parents Are Teachers. Champaign, Illinois: Research Press Co., 1971.
- Bergen, Helen M., and Anton O. Kris. "Services to Parents of Adolescent Mental Patients." Social Casework. 53:2 (February 1972), 85-90.
- Bice, Harry V., and Margaret C. Davitt Holden. "Group Counseling with Mothers of Children with Cerebral Palsy." Social Casework. 30:3 (March 1949), 104-109.
- Bice, Harry V. "Parent Counseling and Parent Education." Cerebral Palsy: Its Individual and Community Concerns. William M. Cruickshank and George M. Raus, eds. Syracuse: Syracuse University Press, 1955.
- Blatt, A. "Group Therapy with Parents of Severely Retarded Children: A Preliminary Report." Group Psychotherapy. 10 (1957), 133-140.
- Bradley, Charles. "Characteristics and Management of Children with Behavior Problems Associated with Organic Brain Damage." Pediatric Clinics of North America. 14:4 (November 1957), 1049-1060.
- _____. "Behavior Disturbances in Epileptic Children." Journal of the American Medical Association. 146:5 (June 1951), 436-441.
- Bradley, Charles M. "A Normal Life for Children with Convulsions." Epilepsy Speaks. Portland: The Epilepsy League of Oregon (September 1958). Two pages mimeograph.
- Bridge, E. M. Epilepsy and Convulsive Disorders in Children. New York: McGraw-Hill Book Co., 1949.
- Broida, Daniel C. "Psychological Aspects of Epilepsy in Children and Youth." Psychology of Exceptional Children and Youth.

New York: Prentice-Hall, 1955, 345-390.

Brullerman, L. H. "Group Therapy with Epileptic Patients at the 'Instituut Voor Epilepsiebestrijding.'" Epilepsia. 13 (1972), 225-231.

Burden, G. "Social Aspects of Epilepsy." Epilepsia. 3 (1962), 201-204.

Caveness, William. "A Survey of Public Attitudes Toward Epilepsy." Epilepsia. 3:3:99 (1954), 102.

Cereghino, James J. Survey of Existing Services and Facilities for the Epileptic in the State of Oregon. Neurological and Sensory Disease Control Program, Division of Chronic Disease Programs, Arlington, Virginia, p. 33.

Chao, Dora Hsi-Chih. "The Over-All Management of the Epileptic Child." Medical Clinic of North America, 42 (1958), 461-478.

Children's Hospital Medical Center. Helping Parents of Handicapped Children. Child Study Association of America, 1959.

Child Study Association. When Parents Get Together: How to Organize a Parent Education Program. New York: Child Study Association of America, Inc. (Rev. February 1964).

Cohen, Lord of Birkenhead. "Epilepsy as a Social Problem." British Medical Journal, 1:5072 (March 22, 1958), 672-675.

Coleman, James C. "Group Therapy with Parents of Mentally Deficient Children." American Journal of Mental Deficiency, 57 (1953), 700-704.

Crow, Maxine S. "Preventive Intervention Through Parent Group Education." Social Casework, 48:3 (March 1967), 161-165.

Crowther, D. L. "Psychosocial Aspects of Epilepsy." Pediatric Clinics of North America, 4:14 (1967), 921-932.

Cummins, Jean. "The Family as a Factor in the Epileptics Social Adjustment." Social Casework, 3:9 (November 1949), 384-387.

Cummins, S. Thomas. "Brief Group Therapy of Mothers of Retarded Children Outside of the Specialty Setting." American Journal of Mental Deficiency, 66 (1962), 739-748.

- Davidoff, Eugene, George M. Doolittle, and Vincent I. Bonafede. "Psychiatric Aspects of Epilepsy." Journal of Nervous and Mental Disease, 100 (1944), 170-184.
- Davidson, Elabe McL., and Joan C. Thomas. "A Social Study of Epileptic Patients." Social Casework, 30:9 (November 1949), 380-384.
- Davis, Jack A. "The Use of Discussion Groups in a Military Setting in Japan." Social Casework, 44:2 (February 1963), 74-80.
- Day, Max, Elvira Day, and Rosalind Herrmann. "Group Therapy of Patients with Multiple Sclerosis." A.M.A. Archives of Neurology and Psychiatry, 69 (February 1953), 193-196.
- Day, Max, and Irving Rosen. "The Group Behavior of Mothers of Schizophrenics." Journal of Nervous and Mental Disease, 119 (1954), 365-369.
- DeColon, Lydia Santiago, Richard D. Trent, and Louis Sanchez Longo. "A Group Work Experience for Mothers of Adolescents with Epilepsy." Counseling Parents of the Ill and the Handicapped. Springfield, Ill.: Charles C. Thomas. 1971, 219-226.
- deFries, Zira, and Sue Browder. "Group Therapy with Epileptic Children and Their Mothers." Bulletin of the New York Academy of Medicine, 28:4 (April 1952), 235-240.
- Deutsch, Leopold, and Louise L. Wiener. "Children with Epilepsy: Emotional Problems and Treatment." American Journal of Orthopsychiatry. 18 (1948), 65.
- Dreikers, Rudolf. "Basic Principles in Dealing with Children." Adlerian Family Counseling: A Manual for Counseling Centers. (ed.) Rudolf Dreikurs, et. al. Eugene, Oregon: University Press, 1959.
- _____. "Do Teachers Understand Children?" School and Society. 87 (1959), 2148.
- _____. "Counseling for Family Adjustment." Individual Psychology Bulletin, 8 (1949), 3.
- _____. The Challenge of Parenthood. Rev. ed. New York: Duell, Sloan, and Pearce. 1958.
- Dreikurs, Sadie Garland. "Psychological Techniques Applied in a Group Situation." Individual Psychology Bulletin, 4 (1954), 4.

- Driscoll, Chancellor B., and A. Harold Lubin. "Conferences with Parents of Children with Cystic Fibrosis." Social Casework, 53:3 (March 1972), 140-146.
- Durkin, Helen E. Group Therapy for Mothers of Disturbed Children. Springfield, Ill.: Charles C. Thomas, 1954.
- Durkin, Helen E., Henriette T. Glatzer, and Jeanette S. Hirsch. "Therapy of Mothers in Groups." American Journal of Orthopsychiatry. 14 (1944), 68-75.
- Epilepsy Center of Michigan. First Aid for Epileptic Convulsions. Detroit: Epilepsy Center of Michigan (March 1971).
- Force, D. "A Descriptive Study of the Incidence of Seizures and Teacher's Attitudes Toward Children with Epilepsy in the Minneapolis, Minnesota, Public Schools." Minnesota Epilepsy League, (December 1965), 75 pages mimeographed.
- Fremont-Smith, Frank. "The Influence of Emotion in Precipitating Convulsions." American Journal of Psychiatry, 13:90 (1934), 717-723.
- French, A. C., Levbarg, M., and H. Michal-Smith. "Parent Counseling as a Means of Improving the Performance of a Mentally Retarded Boy: A Case Presentation." In C. L. Stacey and M. F. DeMartino, eds. Counseling and Psychotherapy with the Mentally Retarded. Glencoe, Ill.: The Free Press. (1957), 438-445.
- Funt, Irene G. "The Application of Casework Principles in Family Life Education." Social Casework, 43:3 (March 1962), 130-137.
- Ganoung, Laura D. "Educational Problems of Epileptic Children." Epileptic Seizures. Baltimore: The Williams and Wilkins Co. (1956), 63.
- Gardner, Harry H. "Personality and Behavioral Aspects." In George N. Wright, Frederic A. Gibbs, and Shirley Motter Linde eds. Total Rehabilitation of Epileptics - Gateway to Employment. Washington, D.C.: U. S. Department of Health, Education, and Welfare. Office of Vocational Rehabilitation (January 1962).
- Garrard, Sterling D., and Julius B. Richmond. "Psychological Aspects of the Management of Children with Defects or Damage of the Central Nervous System." Pediatric Clinics of North America. (November 1957), 1033-1048.

- Gerofski, Ruth. "The Patient Faces Epilepsy." Social Casework, 29:5 (May 1948), 182-187.
- Glidewell, John C. Parental Attitudes and Child Behavior. Springfield: Charles C. Thomas (1961).
- Goldin, George J. The Rehabilitation of the Young Epileptic. Boston: D. C. Heath and Co., 1971.
- Goller, Gertrude. "Use of the Small Discussion Group in Parent Education." Social Work, 2:2 (April 1957), 47-53.
- Goodman, L., and R. Rothman. "The Development of a Group Counseling Program in a Clinic for Retarded Children." American Journal of Mental Deficiency, 65 (1961), 789-795.
- Gordon, Ira J. Early Stimulation Through Parent Education. Gainesville, Florida: Institute for the Development of Human Resources, University of Florida. (1969).
- Gowers, W. R. Epilepsy and Other Chronic Convulsive Diseases: Their Causes, Symptoms and Treatment. New York: Dover Publications, Inc. (1964).
- Graves, Valerie. "The Discussion Group." The Postgraduate Medical Journal, 40:459 (January 1964), 1-3.
- Grunwald, Hanna, and Bernard Casella. "Group Counseling with Parents." Child Welfare, (January 1958), 11-17.
- Hallowitz, Emmanuel, and Bernice Stephens. "Group Therapy with Fathers." Social Casework, 40:4 (April 1959), 183-182.
- Hartlage, L. C., and J. B. Green. "The Relation of Parental Attitudes to Academic and Social Achievement in Epileptic Children." Epilepsia, 13 (1972), 21-26.
- Hereford, Carl F. Changing Parental Attitudes Through Group Discussion. Austin: University of Texas Press (1963).
- Horowitz, Mardi J. Psychosocial Function in Epilepsy. Springfield, Ill.: Charles C. Thomas (1970).
- Hughes, J. G., and J. T. Jabbour. "The Treatment of the Epileptic Child." The Journal of Pediatrics, 53:1 (July 1958), 66-68.

- Ireton, Harold R. "Psychologic Problems of Children with Seizures." Postgraduate Medicine, 64:2 (August 1969), 41-45.
- Jensen, R. A. "Importance of the Emotional Factor in the Convulsive Disorders of Children." American Journal of Psychiatry, 104 (1947), 126-131.
- Kahn, Carl L. "Pills that Control Epilepsy." Your Life. Portland: The Epilepsy League of Oregon (August 1959), two pages mimeograph.
- Kamin, Sheldon H., Charley Jackson Llewellyn, and Winnie L. Sledge. "Group Dynamics in the Treatment of Epilepsy." The Journal of Pediatrics, 53:1 (October 1958), 410-412.
- Kanter, Stanley S. "Dynamic Insights Gained from Group Therapy with Obesity Patients." Journal of Nervous and Mental Disease, 119 (1954), 367.
- Karnes, Merle B., and Earladeen D. Badger. Mother's Training Program: The Group Process. Urbana, Ill: ERIC Clearinghouse for Early Childhood Education (1970).
- Karnes, Merle B., William M. Studley, Willis R. Wright, and Audrey S. Hodgins. "An Approach for Working with Mothers of Disadvantaged Preschool Children." Merrill-Palmer Quarterly, 14:2 (April 1968), 174-183.
- Kemp, Robert. Understanding Epilepsy. London: Tavistock Publications (1963).
- Kemph, J. P., L. A. Zegans, K. A. Kooi, and R. W. Waggoner. "The Emotionally Disturbed Child with a Convulsive Disorder." Psychosomatic Medicine, 25 (1963), 441-449.
- Kimball, O. P. "On the Inheritance of Epilepsy." The Wisconsin Medical Journal, 53 (May 1954), 271-276.
- Laibman, Erwin M. "Group Counseling with Parents in an Agency Serving Adolescents." Social Work, 6:2 (April 1961), 67-73.
- Lampe, J. "Education and Epilepsy." Journal of School Health, 29:6 (June 1959), 220-223.
- Lennox, William G. and C. H. Markham. "The Sociopsychological Treatment of Epilepsy." Journal of the American Medical Association, 152 (August 1953), 1690-1694.

Lennox, William G. and Margaret A. Lennox. Epilepsy and Related Disorders. London: Churchill Press (1960).

Lennox, William G. "Mental Defect in Epilepsy and the Influence of Heredity." American Journal of Psychiatry, 98 (1942), 733-739.

_____. "Psychiatry, Psychology and Seizures." American Journal of Orthopsychiatry, 19 (1949), 432-446.

_____. Science and Seizures. New York: Harper and Brothers (1941).

_____. "The Social and Emotional Problems of the Epileptic Child and His Family." The Journal of Pediatrics, 44:5 (May 1954), 591-601.

Leonhard, Jacqueline T. Diagnosis Epilepsy--A Guide for Parents. Cleveland, Ohio: Parents Committee on Epilepsy, Family Health Association, Inc. (1962).

Levenstein, P. "Cognitive Growth in Preschoolers Through Verbal Interactions with Mothers." American Journal of Orthopsychiatry, 14:3 (April 1970), 426-432.

Liebman, Samuel. Emotional Problems of Childhood. Philadelphia: J. B. Lippencott Co. (1958).

Lippman, Hyman S. Treatment of the Child in Emotional Conflict. New York: McGraw-Hill Book Co., Inc. (1962).

Livingston, Samuel. Living with Epileptic Seizures. Springfield: Charles C. Thomas (1963).

_____. "The Social Management of the Epileptic Child and His Parents." The Journal of Pediatrics, 51:2 (August 1957), 137-145.

Long, Robert T. "Insights Gained Through Group Therapy with Multiple Sclerosis Patients." Journal of Nervous and Mental Disease, 119 (1954), 366.

Love, Harold D. Parental Attitudes Toward Exceptional Children. Springfield: Charles C. Thomas (1970).

Lowrey, Lawson G. "Group Therapy." American Journal of Orthopsychiatry, 13 (1943), 648-690.

Lunt, Carroll. How to Live with Epilepsy. New York: Twayne Publishers (1961).

- Mallison, Ruth. Education as Therapy: Suggestions for Work with Neurologically Impaired Children. Seattle: Special Child Publications (1968).
- Mann, David, Luther E. Woodward, and Nathan Joseph. Educating Expectant Mothers. New York: H. Wolff Book Manufacturing Co. (1961).
- Mann, James. "The Theoretical Concepts of the Group Process." Journal of Nervous and Mental Process, 119 (1954), 365.
- Mannino, Fortune V., and Margaret M. Conant. "Dropouts from Parent Education Groups." The Family Coordinator, 18:1 (January 1969), 54-59.
- Mash, Eric J., Leif Terdal, and Kathryn Anderson. "The Response-Class Matrix: A Procedure for Recording Parent-Child Interaction." University of Oregon Medical School, Crippled Children's Division (In press).
- McGriff, Dorothy. "Working with a Group of Authoritative Mothers." Social Work, 5:1 (January 1960), 63-68.
- McMichael, Joan K. Handicap. London: Staple Press (1971).
- McPherson, Sandra B., and Cyrille R. Samuels. "Teaching Behavioral Methods to Parents." Social Casework, 52:3 (March 1971), 148-153.
- Milman, Doris H. "Group Therapy with Parents: An Approach to the Rehabilitation of Physically Disabled Children." The Journal of Pediatrics, 41:1 (July 1952), 113-116.
- Morgan, Margaret, Harold GoodGlass, Angela Folsom, and Fred A. Quadfasel. "Epilepsy and Social Adjustment." Social Work, 12:2 (April 1967), 70-76.
- Nadal, Robert M. "A Counseling Program for Parents of Severely Retarded Preschool Children." Social Casework, 42:2 (February 1961), 78-83.
- Nardini, John, and Genevieve O'Leary. "How Much Protection?" Portland: The Epilepsy League of Oregon (no date), one page mimeograph.

- _____. "Teaching Him to Manage His Epilepsy." Portland: The Epilepsy League of Oregon (no date), one page mimeograph.
- National Epilepsy League. "Our Schools and Our Children with Epilepsy." National Epilepsy League (1958), 80 pages mimeograph.
- _____. Summaries of Articles on Juvenile Epilepsy. National Epilepsy League; Park, Davis and Co., 1967.
- _____. "The Care and Education of Children with Epilepsy: A Nationwide Survey by John W. Tenny." Chicago: The League (1958), 16 pages mimeograph.
- National Society for the Study of Education. The Twenty-Eighth Yearbook; Preschool and Parental Education. Bloomington, Ill.: Public School Publishing Company (1929).
- Neubauer, Peter B. "The Technique of Parent Group Education: Some Basic Concepts." In Parent Group Education and Leadership Training. New York: Child Study Association of America (1953), 11.
- Otto, John L. "Psychologic Problems in Epilepsy." Epileptic Seizures. Baltimore: The Williams and Wilkins Co. (1956), 63.
- Ounsted, C. "The Hyperactive Syndrome in Epileptic Children." Lancet, 2 (August 1955), 303-311.
- Papademetriou, Marguerite. "Use of a Group Technique with Unwed Mothers and Their Families." Social Work, 16:4 (October 1971), 85-90.
- Patterson, Gerald R. Living With Children. Rev. ed. Champaign, Ill.: Research Press Co. (1971).
- Penfield, Wilder, and Kristian Kristiansen. Epileptic Seizure Patterns. Springfield: Charles C. Thomas (1951).
- Penfield, Wilder, and Theodore C. Erickson. Epilepsy and Cerebral Localization. Springfield, Ill.: Charles C. Thomas (1941).
- Penfield, Wilder, and Herbert Jasper. Epilepsy and the Functional Anatomy of the Human Brain. Boston: Little, Brown and Co. (1954).
- Peterman, M. G. "Behavior in Epileptic Children." The Journal of Pediatrics, 42:6 (June 1958), 758-769.

- Price, Jerry C. "The Epileptic Child in School" Ohio State Medical Journal, 46:3 (1950), 794-805.
- Price, Jerry Seizure Clinic. Brochure for Parents. Los Angeles: Children's Hospital (November 1963), 10 pages mimeograph.
- Price, Jerry C., and Tracy J. Putnam, "The Effect of Intrafamily Discord on the Prognosis of Epilepsy." American Journal of Psychiatry, 100 (1944), 593-598.
- Pond, D. "Psychiatric Aspects of Epileptic and Brain-Damaged Children." British Medical Journal, 2 (1961), 1377-1382; 1454-1459.
- Pond, D. A., and B. Bidwell. "Management of Behavior in Epileptic Children." British Medical Journal, 2 (December 1954), 1520-1523.
- Putnam, Tracy J. Convulsive Seizures: A Manual for Patients, Their Families and Friends. Philadelphia: J. B. Lippincott Co. (1945).
- Puvrez, Marguerite. "Experiences in Working with a Group of Seizure Patients." Differential Diagnosis and Treatment in Social Work. Ed. Francis J. Turner. New York: Free Press (1968), 379-386.
- Redl, Fritz. "Diagnostic Group Work." American Journal of Orthopsychiatry, 14 (1944), 53-60.
- Redwin, Eleanore. "Mothers Therapy Groups." Adlerian Family Counseling: A Manual for Counseling Centers. Ed. Rudolf Dreikurs, et. al. Eugene, Oregon: University Press (1959).
- Rodin, Ernest A. "Medical and Social Prognosis in Epilepsy." Epilepsia, 13 (1972), 121-131.
- _____. The Prognosis of Patients with Epilepsy. Springfield: Charles C. Thomas (1968).
- Rodin, Ernest A., P. Rennic, R. Dennerll, and Y. Lin. "Vocational and Educational Problems of Epileptic Patients." Epilepsia, 13 (1972), 149-160.
- Ross, Alan O. The Exceptional Child in the Family: Helping Parents of Exceptional Children. New York: Grune S. Stratton (1964).

- Rupp, Charles. "Management of Epilepsy." Journal of the American Medical Association, 166 (April 1958), 1967-1970.
- Sands, Harry. "Epilepsy." In M. E. Fraughton and Elena D. Gall, eds. Special Education for the Exceptional. Boston: Porter Sargeant, 3 (1956), 204-214.
- Sands, Harry, and Jacqueline Seaver. Epilepsy--Today's Encouraging Outlook. Public Affairs Pamphlet No. 317, Produced in cooperation with Epilepsy Association of America, 1969.
- Scheidlinger, Saul, and Marjorie Pyrke. "Group Therapy of Women with Severe Dependency Problems." American Journal of Orthopsychiatry, 31 (October 1961), 776-785.
- Schilder, P. "Analysis of Ideologies Psycho-Therapeutic Method, Especially in Group Treatment." American Journal of Psychiatry, 93 (1936), 601.
- Scholl, Mary Louise. "Let Them Ask." Epi-Log. Portland: The Epilepsy League of Oregon. From the Greater Kansas City Epilepsy League, Inc. (no date), one page mimeograph.
- Schwentker, Francis F. "Social Management of Epilepsy" In Samuel Livingston, The Diagnosis and Treatment of Convulsive Disorders in Children. Springfield: Charles C. Thomas (1954), 236-249.
- Scott, Donald. About Epilepsy. New York: International Universities Press, Inc. (1969).
- Siegel, Ernest. Helping the Brain Injured Child. New York: Association for Brain Injured Children (1961).
- Sonstegard, Manford A. "A Center for the Guidance of Parents and Children in a Small Community." The American Journal of Individual Psychology. 11 (1954), 1.
- Slavson, S. R. Child Centered Group Guidance of Parents. New York: International Universities Press, Inc. (1958).
- Speers, Rex W., and Cornelius Lansing. Group Therapy in Childhood Psychosis. Chapel Hill: University of North Carolina (1965).
- Spock, Benjamin, and Marion O. Lerrigo. Caring for Your Disabled Child. New York: MacMillan Co. (1965).

- Staprans, Theodore. "Epilepsy and Personality." Epilepsy Speaks. Portland: The Epilepsy League of Oregon. 5:3 (March 1958), two pages mimeograph.
- Stern, Edith M., and Elsa Castendyck. The Handicapped Child: A Guide for Parents. New York: A. A. Wyn, Inc. (1950).
- Stern, H. H. Parent Education: An International Survey. Hamburg: The University of Hull and the Unesco Institute for Education (October 1960).
- Stone, F. B., and V. M. Rawley. "Children's Behavior Problems and Parental Attitudes." Journal of Genetic Psychology, 107 (1965), 281-287.
- Sullivan, Ellen B., and Lawrence Cahagan. "On Intelligence of Epileptic Children." Genetic Psychology Monographs, 17 (October 1935), 309.
- Suter, C. G. "Psychological Factors in Epilepsy." Neuropsychiatry, 3 (Fall, 1955), 153-171.
- Tavriger, R. "Some Parental Theories About the Cause of Epilepsy." Epilepsia, 7 (1966), 339-343.
- Tempkin, Owsei. The Falling Sickness. Baltimore: The Johns Hopkins Press (1971).
- The Epilepsy League. "Alcoholism and Epileptic Seizures." Epi-Gram. Portland: The Epilepsy League of Oregon. From the Leavenworth Epilepsy League (no date), one page mimeograph.
- _____. A Patient's Guide to EEG. Washington, D. C.: Epilepsy Foundation of America (March 1972).
- _____. "Epilepsy and the Teen-ager." Portland: The Epilepsy League of Oregon (no date), one page mimeograph.
- _____. "Oregon Laws Relating to Epilepsy." Portland: The Epilepsy League of Oregon (no date), one page mimeograph.
- _____. "Suggestions for the Care of Children with Epilepsy." Epilepsy Speaks. Portland: The Epilepsy League of Oregon. 6:8 (November 1959), two pages mimeograph.
- Thomas, Evan W. Brain Injured Children. Springfield: Charles C. Thomas (1969).

- Tretakoff, Maurice. "Counselling Parents of Handicapped Children: A Review." Mental Retardation, (August 1969).
- Tymchuk, Alexander, and Robert M. Knights. A Two-Thousand Item Bibliography: The Description, Etiology, and Treatment of Children with Learning Disabilities or Brain Damage. Carlton University, Department of Psychology, Ottawa, Ontario, Canada, (1969).
- U. S. Department of Health, Education, and Welfare. Epilepsy: A Review of Basic and Clinical Research. Washington, D. C.: Public Health Service, National Institutes of Health, National Institute of Neurological Diseases and Blindness, 1965.
- _____. The Clinical Neurophysiology of Epilepsy: A Survey of Current Research. Washington, D. C.: Public Health Service, National Institutes of Health, National Institute of Neurologic Diseases and Blindness (1968).
- _____. Infant Care. Washington, D. C.: Children's Bureau (1963).
- _____. Your Child From 1 to 6. Washington, D. C.: Children's Bureau, (1962).
- _____. Your Child From 6 to 12. Washington, D. C.: Children's Bureau, (1966).
- Voeller, Kytja K. S., and Michael B. Rothenberg. "Psycho-Social Aspects of the Management of Seizures in Children." A 26-page paper written for the Albert Einstein College of Medicine. Bronx Municipal Hospital Center (no date).
- Walker, Earl A. Posttraumatic Epilepsy. Springfield: Charles C. Thomas (1949).
- Wallin, J. E. Wallace. Children with Mental and Physical Handicaps. New York: Prentice-Hall (1949).
- Ward, M. M. "Group Therapy for Eleven Preschool Cerebral Palsied Children." Exceptional Child, 21 (1955), 207.
- Weingodl, J. T., and R. P. Hormouth. "Group Guidance of Parents of Mentally Retarded Children." Journal of Clinical Psychology, 9 (1953), 118-124.

- Whildin, O. "The Epileptic Child in the Public School." Nervous Child, 6 (1947), 99-104.
- White, B. L. "Clinical Team Treatment of Mentally Retarded Child and His Parents: Group Counseling and Play Observation." American Journal of Mental Deficiency, 63 (1959), 713-723.
- Wiener, Louise L. "group Work with Parents." In Hubert S. Coffey and Louise L. Wiener, eds., Group Treatment of Autistic Children. Englewood Cliff: Prentice-Hall, Inc. (1967), 89-92.
- Williams, Dennis. "Structure of Emotions Reflected in Epileptic Experiences." Brain, 79 (1956), 29-67.
- Wittenburg, Rudolf. "Psychiatric Concepts in Group Work." American Journal of Orthopsychiatry, 14 (1944), 76-83.
- Wittes, Glorianne, and Norma Redin. "Two Approaches to Group Work with Parents in a Compensatory Preschool Program." Social Work, 16:1 (January 1971), 42-50.
- Wolfensberger, Wolf. "Counseling the Parents of the Retarded." In Alfred A. Baumeister, ed., Mental Retardation. New York: Alpine Publishing Co. (1967), 329-400.
- Yahr, Melvin D., and Houston H. Merritt. "Current Status of the Drug Therapy of Epileptic Seizures." Journal of the American Medical Association, 161 (May 1956), 333-338.
- Yahraes, Herbert. Epilepsy--The Ghost is out of the Closet. Public Affairs Pamphlet, No. 98. New York: Public Affairs Committee, Rev. (1954).
- Yaworsky, W., and J. Kemp. "A Study of Affects in an Emotionally Disturbed Child with a Convulsive Disorder." Psychosomatics, 7 (1966), 315-319.
- Zweibel, A. D. "Re-educating Parents and Teachers." Individual Psychology Bulletin, 6 (1946), 1-2.

APPENDIX

- A. Application for Funds
- B. Brochure for Parents
- C. Epilepsy Questionnaire
- D. Evaluation Questionnaire
- E. Handicap Problems Inventory
- F. Letters of Introduction and Contract
- G. Review of the Literature on the Value of Parent Groups
- H. Session Questions
- I. Socio-Economic Inventory and Instructions
- J. Interviews

APPENDIX A

Application For Funds

APPLICATION FOR
RESEARCH DEVELOPMENT FUNDS

1. DATE: May 22, 1972
2. APPLICANT: Research Committee, Good Samaritan Hospital and Medical Center Clinic for Children with epilepsy, learning and behavior problems. A non-profit organization.
3. ADDRESS: 1015 Northwest 22nd Avenue
Portland, Oregon 97210
4. AUTHORIZING PERSON: Robert S. Dow, M.D., Project Director,
2525 Northwest Lovejoy
Portland, Oregon 97210
Telephone 224-5424
5. PROGRAM CONTACT PERSON: James R. Schimschock, M.D.
Research and Program Coordinator
2800 North Vancouver Avenue
Portland, Oregon 97227
Telephone 288-5151
6. ADDRESS OF PROGRAM SITE: Good Samaritan Hospital and Medical
Center
1015 Northwest 22nd Avenue
Portland, Oregon 97210

PART I - FISCAL INFORMATION AND BUDGET

7. Research funds are requested for the period from June 1, 1972 through December 31, 1972.
8. Funds requested from the Epilepsy League of Oregon \$1700.00
9. PROJECTED EXPENDITURES:
 - a. Parent education program development including expendable training supplies \$ 200.00
 - b. Parent education program service equipment (film rentals, video taping blanks, etc.). \$ 150.00

c. General operating expenses:

(1)	Clerical assistance	\$ 250.00
(2)	Office supplies (paper, postage).	\$ 100.00
(3)	Telephone	\$ 50.00
(4)	Reproduction (photocopying, printing and graphic design services).	\$ 200.00
(5)	Transportation.	\$ 200.00
d.	Copyrighted materials	\$ 100.00
e.	Computer programming	\$ 150.00
f.	Data processing	\$ 300.00
g.	TOTAL RESEARCH PROGRAM COST	\$1700.00

PART II - RESEARCH STAFF

PART III - NARRATIVE DESCRIPTION OF RESEARCH PROPOSAL

OBJECTIVES: The proposed research by this committee has two major objectives:

1. To obtain information concerning parent expectations and interpretations of behavior management, in terms of their child's diagnosed epileptic symptoms.
2. To fulfill the research requirements for three members of the committee for their Masters of Social Work Degree, Graduate School of Social Work, Portland State University.

CONCERNS: The basis of this proposed research is founded upon the assumption that parents having children with diagnosed epileptic symptoms hold certain attitudes about epilepsy which may significantly influence their child's performance in academic and social pursuits. A further assumption is that these parental attitudes occur in a majority of cases, and taken as a group perspective, present problematic areas in the therapeutic management of childhood epilepsy.

SCOPE: The areas with which this research will deal are as follows:

1. Parental attitudes about epilepsy will be measured in a sample population of parents having children with diagnosed epileptic symptoms. These parents are associated with the Good Samaritan Hospital and Medical Center Children's Clinic.
 - a. Identify parental interpretations of epilepsy held by all parents having children with suspected epileptic symptoms, at the time of the initial screening interview.
 - b. Identify problematic areas in parental interpretation of epilepsy with regards to the treatment of the childhood epileptic condition.
 - c. Measure the frequency of occurrence of problematic interpretations in the designated target population and comparison population.

2. A parent education program, in conjunction with concurrent child participation in the Clinic's special education classroom, will be designed and implemented.
 - a. The program will be structured on a group basis at a time when eight to ten couples can meet conjointly.
 - b. Professional participants in group instruction will include a pediatric neurologist, social worker, child psychologist, special educator and other allied professions as indicated by parent needs.
 - c. The purpose of the group is to help the parent participants gain a clearer understanding of their children, their role as parents, and the expectations they should have for their children.
 - d. Subject to modification, the tentative schedule of events shall be:
 - (1) Prior to the first session, individual families will meet with the group coordinator at which time the families can express their individual concerns.
 - (2) The primary focus of the group during the first three sessions will be professional presentation of relevant material with limited discussion periods. The remaining three to five sessions will emphasize group discussion of problems based upon individual family concerns as they relate to group concerns.
 - (3) A followup group discussion will be held at a three month interval after formal termination of the group program.
 - (4) Attempts will be made to have families with similar concerns in the same group.
3. An information retrieval system will be established to make clinic data available for current and future research use. Neurological, psychological, school performance and social assessment data will be coded and indexed.

SUMMARY: This research is oriented toward the goal of coordinating clinic efforts to reintegrate children with diagnosed epileptic disorders into the public school system. Further research will be needed to assess the current discrepancies between the Clinic and public school systems, but it is hoped that our proposed research will lay a foundation for future program development in the area of childhood epilepsy management.

PART IV - RESEARCH POPULATION

APPENDIX B

Brochure For Parents

BROCHURE FOR PARENTS

GOOD SAMARITAN HOSPITAL & MEDICAL CENTER

CHILDREN'S CLINIC

EVERYTHING YOU ALWAYS WANTED TO KNOW ABOUT EPILEPSY*

*BUT WERE AFRAID TO ASK

INFORMATION ABOUT SEIZURES

The aims of the staff in the Good Samaritan Hospital and Medical Center Children's Clinic are not limited to the medical treatment of your child's seizure disorder. Resources are extended to include evaluation of other environmental factors affecting your child (i.e., parent-child interaction, child-teacher-school interaction, child-peer relationships). We are all trying to work together, both parents and hospital personnel, to help your child maximize his potential for social adjustment. A child can be happy even though he has seizures, but he cannot be happy if he cannot get along with people. Our goal is to assist your child's growth into a reasonable and responsible adult.

We recognize the difficulties of finding a balance in raising children. A child must learn gradually to assume responsibility and to make decisions for himself as he grows up. He needs to experience self-expression and yet must learn to live within certain limits. He needs to learn to know what he may and what he may not do.

Consistency in child management is an important key to the successful maturation of your child. A child who has seizures should be treated the same as the other children in the family. He should not be allowed to use his seizures as a means of getting his way with parents or other adults who are guiding his growth processes (i.e., teachers, neighbors, grandparents, etc.).

The following are common questions raised by parents seeking a better understanding of their children and new methods of handling them.

MEDICAL INFORMATION ABOUT EPILEPSY

WHAT IS EPILEPSY?

Epilepsy is a term which means convulsions or seizures. Epilepsy involves a group of symptoms which occur periodically and not constantly. The symptoms that we see (that is the type of seizure which occurs) depends upon which area of the brain is involved. The one thing which is common to all forms of epilepsy is that the symptoms arise from the brain. Usually they are associated with a partial or complete loss of consciousness.

WHAT IS THE CAUSE OF EPILEPSY?

In some youngsters no definable cause is apparent. In other children, infections, injuries, congenital defects or growths on the brain may cause seizures. Like many conditions, the actual causes for epilepsy are many and varied. We do know that a seizure results from abnormal electrical activity in the brain. What causes this abnormal activity is not known.

IS EPILEPSY CONTAGIOUS?

No.

WHAT SETS OFF A SEIZURE?

No clear precipitating cause can be found. However, a variety of factors may influence the frequency of seizure activity. In some people a seizure apparently can be traced to such things as a time of great tension, nervousness, a sudden noise, or bright flickering lights. Of course this depends upon each individual.

IS A CHILD LIKELY TO DIE BECAUSE OF HIS SEIZURES?

Epilepsy is a symptom, not a disease, and the symptom will not cause death, unless it is allowed to continue untreated for an extended period of time.

WHAT SHOULD BE DONE DURING A SEIZURE?

Wait until it is over. In the meantime protect the patient from falling off from what he may be lying on, or

otherwise injuring himself. Remove any objects from the immediate area to prevent injury to him, but do not try to interfere with his movements. It is not necessary to restrain him. Turn him, if possible, onto the stomach or the side. Do not attempt to put something between the teeth or the jaws. It would only result in injury to the teeth or the gums and would not help the child. Keep him company so someone is quietly at his side for reassurance when the seizure is over. Let him rest or sleep afterwards if he so desires.

DOES A CHILD SWALLOW HIS TONGUE DURING A SEIZURE?

No. It looks that way because of breathing interference which is part of the seizure. However, precaution can be taken by placing the patient on his side or stomach to prevent the tongue from falling against the back of the throat. Air passages are then kept open more easily.

DO SEIZURES LEAD TO NERVOUS OR MENTAL ILLNESS?

There are certain conditions which may cause both nervous and/or mental illness and seizures. It is possible that improper management of the seizures may eventually lead to one or both, but by obtaining medical attention the chances are very slight.

DOES EPILEPSY CAUSE MENTAL RETARDATION?

No. Remember, epilepsy is merely a symptom. It cannot cause anything. Many people with epilepsy are of normal intelligence. Again, without proper management of the seizures it may be possible over a period of time for the seizure activity to hinder a child's normal progress.

DO SEIZURES CAUSE HEART DAMAGE?

No. The heart beats faster from activity of the seizures just like running makes the heart beat faster. This does not damage the heart.

IF SEIZURES BECOME LESS SEVERE, IS THIS A SIGN OF IMPROVEMENT?

Yes.

SHOULD A DOCTOR BE CALLED FOR EACH SEIZURE?

Usually this is not necessary, unless the seizure is

followed almost immediately by another major seizure, or if the seizure lasts more than about ten minutes.

HOW IS EPILEPSY TREATED?

By the use of medicines called anticonvulsants. Doses are given daily. It is very important that an ample supply be on hand and that no doses be missed. Only in very rare cases are specific surgical procedures attempted.

HOW DOES ANTICONVULSANT MEDICATION HELP SEIZURES?

Anticonvulsant medication helps control epilepsy in two ways: (1) by lessening frequency, (2) by lessening severity. Either one, or both, indicates improvement. In some cases the medication has been known to completely eliminate seizures. Not only medication but age and time can also lessen frequency and severity.

CAN ANTICONVULSANT MEDICATION CAUSE REACTIONS IN MY CHILD?

Yes, almost any medication that has ever been used may cause a reaction or side effect--dizziness, drowsiness, unstable gait, and others--which the physician may eliminate by reducing the dosage. However, only a very few of the medicines that we use in treating epilepsy have any serious reaction. Any child who is receiving one of these is followed closely in the Clinic and by laboratory tests in order to determine when a reaction is occurring.

ARE ANY OF THESE MEDICATIONS HABIT FORMING?

Some of the medicines used in the treatment of epilepsy fall within the habit-forming category, but virtually never lead to undue dependence when administered in connection with treatment of epilepsy. Some medicines, in certain doses and combinations, lead to a certain amount of temporary slowing of mental processes but this does not mean they are habit forming or lead to addiction.

IF ANOTHER CHILD IS BORN, COULD HE HAVE EPILEPSY?

Yes, but the chances are against it. It is very unusual to have more than one child with epilepsy in the same family. In some families the risk will be slight, almost non-existent; in others, it may be higher. Much depends on what causes the epilepsy and whether or not other members of the family, relatives, etc., have had seizures.

WHAT ARE THE KINDS OF SEIZURES?

There are many types. A few are listed here:

Petit mal - (absences) A person stares and blinks and sometimes the head and arms may jerk slightly. He may or may not fall. The seizure lasts a few seconds and sometimes as long as a minute or two.

Grand mal - There may be a preliminary cry or "howl," and can be associated with choking sounds. Consciousness is lost and the body muscles become rigid. This is usually followed by jerking of the arms and legs. When the breathing muscles are involved, there is some loss of normal color. The seizure lasts a few minutes or longer, and is usually followed by a sleeping period. This is part of the seizure.

Minor motor - A person suddenly jerks forward from the neck or the hips which usually results in a fall. Recovery is prompt and seldom followed by sleep.

Psychomotor epilepsy - A person has a seizure which, instead of being a convulsion, appears to be unusual behavior from which he cannot be stopped. He does not remember after the attack what was done during the seizure. It seldom lasts more than a few minutes.

WILL A CHILD WHO HAS GRAND MAL SEIZURES ALWAYS HAVE THE SAME TYPE OF SEIZURE, OR WILL THEY CHANGE?

Some people with epilepsy always have the same type of seizure while others will go through changes. There is no way of telling which child will continue with the same type of seizure and which child may develop other types of seizures.

DO CHILDREN WITH EPILEPSY HAVE LOWER RESISTANCE TO INFECTIOUS DISEASE THAN THE AVERAGE NORMAL CHILD?

No.

IS THEIR DIET EVER AT FAULT?

Generally, no. Like everyone else, persons with seizures need a well-rounded diet. In some patients, use of alcohol tends to lead to a seizure. Excessive fluids, depressants, and stimulants should also be avoided.

CAN A CHILD WHO HAS EPILEPSY BE PERMITTED TO ENGAGE IN SPORTS?

Yes, when the proper precautions are taken. Actually, physical activity is good for these children and seems to reduce the number of attacks. Each case must be decided on an individual basis. When swimming, the child who has epilepsy should be observed closely and continuously by a responsible person. We usually advise against any type of climbing where loss of consciousness might result in a fall and consequent injury. Specific limitations for your child should be discussed with the Clinic physician.

IF IT IS KNOWN AHEAD OF TIME THAT A SEIZURE IS COMING, WHAT CAN BE DONE TO PREPARE FOR IT?

This is a good point to discuss with the doctor who is following your child. He can advise you what measures to take as all individual cases may be different.

ARE STARING SPELLS A SYMPTOM OR FORM OF EPILEPSY?

A true staring spell is true epilepsy.

CAN EPILEPSY BE INHERITED?

Epilepsy, itself, is not passed on to the next generation. In some cases a patient may have inherited tendencies that make it easier to develop seizures, but this is only a tendency, and there are persons who do not have epilepsy who have inherited such traits.

CAN A CHILD HAVE SEIZURES ONLY DURING SLEEP?

Yes. As a person goes to sleep, he goes through various depths of sleep. Certain brain centers which may have been preventing seizures then relax and the child may have a seizure. The most common times for sleep seizures are either shortly after falling asleep or shortly before awakening. These seizures which only occur during sleep are called nocturnal seizures.

ARE SOME CHILDREN WITH EPILEPSY MORE IRRITABLE THAN OTHER CHILDREN IN THE SAME FAMILY?

Yes. Various authorities believe some of the irritability may be caused by the same condition which caused the seizure. Also this irritability may be related to the fact that the child has been treated differently than the other children in the family because of his problem. Some of the

irritability may improve noticeably after the child's seizures are controlled.

CAN ANTICONVULSANT MEDICATION CONTRIBUTE TO A CHILD'S IRRITABILITY?

Yes.

DOES A CHILD WHO HAS SEIZURES HAVE TO TAKE MEDICATION ALL HIS LIFE?

Again this depends upon each individual. Some take it for many years while others only a few.

WHEN THE DOCTOR ADVISES ME TO "PAY AS LITTLE ATTENTION TO SEIZURES AS POSSIBLE," I WONDER IF HE REALIZES WHAT WE PARENTS HAVE TO GO THROUGH.

The child having seizures is a very disturbing thing for parents. But parents can learn not to be overprotective, and can in time understand that seizures are not so terrible. This in turn sets the proper example for the child. Naturally, one wants to protect the child from injury to himself and from getting into situations involving his life just as one would protect any youngster.

EVERYONE TENDS "TO SPOIL" OUR CHILD WHO HAS SEIZURES AND THE OTHER CHILDREN IN THE FAMILY RESENT IT.

Efforts should be made by all persons handling the child to avoid making him a special case by allowing him to have the usual kinds of frustrations and letting him learn how to handle his anger just like everyone else. Then, the child will grow up a better adjusted youngster; otherwise, he will go on expecting everything his special way. Parents will have to assume the responsibility of establishing procedures in those situations which interfere with the child's management program.

OUR FRIENDS SAY OUR CHILD IS NOT NORMAL BECAUSE HE SEEMS TO GET VERY ANGRY EVERY TIME THINGS DO NOT GO HIS WAY.

Just because a child becomes angry does not necessarily mean that he is abnormal; the parents would have more cause for worry if the child never expressed anger. Anger is merely a way the child uses for getting his frustrations out of his system. Moreover, it is not a case of the child working himself up to a seizure; it may be that the child is more irritable preceding a seizure, which may be part of a seizure.

It should be obvious to everyone that children who do not have epilepsy get angry and have temper tantrums too. Temper tantrums may be an example of the child's attempt to express something. When a child is very young he does not know about the things which will hurt him or give him pain; all he knows is that he won't give up things which give him pleasure. If he gets no attention whatsoever with a temper tantrum he will eventually stop using this method of objection. Thus, discipline is many things, which administered in the proper way, is something to keep the child from becoming maladjusted. As time goes on the seizures may become controlled, but the child will become a behavior problem unless he has discipline.

A child should be treated with consistency. One should not love him one day and hate him the next; the consistency of the relationship is the important thing. When a child becomes three, four or five years of age his world only begins to look something like it does to his parents. The type of punishment depends upon the age of the child and depends upon the factors involved. In general terms, we do not think a "pat on the bottom" is going to hurt any child.

WILL A CHILD EVER OUTGROW EPILEPSY?

Yes. Often it is correlated with the type of seizure the child has. Medical research has found that some children whose seizures are well controlled with medicine, later on need less medicine. Eventually they may need none at all. However, there is no way of determining who will and who will not be able to discontinue treatment until several years have passed. In many children the tendency to have seizures appears to become lessened as they grow older.

WILL MY CHILD BE ABLE TO MARRY?

Yes, if the seizures are controlled so that he can undertake the responsibilities of marriage, and the prospective mate is informed of the situation.

CAN MY CHILD HAVE NORMAL INTELLIGENCE?

The intelligence of persons with epilepsy varies markedly, but many have normal or above-normal intelligence. Some children might be encouraged to know that a large number of famous people have been epileptics, including Julius Caesar, Socrates, Buddha, Alexander the Great, Mohammed,

the Duke of Wellington, Lord Byron, Vincent Van Gogh, and Joseph Handel.

WHAT IS THE BRAIN WAVE TEST?

This is what is called an electroencephalogram. The EEG for short, is a graphic recording of the electrical activity of the brain. It does not make a diagnosis of epilepsy, give the patient electric shocks, nor does it hurt. It is an additional means of examining a patient. It is information which must be evaluated along with all the other factors in any case.

HAS ANYTHING BEEN DONE TO EDUCATE THE GENERAL PUBLIC ABOUT EPILEPSY?

Epilepsy is one of the last of the "hush-hush" diseases. Once cancer, tuberculosis and many other diseases were in this category, but public opinion is changing. Research is going on all over the country, results of which are constantly being distributed to educators, doctors, professionals, and the lay public.

HOW CAN A PARENT OF A CHILD WITH EPILEPSY HELP EDUCATE PEOPLE?

- 1) By accepting the fact that epilepsy is a condition of which you need not be ashamed.
- 2) Mentioning without embarrassment the word epilepsy when it is appropriate.
- 3) Recognizing that people who make you feel ashamed are ignorant, and explain to them calmly about epilepsy. This may mean becoming more informed about epilepsy, as you can help by answering any questions in general and provide information to correct any misconceptions.
- 4) Considering the "emergency" measures involved in epilepsy and preparing for them.

Also, there are statewide and national organizations for epilepsy which are working on educational programs, as well as many regional organizations.

AM I WRONG IF I KEEP MY CHILD'S DISORDER A SECRET?

Each member of the family should be encouraged to develop the attitude that it is true that one member of the family has epilepsy, and that they are perfectly willing to talk it

over at an appropriate time. Thus, if adequate control is lacking, it is probably a good idea for the youngster's older brothers and sisters to explain the facts to their friends. This does not mean, of course, that members of the family should begin each and every conversation by proclaiming to one and all that someone in the family has epilepsy.

It is probably a good idea to tell neighbors and other adults who will come in contact with the youngster about his disorder. The explanation should be as simple and direct as possible.

Some people will, of course, react badly to this information and may attempt to keep their children from playing with the child who has epilepsy. This is unfortunate, but it does happen from time to time. Nevertheless, it should be recognized that there are more important considerations in the development of a child than whether he is going to have a particular playmate.

If disclosure to others of the child's disorder does produce an unpleasant reaction, there is no need to burden the child with the resentment this will undoubtedly cause his family. Instead, he should be encouraged to make the best of the friendships he is able to establish with children of more understanding families.

By learning how his family handles this problem, the child will develop patterns of communication that will make his own efforts to get along with others seem much less threatening. Unfortunately many epileptics and their families go through life in constant fear that the "secret" may be disclosed. The constant anxiety this produces naturally tends to prevent normal relationships of any kind from developing.

HANDLING OF CHILDREN WHO HAVE EPILEPSY

DISCUSS THE ATTITUDES OF THE PARENTS AND HOW THEY MAKE THE CHILD A SPECIAL INDIVIDUAL.

Many questions have been asked about the behavior and emotional problems of the child with epilepsy. People are quite aware of the physical developments going on in a child, as such developments can be seen. But the emotional and psychological development going on can sometimes be a little puzzling since it is not as obvious a factor as is the physical development. While the bones and muscles develop independently, the child's emotional growth is largely related to his place in the family and his relationship with the family. Therefore, much more responsibility is placed on the parents in regard to a child's emotional growth than on his physical growth.

When we speak of emotional growth, we mean that aspects of the individual that deals with what he thinks and feels, his attitudes, and his likes and dislikes, which make him an individual. It is not just by chance that we are the individuals we are. Rather, it is because of our relationships with our families and other associations. We take a little bit from each contact, which makes us what we are.

Parents want to know about epilepsy as it relates to emotional growth. They want to know if their child is going to have temper tantrums and if their child behaves as he does just because he has epilepsy, and how to handle a child who has epilepsy. Other factors being equal, the child with epilepsy should be treated as a child without epilepsy! If he is not regarded as a special individual, then the child will not regard himself as a special individual. When problems of behavior come up, the parent should first ask himself, "How would I treat any other child of this age?"

The parent finds himself in the position of looking for something different in the child. The only difference is at the time of a seizure. The attitude parents have toward a child will determine to a large extent the attitude the child will have towards himself. If parents have the attitude of fearfulness and that the child should be watched carefully because he might have a seizure, then the child himself will think of himself as being sick, queer or persecuted. Even though the child has seizures, he will also have other problems in life to which he must adjust. In

most cases he can have a satisfactory life if he has a healthy attitude toward it, in spite of having seizures.

DISCUSS THE DISCIPLINE OF A CHILD WITH EPILEPSY. THIS IS OUR BIGGEST PROBLEM.

This first hurdle to get over is to realize that the child is not going to die because of seizures. The child who is normal in all other respects than seizures can be expected to live a normal happy life if handled in a wholesome way. The child with epilepsy should be treated the same as any other child in the family who does not have seizures. Many people expect children with epilepsy to behave differently than other children, but they do not behave differently if handled properly. Behavior is related to how a child is handled and to parental tensions and moods. Problems can arise from parent attitudes. The child should be handled in such a manner that he can learn to have self-confidence. The only difference between the child with epilepsy and the average child is when the child is having a seizure.

DOES THE EMOTIONAL ATMOSPHERE IN THE HOME, SUCH AS FRICTION BETWEEN PARENTS, OR TROUBLES WITH RELATIVES, HAVE A DEFINITE EFFECT ON SEIZURES?

Family conflicts, crisis, changes, etc., can definitely have an effect upon a child's emotional state which in turn may be reflected in the frequency of seizures. It is important that general procedure patterns and medications be maintained as well as providing a stable emotional attitude.

DISCUSS THE EMOTIONAL DEVELOPMENT OF A CHILD WITH EPILEPSY.

The emotional development of a child with epilepsy will not be materially different from that of the child who doesn't have epilepsy, everything else being equal. True, this child will need to take medicine daily for an indefinite period, but then children are given vitamin preparations daily without any concern of what it might do to their emotional development. And, a child might be limited in certain activities which could be dangerous in the event of a seizure, such as swimming or tree climbing. Yet a child without epilepsy, falling out of a tree or falling from a fence is certainly not a rare thing. There is much tendency to exaggerate the injury potential of a child with epilepsy out of all proportion to the facts.

The years from one to five are the formative years of our lives. The child senses the feelings of the members of his group, parents, brothers, sisters, grandparents and others who handle him, and the child reacts to these feelings. The child with seizures should be handled and treated the same as other children in the family.

Because he has a seizure now and then doesn't make him different during the time between seizures. He needs self-confidence, ability to get along with people and the ability to gain satisfaction out of life. Most of this is gained by imitation of his parents and other associates and by his trials and errors. A good start by the parents can be attained by setting a good example.

CAN OTHER MEMBERS OF THE FAMILY BECOME INVOLVED TO SEE THAT THE MEDICATION IS NOT FORGOTTEN?

The medical aspects of epilepsy should become so routine that taking a pill at certain set periods or following any of the other guidelines laid down by the doctor for the benefit of the individual patient do not dominate the life of the youngster--or, for that matter, that of the whole family.

Brothers and sisters are often more effective than parents in helping to establish this type of routine. In any event, the whole family must take responsibility for medication programs and protective measures suggested by the doctor--but always with the goal of gradually shifting this responsibility to the child. Of course, this is not really different from the training of a child in any other areas of his life. Also, there may be certain specific techniques which may need to be developed in this area. Parents should be cautioned against harrassment or nagging, for this can become a hindrance.

WE HAVE BEEN AFRAID TO SPANK OUR CHILD FOR FEAR OF BRINGING ON A SEIZURE.

The child should be disciplined the same as any other child even if he does have a seizure. He can and will have a seizure even though he isn't disciplined. Discipline which is administered in the proper way is a means of keeping a child from becoming maladjusted, which could become a major problem in addition to the epilepsy.

WHAT IF THE PARENTS DISAGREE ON HOW TO HANDLE THE CHILD? EATING HABITS?

Parents should cooperate with each other even though they may not be in agreement on methods of discipline so that the child will not play one parent against the other. To be consistent is to let the child know what is expected of him. Actually, a child wants the parents to control him because he feels his weaknesses and realizes he needs the control of parents. Therefore, control and discipline must be put on a child for his own protection.

However, eating is such a personal thing that it doesn't lend itself to discipline. "Cleaning-up-the-plate" policy is not recommended. Our appetites vary according to taste, age, and need for food. Health is not a matter of eating vegetables or drinking milk. A helping of one food is only half enough for one child while it is three times too much for another child. The child balances the diet during a three or four-month period, not by the meal. He will eat enough and eat properly without the need for cleaning up the plate. If one parent wants him to clean up the plate, while the other doesn't see why he should, then give the child smaller helpings of food.

If the child is old enough he can be punished by withdrawing certain things or restricting them. Sometimes a parent is angry when he punishes a child; quite often this is exactly why the child is being punished. It doesn't set a good example. We believe punishment should be carried out with firmness and calmness. The most important thing is for a parent to be consistent in his discipline. Punishment serves to let a child know where he stands. Do not confuse him by letting him get by one time and not get by the next. If the situation is one in which you cannot be consistent, then don't bring it up as a matter of discipline in the first place. If the child's behavior is out of proportion to the situation, consultation may be necessary with your doctor.

CAN YOU RECOMMEND A GOOD BOOK ON HOW TO HANDLE A CHILD WITH EPILEPSY?

Perhaps one of the most important things to learn is that the handling of a child with epilepsy is usually no different than the handling of a child without epilepsy. For this reason when a book is recommended it is done from the standpoint of considering every child to be average. Children with epilepsy are no exception. Hence it is recommended that you read material which deals with the "handling of

the average child."

Studies and books are available regarding general development in terms of walking, talking, eating, use of crayons, etc., which may be helpful. However, the danger in reading only this kind is that parents might expect their child to "conform to the pattern." This would be a great mistake because every child is different.

The United States Children's Bureau publishes several good pamphlets which are available at any local Health Department center. The local one for this area is Multnomah County Health Department, 12240 NE Glisan, Portland, Oregon, Phone 284-3681. Several of these pamphlets have been included in your packet, namely:

Infant Care
Your Child From 1 To 6
Your Child From 6 To 12

Some of the information in these has been helpful to many parents.

EDUCATION AND SOCIAL WELFARE

ARE CHILDREN WHO HAVE EPILEPSY ALLOWED TO GO TO SCHOOL?

Yes, and with some children we may recommend a conference with the principal or other school personnel to inform them of the child's problem so that a seizure can be handled in an intelligent way should one occur at school. It may also be recommended that a conference be held with the school physician or nurse. When possible, children with seizures attend regular public school. At times placement in special classes or in one of the special schools is arranged when a child cannot be managed in regular classes. Usually a behavior problem such as hyperactivity or righting, rather than actual seizures, makes it necessary to have a special program for a child. A member of our Staff can send any reports and could frequently hold conferences with a member of the Board of Education Staff, local teachers or principals, or school physicians and nurses, to try to work out the best possible plan for school work.

WHERE CAN A PARENT FIND OUTSIDE HELP WITH FAMILY PROBLEMS?

Children with seizures are faced with many difficulties such as their own feelings about their condition, their family's attitudes and feelings about the seizures, the effect of seizures on school attendance, the way playmates react to seizures, any restriction of activities which may give the child a feeling of being treated differently from other children. These problems oblige a child to make continuous readjustments which in turn create emotional problems which affect the entire family. Many parents have found it helpful to talk over family situations with a social worker, who can help with problems related to your child's having epilepsy. If the social worker cannot be of assistance, he may be able to locate an agency in the community which can provide the help needed.

IS THERE AN EPILEPSY ORGANIZATION IN PORTLAND?

Yes, and the address is:

Epilepsy League of Oregon, Inc.
718 W. Burnside, Rm. 208
Portland, Oregon 97209
Phone 228-7651

WHAT SERVICES ARE OFFERED BY THE EPILEPSY LEAGUE OF OREGON?

The League serves as a source of correct information about epilepsy and related problems. Although it does not function primarily as a casework agency, it does serve as a center of information for anyone seeking services. This is accomplished by providing interviews and acting in a referral capacity to guide persons with specific needs to reliable resources for medical treatment, counseling, employment, rehabilitation, job motivation and other related problems.

The League distributes literature, identification cards (League produced), and publishes a bulletin, Epilepsy Speaks. The League supplies films, speakers, educational exhibits, and tape recordings. A lending library at the League office offers a variety of reliable books and current literature on epilepsy. Students are assisted by the League staff in preparation of papers and talks on epilepsy.

A Medical Advisory Committee assists in presenting educational programs which are regularly provided for schools and colleges in Oregon. Programs are also available for public groups.

WHAT IS THE COST FOR THESE SERVICES?

Nothing. All of the League's services are free, however, both the Clinic and the League encourage all interested parents to participate in and join the Epilepsy League of Oregon. The League's services can be further enhanced with strength from more parents.

ARE THERE ANY SUMMERTIME OUTINGS OR CAMPS WHICH ACCEPT CHILDREN WITH EPILEPSY?

There are several summertime camps in the Portland area which children with epilepsy attend, both day camps and resident camps. More information can be obtained from the Epilepsy League of Oregon. They will be glad to talk with parents individually about the camp programs.

BIBLIOGRAPHY

- Bakwin, Ruth Morris, and Harry Bakwin. "Epilepsy." The Journal Of Pediatrics. 39 (December 1951) 776-784.
- Jerry Price Seizure Clinic. Brochure For Parents. Los Angeles: Children's Hospital (November 1963). 10 pages mimeograph.
- Livingston, Samuel. "The Social Management Of The Epileptic Child And His Parents." The Journal Of Pediatrics. 51:2 (August 1957) 137-145.
- National Institutes Of Health. Epilepsy: Hope Through Research. Public Health Service Publication, No. 938. Washington, D. C.: U. S. Department Of Health, Education, And Welfare, 1957.
- Sands, Harry, and Jacqueline Seaver. Epilepsy--Today's Encouraging Outlook. Public Affairs Pamphlet, No. 387. New York: Public Affairs Committee, Inc., 1966.
- The Epilepsy Foundation. Current Information. Washington, D. C.: Epilepsy Foundation Of America (October 1971).
- _____. Don't Be Afraid Of The Child With Epilepsy. Washington, D. C.: Epilepsy Foundation Of America (October 1971).
- _____. Epilepsy: Answers To Some Of The Most Frequently Asked Questions About Epilepsy. Washington, D.C.: Epilepsy Foundation Of America, 1967.
- _____. Epilepsy: Recognition, Onset, Diagnosis, Therapy. Washington, D.C.: Epilepsy Foundation Of America (October 1971).
- _____. Epilepsy: The Employer's Role. Washington, D.C.: Epilepsy Foundation Of America (July 1968).
- _____. Epilepsy: The Teacher's Role. Washington, D.C.: Epilepsy Foundation Of America (February 1969).
- _____. Occupational Guides For Epilepsy. Washington, D.C.: Epilepsy Foundation Of America (March 1971).
- _____. You, Your Child And Epilepsy. Washington, D.C.: Epilepsy Foundation Of America (October 1971).
- _____. Series A: Children With Epilepsy: "A Child's View", "The Family's View", "The Teenager's View". Washington, D.C.: Epilepsy Foundation Of America, 1965.

The Epilepsy League. A Teacher's Guide On Epilepsy. Portland: The
Epilepsy League Of Oregon (no date).

 . Epilepsy: Symptoms And First Aid. Portland: The
Epilepsy League Of Oregon (no date).

APPENDIX C

Epilepsy Questionnaire

Code # _____

EPILEPSY QUESTIONNAIRE

The questionnaire you are about to fill out is important in helping to set up future educational programs in epilepsy. Your answers will guide us in the areas of greatest need. Do not worry about questions you cannot answer or are unsure of, just circle "Don't know." Take the time you need to finish the questionnaire. Please circle the answer that is the most meaningful to you. Your answers will be confidential. Thank you for your cooperation.

Gender: M F Marital Status: M S
 6 9

Age: _____

- 1) Do you have epilepsy or have you ever
had epilepsy? Yes No Don't
know
- 2) Do you have a child who has epilepsy? . . . Yes No Don't
know
- 3) Has anyone in your family ever had
epilepsy? Yes No Don't
know
- 4) Do you know anyone outside of your
family who has epilepsy? Yes No Don't
know

Code # _____

1. Epilepsy is an emotional disease . . .	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
	0 (1)	13 (14)	2 (0)
2. Epilepsy is inherited	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
	2 (2)	5 (9)	7 (4)
3. Epilepsy may be likened to an electrical storm in the brain . . .	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
	12 (15)	0 (0)	3 (0)
4. I would rather my child had diabetes than epilepsy	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
	2 (1)	7 (7)	6 (6)
5. A person with epilepsy may not drive a car in the State of Oregon	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
	3 (5)	5 (9)	7 (1)
6. A person with epilepsy may participate in the following activities:			
Baseball	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
	12 (12)	0 (0)	3 (2)
Basketball	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
	10 (11)	1 (1)	2 (2)
Football	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
	8 (5)	7 (7)	3 (3)
Swimming	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
	11 (14)	0 (0)	4 (1)

*Considered "nebulous" or disagreed by professionals

#Answer: Trial one

(#)Answer: Trial two

Underlined is professional response

Skiing	<u>Agree</u>	Disagree	Don't know
	13 (11)	0 (0)	2 (3)
Dancing	<u>Agree</u>	Disagree	Don't know
	13 (13)	0 (0)	1 (2)
Music (i.e. band, orchestra). .	<u>Agree</u>	Disagree	Don't know
	13 (13)	0 (0)	1 (1)
Drama (i.e. public performances)	<u>Agree</u>	Disagree	Don't know
	14 (13)	0 (0)	1 (2)
Bicycling	<u>Agree</u>	Disagree	Don't know
	13 (14)	0 (0)	1 (1)
Track	<u>Agree</u>	Disagree	Don't know
	11 (11)	0 (0)	3 (3)
Chess	<u>Agree</u>	Disagree	Don't know
	15 (15)	0 (0)	0 (0)
Clubs (i.e. Boy Scouts, Girl Scouts, etc.)	<u>Agree</u>	Disagree	Don't know
	15 (15)	0 (0)	0 (0)
Hiking or back packing . . .	<u>Agree</u>	Disagree	Don't know
	13 (13)	0 (0)	2 (2)
Caring for animals	<u>Agree</u>	Disagree	Don't know
	14 (15)	0 (0)	1 (0)
Babysitting	<u>Agree</u>	Disagree	Don't know
	12 (10)	0 (0)	3 (4)
Lawn mowing	<u>Agree</u>	Disagree	Don't know
	14 (14)	0 (0)	1 (1)

7. An epileptic child should be kept under close supervision at all times	<u>Agree</u>	<u>Disagree</u>	Don't know
	0 (0)	13 (13)	2 (2)

8.	People with epilepsy should not marry	Agree 0 (0)	<u>Disagree</u> 14 (15)	Don't know 1 (0)
9.	People with epilepsy should not have children	Agree 0 (0)	<u>Disagree</u> 12 (15)	Don't know 3 (0)
10.	Epilepsy prevents learning	Agree 0 (0)	<u>Disagree</u> 8 (13)	Don't know 6 (2)
11.	Epilepsy is caused by bad genes	Agree 1 (0)	<u>Disagree</u> 8 (14)	Don't know 6 (1)
*12.	Epileptic children require special attention	Agree 7 (8)	<u>Disagree</u> 4 (5)	Don't know 4 (2)
13.	A child with epilepsy should not be punished for misbehaving if such punishment aggravates his seizures	Agree 1 (2)	<u>Disagree</u> 6 (11)	Don't know 9 (2)
14.	The epileptic child's brothers and sisters should cater to him	Agree 1 (0)	<u>Disagree</u> 14 (15)	Don't know 1 (0)
*15.	The epileptic child should be protected from ridicule or teasing by other children	<u>Agree</u> 2 (5)	Disagree 6 (5)	Don't know 6 (5)
16.	Only a qualified medical doctor can diagnose epilepsy	<u>Agree</u> 14 (13)	Disagree 0 (2)	Don't know 1 (0)
17.	Epilepsy can be cured through the use of certain medications called anticonvulsants	Agree 1 (7)	<u>Disagree</u> 7 (7)	Don't know 7 (1)

18.	Medicines used in the control of seizures are habit forming . . .	<u>Agree</u> 2 (6)	<u>Disagree</u> 6 (7)	Don't know 7 (2)
19.	I would trust an older epileptic child to handle his own medications	<u>Agree</u> 8 (10)	Disagree 2 (3)	Don't know 5 (2)
20.	Proper rest and diet are essential in the control of epilepsy . . .	<u>Agree</u> 9 (12)	Disagree 2 (1)	Don't know 4 (2)
21.	More frequent but smaller meals help to control the frequency of seizures	<u>Agree</u> 1 (3)	<u>Disagree</u> 6 (8)	Don't know 6 (4)
22.	The programs offered by the Epilepsy League of Oregon are only for people with epilepsy . . .	<u>Agree</u> 0 (0)	<u>Disagree</u> 7 (12)	Don't know 8 (3)
23.	Every child who has seizures should be given an explanation of his problems	<u>Agree</u> 11 (12)	Disagree 3 (3)	Don't know 1 (0)
24.	An epileptic child should usually be placed in a special classroom situation	<u>Agree</u> 1 (0)	<u>Disagree</u> 14 (10)	Don't know 1 (4)
25.	Children with epilepsy seldom finish high school because they are not smart enough	<u>Agree</u> 0 (0)	<u>Disagree</u> 15 (15)	Don't know 0 (0)
26.	Teachers are often anxious about a child who has epilepsy	<u>Agree</u> 12 (12)	Disagree 0 (1)	Don't know 3 (2)

27.	I would be willing for my child to have a teacher who had epilepsy	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
		13 (15)	0 (0)	2 (0)
*28.	An epileptic person should be left alone during and after a seizure	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
		1 (3)	12 (10)	2 (2)
*29.	I am frightened when I see a seizure	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
		4 (3)	11 (11)	1 (1)
30.	I would feel embarrassed by having an epileptic child in the family	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
		0 (0)	15 (14)	0 (1)
31.	Epilepsy can cause heart trouble	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
		1 (0)	6 (13)	9 (2)
*32.	All people who have epilepsy have seizures	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
		5 (6)	7 (9)	3 (0)
33.	Most people who have epilepsy are of low intelligence	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
		0 (1)	14 (14)	1 (1)
*34.	Many people are afraid of an epileptic child.	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
		11 (14)	3 (0)	1 (1)
35.	People with epilepsy generally have good work records	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
		6 (6)	0 (1)	9 (8)
36.	Epilepsy is a handicap in getting a job	<u>Agree</u>	<u>Disagree</u>	<u>Don't know</u>
		10 (9)	1 (1)	4 (4)

37.	Very few people who have epilepsy ever amount to anything	Agree 0 (0)	<u>Disagree</u> 13 (14)	Don't know 2 (1)
38.	Since people who have epilepsy are almost always poor in math, their best vocations lie outside the field of mathematics	Agree 0 (0)	<u>Disagree</u> 11 (11)	Don't know 4 (4)
39.	The types of vocations are very limited for the epileptic person	Agree 0 (3)	<u>Disagree</u> 11 (9)	Don't know 4 (3)
*40.	Children with epilepsy should be placed with other children who have epilepsy	<u>Agree</u> 1 (0)	Disagree 9 (12)	Don't know 5 (3)
41.	Sometimes a child has a seizure deliberately	<u>Agree</u> 2 (4)	Disagree 6 (9)	Don't know 7 (2)
*42.	All parents of children with epilepsy are more understanding of the epileptic child than are other parents	Agree 5 (9)	<u>Disagree</u> 8 (6)	Don't know 2 (0)
43.	Epileptic children generally lead a long and healthy life	<u>Agree</u> 3 (8)	Disagree 0 (1)	Don't know 12 (6)
44.	It is difficult to plan for the future of an epileptic child	Agree 3 (7)	<u>Disagree</u> 6 (5)	Don't know 6 (3)
*45.	A child who has seizures may die in one of his seizures	<u>Agree</u> 3 (1)	<u>Disagree</u> 3 (13)	Don't know 9 (1)

46.	The child with epilepsy suffers no pain during his seizures	<u>Agree</u>	Disagree	Don't know
		5 (8)	0 (2)	10 (5)
*47.	The earlier the onset of epilepsy the more likely the person is to outgrow the condition	<u>Agree</u>	Disagree	Don't know
		4 (9)	1 (3)	10 (3)
48.	Certain types of emotional situations increase the frequency of seizures	<u>Agree</u>	Disagree	Don't know
		9 (12)	1 (1)	5 (2)
*49.	Climate affects the frequency of seizures	<u>Agree</u>	<u>Disagree</u>	Don't know
		1 (2)	3 (9)	11 (4)
50.	Screen doors have been known to trigger seizures	<u>Agree</u>	Disagree	Don't know
		2 (10)	4 (3)	9 (2)
51.	An epileptic child needs more parental discipline than other children	<u>Agree</u>	<u>Disagree</u>	Don't know
		1 (0)	11 (13)	3 (2)
52.	Males have more violent seizures than females	<u>Agree</u>	<u>Disagree</u>	Don't know
		0 (0)	2 (9)	13 (6)
*53.	Epileptic children have fewer seizures when playing quietly alone than with a group of noisy, active playmates	<u>Agree</u>	<u>Disagree</u>	Don't know
		1 (1)	2 (9)	11 (5)
54.	Some parents believe it is their fault that their child has epilepsy	<u>Agree</u>	Disagree	Don't know
		8 (12)	2 (3)	5 (0)
55.	A child may swallow his tongue during a seizure	<u>Agree</u>	<u>Disagree</u>	Don't know
		7 (1)	5 (13)	3 (1)

56.	Never put anything between a person's teeth during a seizure . . .	<u>Agree</u> 5 (13)	Disagree 3 (0)	Don't know 8 (2)
57.	Children with epilepsy have lower resistance to infectious disease than the average normal child	<u>Agree</u> 0 (1)	<u>Disagree</u> 8 (10)	Don't know 7 (4)
58.	An epileptic child should be given less responsibility than other children	<u>Agree</u> 0 (0)	<u>Disagree</u> 13 (15)	Don't know 2 (0)
59.	A child with epilepsy should be treated the same as any other child	<u>Agree</u> 4 (13)	Disagree 8 (2)	Don't know 3 (0)
60.	Children with epilepsy should not associate frequently with other epileptic children lest they imitate their undesirable behavioral patterns	<u>Agree</u> 0 (0)	<u>Disagree</u> 12 (14)	Don't know 3 (1)
*61.	A child with epilepsy will also have many other problems	<u>Agree</u> 4 (4)	<u>Disagree</u> 6 (8)	Don't know 5 (3)

The following films on epilepsy are available. Please circle those you have or have not seen, or are or are not interested in seeing.

* * *

Grand Mal Epilepsy: Diagnosis And Management

16 mm color, sound film, 30 minutes. A doctor is called in the early morning by an anxious parent announcing his teenage daughter has had some "sort of fit." The patient is hospitalized and a neurologist is consulted who institutes a complete diagnostic regimen. The film depicts medical management, treatment, and diagnosis as well as the personal reaction of the girl, her family and friends.

Have Seen
Have Not Seen
Interested
Not Interested

Not Without Hope - 23 minute color. Story of a child with epilepsy who faces a world still prejudiced by antiquated superstitions.

Have Seen
Have Not Seen
Interested
Not Interested

Only A Part Of Life - 5 minute black and white. The story of epilepsy. Shows both petit mal and grand mal manifestations from grammar school into college.

Have Seen
Have Not Seen
Interested
Not interested

Benjamin - 5 minute color cartoon. The story of a young boy who is really no different from other boys and girls except that sometimes he has seizures.

Have Seen
Have Not Seen
Interested
Not Interested

The Dark Wave - 23 minute color. Story of a 12 year old girl with petit mal seizures. Shows the parents' shock, school board members' reactions, playmates' misunderstanding.

Have Seen
Have Not Seen
Interested
Not Interested

Boy In A Storm - 30 minute color. From the "Medic" television program. Story of a high school boy and his difficulties related to epilepsy.

Have Seen
Have Not Seen
Interested
Not Interested

Please list below any comments you wish to make in areas that are of particular concern to you regarding epilepsy.

Please list below any specific problems or questions you may have about epilepsy in which we could be of further assistance to you.

APPENDIX D

Evaluation Questionnaire

Name: _____

Date: ____/____/____

EVALUATION QUESTIONNAIRE

Please answer the questions below. If you need more space, write on the back of the sheet.

1. Which parts of the Parent Seminar did you find most informative?

Physical condition of epilepsy, definition of epilepsy, history of seizure treatment, treatment limitations on the epileptic child, types of seizures represented, video-taping and psychological assessment, some films. Guest speakers, group discussion, parent interaction, socialization.

2. Did you feel emotionally disturbed by some parts of the seminar?

(Check one) Yes 7 No 8

- A. If yes, in what way?

Participants idealistic attitudes, initial apprehension, thought provoking, outdated movies, when session ended felt alone.

3. Did the seminars answer all of your questions concerning seizure disorders?

(Check one) Yes 7 No 8

If no, what questions were not answered?

*Medications, other treatments available, not enough about specific individual case problems, more guest speakers, more on causes of epilepsy and seizures, why some side effects, *what happens during a seizure.

* Indicates material was presented.

Items that were mentioned by more than half of the parents are underlined.

4. Which of the material presented did you find most interesting?

Doctors' thoughts and experiences, informatio on indivi-
dual cases, group discussion, the more severely ill--the
more truthful the parent (and forthright), history of
epilepsy, current work and research in epilepsy, staff
interest in parents questions.

5. Which material did you find least interesting?

Outdated movies, chemical formulas of anti-convulsants,
one of the speakers.

6. Did you find some of the material vague and confusing?

(Check one) Yes 6 No 9

- A. If yes, what?

Material was vague because the subject matter was
vague. Certain specific points about epilepsy.
Needed summary of information, point by point answers
to questionnaire.

7. Do you think the number of weekly sessions was: (Check one)

too few 1 too many 4 about right 10

8. What material, if any, do you think could be eliminated?

Outdated movies

9. What kinds of information do you feel should be added?

*Practical ramifications of epilepsy (employment restrictions,
insurance, eligibility, physical limitations), service obli-
gations, specific case problems in the adult population (i.e.
adulthood), study of the brain and its function, better
films, parents as teacher aids in school, more time for
discussion and questions regarding Epilepsy League of Oregon,
public education and more information on special schools
preschools, should the teacher be told, increase speakers,
include public education and Westside schools.

*Kinds of seizures.

10. What do you feel is the best size of the group? (Circle one)

<u>8</u>	<u>10</u>	<u>12</u>	<u>14</u>	<u>16</u>	<u>18</u>	<u>20</u>	Other _____
2	3	2	1	5	2		

11. Would you recommend this type of seminar to other parents of children with seizure disorders?

(Check one) Yes 15 No _____

A. Why or why not?

Common problems, sharing, exchange of experiences,
provides reference for resource material, can recognize possible problems and solutions, enhances perspective, develops friendships, exchange assistance, staff experience.

12. We would appreciate any additional comments (either positive or negative) you care to make.

Want testimonials from "successful" and "unsuccessful" epileptics, continue the meetings, more participation, group should continue to be mandatory, more information on convulsions, a session on legal and educational constraints.

Thank you very much for your cooperation.

George R. Jacobsen

Grant R. Kane

Joan Sacia

APPENDIX E

Handicap Problems Inventory

MANUAL

for

THE HANDICAP PROBLEMS INVENTORY*

by

G. N. WRIGHT, PH. D.
Program Director
National Epilepsy League, Inc.

and

H. H. REMMERS, PH. D.
Professor of Psychology and Education
Purdue University

The Handicap Problems Inventory (H.P.I.) is a checklist of 260 problems attributable to physical disability. It is intended for use with all kinds of physically handicapped teenagers and adults. By marking those problems for which he "blames" his handicap, the disabled person systematically reveals the significance he attaches to his impairment. Scores, therefore, represent a quantification of the impact of the disability upon the person as he sees it.

A feature of the H.P.I. is that disability related problems are categorized into four life areas: vocational, social, family, and personal (the latter reflecting the internal press, i.e., factors not ascribed to an environmental context). Thus four separate scores are obtained by simply counting the number of marks for each of the four kinds of problems the individual believes are related to his disability. In other words, the instrument provides an index of the verbalized impact of disability as it affects personal (internal), family, social and vocational adjustments.

GENERAL DESCRIPTION

The H.P.I. has been designed for the use of psychologists, counselors and other professional people serving

Copyright Purdue Research Foundation, 1963

the disabled. It is the only instrument of its kind especially constructed for the disabled population. Norms are based upon a sample of over 1000 individuals determined by thorough medical examinations to have substantial and permanent physical disability.

Practical considerations as to the intended use of the H.P.I. guided its construction. This is reflected in its simplicity of administration and scoring. The four areas (personal, family, social and vocational) are workable divisions of the seats of handicaps resulting from disability; statistical evidence substantiating the reasonableness of this categorization is presented later.

Furthermore, the H.P.I. has been designed for a wide variety of situations. It is suitable for use with persons of low educational attainment (down to the fifth grade level); this is a particularly important requirement in view of the inferior school experience of the disabled population. In this respect both the simplicity of test taking and easy vocabulary level of the H.P.I. are noteworthy. Also important is the fact it is intended for all kinds of substantial physical disabilities, whether sensory, orthopedic, or whatever. The H.P.I. is thus appropriate for clients typically seen by agencies serving the disabled.

* This research was supported in part by a grant from the Federal Office of Vocational Rehabilitation and also by the School of Science, Education and the Humanities of Purdue University.

PURPOSE

Disablement is a relative term in that no individual is completely physically fit. It is generally agreed, however, that ten per cent of the general population suffer disability sufficient to cause significant limitations in daily living. For this group of substantially handicapped people the H.P.I. is appropriate.

The enormity of the conditions of disablement in terms of incidence and personal consequences justifies the development and use of a special psychological instrument. Measurement devices not tailored for the disabled fail in at least three respects: 1) they do not emphasize the unique and powerful stimulus, the disablement, and its adverse effects upon adjustment; 2) norm scores are based upon the general population or some segment of it, rather than a disabled population; and 3) items of general tests are frequently inappropriate and convey a different meaning to one suffering a physical handicap.

Counselors of the handicapped are well aware of the need to determine the impact of disablement upon the counsellee. Disability can and does create a variety of handicaps or special problems which must be identified and dealt with in rehabilitation planning. The H.P.I. gives the counselor quickly and quantitatively an estimate of the impact of disability as the client sees it and is able to verbalize it.

The four area scores provide in relative terms the meaning of the disability the client places upon the various aspects of his life. Additional information is had by qualitative inspection of specific problems checked. Here insights may be obtained as to the adjustment mechanisms employed, e.g., withdrawal, aggression, denial, etc. Furthermore, discussion of problems checked provides an easy entry into interviews concerned with the psychological implications of the disablement.

Of course, H.P.I. scores per se do not directly measure the personality adjustment of individuals. A very high score may reflect an exaggeration of the effects of the disablement indicative of a deep personality difficulty, or the checking of many problems may show an objective and accurate appraisal of the multiple effects of serious disablement. Conversely, a low score may suggest pathological denial of the disability, or it may indicate healthy solution of problems associated with a minor limitation. The experienced counselor will readily recognize the underlying significance of the score and will thus be provided important additional diagnostic information on the individual.

In effect the administration of the H.P.I. is a structured interview. By systematical querying the client is given opportunity to make known in a relatively painless way factors about his disability which bother him and impede adjustment. The 280 items are a comprehensive representation of problems related to physical disability.

DEVELOPMENT OF THE INSTRUMENT

Described here is the method by which the H.P.I. was constructed: the collection of problems concomitant to

physical disablement, i.e., H.P.I. items; the classification of items into four life areas; and the trial administrations of the H.P.I.

Initially a 70 item sentence completion test was devised to determine the problems physically disabled people relate to impairment. Of "open-end" type requiring of the respondent a written completion, all sentence stems as well as the written instructions were designed to uncover the self-perceived results of disability. The stems were constructed to permit projection of respondent's feelings by incorporating the terms "a handicapped person" or "handicapped people" instead of a personal pronoun. Stems varied widely as to degree of structuring.

Administration of this sentence completion test was to a random sample of 100 disabled people selected from the case file of a district office of a state vocational rehabilitation agency. Review of these cases revealed comprehensive variation according to these factors: age (more than 16 years), occupational status, socio-economic level, education, sex and type of disability. In each instance medical diagnosis had confirmed the disability.

The original list of problems was obtained from 2870 completions of the above described respondents to the specially constructed sentence completion test. Eliminated were duplicates and unmeaningful problems and those only applicable to a specific impairment. This method resulted in the very comprehensive coverage of general handicap problems found in the H.P.I.

These problems statements sifted from the sentence completions were edited to make a total of 280 uniform and clear items. Changes were minimal in order to preserve the meaning expressed by the disabled person. To prevent difficulty for people with limited reading vocabularies all words used in the H.P.I. are at or easier than the fifth grade level (according to Thorndike's *Teacher's Word Book*).

Items were then randomized and submitted to 27 psychologists for assignment of each item to one of four predetermined context categories. Of the total 280 items, the categorization is as follows: 96 personal items, 68 family items, 54 social items, 62 vocational items. A fifth category "too general" (to classify) was not found applicable to any of the 280 items by a significant number of judges. Agreement of the judges on all of the items was significant at or beyond the one per cent level (by an approximation of the binomial expansion indicating a probability of less than one in 100 of obtaining by chance alone one or more similar judgments when given five classification alternatives). Most items obtained such close agreement by judges as to be significant far beyond the one per cent level of confidence.

Further development of the instrument included a try-out of the preliminary form of the H.P.I. using another sample of 100 disabled individuals. Primary purposes served by this trial administration were to further improve clarity of individual items and the mechanics of administration (directions), and to determine testee attitudes toward the instrument.

Unstructured interviews with 35 of this trial group, plus an additional 50 counselees who have taken the refined form of the H.P.I., indicate: a positive attitude toward test taking (reflected by care and sincerity), a high degree of understanding of instructions and individual items, and completeness of the list of problems, i.e., no unlisted handicap problems were reported.

It is to be noted that administration of the sentence completion test from which items were collected, the trial administration of the preliminary form of the problems list and the administration of the final form for reliability, normative and other data were all by mail. The per cent of return of the latter group exceeded 86 per cent; this, and statistically derived information of a technical nature, leads to the conclusion that no important bias resulted from the nonparticipating group.

RELIABILITY AND VALIDITY

Reliability coefficients from each of the four areas of the H.P.I. have been estimated from the previously mentioned sample of 1027 randomly selected physically disabled clients of the Indiana Division of Vocational Rehabilitation.* The internal consistency coefficients of reliability (Kuder-Richardson formula 20) are shown in Table 2. Reliability estimates range from .91 to .95 for the four areas. These high indices of internal consistency reliability suggest that the area scores are a measure of a generalized homogeneous collection of problems.

Scores directly measure the phenomenological report of the individual. No claim is made for scores beyond the fact that they reflect self perceptions (and, of course, willingness to report). In this sense the "validity" is equivalent to the reliability coefficient.

TABLE 1
COMPOSITION OF SAMPLE - INTERRELATIONSHIPS
(Given in Percentages)

Total N = 1027	N	Percent		N	Percent
SEX			MAIN DISABILITY		
Male	712	69.3	Other	141	13.7
Female	315	30.7	Amputated Leg	85	8.2
MARITAL STATUS			Amputated Arm	28	2.7
Married	305	29.6	Impaired Leg	211	20.5
Single	636	61.9	Impaired Arm	100	9.7
Other	86	8.3	Spine	131	12.7
EDUCATION			Hearing	93	9.0
0-8	143	13.9	Vision	94	9.1
9-12	461	44.8	Pulmonary Tuberculosis	75	7.3
13+	423	41.1	Heart	69	6.7
RELIGION			SECOND DISABILITY		
Roman Catholic	151	14.7	Yes	341	33.2
Protestant	773	75.2	No	686	66.7
Not Listed	20	1.9	YEARS DISABLED		
None	83	8.0	0-5	297	28.9
RURAL-URBAN			6-10	189	18.4
City	319	31.0	11-15	146	14.2
Town	466	45.3	16-20	229	22.2
Rural	242	23.5	21+	166	16.1
AGE			SUPPORT SOURCE		
16-20	410	39.9	Earnings	337	31.8
21-30	338	32.9	Family	493	48.0
31+	279	27.1	Insurance	85	8.2
HOW DISABLED			Relief	112	10.9
Disease	523	50.9			
Accident	268	26.0			
Congenital	236	22.9			

*Clients for vocation rehabilitation services are selected nationally on essentially identical criteria of disability and services provided. Other groups of disabled people, such as seen in different kinds of agencies, however, may not be comparable. For this reason

other agencies will need to examine the appropriateness for their own group of data reported in this manual for state rehabilitation clients. For comparison purposes, composition of the norm group is described in detail in Table 1.

TABLE 2
RELIABILITIES OF SUBTESTS
(Internal Consistency*)

Subtest	r_{tt}
Personal	.95
Family	.92
Social	.91
Vocational	.93

*Kuder-Richardson #20.

It is acknowledged that there may be discrepancy between the frequency of problems checked by the respondent and the actual number of disability incurred problems. The mechanism of denial of disability and, conversely, exaggeration of the limitation have been cited as phenomena which could influence the response set of a specific individual. The degree to which the H.P.I. scores represent the objective situations of the individual or how well it can predict future situations is not definitely known. His attitudes, however, as measured by the H.P.I. are important data for the rehabilitation counselor.

The lack of correlational studies using outside criteria simply means that the H.P.I. should not be employed for screening purposes. Its uses should be confined to those outlined in the paragraphs on "interpretation." Briefly stated, the H.P.I. provides the counselor reliable (internally consistent) data about his client's present stated views concerning the effect of his disability.

NORMS AND DEMONSTRATED RELATIONSHIPS

Through the above mentioned final trial administration of the refined H.P.I. to the 1000-odd disabled people, several situations and characteristics of the handicapped person have been shown to influence the kind and number of problems he experiences. Results of this study are reported in Table 3. These data have two values:

1) The reports of statistical differences substantiate the assumption of concurrent validity in that the relationships found between H.P.I. scores and outside criteria are in the logically expected direction, e.g., a high H.P.I. score (many problems) is positively related to having a second disability, negatively related to amount of education, etc.

2) The report of mean scores in these tables provides the counselor a more detailed picture of the expectancy of an individual's score (on the basis of comparison to

his subgroup membership viz., age, sex, etc.) than the table of norms which averages these factors.

Normative data are provided in Table 4. These are presented as percentile scores for the over 1000 participants in the final trial administration. Only "subtest scores" should be used for counseling purposes; "total test" norms are reported for technical reasons only and have no reliability estimates computed.

ADMINISTRATION

The H.P.I. can be given either individually or to a group. Only about 30 minutes need be scheduled for administration; however, the slow testee should be allowed time to finish.

As with other self-report devices, it is important that good rapport be established before H.P.I. is administered. The individual must feel that his answers will be confidential and used in his interest.

In discussing the value of the H.P.I. before its administration, it is well to assess the rapport factor. Any lack of cooperation should be corrected before beginning. Generally the only introduction required will be the directions.

TABLE 3
MEAN COMPARISONS FOR EACH SUBTEST BY PERSONAL BACKGROUND VARIABLES

Personal Background Variable	Subtest							
	Personal		Family		Social		Vocational	
	Mean	s ²	Mean	s ²	Mean	s ²	Mean	s ²
SEX								
Male.....	14.09	180.38	5.25	48.21	6.76	52.82	9.57	85.79
Female.....	14.15	165.32	5.34	47.12	7.30	53.34	7.19	52.99
	F' = .00		F' = .04		F' = 1.87		F' = 19.58**	
	1 and 626 df		1 and 608 df		1 and 599 df		1 and 754 df	
	t' = .06		t' = .20		t' = 1.09		t' = 4.43**	
MARITAL STATUS								
Married.....	13.76	165.59	5.59	43.72	6.34	46.92	10.81	89.80
Single.....	13.78	167.97	4.58	39.56	6.99	52.08	7.60	65.51
Other.....	17.78	257.47	9.21	105.77	8.52	78.82	11.01	87.02
	F' = 2.52		F' = 9.75**		F' = 2.49		F' = 16.00**	
	2 and 217 df		2 and 208 df		2 and 218 df		2 and 218 df	
EDUCATION								
0-8.....	16.37	232.74	7.31	56.31	7.92	66.86	12.51	124.28
9-12.....	15.02	179.20	6.00	53.76	7.41	55.02	9.83	76.68
13+.....	12.35	147.68	3.80	31.27	6.06	45.06	6.51	50.53
	F' = 6.90**		F' = 19.55**		F' = 5.44**		F' = 30.49**	
	2 and 375 df		2 and 367 df		2 and 378 df		2 and 360 df	
AGE								
16-20.....	13.63	169.71	4.14	37.39	6.99	52.69	7.06	56.26
21-30.....	13.43	153.72	4.97	38.81	6.68	48.30	8.83	76.47
31+.....	15.64	208.99	7.34	68.41	7.13	59.42	11.49	96.78
	F' = 2.31		F' = 15.12**		F' = <1		F' = 20.62**	
	2 and 631 df		2 and 607 df		2 and 636 df		2 and 607 df	
YEARS DISABLED								
0-5.....	15.53	185.99	6.44	52.75	6.49	48.55	9.93	82.97
6-10.....	13.35	163.91	4.87	36.07	6.44	48.64	8.03	69.24
11-15.....	11.85	145.12	4.16	45.52	5.85	35.92	7.45	48.98
16-20.....	14.24	186.26	4.93	56.07	8.03	66.66	7.84	73.52
21+.....	14.23	177.65	5.10	40.20	7.69	59.38	10.39	97.15
	F' = 2.23		F' = 3.25*		F' = 3.02*		F' = 4.57**	
	4 and 469 df		4 and 470 df		4 and 468 df		4 and 471 df	

TABLE 3 (Cont.)

Personal Background Variable	Personal		Family		Social		Vocational	
	Mean	s ²	Mean	s ²	Mean	s ²	Mean	s ²
SECOND DISABILITY								
No.....	12.52	137.11	4.27	32.44	6.17	41.73	7.43	56.10
Yes.....	17.29	238.95	7.29	72.84	8.44	72.37	11.55	107.75
	1 and 541 df		1 and 495 df		1 and 541 df		1 and 522 df	
	t' = 5.03**		t' = 5.91**		t' = 4.33**		t' = 6.46**	
PRIMARY DISABILITY								
Not listed.....	13.68	168.95	5.53	46.82	7.09	57.31	8.27	83.31
Amp. Leg.....	14.79	237.40	7.07	87.51	7.49	82.45	10.37	102.57
Amp. Arm.....	12.79	126.40	3.89	38.99	7.00	41.47	8.71	56.29
Impair. Leg.....	14.01	145.84	4.70	37.35	7.00	42.28	7.63	52.84
Impair. Arm.....	16.93	243.26	5.87	50.40	8.18	67.30	11.00	98.69
Spine.....	16.09	229.19	6.69	62.31	7.22	70.71	10.47	105.99
Hearing.....	13.57	148.10	4.44	32.08	8.52	51.51	9.48	74.73
Vision.....	10.38	122.39	2.46	23.93	5.28	31.14	5.68	42.93
Pul. Tbc.....	12.40	162.78	5.59	52.89	5.12	30.86	8.12	73.70
Heart.....	14.78	127.19	5.99	37.93	5.83	26.29	9.81	53.95
	F' = 1.98*		F' = 4.60**		F' = 2.77**		F' = 4.15**	
	9 and 302 df		9 and 300 df		9 and 303 df		9 and 300 df	
INCOME SOURCE								
Earnings.....	12.50	153.93	4.27	40.31	6.25	47.28	8.87	79.03
Family.....	14.05	167.07	5.08	45.71	7.16	53.52	7.87	66.81
Insurance.....	14.09	142.85	5.95	33.57	5.62	37.48	8.62	42.09
Relief.....	19.27	274.87	8.65	77.43	8.96	74.22	13.19	20.46
	F' = 5.30**		F' = 8.47**		F' = 4.48**		F' = 7.84**	
	3 and 257 df		3 and 260 df		3 and 263 df		3 and 266 df	
RURAL-URBAN								
City.....	13.72	171.33	5.36	45.52	6.74	53.88	9.01	83.94
Town.....	15.35	194.13	5.65	51.85	7.36	56.82	9.38	81.49
Rural.....	12.23	140.24	4.45	42.58	6.35	43.37	7.55	56.94
	F' = 4.97**		F' = 2.60		F' = 1.78		F' = 4.22*	
	2 and 611 df		2 and 602 df		2 and 606 df		2 and 611 df	
SOCIO-ECONOMIC†								
0.....	13.41	191.43	4.61	21.22	6.65	56.09	9.25	97.33
1.....	14.10	212.88	5.31	33.22	6.74	59.62	12.28	112.52
2.....	13.83	191.36	6.27	72.76	7.52	52.72	10.26	94.03
3.....	15.97	205.71	6.36	63.35	7.15	48.56	10.67	87.43
4.....	16.25	211.51	6.21	58.51	7.96	68.50	9.44	68.35
5.....	13.11	157.87	4.75	39.20	6.48	48.64	7.91	63.04
6.....	13.42	142.17	4.36	34.57	6.58	43.17	7.19	58.31
7.....	14.43	133.89	6.96	73.50	6.78	39.81	8.26	81.66
	F' = 1.16		F' = 1.83		F' = <1		F' = 3.11**	
	7 and 202 df		7 and 201 df				7 and 200 df	

*Significant at five percent level; **significant at one percent level.

† The higher the number, the higher the status.

TABLE 4
PERCENTILE NORMS FOR TOTAL TEST AND SUBTESTS

Percentile Score	Raw Score Equivalent				
	Total Test	Personal	Family	Social	Vocational
99	149	57	34	32	37
98	132	53	26	28	34
97	122	48	23	25	32
96	110	45	21	25	29
95	104	43	19	22	27
90	82	33	14	18	23
85	64	27	11	14	17
80	54	23	9	11	15
75	48	19	7	9	12
70	42	16	6	8	11
65	36	15	5	7	9
60	31	13	4	6	8
55	28	12	3	5	7
50	25	10	3	4	6
45	22	9	2	4	5
40	19	7	2	3	4
35	16	6	1	3	4
30	14	5	1	2	3
25	10	4	1	2	2
20	9	3	-	1	2
15	7	3	-	1	1
10	5	2	-	1	1
5	3	1	-	-	-
4	2	1	-	-	-
3	1	-	-	-	-
2	-	-	-	-	-
1	-	-	-	-	-

Table 5

Rank Order of Personal Items and Their Frequencies
(by Total, Primary and Secondary Disability Groups)

		Frequency: Percentage Checking the Item															* Second Disability
Rank	Item	Item	Total (N=100)	Primary (N=50)	Secondary (N=50)	Blind (N=25)	Deaf (N=25)	Deaf-Blind (N=15)	Paralyzed (N=15)	Spina (N=15)	Amputee (N=15)	Multiple (N=15)	Other (N=15)	Other (N=15)	Other (N=15)	Other (N=15)	
Order	Number																
1	15	Want to be normal	55	54	48	43	57	46	60	53	41	36	58	61			
2	211	Act as if not handicapped	48	54	40	52	60	45	47	51	53	45	51	43			
3	84	Try to forget about being handicapped	45	43	48	43	55	52	43	43	44	30	51	45			
4	68	Feel comforted by fact that some handicaps are worse	42	37	44	57	48	48	31	37	39	38	47	42			
5	102	Have concern about security in later years	38	29	60	29	27	28	40	27	21	30	40	50			
6	1	Feel discouraged more easily	34	33	31	38	22	26	26	29	31	36	30	44			
7	229	Do still miss things which handicap prevents	34	25	44	24	32	35	30	20	16	21	45	43			
8	278	Seem more nervous	31	24	37	29	18	25	23	39	23	36	49	38			
9	164	Worry about personal appearance	27	25	23	24	34	30	26	12	26	13	13	32			
10	172	Feel more conscious of self (self-conscious)	25	23	23	14	28	33	22	16	24	16	17	29			
11	71	Prefer not to discuss handicap with others	22	28	12	10	22	26	31	14	26	21	21	20			
12	119	Prefer others don't know about handicap	21	18	21	5	24	31	17	24	28	25	26	17			
13	128	Daydream about what might have been	21	16	12	14	24	24	25	16	11	18	20	25			
14	120	Want hopelessly to overcome or grow out of handicap	21	22	17	18	19	19	10	18	14	30	27				
15	137	Feel ashamed to ask for help when needed	21	13	23	14	16	26	17	18	15	23	25	26			
16	36	Fear having more handicap later	21	10	13	5	17	6	22	27	21	35	38	23			
17	41	Feel it better to suffer in silence	20	12	21	14	20	13	21	18	10	20	13	28			
18	181	Have more ambition because of handicap	20	22	21	29	22	28	17	24	10	18	19	21			
19	28	Feel embarrassed by experiences caused by the handicap	20	23	17	19	18	19	16	24	21	9	6	26			
20	185	Wonder why fate caused it	20	17	15	38	20	26	19	16	16	21	19	21			
21	225	Daydream about doing big things or being a hero	19	22	10	19	22	22	19	16	14	13	23	21			
22	145	Have to do things differently	19	15	19	46	14	31	18	6	8	4	19	26			
23	273	Feel unsure of self	19	15	12	19	7	16	20	19	18	23	22				
24	111	Be come discouraged by time wasted because of handicap	19	15	27	14	10	13	10	20	14	21	15	27			
25	138	Fear not getting anywhere in life	19	18	29	14	11	22	18	20	10	23	21				
26	58	Envy people who aren't handicapped	18	16	17	24	22	15	16	14	10	11	25	20			
27	260	Daydream about things beyond ability	17	12	15	10	20	13	14	20	8	16	26	21			
28	208	Have personal feelings hurt easily	17	14	10	19	14	24	16	24	16	11	19	19			
29	173	Do not like being center of attraction	17	20	12	19	19	20	13	16	13	11	17	19			
30	65	Have ambitions too high for condition	17	13	12	10	13	19	14	14	10	16	25	22			
31	45	Worry about overcoming handicap	17	18	12	14	14	13	16	13	14	15	24				
32	110	Feel lonesome	17	12	23	10	9	13	12	22	10	16	13	24			
33	124	Try to hide handicap	17	11	21	10	16	13	14	24	15	5	9	10			
34	32	Think about not being equal to normals	16	16	13	13	14	19	19	11	11	13	17	20			
35	216	Need extra courage	16	14	17	14	11	11	16	18	13	14	15	22			
36	10	Feel bothered because people do needless things to help	16	18	13	57	13	20	12	12	6	11	9	19			
37	23	Feel inferior	16	16	8	19	11	20	10	16	9	13	21				
38	255	Need to show ability to do as much as others	16	14	12	5	16	17	13	11	7	7	19	18			
39	40	Find it is harder to face life	15	13	13	24	9	19	9	18	5	9	13	23			
40	133	Seem unable to admit certain things can't be done	15	11	13	19	18	19	16	10	8	5	21	17			
41	6	Feel more need for religion because of handicap	15	11	13	5	11	11	17	14	9	25	11	19			
42	100	Dislike having a different way of life	15	15	15	19	10	11	18	12	5	11	13	21			
43	220	Worry about self	15	10	13	5	7	11	9	10	13	16	19	23			
44	277	Do not use leisure (spare) time fully	14	15	12	5	11	13	12	12	13	11	21	17			
45	98	Feel different from others	14	16	13	14	8	7	14	22	9	5	11	19			
46	242	Do not feel proud of self	13	12	10	11	19	10	17	11	9	13	18				
47	224	Fear other people watching	13	10	13	14	16	22	13	6	11	2	6	16			
48	14	Find trouble in accepting handicap	13	13	8	5	7	6	17	22	6	14	21	16			
49	166	Face extra hardships	13	14	13	14	7	7	10	14	6	4	11	21			
50	207	Need to feel of more value	12	13	6	5	8	9	12	12	11	11	8	18			
51	269	Have to seem cheerful	12	10	15	10	9	12	12	9	7	4	19				
52	106	Feel it important to do work the handicap makes difficult	12	8	13	14	13	19	12	14	8	5	11	14			
53	24	Feel unhappy	12	5	13	5	7	9	8	18	9	7	15	19			
54	159	Feel bothered by thoughts about handicap	12	6	10	10	6	13	13	14	11	13	13	16			
55	198	Feel ill at ease	12	13	12	10	9	13	5	12	13	11	6	15			
56	190	Find it hard to take care of personal needs	11	4	5	19	6	2	14	4	5	5	6	19			
57	19	Have trouble in finding happiness	11	10	12	5	7	11	8	10	9	13	11	16			
58	67	Need to find substitute joys and pleasures	11	9	15	10	5	11	13	12	4	14	11	15			
59	218	Feel ashamed of body	11	5	17	10	11	19	14	4	1	5	2	16			
60	150	Feel like running away from it all	11	11	12	14	6	7	8	10	5	16	17	14			
61	239	Do not feel like a whole or complete person	11	5	13	3	9	12	12	6	11	11	17				
62	155	Fear not being wanted around	10	5	10	14	6	9	5	12	11	8	15				
63	39	Get too little chance for hobbies and pastimes	10	6	6	10	6	6	10	12	5	14	8	14			
64	264	Expect critical science to find a complete cure	10	17	6	5	4	5	4	9	21	19	11				
65	5	Do not like being around other handicapped people	10	10	8	5	13	13	8	6	9	4	8	11			
66	63	Want to talk about the handicap	10	9	13	5	6	13	6	8	5	7	13	13			
67	154	Lack will power (ability to stick-to-it)	10	10	8	10	11	6	6	20	9	9	8	9			
68	176	Tend to hang back	10	12	4	5	7	9	8	10	10	7	6	12			
69	250	Cannot accept fact that handicap is permanent	10	8	2	9	6	8	8	8	9	15	14				
70	268	Tend to feel sorry for self	10	11	4	5	7	17	5	10	10	9	17	11			

* Individuals with a second disability were removed from preceding primary disability categories

Table continued on next page

Table 5 (cont.)

			Frequency: Percentage Checking the Item												Second Dist.*
Rank	Item	Item	Total Sample (N = 1027)	Not Listed (N = 92)	App. Leg (N = 52)	App. Arm (N = 21)	Impair. Leg (N = 152)	Impair. Arm (N = 54)	Spine (N = 77)	Hearing (N = 49)	Vision (N = 80)	Pub. Inc. (N = 56)	Heart (N = 53)	Second Dist.* (N = 341)	
Order	Number														
71	233	Need more information about handicap	9	8	12	14	6	6	9	6	8	5	9	11	
72	203	Tend to secretly blame handicap too much	8	11	8	5	4	9	5	16	5	5	2	12	
73	89	Feel must persist more than other people	8	8	6	5	5	13	6	4	5	5	9	11	
74	93	Feel shouldn't have been handicapped	8	5	8	14	7	7	6	8	6	4	6	11	
75	75	Wonder if handicap happened because of sinning	7	3	0	24	3	6	8	6	3	9	11	10	
76	194	Would rather fail than ask for help	7	2	8	14	5	9	5	2	8		6	10	
77	76	Withdraw from other people	7	10	4	10	3	7	4	12	8	4		9	
78	146	Turn attention from handicap by over-working	7	3	10	5	6	7	5	14	1	4	4	9	
79	251	Blame self for being handicapped	6	4	8	5	6	4	9	4	4	13	6	6	
80	54	Become less careful about own well being	6	5	2	10	7	4	5	8	3	4	15	6	
81	141	Feel handicap may affect the mind	5	6	4		2	2	6	8	1	7	8	8	
82	243	Wonder why it couldn't happen to someone else	5	5	6	5	8	4	3	2	4	2	8	6	
83	129	Worry over an early death	5	3	4	10	1	2	5	2		5	19	6	
84	199	Feel there is no hope	4	2	4	5	3	4	3	4	1		4	6	
85	50	Hold a grudge against those who feel superior	4	4	6		7	4	4	4	1	2	4	6	
86	163	Use handicap as an excuse to avoid things	4	4	10	5	5		1	6	1	4	6	5	
87	246	Do not have much ambition	4	4		5	4	6	4	10	4	2	4	4	
88	115	Spend too little time alone	4	1	2		3	2	6	6	4	4	4	4	
89	49	Blame handicap upon someone else	3	3	2	5	1	9	3	2	1		4	4	
90	94	Need to live where born and raised	3	2	2		2	4	6	6	1		2	4	
91	33	Feel bitter toward the world													
92	215	Need to have own way	2	1	2		1	4	1	8		2	2	4	
93	80	Do not want to live	2	2	2		3			2			6	4	
94	234	Have reason for not even trying	2	2			1	2	1		1			4	
95	189	Deserve more help from others	2	2	2			4	1	2		4		2	
			1	1	4		1			2	1			2	
96	103	Need more sympathy from others	1	1						2	1			1	

Table 7
Rank Order of Social Items and Their Frequencies
(by Total, Primary and Secondary Disability Groups)

			Frequency: Percentage Checking the Item											
Rank	Item	Item	Total (N = 1027)	Not Listed (N = 33)	Asp. Leg (N = 52)	Asp. Arm (N = 21)	Spinal Leg (N = 15)	Spinal Arm (N = 14)	Deaf (N = 77)	Hearing (N = 43)	Vision (N = 90)	Pol. Dis. (N = 30)	Heart (N = 23)	Second, Disab. (N = 341)
Order	Number													
1	17	Do not like pity shown by other people	51	58	60	67	62	54	48	47	46	36	40	48
2	227	Lack ability to do sports	30	23	29	24	37	39	34	6	15	13	43	34
3	166	Have too little chance to get into sports	27	17	29	29	35	28	30	12	16	23	55	25
4	82	Have been made fun of sometimes by rude people	26	34	19	29	22	30	9	37	30	5	11	33
5	183	Find it hard to give a talk or a speech	24	28	13	14	22	26	17	35	28	14	26	25
6	3	Do not get out with people enough	22	24	29	10	14	17	18	31	15	21	23	27
7	157	Think others don't know enough about being handicapped	21	23	19	38	19	15	14	31	13	14	13	26
8	21	Lack a well-rounded social life	21	23	27	17	17	22	18	14	13	18	15	27
9	248	Feel more need to help others	20	22	17	14	24	15	18	18	16	25	8	24
10	43	Feel unsure what others think about the handicap	20	26	12	19	18	26	18	24	16	21	11	21
11	113	Fear making a "bobo" in public which points out handicap	18	19	12	19	20	26	9	22	21	2		22
12	87	Feel awkward in meeting people	17	19	13	19	14	22	10	31	14	7	6	22
13	244	Owe debt to society for benefits received	17	19	19	5	17	13	16	12	9	20	25	18
14	12	Do not like entering into social gatherings and parties	17	19	21	5	16	13	13	12	14	13	2	22
15	8	Feel embarrassed by others	16	18	13	14	14	17	8	20	18	13	11	20
16	78	Do not feel on equal terms with others socially	16	17	10	14	13	11	13	22	16	11	8	21
17	178	Try to hide handicap from others	16	9	17	14	18	28	13	27	15	9	13	16
18	213	Need more people to understand problems of handicap	16	13	12	43	14	13	9	29	9	13	4	22
19	56	Do not feel free to enter into social events	16	16	10	14	9	15	17	22	15	9	4	22
20	38	Want to be more popular	15	22	13	5	14	7	10	18	14	4	13	19
21	280	Have trouble mixing with other people	15	15	13	14	14	15	10	22	18	13	11	16
22	236	Become embarrassed when the center of attention	15	19	10	5	16	22	7	14	11	9	15	16
23	201	Think public opinion about handicapped people is bad	14	11	6	14	16	11	12	10	9	9	13	19
24	34	Feel despair when not treated as normal by others	13	12	17	14	17	15	8	9	9	5	9	15
25	271	Seem slow in getting to know people	12	12	8	14	12	13	10	24	9	13	15	13
26	161	Get annoyed by people wanting to help too much	12	15	15	38	12	20	9	6	6	7	13	12
27	174	Lead a boring social life	12	14	10	14	12	7	10	10	4	9	13	15
28	131	Need friends to encourage	12	17	13	10	9	6	5	12	4	9	9	16
29	152	Feel annoyed by other people asking about handicap	11	9	10	14	15	13	8	8	10	9	11	13
30	47	Get angry when not treated by others as normal	10	13	12	14	12	13	9	8	6	5	6	10
31	231	Seem to be looked upon by people as different	9	9	10	14	5	6	5	10	5	5	4	13
32	117	Do not feel part of a group of people	8	10	8	10	5	7	4	14	8	2	9	11
33	253	Have feelings more hurt by others	8	5	6	5	9	8	14	3	2	8	10	
34	192	Feel must excel when the center of attention	8	8	6	6	9	4	8	10	4	17	9	
35	222	Appear left out of social affairs	8	13	10	5	5	4	8	4	5	6	11	
36	73	Prefer to leave other people alone	8	9	6		3	6	5	10	6	4	4	12
37	148	Seem to be treated as a second-class person	7	8	8	10	3	9	3	12	9	4	4	11
38	26	Cannot make friends easily	7	9	8	5	3	4	4	14	8	4	4	10
39	96	Do not have many friends	7	10	10	5	2	2	5	8	5	9	6	10
40	210	Appear to be a social failure	7	13	4	10	5	6	3	6	5	4	9	8
41	143	Seem to be considered by others as inferior	7	11	4	5	5	13	5	8	8	2		8
42	91	Do not have help from friends when odds are bad	6	2	15	5	3	2	1	6		1	6	11
43	108	Need to live where there are people who will help	6	4	6	10	3	6	1	6	3	2		11
44	61	Feel pushed aside as being in the way	5	6	6	5	1	6	3	8			6	9
45	104	Seem left out of things in community	5	6	6	10	5	4	3	4	5			7
46	52	Seem not liked because of handicap	4	5	4		1	6		14	3		2	7
47	196	Prefer being around other handicapped people	4	2	6		2	4	3	10	1	2	2	8
48	237	Feel more friends than other people do	4	2	4		3	6	4	4	1	2	2	6
49	266	Have trouble getting along with others	4	3	6	5	2	2	3	6	3	2	2	6
50	126	Feel friends afraid they will be asked to help	4	2	8	5	1	4	3	6				6
51	187	Seem to be looked upon as someone to leave alone	3	4	6		1	4	3	4	1	2		5
52	122	Find it hard to get accepted into a club	3	4	4	5		4		2	3			4
53	218	Cannot do the needed things of a club	3	3	2		1		3	2		4		5
54	262	Take advantage of the sympathy of others	1	1	4		1	2	1				2	1

* Individuals with a second disability were removed from preceding primary disability categories

Table 8
Rank Order of Vocational Items and Their Frequencies
(by Total, Primary and Secondary Disability Groups)

		Frequency: Percentage Checking the Item													
Rank	Item	Item	Total (N = 1027)	Ext. Disab. (N = 93)	1st (N = 52)	2nd (N = 21)	3rd (N = 152)	4th (N = 54)	5th (N = 17)	6th (N = 46)	7th (N = 80)	8th (N = 96)	9th (N = 55)	10th (N = 341)	
Order Number															
1	18	Need to get extra education for suitable job	53	41	44	52	52	52	55	49	49	54	68	56	
2	149	Find some jobs are beyond physical ability	40	30	35	31	40	31	45	16	20	41	57	49	
3	13	Find two strikes against a handicapped person job hunting	36	27	40	43	26	46	35	37	30	23	26	45	
4	53	Work harder to succeed than if not handicapped	34	31	33	52	34	41	35	45	17	13	34	45	
5	27	Feel unsure about earning a good income	34	30	33	38	19	28	36	43	26	32	30	43	
6	263	Need to get work suited to physical limits	30	26	31	19	27	19	36	12	9	30	42	41	
7	105	Try to get decent job	29	23	31	29	20	30	29	27	28	21	21	38	
8	171	Cannot be sure about future work chances	29	24	35	29	16	26	29	33	18	25	36	16	
9	140	Think must hold own at work with normals	25	27	27	19	24	31	19	27	20	21	28	26	
10	57	Get discouraged because not fit for all work	24	8	23	24	18	30	25	14	16	21	25	34	
11	175	Work harder to prove handicap is not important	23	24	29	29	21	31	17	22	16	18	25	26	
12	153	Worry about success in life's work	23	14	25	24	18	19	17	37	15	25	23	29	
13	249	Need help in finding work	23	23	27	19	14	19	21	22	15	20	11	31	
14	101	Dislike depending on others at work	21	15	29	14	18	24	17	29	9	11	23	27	
15	167	Want to prove greater ability on the job	20	20	19	14	11	13	17	31	16	16	26	26	
16	184	Cannot do things as well as able-bodied workers	20	6	17	14	16	28	25	8	6	7	25	30	
17	97	Find it hard to make a living	19	10	25	24	10	13	26	24	5	13	11	31	
18	219	Feel unjustly turned down for a job because of handicap	18	15	21	29	13	20	14	16	9	14	13	25	
19	4	Loss confidence in work ability	18	19	6	10	13	13	17	20	20	13	23	24	
20	241	Grows success in work more than others do	17	15	15	24	16	11	13	10	11	14	19	24	
21	202	Worry about getting a better job	17	14	21	33	9	15	13	29	8	14	11	22	
22	272	Miss out on getting suitable work due to handicap	16	11	21	14	7	17	16	16	9	5	9	25	
23	74	Need to get an easy job	15	8	25	5	9	9	19	6	1	18	25	21	
24	237	Lack good job opportunities	15	12	25	14	5	11	12	14	10	13	8	23	
25	258	Think not wanted for job because of handicap	15	15	19	14	9	17	12	20	5	11	8	20	
26	254	Want work where handicap will be less noticed	14	9	12	14	13	20	14	16	9	9	11	16	
27	168	Fear job failure due to handicap	14	12	19	5	6	19	13	18	10	7	13	19	
28	232	Need to work harder in order to keep up	14	8	15	19	7	22	9	16	10	9	11	19	
29	132	Try to work beyond ability	13	8	17	9	15	12	18	5	4	23	18	18	
30	118	Avoid jobs which are made hard by the handicap	12	12	10	5	9	7	8	22	10	11	23	15	
31	228	Cannot apply full amount of knowledge and talent	12	10	8	10	11	6	9	14	14	14	13	16	
32	39	Fear loss of ability to work	12	2	13	10	8	9	14	10	9	16	9	18	
33	127	Try harder to please "boss"	12	5	12	10	11	15	8	18	9	7	21	14	
34	92	Get low wages because of handicap	11	9	17	19	3	7	8	12	5	9	13	17	
35	114	Feel job ability is overlooked	11	5	10	24	6	11	10	14	8	14	9	14	
36	245	Have no chance to prove job ability	11	10	12	14	7	6	9	10	4	13	4	16	
37	70	Require change of job plans	10	4	15	14	5	4	10	12	8	11	6	15	
38	179	Have to take it easy at work because of handicap	10	4	8	6	7	10	1	14	32	14	11	11	
39	35	Fear losing job to one who isn't handicapped	9	8	13	10	6	11	6	6	3	5	15	13	
40	267	Seem prevented by handicap from getting ahead in career	9	9	6	10	5	11	6	16	5	2	6	13	
41	193	Worry because some others are doing better work	9	9	8	5	4	13	6	12	6	7	11	11	
42	206	Feel inferior when others do a better job	8	4	8	5	19	6	14	10	4	4	10	10	
43	31	Think others dislike working with a handicapped person	8	4	12	3	7	5	16	7	7	2	13	13	
44	144	Tend to hang back instead of trying a job	7	5	8	5	7	5	10	10	4	4	2	9	
45	66	Prefer work with other handicapped people	6	2	13	5	6	3	14	3	4	4	8	8	
46	22	Require special privileges on the job	5	2	4	10	4	2	5	6	5	9	7	7	
47	276	Lack spirit to keep trying for a good job	5	6	6	10	5	6	6	8	3	2	5	5	
48	83	Seem to be expected to work too hard	5	2	6	2	3	3	10	5	5	8	8	8	
49	214	Do not like present job	4	5	6	3	6	3	8	5	7	6	4	4	
50	9	Do not apply self at work	4	2	5	6	7	4	4	4	2	6	6	6	
51	88	Cannot feel important in present job	4	4	4	5	1	2	4	6	7	8	6	6	
52	44	Find fellow workers take advantage of handicapped people	4	3	2	5	1	4	3	12	7	8	2	6	
53	48	Hold no chance of making good in life's work	4	1	4	2	4	2	2	3	2	2	7	7	
54	109	Need help of fellow workers	4	2	8	2	2	1	2	1	4	4	6	5	
55	62	Fear having to take up "panhandling" (begging)	3	2	10	5	2	2	4	2	1	4	4	5	
56	123	Cannot make up for work limitation	3	1	4	1	1	1	1	1	2	2	6	6	
57	158	Feel tempted to use handicap to make work easier	3	2	6	5	2	2	6	2	2	8	3	3	
58	79	Fear more job duty	2	3	4	1	2	2	2	2	2	6	2	2	
59	223	Need more consideration from fellow workers	2	1	6	1	1	1	6	3	2	2	2	2	
60	197	Use handicap as an excuse for not getting work	1	3	1	1	1	1	4	2	2	2	2	2	
61	162	Tend to use handicap as an excuse to be lazy at work	1	2	4	1	1	1	2	2	2	4	1	1	
62	136	Think "boss" should make work easier	1	2	2	1	1	1	2	2	2	2	1	1	

* Individuals with a second disability were removed from preceding primary disability categories

SCORING

For hand scoring items have been arranged so that a single hand scoring template for each of the four subtests can be applied to the four separate pages of the test, i.e., the first item of pages one, two, three and four is a personal subtest item; the second item on every page is a family item; etc. (The one exception is that the last item on pages one and two is vocational and on pages three and four is social.) This scoring order facilitates ease in hand scoring. Items were placed successively into these scoring positions according to their original random order, the exception being item one which was arbitrarily placed in that position for subjective reasons.

Use of four scoring templates—one for each of the four areas—70 items long, provides the raw scores. Raw scores for the four areas are quickly converted to percentile scores by referral to the table of percentile norms, Table 4. "Total test" scores should not be used as they cannot give the valuable differential information contained in area scores and do not have computed reliability coefficients.

INTERPRETATION

The higher the percentile score in each separate area, the greater the indication of impact of the disability in that area. Psychological meaning of the area scores is demonstrated by the high internal consistency of the four separate areas. Although these areas are accurately defined by the terms personal, family, social and vocational (as established statistically by agreement of judges who categorized items on the sole basis of these four terms), users of the test may obtain more definitive understanding of the four terms by reading through items in each of the areas. Items in each area are listed in Tables 5 to 8 along with average scores for several disability groups.

Area scores indicate which life situations bear the brunt of the greatest impact of the disablement. A relatively high number of family type problems, for example, would be the counselor's clue that special attention should be given to the adjustment situation in that area.

On the other hand, it does not necessarily follow that only high scores are to be inspected for adjustment difficulties. The tendencies to either exaggerate or to minimize one's handicap have been pointed out. Then, too, people vary as to how big the problem seems before checking it. The level of score should be confirmed by other sources of information about the person. Inconsistencies—either unexpectedly high or low score areas—are especially illuminating and warrant further investigation. Assistance in identifying or rationalizing inconsistencies may also be obtained by inspecting the tables of mean scores for various organismic variables (see "Demonstrated Relationships" and Table 3).

Study of individual problems checked also gives the counselor valuable information. The intensity with which

the problem is felt must, of course, be determined by personal discussion. Frequently the client reveals problems in the impersonal setting of the H.P.I. that he would not bring up in personal conversation. Naturally the systematic method of inquiring about 280 common disability related problems is a highly efficient and thorough coverage.

The client may reveal a problem that would never occur to the counselor to explore. For example, a young epileptic man checked item 129, "Worry over an early death." Thus identified, this important source of anxiety could be removed by the counselor's explaining that epilepsy does not cause death.

The counselor should look over individual items checked and plan his interview accordingly. As indicated before, the typical defense mechanism employed or other personality cues may be suggested by the pattern of the items checked.

The counselor must be particularly sensitive to items and to areas which are *not* checked due to a desire to cover up serious problems. Avoidance of known problems or problem areas suggests the possibility of intense emotional feelings which must be handled with great caution. Only counselors well trained in clinical psychology should attempt to probe into such defenses. Otherwise it is best to limit discussion to those problems which the client is ready to acknowledge.

Tables 5, 6, 7, and 8 list the frequency of response by each of several kinds of disability-groups for each individual problem. The counselor may wish to refer to these tables to learn whether any particular problem checked by his client is one which is commonly experienced by those of his disability group.

Just the act of thinking about and verbalizing his problems in taking and discussing the H.P.I. has direct value to the disabled person. Sudden insights are not uncommon. It may be the first time the client has allowed himself to admit the existence of the difficulty. Stating the problem is, of course, the first step in arriving at a solution. It also provides a natural way to get the interview started. People are usually willing to discuss the checked problems.

SUGGESTED RESEARCH

Many new areas of research are opened up by the publication of the H.P.I. A few suggestions for such study are mentioned below:

1. The relationship between H.P.I. item or area scores and personality adjustment.
2. The predictive validity of H.P.I. scores in reference to the success or failure of rehabilitation outcomes.
3. The concurrent validity of H.P.I. scores in terms of outside criteria such as rating scale judgments.
4. Methods and effectiveness of use of H.P.I. in the counseling function.

5. Dynamics of the mechanisms of denial and exaggeration of disability.

6. Groups of disabled not included in studies to date, viz. blind, emotionally disturbed, younger and older age groups, clients of other agencies serving the disabled and other segments of the handicapped population.

7. Effectiveness of various types of rehabilitation services in reducing problems (by retest procedures).

8. Stability (reliability) of H.P.I. scores by test-retest methods.

9. The relationship of H.P.I. scores to variables not yet studied, e.g., degree of impairment, intelligence, personality test scores, etc.

10. Underlying reasons for relationship thus far demonstrated.

11. Empathy with the disabled person by his family, counselor and others through dual administration of the H.P.I.

12. Factor analytic study.

Special pricing considerations are given those who wish to use the H.P.I. in connection with research and are willing to make results available for publication. Applications should be addressed to:

The Purdue Research Foundation, Lafayette, Indiana.

HANDICAP PROBLEMS INVENTORY

Instructions:

This is a list of difficulties reported by physically handicapped people. Your responses to this list will enable us to better visualize the problems you feel result from your child's disability. By giving us a better picture of how you feel your child's disability bothers him, something may be done about them. Your answers will be confidential. Some of the items were written for older individuals than your child may be. Answer them anyway as to how you expect they may or may not affect him in the future.

Mark with a soft pencil the space between the vertical lines all problems which you interpret as caused by, added to, or related to your child's disability. Skip over, do not mark, those problems which your child does not have or which you feel have nothing to do with his being handicapped. The way you feel is the "right" or best answer.

Your Gender: M F

Your Child's Gender: M F

HANDICAP PROBLEMS INVENTORY

GEORGE N. WRIGHT and H. H. REMMERS

INSTRUCTIONS: With a soft pencil, blacken the space between the vertical lines, in back of all problems caused by or added to by your disability. Skip over, do not mark, those problems which you do not have or which you feel have nothing to do with being handicapped. The way you truly feel is the "right" or best answer.

As you read through the Handicap Problems Inventory mark between the two lines (||) after the items which have something to do with your handicap.

1. Feel discouraged more easily	24. Feel unhappy	47. Get angry when not treated by others as normal
2. Feel left out with own family	25. Wonder what family think about handicap	48. Hold no chance of making good in life's work
3. Do not get out with people enough	26. Cannot make friends easily	49. Blame handicap upon someone else
4. Lose confidence in work ability	27. Feel unsure about earning a good income	50. Hold a grudge against those who feel superior
5. Do not like being around other handicapped people	28. Feel embarrassed by experiences caused by the handicap	51. Wonder if family did enough to prevent handicap
6. Feel more need for religion because of handicap	29. Do not have good relations with opposite sex	52. Seem not liked because of handicap
7. Love someone without being loved	30. Feel unsure about future home life	53. Work harder to succeed than if not handicapped
8. Feel embarrassed by others	31. Think others dislike working with a handicapped person	54. Become less careful about own well being
9. Do not apply self at work	32. Think about not being equal to normals	55. Do not take part in all the family does
10. Feel bothered because people do needless things to help	33. Feel bitter toward the world	56. Do not feel free to enter into social events
11. Do not get along with family members	34. Feel despair when not treated as normal by others	57. Get discouraged because not fit for all work
12. Do not like entering into social gatherings and parties	35. Fear losing job to one who isn't handicapped	58. Envy people who aren't handicapped
13. Find two strikes against a handicapped person job hunting	36. Fear having more handicap later	59. Get too little chance for hobbies and pastimes
14. Find trouble in accepting handicap	37. Cannot have sex relations	60. Feel bothered that no one else in family is handicapped
15. Want to be normal	38. Want to be more popular	61. Feel pushed aside as being in the way
16. Have less chance for a normal family life	39. Fear loss of ability to work	62. Fear having to take up "panhandling" (begging)
17. Do not like pity shown by other people	40. Find it is harder to face life	63. Want to talk about the handicap
18. Need to get extra education for suitable job	41. Feel it better to suffer in silence	64. Seem to be treated as an inferior person by family
19. Have trouble in finding happiness	42. Cannot financially support family	65. Feel dissatisfied with treatment from sweetheart or mate
20. Think family doesn't show enough respect	43. Feel unsure what others think about the handicap	66. Prefer work with other handicapped people
21. Lack a well-rounded social life	44. Find fellow workers take advantage of handicapped people	67. Need to find substitute joys and pleasures
22. Require special privileges on the job	45. Worry about overcoming handicap	68. Feel comforted by fact that some handicaps are worse
23. Feel inferior	46. Feel not treated as normal by some in family	69. Fear losing loved one
		70. Require change of job plans

YOUR NAME _____

71. Prefer not to discuss handicap with others	94. Need to live where born and raised	117. Do not feel part of a group of people
72. Cannot physically do some things around the house	95. Need to play up handicap to get things from family	118. Avoid jobs which are made hard by the handicap
73. Prefer to leave other people alone	96. Do not have many friends	119. Prefer others don't know about handicap
74. Need to get an easy job	97. Find it hard to make a living	120. Want hopelessly to overcome or grow out of handicap
75. Wonder if handicap happened because of sinning	98. Feel different from others	121. Get mad because family watch every step
76. Withdraw from other people	99. Feel neglected by family	122. Find it hard to get accepted into a club
77. Find home life less happy	100. Worry about duties and burdens at home	123. Cannot make up for work limitations
78. Do not feel on equal terms with others socially	101. Dislike depending on others at work	124. Try to hide handicap
79. Fear more job duty	102. Have concern about security in later years	125. Fear pity from husband or wife or sweetheart
80. Do not want to live	103. Need more sympathy from others	126. Feel friends afraid they will be asked to help
81. Worry because family cannot depend on support	104. Seem left out of things in community	127. Try harder to please "boss"
82. Have been made fun of sometimes by rude people	105. Try to get decent job	128. Daydream about what might have been
83. Seem to be expected to work too hard	106. Feel it important to do work the handicap makes difficult	129. Worry over an early death
84. Try to forget about being handicapped	107. Tend to be spoiled by family	130. Need to live away from family for personal independence
85. Have ambitions too high for condition	108. Need to live where there are people who will help	131. Need friends to encourage
86. Think family speaks too often of the handicap	109. Need help of fellow workers	132. Try to work beyond ability
87. Feel awkward in meeting people	110. Feel lonesome	133. Seem unable to admit certain things can't be done
88. Cannot feel important in present job	111. Become discouraged by time wasted because of handicap	134. Feel treated differently from other members of family
89. Feel must persist more than other people	112. Get less chance for marriage happiness	135. Feel guilty because family does so much
90. Have more than ordinary need for a happy marriage	113. Fear making a "bobbie" in public which points out handicap	136. Think "boss" should make work easier
91. Do not have help from friends when odds are bad	114. Feel job ability is overlooked	137. Feel ashamed to ask for help when needed
92. Get low wages because of handicap	115. Spend too little time alone	138. Fear not getting anywhere in life
93. Feel shouldn't have been handicapped	116. Have to live with family for special help	139. Feel family ask for too little
		140. Think must hold own at work with normals

YOUR NAME _____

141. Feel handicap may affect the mind
142. Do not feel needed by family
143. Seem to be considered by others as inferior
144. Tend to hang back instead of trying a job
145. Have to do things differently
146. Turn attention from handicap by over-working
147. Feel hurt because family bring attention to handicap
148. Seem to be treated as a second-class person
149. Find some jobs are beyond physical ability
150. Feel like running away from it all
151. Get told what to do too much by family

152. Feel annoyed by other people asking about handicap
153. Worry about success in life's work
154. Lack will power (ability to stick-to-it)
155. Fear not being wanted around
156. Wonder how loved ones can be repaid for help given
157. Think others don't know enough about being handicapped
158. Feel tempted to use handicap to make work easier
159. Feel bothered by thoughts about handicap
160. Seem to be treated by family as though they owe an obligation
161. Get annoyed by people wanting to help too much
162. Tend to use handicap as an excuse to be lazy at work
163. Use handicap as an excuse to avoid things

164. Worry about personal appearance
165. Do not feel satisfied with treatment from father
166. Have too little chance to get into sports
167. Want to prove greater ability on the job
168. Face extra hardships
169. Do not feel truly loved
170. Feel family ask for too much in view of handicap
171. Cannot be sure about future work chances
172. Feel more conscious of self (self-conscious)
173. Do not like being center of attraction
174. Lead a boring social life

175. Work harder to prove handicap is not important
176. Tend to hang back
177. Do not get enough needed consideration from family
178. Try to hide handicap from others
179. Have to take it easy at work because of handicap
180. Dislike having a different way of life
181. Have more ambition because of handicap
182. Need more admiration from family members
183. Find it hard to give a talk or a speech
184. Cannot do things as well as able-bodied workers
185. Wonder why fate caused it
186. Feel better with family than with others

187. Seem to be looked upon as someone to leave alone
188. Fear job failure due to handicap
189. Deserve more help from others
190. Find it hard to take care of personal needs
191. Feel "babied" by family
192. Feel must excel when the center of attention
193. Worry because some others are doing better work
194. Would rather fail than ask for help
195. Wish family gave more sympathy
196. Prefer being around other handicapped people
197. Use handicap as an excuse for not getting work

198. Feel ill at ease
199. Feel there is no hope
200. Want more love
201. Think public opinion about handicapped people is bad
202. Worry about getting a better job
203. Tend to secretly blame handicap too much
204. Fear family expect too much success in spite of handicap
205. Lean on family too much
206. Feel inferior when others do a better job
207. Need to feel of more value
208. Have personal feelings hurt easily
209. Feel better with others than with family
210. Appear to be a social failure

211. Act as if not handicapped	234. Have reason for not even trying	257. Need more friends than other people do
212. Get no chance for marriage happiness	235. Worry because handicap works a hardship on family	258. Think not wanted for job because of handicap
213. Need more people to understand problems of handicap	236. Become embarrassed when the center of attention	259. Do not feel like a whole or complete person
214. Do not like present job	237. Lack good job opportunities	260. Daydream about things beyond ability
215. Need to have own way	238. Feel ashamed of body	261. Think family takes no consideration of handicap
216. Need extra courage	239. Do not feel satisfied with treatment from family	262. Take advantage of the sympathy of others
217. Worry because family draws apart	240. Believe family shows too much sympathy	263. Need to get work suited to physical limits
218. Cannot do the needed things of a club	241. Crave success in work more than others do	264. Expect medical science to find a complete cure
219. Feel unjustly turned down for a job because of handicap	242. Do not feel proud of self	265. Lack family praise for doing well
220. Worry about self	243. Wonder why it couldn't happen to someone else	266. Have trouble getting along with others
221. Feel family thinks success is doubtful due to handicap	244. Owe debt to society for benefits received	267. Seem prevented by handicap from getting ahead in career
222. Appear left out of social affairs	245. Have no chance to prove job ability	268. Tend to feel sorry for self
223. Need more consideration from fellow workers	246. Do not have much ambition	269. Have to seem cheerful
224. Fear other people watching	247. Do not feel satisfied with treatment from mother	270. Feel dissatisfied with treatment from children of family
225. Daydream about doing big things or being a hero	248. Feel more need to help others	271. Seem slow in getting to know people
226. Think not considered as normal by all in family	249. Need help in finding work	272. Mix out on getting suitable work due to handicap
227. Lack ability to do sports	250. Cannot accept fact that handicap is permanent	273. Feel unsure of self
228. Cannot apply full amount of knowledge and talent	251. Blame self for being handicapped	274. Feel family disappointed about handicap
229. Do still miss things which handicap prevents	252. Have trouble in sex matters	275. Fear may need to depend on loved ones for a living
230. Think no one wants a husband or wife who is handicapped	253. Have feelings more hurt by others	276. Lack spirit to keep trying for a good job
231. Seem to be looked upon by people as different	254. Want work where handicap will be less noticed	277. Do not use leisure (spare) time fully
232. Need to work harder in order to keep up	255. Need to show ability to do as much as others	278. Seem more nervous
233. Need more information about handicap	256. Regret not being able to do enough for family	279. Have trouble in love matters
		280. Have trouble mixing with other people

APPENDIX F

Letters Of Introduction And Contract

Children's Clinic

Dear

Good Samaritan Hospital and Medical Center, Epilepsy League of Oregon, Oregon Mental Health Division, and Multnomah County have, in one capacity or another, granted funds to be used in developing an effective educational experience for preschool children who are experiencing some degree of developmental difficulty because of neurological impairment. The program will be administered by Good Samaritan Hospital Children's Clinic for Neurologically Impaired Children.

The preschool program is planned to provide selected children with many positive, encouraging school experiences. It is intended to produce significant development in the areas of academic, social and emotional growth. The basic approach includes individualized academic instruction and a well-planned intensive period of intervention designed to promote appropriate behavior. An effective program is possible when parents become interested and active participants in the work done with their child.

_____ has been recommended by Mrs. Jill West, M.Ed., as a child who might benefit from our program. We would like to make this opportunity available and solicit your cooperation in attending required conferences and group meetings. Because the parents' influence is considered so important to a child's progress, unsatisfactory parental involvement in this program may make continuation of the child's classroom enrollment impossible.

Your signature on this letter indicates consent for your child's participation in the preschool program and your willingness to cooperate with the staff. Please call if you wish further clarification.

Sincerely,

James R. Schimschock, M.D.
Project Director

Signature of parent or guardian

Signed _____
Group Facilitator

Children's Clinic

NOTIFICATION OF THE RESEARCH IMPLICATIONS
OF THE PARENTS' DISCUSSION GROUP

_____ I consent to participate in the Parents' Discussion Group as a member of the research population described in "The Research Aspects of the Children's Clinic Parents' Discussion Group."

Date ____/____/____ Signed _____

Date ____/____/____ Signed _____

_____ I consent to participate in the Parents' Discussion Group but not as a member of the research population described in "The Research Aspects of the Children's Clinic Parents' Discussion Group."

Date ____/____/____ Signed _____

Date ____/____/____ Signed _____

PARENT DISCUSSION GROUPS

Planning For Cooperation Between Parent And Child

An Experimental Research Project With The
Focus Of Discovering And Discussing Some
Of The Difficulties In Parenting A Child
With A Seizure Disorder

Sponsored By

Good Samaritan Hospital & Medical Center

Children's Clinic

For

Neurologically Impaired Children

*

James R. Schimschock, M.D.

Program Director

INTRODUCTION

New experiences, especially new group experiences, create anxious moments for many people. In a majority of cases this expectational anxiety can be overcome, in varying degrees, if the participants are aware of what the new experience has to offer. In response to this supposition, the following information is available on our plans for Parent Discussion Groups, held in conjunction with the preschool program at the Children's Clinic. Many of the ideas and statements recorded below have been extracted from two resource books.^{1, 2}

WHY PARENT DISCUSSION GROUPS?

Preschool education is an extension of parental care. The preschool years, so important for the development of a child's personality, demand from parents considerable skill and understanding. Inasmuch as the preschool child needs opportunity for free play, skilled help and contact with other children, he also needs parents who are secure in their knowledge and their feelings of adequacy to face and cope with the unique problems he presents. It is the feeling

¹ Auerbach, Aline B., Parents Learn Through Discussion: Principles And Practices Of Parent Group Education, The Child Study Association Of America (New York: John Wiley and Sons, Inc.), 1968.

² Stern, H. H., "Parent Education: An International Survey," The Journal Of The Institute Of Education (Hamburg, Germany: The University Of Hull And The UNESCO Institute For Education), 1960.

of our staff that these two demands can be reconciled in the Pre-School program at the Children's Clinic.

We are committed to a close cooperation with the parents. We realize that in spite of all the external educational resources available to a family, the immediate and most potent educational area in any family is still parents. Our program, like any other system of education, is powerless in the face of parental indifference, opposition or serious and unreconcilable divergence of opinion. We need your commitment!

WHAT IS A PARENT DISCUSSION GROUP?

A parent discussion group, only one of many kinds of group educational services for parents, aims to help parents:

1. Become more familiar with basic concepts of child growth and development and parent-child-family interaction from a dynamic point of view as well as problems specifically related to raising a child with seizures.
2. Recognize some of the crisis points in different stages of child development.
3. Learn to approach problems and situations with new skills and discrimination.
4. Gain a better understanding of the complexities of their everyday situations so that they will have a broader background against which to make choices.

In short, a parents' discussion group involves the exchange of concepts, personal knowledge, feelings, opinions, attitudes, emotions and skills which contribute to the physical, emotional and mental

health of participant parents as well as their children.

A parents' discussion group, as an integral part of the preschool program, is conceived as being an exchange of help, ideas and information between parent participants, between parents and clinic staff and between clinic staff members, rather than as an opportunity for a one-way, formal instruction given by the staff and received by parents. In summary, this is an opportunity for every participant to teach others as well as learn from others.

WHAT CAN THE DISCUSSION GROUP ACCOMPLISH?

Parents learning from the experiences of other parents with children who have similar problems gives each group member a broader base of information which can serve as a background against which they can look at their own children and themselves. Hopefully, the group experience can assist parents:

1. To a better understanding of their children's needs at different stages of their growth, recognizing their basic similarities, yet appreciating the individual differences that make each child a unique person with his own constitutional make-up, his own rate of growth, his own wishes and his own drives, hopefully erasing misconceptions about epilepsy and child rearing.
2. To examine what they expect of themselves as parents and how their goals have been influenced by their earlier experiences, their social and economic environment, and previous knowledge about children and family life.
3. Gain further knowledge of the interaction that takes place between parent and child, sibling and child, child and the total family by self-assessment of their own attitudes and practices

not as "good" or "bad" but dynamically in terms of what is actually happening.

4. Appreciate the many influences on their child and on themselves as parents by using new insights to sort out the particular influences to which they are responding, and thus to understand their significance and learn to deal with them.
5. Develop a realization that other parents have similar problems in child rearing.

WHAT THE GROUP CANNOT ACCOMPLISH:

Even with specific recommendational input from participants, this group cannot function to give explicit help in solving individual problems. Parents and staff members may, however, realize a need for individual professional intervention, outside of the group experience, and these services will be available through the Clinic on a consultant basis. These consultant services include, but are not limited to, psychiatric, psychological, social work, educational and medical assistance.

The Specifics of the Children's Clinic

Parents' Discussion Group

GUIDELINES FOR GROUP PARTICIPATION:

1. Each participant will be required to commit himself to attending the first six sessions of the parent discussion group by signing the contract of commitment. The meetings will be held in accordance with the information presented in the letter of invitation to the program.
2. The group will not be presented with any set curriculum but will develop its own "agenda" in relation to seizures during the first group meeting and as each session progresses.
3. Because of the wide differences in individuals, there will be no pressure on an individual member to move into the discussion any faster than he is prepared to or to come to any set conclusions. Rather, participants are encouraged to expand their horizons at their own rate of speed; free to pick up what they feel is meaningful.
4. At no time will there be any pressure toward group consensus or conformity; on the contrary, each member is encouraged to come to his own decisions. An open exchange of related experiences and opinions is encouraged, as well as careful listening to the comments of other group members.
5. When possible, members are encouraged to be specific when they pose their questions or concerns and to describe in some detail the immediate occurrences which brought the issues to the fore.
6. This experience can be as much of an emotional experience as it is an intellectual one. Expression of feelings are encouraged, not just for their own sake in a vacuum, but in relation to the substance of parent-child relationships and family living.

Parents as well as professionals have a wealth of material that

can be put "on the table" for discussion. Parents will be encouraged to respond freely to one another, questioning, observing, explaining, agreeing, adding, commenting, disagreeing as they examine their own ideas and convictions and progressively assume new positions for themselves. Hopefully, there will be an exchange of information by group members and/or the contribution of additional information by outside sources.

WHO MAKES UP THE DISCUSSION GROUP?

The group will be comprised of the parents whose children are enrolled in Good Samaritan Hospital and Medical Center Children's Clinic preschool program. There will be nine couples who will meet with a neurologist, special educator, psychologist, social worker, or other specialists as requested. At one time or another, each of these consultants will co-facilitate (lead) the group discussions.

WHAT ARE THE GOALS?

1. To help parents better deal with their child's seizure disorder.
2. To help parents feel more comfortable with their child who has seizures.
3. To help parents better understand and deal more effectively with their child's:
 - a. Needs
 - b. Level of functioning
 - c. Potential
 - d. Limitations
 - e. Future
4. To allow parents a secure environment in which to talk

about their own needs and feelings which may contribute to prejudicial misunderstandings about their child.

5. To help parents gain a better understanding of their own strengths and how to benefit from these.
6. To give parents an opportunity to express their feelings in relation to the handling of seizures.
7. To help parents better understand themselves and other parents within the group.
8. Provide an opportunity for parents to obtain accurate information relating to epilepsy and child rearing.

WHAT WILL BE EXPECTED OF THE PARENTS?

1. To share experiences, insights, and problems of their child and family.
2. Make an effort to talk about the things that concern them the most (fears, suspicions, worries, embarrassment, etc.).
3. To be willing to listen to the others.
4. To be honest and become involved.
5. To keep all discussion of the group confidential and show respect for others in the group.
6. To be to the group meetings on time.

IS THE PARENT DISCUSSION GROUP MANDATORY?

Yes, and all invited parents are encouraged to participate.

The Parents' Group is part of the educational curriculum being offered your child when he is enrolled in the preschool program, and attendance at the Parents' Discussion Group can possibly aid your child's development in the classroom and at home.

TOPICS FOR DISCUSSION:

The agenda for discussion is open for parental input. While the topics for discussion are not yet determined, hopefully some of the topics will center around the discussion of seizures. The major focus of the group, however, will be dependent upon parental interest and active participation.

The Research Aspects of the Parents' Discussion Group

As with most programs funded by public and/or private grants of monies, an accounting for program expenditures is required. The accounting requirement for the Children's Clinic is met in two ways:

1. Through financial statements
2. Through research findings

The research requirements of the Children's Clinic encompasses two major areas. These areas are the collection of numerical data on its patients and programs, and the development of new programs. One of the Children's Clinic's responses to these requirements is the funding and evaluation of the Parents' Discussion Group.

The Children's Clinic research committee that developed and will evaluate the Parents' Discussion Group is composed as follows:

SPONSORS:

The primary sponsoring agency for this research is the Good Samaritan Hospital and Medical Center Children's Clinic for Neurologically Impaired Children. Additional sponsoring agencies are the Epilepsy League of Oregon, and Portland State University.

OBJECTIVES:

The proposed research by this committee has two major objectives:

1. To obtain information for future program development concerning parental expectations, needs, and interpretations of parenting a child, in terms of their child's seizure activity.
2. To fulfill the research requirements for three members of the committee for their Masters Degrees in Social Work, Graduate School of Social Work, Portland State University.

PARTICIPANT PROTECTION:

Before continuing with a detailed description of your involvement in the research aspects of the Parents' Discussion Group, let us explain the protections of anonymity and confidentiality we assure each participant member in the group and their families.

All research findings, including numerical data which is part of the ongoing clinic reporting system, will not divulge any identifying information of participants or their children. The research findings will be recorded in a non-published thesis, submitted to the Graduate School of Social Work, Portland State University, as partial fulfillment of the requirements for a Masters Degree in Social Work by George Jacobsen, Grant Kane, and Joan Sacia, members of the research committee. Additional copies of this thesis will be available to the Epilepsy League of Oregon and the Children's Clinic with the express understanding that the information be used for future program development.

Any other use of the material gathered during the research on the Parents' Discussion Group or the written thesis summary thereof without the express written permission of the participants will not be authorized.

ELEMENTS OF THE RESEARCH PROGRAM:

Prior to the first group session, the parent(s) will meet individually with the group facilitator (leader). This meeting will provide the parent(s) time to express their individual concerns about their child's range of problems. The parent(s) will be encouraged to make their desires known about what they would like to obtain from the parent group sessions. Also, at this time, the following will be done:

1. Information from the Group Explanation Sheet will be discussed.
2. The Socio-Economic Inventory used for gathering baseline information will be issued.
3. The Epilepsy Questionnaire will be administered.
4. The Handicap Problems Inventory will be administered.
5. The Brochure For Parents and other related material will be distributed to allow the parents an opportunity to read and discuss the information presented before the first group session.
6. The Parents' Discussion Group meetings will be audio tape recorded for use in assessing the value of the group sessions.
7. At some time during the period in which the group meets, and in close cooperation with the scheduled attendance of your child in the preschool program and parents' personal schedules, a team of clinical

psychologists will observe and chart the interaction of mother and child in a play situation. Part of the charting process will include a video tape of the interaction.

SUMMARY:

Any changes in the afore described research design should be submitted to the group participants in writing for authorization.

George R. Jacobsen

Grant R. Kane

Joan Sacia

APPENDIX G

Review Of The Literature On The Value Of Parent Groups

REVIEW OF THE LITERATURE ON THE VALUE OF GROUP INFLUENCE

In numerous areas dealing with groups for parents, many published findings reveal how the various types of treatment techniques used within each group are successful after several sessions, while others¹ are successful from the onset. In a group of people brought together for any purpose, the degree in which the anticipated goals are successfully realized is dependent upon the capacity of the member's purpose and need plus the amount of appropriate knowledge and experience proposed. The use of groups is not a substitute for other types of psychotherapy, but may be effective with specific clients.

Group Approach Preferred Over Individual Approach

Crow discovered the effectiveness of discussion groups in helping parents with the task of child rearing.² Durkin experienced the use of the group approach with mothers who were given a chance to gain insight into their attitudes instead of having to try to make futile conscious attempts to improve individually their way of handling their children.³

Scheidlinger and Pyrke feel that groups should be tried simultaneously with individual contact to appreciate what influence the group discussion has upon its members. When geared to the unique problems of adults, groups may hold a promise for a speedier and more

effective way of helping the participants.⁴ Lewin found that discussion proved more effective than lectures or individual conferences in aiding a specific group of people to change a mode of behavior.⁵

One group education study in particular, outside of the United States, was approached with seven epileptic patients at Heemstede (the Netherlands). Brullerman's findings revealed that:

. . . group therapy can serve to support or even make possible medical treatment, even if it does not directly combat epilepsy. Even if the functioning of an epileptic patient in a group proves to be unsatisfactory, group discussion can still be an important means towards a better integration and therefore a better functioning of that patient.⁶

Wittenburg reports that groups offer such encouraging results that:

The application of psychiatric and casework knowledge and concepts to all fields of human behavior . . . necessitate the inclusion of group work courses and practice in the training of case workers, and more psychiatric knowledge and practice for group workers.⁷

The getting together and sharing with one another has advantages. The dynamics and general characteristics of nearly any goal-directed and facilitated parents group can have impact if even to a limited degree. Slavson believes the mere influence of the group experience is in a sense therapeutic in effect, even if it were not so intent.⁸ Grunwald and Casella found that getting together brought success in learning where other efforts had not been so rapidly successful.⁹ Their report states that the father's

attitude was at a disadvantage when involved in individual contact. The result was resentment upon the mother. Groups were then instituted to help overcome the parental difficulties with the goal of dealing with the resentment and impressing upon the parents minds the purpose of the "get together."

The collection of individuals into a group provides a setting in which the group atmosphere can minimize the amount of individual feelings of isolation and difference, the hypothesis being that the parent derives a feeling of strength and solace from discovering that he is not unique in his situation.¹⁰ Hallowitz and Stephens report how the group approach enabled fathers to participate in discussions and to become both emotionally involved and to attain unity.¹¹

Experiences With Parent Groups

Parent groups have been attempted with varying success in numerous areas, educational as well as therapeutic. While Schilder first used this form over thirty years ago,¹² Amster pioneered in applying the technique to mothers of children with behavioral problems;¹³ Lowry found groups to be surprisingly successful;¹⁴ Milman reports of her group approach to the parents of physically disabled children;¹⁵ Wittes and Radin discussed their two group approaches to parents of preschool children (to improve child-rearing attitudes and practices). These two groups were experimental while the third, a control group, was a prediction that preschool and

parent discussions being programmed simultaneously would have greater impact.¹⁶ Day and Rosen worked with groups with mothers of schizophrenic children;¹⁷ Bakwin and Bakwin worked with a group of parents whose children were schizophrenic and dealt with childhood schizophrenia in general;¹⁸ Durkin described his group experience with mothers of disturbed children;¹⁹ Durkin, Glatzer and Hirsch introduced the group methods to the mothers whose children were receiving psychiatric work;²⁰ Speers and Lansing dealt with simultaneous groups for the mothers with groups for their psychotic children;²¹ Wiener reported success with groups for parents of autistic children;²² Funt objectively tells of three different discussion groups, one with parents of preschool children, the second with parents of adolescents, and the third, discussion groups with older adults;²³ Bergen and Kris engaged parents in a group in a hospital setting;²⁴ Papademetriou used parent discussion groups with a focus upon unwed daughters;²⁵ Driscoll and Lubin worked with groups for parents of children with cystic fibrosis;²⁶ McPherson and Samuels held groups for parents of hyperactive and aggressive children;²⁷ Laibman offered groups for parents of adolescents;²⁸ and more recently is the work of Frisbie who is finding simultaneous groups for parents and groups for their children with physical handicaps to be adequate treatment when time and funds are apparent (some children whose handicaps were obvious and some which were not so obvious were in attendance, while some of them may or may not have had epilepsy).²⁹

Still in other areas is the work of Goodman and Rothman;³⁰ Siegel;³¹ Bice;³² Weingold and Hormouth;³³ White;³⁴ Nadal;³⁵ Appell, Williams and Fishell;³⁶ McGriff;³⁷ Coleman;³⁸ Cummins;³⁹ and French and Levbarg,⁴⁰ who have all held parent groups. Groups for parents of children with emotional, learning and behavioral problems are highly recommended by others.^{41, 42}

The Value Of Parent Group Education

Parents of children with handicapping conditions need to understand not only their children, their needs, potentials and motivations at each stage of development, but also themselves as parents, their own attitudes, feelings, and expectations, and the role they play in the parent-child relationship.^{43, 44, 45, 46}

Parent group education offers a methodology which may be applied flexibly to further the growth and learning of the particular parents who attend.⁴⁷ Auerbach, in a joint study with the Child Study Association of America, reports:

We are convinced that various types of groups for parents of handicapped children are a valid and important part of programs of service to these parents and that different kinds of groups may serve different kinds of needs. Parents can gain a great deal, according to the purpose of the project, skills which are used and the way in which the programs are related to the essential concerns of parents and their readiness to move ahead to new knowledge and insights.⁴⁸

Parent group education has a value, not as a substitute, but in and of itself, contributing in a very positive sense to the

parents' growth and increased strength in a way that often cannot be achieved in other ways. Through parent group education, parents gain much of the factual knowledge they want about their children and the immediate situations they are facing in dealing with them.⁴⁹

As parent group education stresses primarily the need to understand the meaning of behavior and communication within a family so that parents may respond more freely, parent group education must not prescribe curriculum but proceed from the interests and concerns of the parent members as they emerge in their daily lives with their children. This process allows parents to be deliberately encouraged to develop independent thinking, which in turn, coincides with the goal of parent group education, of helping the parents find their own place in their individual thinking and come to their own conclusions.⁵⁰ Mann states that the primary goal of any group should be the attainment of group unity for the purpose of mutual exploration, analysis, and synthesis.⁵¹

Since "a discussion group is a group of people of equivalent status meeting deliberately to discuss a previously agreed-upon subject and to learn together,"⁵² along with building of the parents strength and helping them improve through an experience of guided group discussion, the effective handling of a child with seizures necessitates changes in parental attitudes which enter into the child's development.^{13, 43, 44, 45, 53, 54, 55} This Clinic agrees with Lowry, that "with preschool children (where) the mother-child

relationship is the primary consideration,"⁵⁶ both parents can utilize the group experience even more to gain additional understanding of their preschool children, their family relationships, their knowledge of epilepsy, communication patterns, child growth and development, and the emotional strain under which they are living.⁵⁷ Because of both parents' own active role in the group educational process, they should have an opportunity to respond and digest the matters discussed, which hopefully allows the content of the discussions to closely meet both of their developing interests and concerns. Together they have the opportunity and responsibility to see that the learning is directed toward the realities of their daily lives and therefore has meaning for them as they need it.

Social/Emotional Behavior Of The Child

The child who has a severe and frequent seizure disorder:

. . . may be unable to experience comfort and normal feelings in early childhood. Later he may be affected by inconsistency, hostility, rejection, overprotection and many detrimental influences symptomatic of the adjustment of the parents to the problem.⁵⁸

Bridge has described the child's feelings regarding his seizure disorder as obtained from interviews with parents:

After the world is no longer black, he awakens to find himself surrounded by excited, agitated adults, who are unusually solicitous about him. In addition to the fear of death, children with seizures experience feelings of hopelessness and resentment against the attitudes which others show toward them. Emotional difficulties in the child with seizures arise as a result of awareness that he is different from peers and because of the need to adjust hopes and ambition to the limitations set by the seizure activity.⁵⁹

Parental attempts to meet these difficulties are frequently met with confusion and feelings of anxiety and inadequacy, as well as fear, rejection and isolation. Because of the child's difficulties in being allowed to develop independence (learning from structured or constantly supervised experience, perceiving his emotional environment appropriately, and conceptualizing), behavior is often aberrant and tends to arouse antagonism or enforced isolation. The parents have not been prepared by their past experience to respond with understanding to this behavior. Eventually the child is likely to experience progressive restriction in social contacts, inadequate training facilities, difficult community attitudes, and limited opportunities for employment and recreation. Innumerable influences in the life of the child with epilepsy, therefore, tend to create social/emotional disturbance. Ultimately, intellectual and social limitations may make it impossible for him to find a solution to conflicts between his instinctual needs and social adaptation.

With the onset of seizures, however, parents frequently describe a change in behavior. Though some children appear unaffected by the disorder, the majority become unstable, dissatisfied, restless and distractible, demanding, resentful, quarrelsome, and disobedient. Outbursts of temper are frequent. Interest in school lags and they may become disturbing and annoying in the classroom. Continuance of these symptoms is likely to exaggerate the epilepsy as time goes on.⁶⁰

Deutsch and Wiener studied a group of children with epilepsy in

their homes. Behavior and personality varied widely. Although narcissistic behavior was found in some it was not characteristic of the entire group, and the same was true for aggressive behavior. Some of the children, especially those with petit mal and psychomotor attacks, inhibited their aggression because of fear of retaliation.⁶¹

Sullivan and Gahagan found that almost half of the children with epilepsy exhibited conduct disorders of various degrees. Most of them were hyperkinetic, antisocial, cruel, stubborn, and destructive. Their problems took the form of rage, temper tantrums, lying, stealing, nailbiting, and speech difficulties. Many of these children came from homes where siblings also had problems.⁶²

Much of the aggressive behavior of children with epilepsy has been thought to be the reaction to rejection by the parents and by society. Feelings of guilt may produce antisocial behavior. Demands for attention or frustration have in some instances caused children with seizures to simulate clinical seizures.⁶³

Bradley divides the behavior difficulties associated with epilepsy into two general groups. The first are those which are direct and primary expressions of disordered cerebral function. Since such symptoms arise, presumably, from the same alterations in brain function as produce the convulsions, a certain similarity in symptoms is to be expected. In the second group, the symptoms are expressions of the patient's own reactions to his illness. Such reactions will de-

pend on the child's personality and on the way his illness is regarded by the people around him. Since these vary from child to child, the secondary symptoms will also vary in different individuals.

According to Bradley, the general behavior that is primarily characteristic of the child with seizures consists of a cluster of five traits. No one or two of these are characteristic but the presence of several gives a general pattern. The traits are (1) erratic variability in mood or behavior, (2) hypermotility, (3) irritability, (4) short and vacillating attention span, and (5) a rather selective difficulty in mathematics as a school subject.

He also states that erratic variability in mood or behavior expresses itself by fluctuations in social adaptability with apparent cause or purpose, occurring, usually, at irregular intervals. The child has good days and bad days at home and at school and he may be puzzled and frustrated by them as are his parents and teachers. The hypermotility or overactivity and the distractibility or short attention span are similar to that seen in other children with organic brain disease. It tends to decrease as the child matures. Irritability is a frequent symptom of many sorts of emotional maladjustment but it is often developed to a high degree in the child with seizures. Its occurrence without any relationship to circumstances in the child's environment sometimes makes it difficult to understand.⁶⁴

Characteristic Symptoms

A certain number of children have been described who show the grouping of symptoms considered by Bradley to be characteristic of the

child with epilepsy, yet have no convulsions. A considerable proportion of these children show electroencephalographic changes resembling those found in epilepsy!

According to Bakwin and Bakwin:

Parental mishandling, especially overprotection and oversolicitousness, is not uncommon. A number of parents believe that epileptic children are more vulnerable to the risks of everyday life than others and they therefore limit normal social relationships and play. Dependency and infantilism are encouraged in this way.

When the convulsions persist over a long period the child is often rejected because of the difficulties involved in caring for him. He may react to the rejection with feelings of guilt and shy, sensitive, and antisocial behavior. This is intensified when he is unable to attend school or when he is not accepted in the community. Other children react to parental rejection with hostility, aggressiveness, and incessant demands for attention.⁶⁵

Fortunately, the outlook for the child with epilepsy is now more optimistic than ever. This may be attributed to more widespread interest in epilepsy and the recent advances in diagnostic techniques, together with remarkably vigorous pharmacologic research and greater appreciation of the necessity for comprehensive evaluation and management of related problems in the child with seizures, in whom epilepsy may be the major, but not the only, problem.

Primary Parental Reactions

Few events are so frightening to parents as is expressed in their first reaction to a diagnosis of epilepsy in their child. Some are frightened that death may occur, that subsequent seizures will

ensue, and mental deterioration may take place. The general idea that epilepsy is a shameful disease--a stigma--is often foremost in the minds of the parents.^{43, 45, 46}

Several authors have found psychological and social complications to be puzzling,¹⁰ frustrating,⁵³ subtle,⁵⁴ severe,⁵⁵ and long lasting.⁶⁰ Others found the first reaction of parents to a diagnosis of epilepsy in their child is one of horror and frequently disbelief.^{66, 67} In many cases it was found that the development of epilepsy in their child was considered to be "punishment for their sins."⁶⁸ In other cases it was not surprising to find parents class epilepsy with Frankenstein and vampire bats.⁶⁹

As epilepsy is one of the last of the "hush-hush" diseases,⁷⁰ the prevailing attitude of fear, misunderstanding and prejudice is still hampering many of these parents.^{45, 71, 72, 73} Parents of children with seizures are not always free of these fears, suspicions, and misunderstandings, and doctor-parent discussions about the emotional and behavioral problems created in the family are not always conclusive.

The occurrence in one way or another of defect or damage of the central nervous system in a child is a difficult realistic problem which is likely to be of sufficient nature to cause an unlimited amount of distress in the parents. The most that can be expected of any prolonged application of professional skills to the management of the problem usually is some degree of improvement within the limitations imposed by the basic seizure disorder. Such

a problem places heavy demands on the capacities of parents and produces feelings and reactions which are important factors in the lives of the parents and the child. In the majority of instances the lives of both the parents and the child tend to be adversely affected.

Garrard and Richmond, in pointing this out, said:

Once defect or damage of the central nervous system is identified, parents do not feel toward the affected child as they would toward a normal child. How profoundly parental feelings are altered influences the extent to which healthy relations are present or absent for the child. Some parental feelings may be symptomatic of unsatisfactory adaptation to the disorder and may tend to impair effective integration of the problem into the daily life of the family.⁷⁴

Acceptance is a term which is often used, but which does not adequately describe the process of adaptation of parents to a child diagnosed as having epilepsy. It is possible that some parents may never succeed in arriving at a complete understanding of the problem, and a neurologically handicapped child does not present a single problem for which there is a single or final solution. Problems continually arise at different developmental stages as the full extent of the process unfolds.

Groups For Parents Of Children With Epilepsy

The primary purpose in the therapy of any disability is the rehabilitation of the patient to a life as nearly normal as possible within the limits of the disability.⁷⁵ The need for such a consistent and well-organized group program has long been recognized.⁷⁶

Those who have published their findings on parent discussion groups^{1, 72, 73, 77} (where the common focus of the group has revolved around seizure disorders in their children) all agree that group discussion in this type of situation also makes for better and sometimes more rapid improvement in their adjustment. Direct discussion of seizures in a group can also make for rapid improvement in the parent-child relationship.⁷⁸

The use of groups as a method for giving parents the opportunity to discuss their child's seizure disorder, and related behavioral difficulties, first dates back twenty years when deFries and Browder found group psychotherapy with children who had epilepsy and their mothers to be an effective and useful part of the therapy of the child suffering from both seizures and personality disturbances. By using the common problem of seizures in their children to bring the mothers and the children together in a group, they reported moving forward with surprisingly successful results.⁷³

In another study,⁷⁷ similar results were obtained. Parents whose life revolved around superstitions about and fears of seizures in their children were partially effectively cleared up in doctor-parent talks, reading of pamphlets, and listening to professionals. After the parents were part of groups aimed at educating themselves, in which they discussed common problems and fears and shared individual successes, the parents could then be more optimistic. By having teenagers who had seizures address the group and tell of playing football and dating, the parents' optimism was encouraged. When

the groups had later dissolved, each parent had gained in learning about his child's problems and how to cope with them. The parents' expressions of enthusiasm and gratitude made the discussion groups seem even more worthwhile.

Others¹ reported such encouraging results with the parents of children suffering from seizures that their group discussions continued for over two years. They felt that they had actually fulfilled all of the objectives for which the groups were originally designed.

Other education groups have been reported, several outside of the United States, one of which was specifically dealing with seizures. DeColon, Trent and Longo⁷² made an attempt in Puerto Rico to hold discussion groups which involved ten mothers of adolescents who suffered from seizure disorders. The mothers were able to overcome many of their fears and misconceptions about seizure activity, emotional tension, and a reduction of anxiety. In nine of the ten cases it appeared that the group sessions had also led to a general reduction of tension within the home.

The Process Of Education

Hughes and Jabbour⁴³ feel that one of the first priorities in the treatment of a child who has a seizure disorder is to indoctrinate his parents so thoroughly in the nature of his condition that the need for continuous, discreet supervision is fully appreciated, and the general fears, suspicions, and misbeliefs are dispelled. Lennox

feels that, more than with most other diseases, the only unit of treatment is the family.⁴⁴

In addition to his primary symptoms, the child shows behavior which reflects his feelings about himself, his adequacy and the special problems which his seizure disorder creates for him. Realizing the anxiety created in the parents of a child with seizures, concern over parental attitudes about the child's seizures are of extreme importance as these attitudes prevail over and influence the behavior of the child. The child's attitude in turn reflects the way the parents feel about him and his seizures, and are to a large extent influenced by the way significant other people deal with him.^{18, 44, 45, 72}

As Bradley has stated:

. . . there are behavior symptoms . . . that are directly or secondarily associated with the basic disorder and represent the patient's personal reaction to being ill as well as to the way his illness is regarded by those about him.⁷⁹

Summary

Group discussion as an education and learning experience has been reported of considerable value⁸⁰ in the treatment of the child with a seizure disorder. Furthermore, topical group discussion of epilepsy with the child's parents beneficially affects the attitudes of the parents.

Group discussions do have some precedence over other approaches, because of the favorable ratio of participant to professional, but their ultimate effectiveness hinges on the active participation of

the individual group members. This participation is motivated by the emotional needs of the participant, and the relevance of the group discussion.⁸¹

With lasting results measured in reduction of parental anxiety and greater parental knowledge of their child's condition, the parent group education and discussion method appears to be a successful approach in accomplishing these goals.^{1, 72, 73, 77}

Since emotional factors are among the most potent agents precipitating seizures in children,^{18, 44, 45, 58, 60, 82, 83, 84, 85, 86, 87} the family attitudes must be dealt with by first educating the parents to the medical and emotional needs of their child.^{43, 54, 55}

FOOTNOTES

1. Gaston J. Baus, L. LaVerne Letson, and Edith Russell, "Group Sessions For Parents Of Children With Epilepsy," The Journal Of Pediatrics, 52:3 (March 1958), pp. 271-273.
2. Maxine S. Crow, "Preventive Intervention Through Parent Group Education," Social Casework 48:3 (March 1967), pp. 161-165.
3. Helen E. Durkin, Group Therapy For Mothers Of Disturbed Children (Springfield, Ill.: Charles C. Thomas, 1954), p. 212.
4. Saul Scheidlinger and Marjorie Pyrke, "Group Therapy Of Women With Severe Dependency Problems," American Journal Of Orthopsychiatry 31 (October 1961), pp. 775-785.
5. Kurt Lewin, "Frontiers In Group Dynamics I-Concept, Method And Reality In Social Science; Social Equilibria And Social Change," Human Relations 1:1 (June 1947), pp. 5-41; and "Frontiers In Group Dynamics II-Channels Of Group Life; Social Planning And Action Research," Human Relations 1:2 (November 1947), pp. 143-153.
6. L. H. Brullerman, "Group Therapy With Epileptic Patients At The 'Instituut Voor Epilepsiebestrijding,'" Epilepsia 13 (1972), p. 231.
7. Rudolf Wittenburg, "Psychiatric Concepts In Group Work," American Journal Of Orthopsychiatry 14 (1944), p. 83.
8. S. R. Slavson, Child Centered Group Guidance Of Parents (New York: International Universities Press, Inc., 1958), p. 73.
9. Hanna Grunwald and Bernard Casella, "Group Counseling With Parents," Child Welfare (January 1958), pp. 11-17.
10. Doris H. Milman, "Group Therapy With Parents: An Approach To The Rehabilitation Of Physically Disabled Children," The Journal Of Pediatrics 44:1 (July 1953), pp. 113-116.
11. Emmanuel Hallowitz and Bernice Stephens, "Group Therapy With Parents," Social Casework 40:4 (April 1959), pp. 183-192.
12. P. Schilder, "Analysis Of Ideologies Psychotherapeutic Method, Especially In Group Treatment," American Journal Of Psychiatry 93 (1936), pp. 601-613.
13. Fanny Amster, "Collective Psychotherapy Of Mothers Of Emotionally Disturbed Children," American Journal Of Orthopsychiatry 14 (1944), pp. 44-46.

14. Lawson G. Lowry, "Group Therapy," American Journal Of Orthopsychiatry 13 (1943) p. 648.
15. Milman, pp. 113-116.
16. Glorianne Wittes and Norma Radin, "Two Approaches To Group Work With Parents In A Compensatory Preschool Program," Social Work 16:1 (January 1971), pp. 42-50.
17. Max Day and Irving Rosen, "The Group Behavior Of Mothers of Schizophrenics," Journal Of Nervous And Mental Disease 119 (1954), 366-367.
18. Harry Bakwin and Ruth Morris Bakwin, Clinical Management Of Behavior Disorders In Children (Philadelphia: W. B. Saunders Co., 1967), p. 154.
19. Durkin, p. 14.
20. Helen E. Durkin, Henriette T. Glatzer, and Jeanette S. Hirsch, "Therapy Of Mothers In Groups," American Journal Of Orthopsychiatry 14 (1944), pp. 68-75.
21. Rex W. Speers and Cornelius Lansing, Group Therapy In Childhood Psychosis (Chapel Hill: University of North Carolina, 1965).
22. Louise L. Wiener, "Group Work With Parents," in Hubert S. Coffey and Louise L. Wiener (eds.) Group Treatment Of Autistic Children (Englewood Cliffs: Prentice-Hall, Inc., 1967), pp. 89-92.
23. Irene Funt, "The Application Of Casework Principles In Family Life Education," Social Casework XLIII:3 (March 1962) 130-137.
24. Helen M. Bergen, and Anton O. Kris, "Services To Parents Of Adolescent Mental Patients," Social Casework 53:2 (February 1972) 85-90.
25. Marguerite Papademetriou, "Use Of A Group Technique With Unwed Mothers And Their Families," Social Work 16:4 (October 1971) 85-90.
26. Chancellor B. Driscoll, and A. Harold Lubin, "Conferences With Parents Of Children With Cystic Fibrosis," Social Casework 53:3 (March 1972) 140-146.
27. Sandra B. McPherson, and Cyrille R. Samuels, "Teaching Behavioral Methods To Parents," Social Casework 52:3 (March 1971) 148-153.
28. Erwin M. Laibman, "Group Counseling With Parents In An Agency Serving Adolescents," Social Work 6:2 (April 1961) 67-73.

29. Personal contact with Dennis Frisbie, M. D., University of Oregon Medical School, Psychiatry Department, Portland, Oregon, 1972.
30. L. Goodman and R. Rothman, "The Development Of A Group Counseling Program In A Clinic For Retarded Children," American Journal Of Mental Deficiency 65 (1961) 781-795.
31. Ernest Siegel, Helping The Brain Injured Child (New York: Association For Brain Injured Children, 1961).
32. Harry V. Bice, and Margaret C. Davitt Holden, "Group Counseling With Mothers Of Children With Cerebral Palsy," Social Casework 30:3 (March 1949) 104-109.
33. J. T. Weingold and R. P. Hormouth, "Group Guidance Of Parents Of Mentally Retarded Children," Journal Of Clinical Psychology 9 (1953) 118-124.
34. B. D. White, "Clinical Team Treatment Of Mentally Retarded Child And His Parents: Group Counseling And Play Observation," American Journal Of Mental Deficiency 63 (1959) 713-723.
35. Robert M. Nadal, "A Counseling Program For Parents Of Severely Retarded Preschool Children," Social Casework 42:2 (February 1961) 78-83.
36. Melville V. Appell, Clarence Williams, and Kenneth N. Fishell, "Changes In Attitudes Of Parents Of Retarded Children Effected Through Group Counseling," American Journal Of Mental Deficiency 68:6 (May 1964) 807-812.
37. Dorothy McGriff, "Working With A Group Of Authoritative Mothers," Social Work 5:1 (January 1960) 63-68.
38. James C. Coleman, "Group Therapy With Parents Of Mentally Deficient Children," American Journal Of Mental Deficiency 57 (1953) 700-704.
39. S. Thomas Cummins, "Brief Group Therapy Of Mothers Of Retarded Children Outside Of The Specialty Setting," American Journal Of Mental Deficiency 66 (1962) 739-748.
40. A. C. French, M. Levbarg, and H. Michal-Smith, "Parent Counseling As A Means Of Improving The Performance Of A Mentally Retarded Boy: A Case Presentation," in C. L. Stacy and M. F. Demartino, (eds.) Counseling And Psychotherapy With The Mentally Retarded (Glencoe, Ill.: The Free Press, 1957), pp. 438-445.

41. Bakwin and Bakwin, "Clinical Management Of Behavior Disorders In Children," p. 154.
42. Hyman S. Lippman, Treatment Of The Child In Emotional Conflict (New York: McGraw-Hill Book Co., 1962), p. 351.
43. J. G. Hughes and J. T. Jabbour, "The Treatment Of The Epileptic Child," The Journal Of Pediatrics 53:1 (July 1958) 66-68.
44. William G. Lennox, "The Social And Emotional Problems Of The Epileptic Child And His Family," The Journal Of Pediatrics 44:5 (May 1954) 591-596.
45. Samuel Livingston, "The Social Management Of The Epileptic Child And His Parents," The Journal Of Pediatrics 51:2 (August 1957) 137-145.
46. Milman, p. 115.
47. Aline B. Auerbach, Parents Learn Through Discussion: Principles And Practices Of Parent Group Education (New York: John Wiley and Sons, Inc., 1968), p. 15-16.
48. Aline B. Auerbach, "What Can Parents Of Handicapped Children Gain From Group Experience," Helping Parents Of Handicapped Children (Boston: Children's Hospital Medical Center And Child Study Association Of America, October 1959), p. 16.
49. Auerbach, "What Can Parents Of Handicapped Children Gain From A Group Experience," p. 18.
50. Auerbach, "Parents Learn Through Discussion," p. 32.
51. James Mann, "The Theoretical Concepts Of The Group Process," Journal Of Nervous And Mental Process 119 (1954), p. 365.
52. Valerie Graves, "The Discussion Group," The Postgraduate Medical Journal 40:459 (January 1964) 1-3.
53. J. Beasley, "Social Aspects Of Epilepsy In Childhood," Postgraduate Medical Journal 40:464 (June 1964) 344-345.
54. D. A. Pond and B. Bidwell, "Management Of Behavior In Epileptic Children," British Medical Journal 2 (December 1954) 1520-1523.
55. Sterling D. Garrard and Julius B. Richmond, "Psychological Aspects Of The Management Of Children With Defects Or Damage Of The Central Nervous System," Pediatric Clinics Of North America (November 1957) 1033-1048.

56. Lowry, p. 648.
57. Auerbach, Parents Learn Through Discussion, p. 21.
58. Garrard and Richmond, p. 1040.
59. E. M. Bridge, Epilepsy And Convulsive Disorders In Children (New York: McGraw-Hill Book Co., 1949) p. 434-435.
60. R. M. Bakwin and Harry Bakwin, "Epilepsy," The Journal Of Pediatrics 39:4 (December 1951) 775.
61. L. Deutsch and L. L. Wiener, "Children With Epilepsy: Emotional Problems And Treatment," American Journal Of Orthopsychiatry 18 (1948) p. 65.
62. E. B. Sullivan and L. Gahagan, "On Intelligence Of Epileptic Children," Genetic Psychology Monographs 17 (1935) 309.
63. Bakwin and Bakwin, "Epilepsy," p. 779.
64. Charles Bradley, "Characteristics And Management Of Children With Behavior Problems Associated With Organic Brain Damage," Pediatric Clinics Of North America (November 1957) 1049-1060.
65. Bakwin and Bakwin, "Epilepsy," p. 780.
66. Ruth Gerofski, "The Patient Faces Epilepsy," Social Casework 29:5 (May 1948) 183.
67. Frances F. Schwentker, "Social Management Of Epilepsy," in Samuel Livingston, The Diagnosis And Treatment Of Convulsive Disorders In Children (Springfield: Charles C. Thomas, 1954) 236.
68. Livingston, p. 139.
69. Beasley, p. 345.
70. Jerry Price Seizure Clinic, Brochure For Parents (Los Angeles: Children's Hospital, November 1963) 10 pages mimeograph.
71. Lennox, p. 593.
72. Lydia Santiago DeColon, Richard D. Trent, and Luis Sanchez Longo, "A Group Work Experience For Mothers Of Adolescents With Epilepsy," in Robert F. Noland, Counseling Parents Of The Ill And Handicapped (Springfield: Charles C. Thomas, 1971) 219-240.

73. Zira deFries and Sue Browder, "Group Therapy With Epileptic Children And Their Mothers," Bulletin Of The New York Academy Of Medicine 28 (April 1952) 235-240.
74. Garrard and Richmond, p. 1037.
75. Livingston, p. 137.
76. Baus, et al., p. 270.
77. Sheldon H. Kamin, Charley Jackson Llewellyn, and Winnie L. Sledge, "Group Dynamics In The Treatment Of Epilepsy," The Journal Of Pediatrics 53 (October 1958) 410-412.
78. deFries, et al., p. 235.
79. Bradley, p. 1055.
80. Kamin, et al., p. 410.
81. Ruth Mallison, Education As Therapy: Suggestions For Work With Neurologically Impaired Children (Seattle: Special Child Publications, 1968).
82. R. A. Jensen, "Importance Of The Emotional Factor In The Convulsive Disorders Of Children," American Journal Of Psychiatry 104 (1947) 126-131.
83. William G. Lennox, and Margaret A. Lennox, Epilepsy And Related Disorders (London: Churchill Press, 1960).
84. Frank Fremont-Smith, "The Influence Of Emotion In Precipitating Convulsions," American Journal Of Psychiatry 13:90 (1934) 717-723. Also In Archives Of Neurology And Psychiatry 30 (1933) 234-236.
85. J. R. Stevens, "The Emotional Activation Of Electroencephalogram In Patients With Convulsive Disorders," Journal Of Nervous And Mental Disease 128 (1959) 339.
86. Elabe M. Davidson, and Joan C. Thomas, "A Social Study Of Epileptic Patients," Social Casework 3:9 (November 1949) 380-384.
87. Jean Cummins, "The Family As A Factor In The Epileptic's Social Adjustment," Social Casework 3:9 (November 1949) 384-387.

APPENDIX H

Session Questions

SESSION QUESTIONS

First Session

Sex

- F What is the problem with the funds? Do they want you to cut down on teaching time? Less students? Or what?
- F Where did the toys come from?
- M How do you determine what will be measured of the child?
- M What scales or tools do you use?
- M What is their position if parents have their own objectives?
- F Do they want him to achieve in both verbal and motor skills?
- F Do they take the chronological age into consideration?
- M Is the criteria reasonable?
- M How can you measure in comparison to his being enrolled in another place?
- M Do we have objectives that need emphasis?
- M Do you ever use video-taping with both parents?
- F Are you really natural during this situation?
- F Has this technique ever been used with siblings?
- F These meetings are going to adjourn on a prescribed time?
- F Could the doctor more fully explain the EEG to us?
- F Otherwise, how can she explain his problem to others?
- M I would like to be better informed about this, but will it help me to become a more effective parent?
- M What level or degree of seizure activity is within this group?
- F What causes the different kinds of seizures?

- F Will different kinds affect learning potential?
- F Did the increase in knowledge help you?
- F Would specific information be helpful?
- F How do you handle a child when he has a seizure?
- F What makes people scared?
- M Who made out the questionnaire?

Second Session

- M Is participation in sports a relative issue for each child?
- F What about the intake of excessive liquids?
- F What about the stimulants and depressants? What are they that they cause a seizure?
- F Do little seizures often turn into big seizures?
- M If a child with petit mal seizures goes on unchecked, can they develop into grand mal seizures?
- F Did you mention your condition when you applied for a job or driver's license?
- F When was your first seizure?
- F To what degree is epilepsy hereditary?
- M Is it possible that stimulation of attacks dies out or can there be a fluctuation where at times attacks may be stimulated by the environment, and other times not?
- M Where can we look for more scientific information about epilepsy?
- F Do you feel as a group that each child represented here is representative of all types of seizures that a child might have?
- F Are the seizures occurring at the same time?
- F What kinds of seizures are they having?
- M What age did they start seizuring?
- M Did both start seizuring about the same time?

- M How long do they last?
- M Are they identical twins or fraternal?
- M Are you as a parent going to tell the schools that she has seizures?
- M Have you noticed any developmental delay in your children?
- M With what frequency does your child have seizures?
- M Is this a consistent pattern?
- M Do his eyes roll back or just stare?
- F Does he have a fear that he is going to have a seizure?
- M Does he have trouble walking?
- M How old was he when he started seizing?
- M Is he afraid just before he has a seizure?
- M Does he have brothers and sisters?
- F Where speech is concerned, do you find yourself comparing your son to his older sister?
- M How do you account for the older sister being so capable of handling the seizures?
- F Do you wish that adults could accept his seizures as easily?
- F What medication is he on?
- F What is the significance of these different medications?
- M Would you classify your child as an epileptic?
- M I'm wondering if the physician does not brand the seizure condition for the parents sake, or is it to make the condition more palatable for the parents sake or so the parent will attach no stigma to the child?
- F Would it help parents to have a label?
- M I wonder if some status is assumed about the child?
- M Why do doctors "beat around the bush" rather than give us a diagnosis?
- F I wonder if the physician knows himself?

F Could it be that epilepsy is a problem of definition and not a black and white extreme?

Third Session

F At what age do seizures usually begin?

F Does it show on the EEG where something is wrong?

F Was this a first pregnancy?

F What was the weight gain during the first year?

F Was your labor prolonged or difficult?

F Do you feel from your own experience that problems can happen if you tell the school district?

F Does it help to take an EEG both while asleep and awake?

M Does she have muscle contractions with seizures?

F Has she ever done any physical damage to herself while seizing?

F You mean they were questioning you about how she got the bruises?

M You said you were not going to inform the school? Why?

M If the child's seizures are under control, why should the school have to know?

M What difference would it make?

F Does valium control his seizures?

F Are you saying he is slow in motor development as well as being small in size?

F Is he an affectionate child?

M Does he have seizures in his sleep?

F Has he been a healthy child?

M How does he behave around other children other than his baby brother?

M What objectives do you have for him in his schooling?

M What things are you hoping to see?

F What is his primary problem now, seizures or growth problem?

- F Why is there such a high percentage of children who are adopted that have seizure problems?
- F Was one of your children adopted?
- M Have her sisters and brothers seen her have a seizure in public?
- M Were they ever embarrassed?

Fourth Session

- M Will we have any conflicts with official things, such as insurance, federal draft, and so on?
- M Do we still have to classify them?
- M Do different leagues lobby? Especially regarding insurance?
- M Does the doctor know any more than we do?
- M Why don't you perform a 24 hour observation and take a total approach?
- M Don't you think it would be damaging to us to tell us that the problem is one of definition?
- M Should you feel out each individual parent as a more practical approach?
- F Does a different severity of seizures affect parental reaction to classification used?
- M Are there any problems with parents who get turned off when they discover the doctor does not have all the answers?
- F What is the principle behind the emotional build-up prior to a seizure and release of emotion afterwards?
- F Are brain cells destroyed during a seizure?
- M What is the connection between heredity and epilepsy?
- M What about things that cause or induce seizures such as stimulants?
- F Why is sleep disturbed because of some stimulants?
- F Are there emotional factors which can induce seizures?
- M What are your observations regarding activity?

- M How is it possible to run these kids through your program to get them ready for the schools if the consenses definition of epilepsy is not changed?
- F Is epilepsy a static condition relative to maturity nervous system?
- M Is the Epilepsy League of Oregon under United Good Neighbors?
- F If you won't say the word, how can we say it?
- F How can we clean up the word epilepsy before we try to change it or group it with something else?
- F What if we are trying to get medical insurance and need a medical reference?
- M How do you respond to letters asking about risk factors?
- F You mean you leave it up to them to interpret?
- M How is the word epilepsy interpreted then?
- M Seizure sounds better than epilepsy, so is the difference only in social acceptance?
- F Should we say seizure disorder or epilepsy?
- M How will this affect kids in the future?
- F Who makes up the membership of the Epilepsy League?
- M Is epilepsy a static condition or isn't it?
- M Shouldn't parental efforts be more focused on static diseases rather than transient illness like epilepsy?
- F What is the incidence that epilepsy might get worse?

Fifth Session

- F Is it a question of educating our boy to the extent of helping him explain to other people or are we hurting him by informing him?
- F Do you think it will ever happen that epilepsy will become a clean word?
- F What would you recommend we do to change the attitudes of this community?

- F Should each and every teacher behave in such a manner as to force us to move to another school district, where do we stand when in this kind of situation?
- M Do you get any feedback from speaking to schools?
- F Do you reach many people at high school age?
- M Do some medications lose their effectiveness?
- F Can too much penicillin have dire affects, like on an insensitive person?
- F Should young adult epileptics have children?
- M Are there hereditary implications in the Gibbon Ape colony?
- F Do our children feel anything from the drugs they take?
- F Is it a normal feeling?
- F Is it anything different from droggy, dizzy, drunk or sleepy?
- F Are seizures painful?

Sixth Session

- F Are any parents interested in contacting any other parents?
- F Do any of these other parents have children with epilepsy?
- M Could some of these parents join us and allow us to split into two groups?
- M Does anyone here prefer a smaller or larger group?
- F Should we limit our program only to the parents of the children in the classroom?
- F Since this was a program scheduled for six weeks, was this set down this way for a purpose?
- F What if we did have a new group come and Dr. Schimschock and Watson spoke to them, and they saw the movies and everything, would this bring them up to where we are?
- F Would this prevent it from be repetitive to us?
- M Can we have this as our facility?
- M Can you give us the bill number which is at Salem?

- F What can we do as a group?
- F Before we complete our program this evening, can we find out about the Epilepsy League of Oregon and where to obtain money to send to the Clinic or any other service?
- M What can we do to help the League?
- F What can we do to erase the stigma?
- F Would Betty Stokes be willing to be one of our speakers?
- M Could she support us in any bill pushing or lobbying at the Legislative process?
- M Was there any decision made as to who you're going to invite into the group?
- F Is it fair for us to hold anyone out of our group?
- M Aren't we defeating our own purposes if we bring in too many?
- M How many couples are we talking about?
- M Shouldn't we invite people to social things first?
- M Can we get them to come to the meetings later on?
- M Wouldn't this be a good "in" with the schools too?
- F Where can we get facilities?
- F Should we limit ourselves to epilepsy children or include all others?
- F Could we get other people who are merely interested in attending?
- M Is any funding coming from the State?

APPENDIX I

Socio-Economic Inventory And Instruction

SOCIO-ECONOMIC INVENTORY
INSTRUCTION SHEET

The Socio-Economic Inventory is being developed for use as an investigative tool in the diagnostic evaluation of children suspected of having neurologically based learning and behavioral problems. This inventory takes the form of a structured questionnaire, administered to the child's parent during an interview.

Although any form of structured interview has the obvious fault of confining one's investigation to circumscribed areas of inquiry, the requirements for (1) collecting relevant diagnostic information in a single two-hour interview, and (2) the maintenance of some degree of consistency in the diagnostic information collected from differing sources, precluded the use of an entirely open-ended, unstructured interview.

This questionnaire focuses on the identified child in his or her social milieu at home, at school and in the immediate neighborhood. It is intended merely to obtain a number of facts about the child, each fact being covered by a single question or by several related questions. The several related questions, bearing on a single area of information or Field, are intended to cover different dimensions of the area.

Administration Of Inventory

1. Allow a minimum of two hours for the completion of the inventory.
2. This inventory is not self-administered. The interviewer

keeps possession of the schedule, reading the questions to the respondent, who is then requested to make verbal responses to the questions. No questions should be omitted, and the questions should always be asked in the same order. If a subject does not understand the question, it may simply be repeated. If the respondent gives an answer which the interviewer does not understand, or which he thinks is beside the point, the interviewer may merely ask the subject what he meant, and continue asking this until the answer appears appropriate and clear. If a question cannot be successfully handled in this way, it should be marked for further investigation and possible deletion.

3. Maximum effort should be made to have the child's biological mother (or female guardian) respond to the questionnaire. If, however, the situation indicates that both parents should respond to the questionnaire, then the questionnaire may be administered during a joint interview with both biological parents (or legal guardians).

Detailed Instructions

SECTION ONE: (identifying information) This section comprises Fields 1-12d, and with the exception of Fields 5, 12c and 12d, this section can be completed by the interviewer prior to the commencement of the interview. However, the information recorded prior to the interview should be verified by the respondent before beginning section two.

<u>Field</u>	<u>Special Instructions</u>
1	Case number is assigned by Clinic secretary.
2	(biological, step, foster - mother, father)
8	Example: 5 years 4 months $\frac{0}{0} \frac{5}{4}$

FieldSpecial Instructions

- 12a If more than one referral source, check the basic letter of referral.
- 12b This requires two responses. Card column 9 can be filled in from the information received on the letter of referral. Card column 10 can be filled in only by asking the informant which of the three reasons or combination thereof, are the reasons for having their child evaluated.
- 12c Filled in by interviewer without asking the informant.
- 12d Careful consideration should be given this question. List pediatricians, neurologist, clinics, state, county, city and private agencies.

SECTION TWO: (current functioning) This section is the heart of the interview, and is comprised of the subsections, child's health history, child's problems areas, parental assessment of the child, and a review of areas including school, vocational, avocational, social and emotional adjustment.

Subsection (health history)

FieldSpecial Instructions

- 13a Read the question to the respondent, but modify it for proper usage. If the respondent is not the biological parent of the child and there is no information, check response number 9 and explain.
- 13b & c Same instruction as 13a.

FieldSpecial Instructions

14a

This section provides the respondent with an opportunity to tell what areas of the child's functioning concern the parent at the present time. (Detailed verbatim descriptions required)

Problem: As the respondent sees it; record the statement verbatim.

Frequency: How often does it occur and how long has it persisted.

Intensity: Is it static or does it change with different environments?

Conditions: What is the general atmosphere of the problem situation?

Precipitating: What brings it on?

14a-f

Read the questions to the respondent, modifying the question for proper usage. Example: "Are Sally's behavior problems a major concern, secondary concern, etc." Amplify the responses by using the blank space in the columns.

15a & b

If the child acts his age, reflect his or her chronological age. If he acts older or younger than their chronological age, reflect that age in years.

15c, d & e

Read the questions substituting the child's name for (your child). Read all the responses and let the respondent choose and explain the choice.

15f & g

After the question is read to the respondent, the

FieldSpecial Instructions

respondent's first word will be the key to the selection of the appropriate response. The use or non-use of qualifiers in the explanation will assist the further classification of the response.

Subsection (review of areas)

This section provides some difficulties in completion when the identified child is very young (preschool) or when the identified child has a very low mental age (retardation). Carefully weigh the relevance of each question in this area before presenting the question to the respondent.

- 16a & b For preschool-aged children, response 6 is an appropriate response. Those children unable to attend school because of a very low mental age (mental retardation) response 6 is again an appropriate response. However, indicate the condition by specifying MR after the response.
- 16c If a child is retarded and attending either a Trainable Mentally Retarded or an Educable Mentally Retarded classroom setting, response 3 is the appropriate response. Indicate the type of classroom by TMR or EMR.
- 16d If the child is not attending school, specify Not In School.
- 16e This response is the total years in school, discounting preschool and kindergarten. For preschool-aged children, 00 is the appropriate response.

FieldSpecial Instructions

- 16f For mentally retarded children in non-graded classes, as well as preschool children never attending classes, 00 is the appropriate response.
- 16g For preschool-aged children the appropriate response is 8, but use the explanation to indicate the child is too young to attend any school
- 16h & i After reading the response areas to the informant, circle all responses indicated. Then total the number and place this number in the appropriate card column.
- 16j Many parents are able to discern academic readiness deficiencies in their child at an early age. This is a workable question for parents of all aged children, including preschool and mentally retarded children.

Field (vocational)Special Instructions

- 17a & b If the child is too young to have responsibilities at home or away then indicate the child is Too Young in the card column and select response 8.
- 17c, d & e Listen very closely for inconsistencies in responses, which at first indication one might infer that the child manages his own money, but upon closer examination it becomes evident that the parent actually manages the child's money. If the child is actually too young to know the meaning of money or because of a retarded condition, cannot realize the meaning of money, then response 7 is appropriate. Complete (why?)

FieldSpecial Instructions

by indicating either MR or Too Young

(Avocational)

18a Stress the word PRIMARILY.

18b Activity (what he/she does)

Delete % of time spent.

Activity level (physical activity)

18c Often because of the limitations of available children to play with, some children are forced to play in either a group made up of younger or older children. If this is the case, indicate your findings in the card column. Obtain the average age of all the children the child plays with.

18d Same as 18b

18e & f Stress RECREATIONAL on the child's terms.

Never: Once a month or less

Sporadic: Scattered sessions, but usually don't play together.

Frequent: Play together often or habitually play together.

Scheduled: Routinely planned play activities.

(Social)

19a-e The determination of appropriate or inappropriate behavior must be made by the respondent and not the interviewer. Special notes should be made if the

FieldSpecial Instructions

interviewer feels there is a gross inconsistency between the respondent's explanation and his choice of appropriate or inappropriate behavior.

(Emotional)

20a & b Description provided must be in the words of the respondent.

SECTION THREE: (family history)

This section is comprised of fields 21 through 23 which provides general information on the living environment of the child by looking at the composition of the family, siblings with similar problems, parental background, status of marriage and family economics.

FieldSpecial Instructions

21b & c Can be completed by the interviewer.

21e Include neighbors, scout masters, baby sitters, etc.

22a-i Read question to the respondent, modifying (your child) for proper usage.

23a-i Read question to the respondent, modifying (your child) for proper usage.

25a-27d Discuss the marriage history of both spouses but primarily in terms of the responses listed.

SOCIO-ECONOMIC INVENTORY

SECTION ONE: Identifying Information

<u>Field</u>	<u>Field Name And Description</u>	<u>Card Column</u>
1.	Case number:	1-3 _ _ _
2.	Child's name: _____ last first initial	
3.	Date of interview: _____ / _____ / _____	
4.	Interviewer: _____ last first initial	
5.	Informant: _____ last first initial _____ relationship to child	
6.	Sex of child: 1= Male 2= Female	4 _
7.	Child's date of birth: _____ / _____ / _____ month day year	
8.	Child's current age: years 5-6 _ _ months 7-8 _ _	
9.	Child's present address: _____ number street city state zip	
10.	Telephone number: _____	
11.	Child's legal guardian: _____ last first initial _____ address (if different from number 9)	

12a Referring person or agency:

name

name

address

address

contact person

contact person

12b Reason for referral: (from letter of referral)
(from the informant)

9 —
10 —

- 1= Academic evaluation
- 2= Medical evaluation
- 3= Psychological evaluation
- 4= Combination 1, 2 and 3
- 5= Combination 2 and 3
- 6= Combination 1 and 2
- 7= Combination 1 and 3
- 8= Don't know
- 9= No information

12c Does the informant's interpretation of the reason for referral concur with the referral source?

11

1= Yes
2= No
9= No information

12d Is (your child) currently receiving services
or has received services from any other public
or private agency?

12

1= Yes

Agency	Worker	Phone

2= No
9= No information

SECTION TWO: Current Functioning

<u>Field</u>	<u>Field Name And Description</u>	<u>Card Column</u>
	(Health History)	
13a	<p>Prenatal: While carrying the child, did the child's mother have any of the following:</p> <p>1= German measles 2= Viral Episode 3= Other _____</p> <p>8= Normal 9= No information (Explanation) _____</p>	13 ____
13b	<p>Natal: At or around birth, did (your child) experience any of the following:</p> <p>1= Prolonged labor, cord around neck, difficult delivery 2= Premature 3= Congenital anomaly 8= Normal delivery 9= No information (Explanation) _____</p>	14 ____
13c	<p>Postnatal: Since birth, has (your child) experienced any of the following:</p> <p>1= Severe illness, possibility of brain impairment from meningitis, encephalitis, high fever, dehydration 2= Sever illness, prolonged hospitalization with surgery 3= Sever illness, prolonged hospitalization without hospitalization without surgery 8= Normal 9= No information (Further information) _____</p>	15 ____

(Child's Problem Areas)

14a In a hierarchy of concerns about (your child),
listed in descending order of importance, what
would they be?

1a Problem: _____

b Frequency: _____

c Intensity: _____

d Conditions of onset: _____

e Precipitating situation: _____

2a Problem: _____

b Frequency: _____

c Intensity: _____

d Conditions of onset: _____

e Precipitating situation: _____

3a Problem: _____

b Frequency: _____

c Intensity: _____

d Conditions of onset: _____

e Precipitating situations: _____

14b Behavior problems as seen by the parents are:

16 _____

1= Major concern

2= Secondary concern

7= Not applicable

8= State report of no concern

9= No information

(Child's Problem Areas)

14a In a hierarchy of concerns about (your child), listed in descending order of importance, what would they be?

1a Problem: _____
b Frequency: _____
c Intensity: _____
d Conditions of onset: _____
e Precipitating situation: _____

2a Problem: _____
b Frequency: _____
c Intensity: _____
d Conditions of onset: _____
e Precipitating situation: _____

3a Problem: _____
b Frequency: _____
c Intensity: _____
d Conditions of onset: _____
e Precipitating situations: _____

14b Behavior problems as seen by the parents are:

16 _____

- 1= Major concern
- 2= Secondary concern
- 7= Not applicable
- 8= State report of no concern
- 9= No information

<u>Field</u>	<u>Field Name And Description</u>	<u>Card</u> <u>Column</u>
14c	Hyperactivity as seen by the parents is: 1= Major concern 2= Secondary concern 7= Not applicable 8= Stated report of no concern 9= No information	17 ____
14d	Short attention span as seen by the parents is: 1= Major concern 2= Secondary concern 7= Not applicable 8= Stated report of no concern 9= No information	18 ____
14e	Inability to concentrate and complete assigned tasks as seen by the parents is: 1= Major concern 2= Secondary concern 7= Not applicable 8= Stated report of no concern 9= No information	19 ____
14f	Health problems as seen by the parents are: 1= Major concern 2= Secondary concern 7= Not applicable 8= Stated report of no concern 9= No information	20 ____
14g	Seizure control problem as seen by the parents is: 1= Major concern 2= Secondary concern 7= Not applicable 8= Stated report of no concern 9= No information	21 ____
	(Parental Assessment Of Child)	
15a	Viewing (your child) in terms of other children his/her age, would you say he/she: 1= Acts younger than his/her age (con't.)	22 ____

- 2= Acts his/her age
 3= Acts older than his/her age
 9= No information

(Explanation) _____

15b What age is (your child) most like? 23-24 _____

15c Projecting (your child) into adulthood, how
 would you assess his/her potential for a
 successful marital relationship? 25 _____

- 1= Severely restricted
 2= Somewhat restricted
 7= Too young; don't know
 8= Normal (unrestricted)
 9= No information

(Explanation) _____

15d How would you assess his/her ability to find
 suitable employment? 26 _____

- 1= Severely restricted (will need institutional
 setting)
 2= Somewhat restricted (will need sheltered
 workshop)
 3= Average (laborer, housewife)
 4= Above average (skilled laborer/white collar)
 5= High (professional)
 6= Too young; don't know
 7= Don't know
 9= No information

15e Looking back over (your child's) life, what do
 you see as the primary cause of his/her current
 problem? 27 _____

- 1= Health related
 2= Related to home environment
 3= Poor schools
 4= Poor teachers
 5= Other (specify) _____
 6= Don't know
 9= No information

Field	Field Name And Description	Card Column
15f	<p>Do you see (your child) as being delayed but having the ability to catch up?</p> <p>1= No (unqualified) 2= No (qualified) 3= Yes (unqualified) 4= Yes (qualified) 6= Don't know 9= No information</p> <p>(Explanation) _____</p>	28 ____
15g	<p>Do you see (your child) as being mentally retarded in any way?</p> <p>1= No (unqualified) 2= No (qualified) 3= Yes (unqualified) 4= Yes (qualified) 6= Don't know 9= No information</p> <p>(Review Of Areas)</p> <p><u>Child's School Background</u></p>	29 ____
16a	<p>At what age did (your child) enter kindergarten?</p> <p>1= Never attended 2= Age four 3= Age five 4= Age six 5= Age seven 6= Too young (not yet attending) 9= No information</p>	30 ____
16b	<p>What type of kindergarten did (your child) attend?</p> <p>1= Public school _____ name</p> <p>2= Private school _____ name</p> <p>6= Too young (not applicable) 9= No information</p>	31 ____

Field	Field Name And Description	Card Column
16c	In what type of school setting is (your child) now participating? 1= Preschool 2= Kindergarten 3= Special Education 4= Regular classes 8= Not in school (specify) _____ 9= No information	32 ____
16d	What is the name of (your child's) current school? _____ name district area	
16e	How many years has (your child) attended public or private elementary or high school? 00-98 99= No information	33-34 ____
16f	How many years of school has (your child) repeated? 0-8 9= No information	35 ____
16g	Has (your child) ever been placed in special education classes? 1= Yes 2= No 8= Not applicable 9= No information (Explanation) _____	36 ____
16h	In what academic areas do you feel (your child) excells? 1= Reading (total # of areas) 2= Spelling 3= Mathematics 4= Art 5= Music 6= Manuel arts/home economics 7= Other (specify) _____ 8= None 9= No information	37 ____

<u>Field</u>	<u>Field Name And Description</u>	<u>Card Column</u>
16i	In what academic areas do you feel (your child) is deficient? 1= Reading (total # of areas) 2= Spelling 3= Mathematics 4= Art 5= Music 6= Manual arts/home economics 7= Other (specify) _____ 8= None 9= No information	38 ____
16j	At what age did (your child's) academic deficiencies become apparent?	39-40 ____
16k	How much formal education do you hope (your child) will be able to complete? 1= Elementary education 2= High school or equivalent (GED, etc.) 3= Some college or trade school 4= College degree 5= Advanced college degree 6= Other (specify) _____ 9= No information (Vocational)	41 ____
17a	Does (your child) have responsibilities or chores at home? 1= Household (garbage, room, general cleaning, etc.) 2= Yard work 3= Pets 4= Child care 5= Combination 1 and 2 6= Combination 1, 2 and 3 7= Combination 2, 3 and 4 8= None 9= No information	42 ____
17b	Does (your child) have responsibilities or jobs away from the home? 1= Paper route 2= Seasonal harvest 3= Baby sitting 4= Gardening (con't.)	43 ____

- 5= Housework
- 6= Other (specify) _____
- 7= Errands
- 8= None
- 9= No information

17c	Does (your child) receive an allowance or earn money at home?	44 _____
-----	---	----------

- 1= Yes
- 2= No
- 7= Not applicable (why?) _____
- 9= No information

17d	Who manages (your child's) money?	45 _____
-----	-----------------------------------	----------

- 1= The child
- 2= The parents
- 7= Not applicable (why?) _____
- 9= No information

17e	How does (your child) manage his own money?	46 _____
-----	---	----------

- 1= Spends it all
- 2= Saves it all (toward what goal?) _____
- 3= Saves part and spends part (what goal?) _____
- 7= Not applicable (why?) _____
- 9= No information

(Avocational)

18a	Looking at the full range of (your child's) play activities, who does (your child) <u>primarily</u> play with?	47 _____
-----	--	----------

- 1= Self (alone)
- 2= Self and one peer (including siblings)
- 3= Self and groups of peers (including siblings)
- 4= Self with mother alone
- 5= Self with father alone
- 9= No information

18b	When (your child) plays by him/her self, what does he/she do?
-----	---

(con't.)

Activity	% Time	Activity Level

18c What are the average ages of (your child's) playmates?

48 _____

- 1= 1 year or less older
 2= 2 years or less, but more than 1 year older
 3= 2 or more years older
 4= 1 year or less younger
 5= 2 years or less, but more than 1 year younger
 6= 2 or more years younger
 7= Same age
 8= Does not play with other children
 (Why?) _____
 9= No information

18d When (your child) plays with other children, what do they do?

Activity	% Time	Activity Level

18e When (your child) plays with mother alone
 (STRICTLY RECREATIONAL IN TERMS OF THE CHILD),
 what do they do together?

49 _____

- 1= Never play together
 2= Sporadic play together
 3= Frequently play together
 4= Scheduled play periods together
 9= No information

Activity	Time Spent / Week

18f When (your child) plays with father alone 50 ____
 (STRICTLY RECREATIONAL IN TERMS OF THE CHILD),
 what do they do together?

- 1= Never play together
- 2= Sporadic play together
- 3= Frequently play together
- 4= Scheduled play periods together
- 9= No information

Activity	Time Spent / Week

18g What recreational activities does your family 51 ____
 do together?

- 1= Many (4 or more)
- 2= Few (3 or less)
- 3= None
- 9= No information

Activity	Time Spent / Week

(Social Adjustment)

19a How does (your child) relate to his/her parents 52 ____
 in the family setting? (parental interpretation)

- 1= Appropriate behavior for age
- 2= Inappropriate behavior for age

(Explanation) _____

9= No information

19b He/she acts most like what age? (00-99) 53-54 ____

<u>Field</u>	<u>Field Name And Description</u>	<u>Card</u>	<u>Column</u>
19c	How does (your child) relate to adults in his/her extended family (like grandparents, cousins, etc.)? (<u>parental interpretation</u>) 1= Appropriate behavior for age 2= Inappropriate behavior for age (Explanation) _____ _____	55	___
	9= No information		
19d	He/she acts most like what age? (00-99)	56-57	___
19e	How does (your child) relate to adults outside of the family? (<u>parental interpretation</u>) 1= Appropriate behavior for age 2= Inappropriate behavior for age (Explanation) _____ _____	58	___
	9= No information		
19f	He/she acts most like what age? (00-99)	59-60	___
19g	How does (your child) relate to other children in his/her nuclear or extended family? (<u>parental interpretation</u>) 1= Appropriate behavior for age 2= Inappropriate behavior for age (Explanation) _____ _____	61	___
	9= No information		
19h	He/she acts most like what age? (00-99)	62-63	___
19i	How does (your child) relate to other children outside of his/her nuclear and extended family? 1= Appropriate behavior for age 2= Inappropriate behavior for age (Explanation) _____ _____	64	___
	9= No information		

<u>Field</u>	<u>Field Name And Description</u>	<u>Card Column</u>
19j	He/she acts most like what age? (00-99)	65-66 ____
	(Emotional Adjustment)	
20a	How would you describe the current emotional disposition of (your child) in the home environment?	67 ____
	_____ _____ _____	
	1= Cannot describe 2= Inadequate description 3= Adequate description 9= No information	
20b	How would you describe the current emotional disposition of (your child) in the school environment?	68 ____
	_____ _____ _____	
	1= Cannot describe 2= Inadequate description 3= Adequate description 9= No information	
	(Health)	
21	What health problems does (your child) have which require a doctor's care outside of this Clinic?	69 ____
	1= Physical problems 2= Neurological problems 3= Psychological problems 4= Other (specify) _____ 5= Combination 1 and 2 6= Combination 1 and 3 7= Combination 2 and 3 8= None 9= No information	

Field	Field Name And Description	Card Column
-------	----------------------------	-------------

19j	He/she acts most like what age? (00-99)	65-66
-----	---	-------

(Emotional Adjustment)

20a	How would you describe the current emotional disposition of (your child) in the home environment?	67
-----	---	----

-
-
-
- 1= Cannot describe
 - 2= Inadequate description
 - 3= Adequate description
 - 9= No information

20b	How would you describe the current emotional disposition of (your child) in the school environment?	68
-----	---	----

-
-
-
- 1= Cannot describe
 - 2= Inadequate description
 - 3= Adequate description
 - 9= No information

(Health)

21	What health problems does (your child) have which require a doctor's care outside of this Clinic?	69
----	---	----

-
-
-
- 1= Physical problems
 - 2= Neurological problems
 - 3= Psychological problems
 - 4= Other (specify) _____
 - 5= Combination 1 and 2
 - 6= Combination 1 and 3
 - 7= Combination 2 and 3
 - 8= None
 - 9= No information

<u>Field</u>	<u>Field Name And Description</u>	<u>Card Column</u>
22b	<p>What is the age difference between (your child) and the next oldest child in the family?</p> <p>00= The oldest 1= 1 year or less 2= 2 years or less but more than 1 year 3= 3 years or less but more than 2 years 4= 4 years or less but more than 3 years 5= 5 years or less but more than 4 years 6= 6 years or less but more than 5 years 7= 7 years or less but more than 6 years 8= 8 years or less but more than 7 years 9= No information 10= 10 years or more 11= Only child</p>	71-72 _ _
22c	<p>What is the age difference between (your child) and the next younger child in the family?</p> <p>00= The youngest 1= 1 year or less 2= 2 years or less but more than 1 year 3= 3 years or less but more than 2 years 4= 4 years or less but more than 3 years 5= 5 years or less but more than 4 years 6= 6 years or less but more than 5 years 7= 7 years or less but more than 6 years 8= 8 years or less but more than 7 years 9= No information 10= 10 years or more 11= The only child</p>	73-74 _ _
22d	<p>With regard to (your child's) brothers and sisters, do they currently have or have they had any similar problems?</p> <p>1= 1 or more with similar behavior problems 2= 1 or more with a history of school failure 3= 1 or more with similar history of health problems 4= 1 or more on juvenile probation 5= 1 or more institutionalized for emotional/mental retardation problems 6= 1 or more separated from family by court action 7= Siblings normal, no problems, no separations 99= No information 10= Combination 1, 2 and 3 (con't.)</p>	75-76 _ _

FieldField Name And DescriptionCard Column

- 11= Combination 2 and 3
 12= Combination 1 and 3
 13= Combination 1 and 3, 5 or 6
 14= Combination 1 and 3, 4 or 5
 15= Combination 1 and 2, 5 or 6

- 22e What members of (your child's) extended family (aunts, uncles, grandparents, etc.) or special people in (your child's) life (neighbors, etc.) associate with (your child) on a regular basis?

Relationship To Child	Frequency Of Visits

- 22f What brothers or sisters to (your child) have illnesses requiring a physician's care?

74

- 1= Physical problems

Sibling	For What	Who Seen

- 2= Neurological problems

Sibling	For What	Who Seen

- 3= Psychological problems

Sibling	For What	Who Seen

- 4= Combination 1, 2 and 3
 5= Combination 1 and 3
 6= Combination 1 and 2
 (con't.)

<u>Field</u>	<u>Field Name And Description</u>	<u>Card Column</u>
--------------	-----------------------------------	--------------------

7= Combination 2 and 3
 8= None
 9= No information

(Nuclear Family - Parental Background)

Child's Mother

23a	What is the mother's relationship to the child? (<u>CHILD'S LEGAL GUARDIAN</u>)	78 ____
-----	--	---------

1= Biological mother
 2= Adoptive mother
 3= Step mother
 4= Foster mother
 5= Other (specify) _____
 9= No information

23b	Mother's place of birth:
-----	--------------------------

_____ City	_____ State
---------------	----------------

23c	Mother's date of birth: ____/____/____
-----	--

23d	Mother's current age:	79-80 ____
-----	-----------------------	------------

00= Less than 20
 1= 21-25 4= 36-40 7= 51-55
 2= 26-30 5= 41-45 8= 56-60
 3= 31-35 6= 46-50 9= 61 or over

23e	Mother's educational attainment:	81 ____
-----	----------------------------------	---------

0= Less than 8 years
 1= Less than 10 years
 2= Less than 12 years
 3= High school diploma or equivalent (GED, etc.)
 4= Some college (no degree)
 5= College degree
 6= Advanced or professional
 9= No information

<u>Case Number</u>	82-84 ____
--------------------	------------

Field	Field Name And Description	Card Column
23f	How did mother get along in school? 1= Good student (no problems) 2= Fair student (few problems) 3= Poor student (many problems) 9= No information	85
23g	How many children were there in the mother's family? (Include step, foster, adopted, etc.) 00-98 99= No information	86-87
23h	What was the mother's position in her family? 1= Oldest 2= 2nd oldest 3= 3rd oldest etc. 99= No information	88-89
23i	One a scale of one to nine, how does the child's mother rate her childhood? 1 2 3 4 5 6 7 8 9 Bad So-so Average Good Excel	90
23j	Mother's employment: 1= Presently not employed (but normally employed) 2= Employed part time 3= Employed full time 4= Not normally employed 9= No information	91
23k	What type of work does she do? _____ Employer	

23m What history of illness does the mother have requiring a physician's care?

93 ____

1= Physical problems

Problem	Physician

2= Neurological problems

Problem	Physician

3= Psychological problems

Problem	Physician

4= Combination 1, 2 and 3

5= Combination 1 and 2

6= Combination 2 and 3

7= Combination 1 and 3

8= None

9= No information

Child's Father

24a What is the father's relationship to the child?
(CHILD'S LEGAL GUARDIAN)

94 ____

1= Biological father

2= Adoptive father

3= Step father

4= Foster father

5= Other (specify) _____

9= No information

24b Father's place of birth:

_____ City _____ State

24c Father's date of birth: _____ / _____ / _____

<u>Field</u>	<u>Field Name And Description</u>	<u>Card</u> <u>Column</u>
24d	Father's current age:	95 ____
	00= Less than 20	
	1= 21-25	4= 36-40
	2= 26-30	5= 41-45
	3= 31-35	6= 46-50
		7= 51-55
		8= 56-60
		9= 61 or older
24e	Father's educational attainment:	96 ____
	0= Less than 8 years	
	1= Less than 10 years	
	2= Less than 12 years	
	3= High school diploma or equivalent (GED, etc.)	
	4= Some college	
	5= College degree	
	6= Advanced or professional	
	9= No information	
24f	How did the father get along in school?	97 ____
	1= Good student (no problems)	
	2= Fair student (few problems)	_____
	3= Poor student (many problems)	_____
	9= No information	
24g	How many children were there in the father's family? (Include step, foster, adopted, etc.)	98-99 ____
	00-98	
	99= No information	
24h	What was the fathers' position in his family?	100-101 ____
	1= Oldest	
	2= 2nd oldest	
	3= 3rd oldest	
	etc.	
	99= No information	
24i	On a scale of one to nine, how does the child's father rate his childhood?	102 ____
	1 2 3 4 5 6 7 8 9	
	Bad So-so Average Good Excel	

24j	Father's employment:	103 ____
-----	----------------------	----------

- 1= Presently not employed (history of unemployment)
- 2= Presently employed (history of unemployment)
- 3= Presently employed (no history of unemployment)
- 9= No information

24k	What type of work does he do?	
-----	-------------------------------	--

<u>Employer</u>	<u>Duties</u>
-----------------	---------------

24l	What history of illness does the father have requiring a physician's care?	104 ____
-----	--	----------

1= Physical problems

Problem	Physician

2= Neurological problems

Problem	Physician

3= Psychological problems

Problem	Physician

- 4= Combination 1, 2 and 3
- 5= Combination 1 and 2
- 6= Combination 2 and 3
- 7= Combination 1 and 3
- 8= None
- 9= No information

(Current Family Status)

Financial

<u>Field</u>	<u>Field Name And Description</u>	<u>Card Column</u>
25a	What is the source of the family's income? 1= Father's income 2= Mother's income 3= Combination 1 and 2 4= AFDC 5= Other welfare grants 6= Social Security grant 7= Unemployment compensation 8= Other (specify) _____ 9= No information	105 ____
25b	What is the amount of the family's annual income? 1= Under \$3,000 2= \$3-\$4,999 3= \$5-\$6,999 4= \$7-\$8,999 5= \$9-\$14,999 6= \$15-\$19,999 7= \$20,000 and over 9= No information	106 ____
	<u>Housing</u>	
26a	Does your family: 1= Live in your own home (buying) 2= Rent a house 3= Rent an apartment 4= Other (specify) _____ 9= No information	107 ____
26b	How many years has your family resided in your present community? (00-99)	108-109 ____
26c	Are you satisfied with your current housing situation? 1= Yes 2= No 3= Don't know 9= No information	110 ____
26d	How many moves have you made in the last ten years? 0= No moves 1= 1 move 2= 2 moves etc. 9= No information	111 ____

Field	Field Name And Description	Card Column
-------	----------------------------	-------------

26e	Do you have any plans to move in the next year or so?	112
-----	---	-----

- 1= Yes
- 2= No
- 3= Don't know
- 9= No information

Status Of Marriage

27a	Marriage situation at present:	113-114
-----	--------------------------------	---------

- 1= Marriage divided. Father not at home (divorced, separated, dead). Mother has custody of natural children.
- 2= Marriage divided. Mother not at home (divorced, separated, dead). Father has custody of natural children.
- 3= Marriage divided. Father not at home. Clinic child adopted.
- 4= Marriage divided. Mother not raising children. Responsibility for care of children assumed by relatives.
- 5= Child in foster home.
- 6= Family intact. Child adopted.
- 7= Family intact. Child born to marriage partners. One or more siblings adopted or foster child reared as foster sibling.
- 8= Family intact. One or more previous marriages by either parent. Child born in previous marriages.
- 9= No information.
- 10= Family intact. Always intact. All children born to marriage partners.
- 11= Family presently intact. One or more previous marriages by either partner. Child born in present marriage.
- 12= Family presently intact. One or more previous marriages by either partner. Child adopted in previous marriage.
- 13= Family intact. One or more previous marriages by either partner. Child adopted in present marriage.
- 14= Other (specify) _____

(Explanation) _____

<u>Field</u>	<u>Field Name And Description</u>	<u>Card Column</u>
--------------	-----------------------------------	--------------------

27b	What was the date of your current marriage?	
-----	---	--

____ / ____ / ____		
Month	Day	Year

27c	How long have you been married? (In years)	115-116 ____
-----	--	--------------

27d	On a scale of one to nine, how would you rate the current state of your marriage?	117 ____
-----	---	----------

1	2	3	4	5	6	7	8	9
Bad		So-so		Average		Good		Excel

(Explanation) _____

SOCIAL WORKER'S SUMMARY

I. Description of problem:

II. Peculiarities of circumstances and personalities involved:

III. Enumeration of causal factors in order of importance:

IV. Appraisal of assets for reconstruction:

A) Within identified patient

B) Within nuclear and extended family

APPENDIX J

Interviews

INTERVIEWS

Ms. Patsy Carter, A.C.S.W., Seizure Clinic, University of Washington,
Seattle, Washington. Date: May 16, 1972.

Staff, Epilepsy Center of Michigan, 10 Peterboro, Detroit, Michigan.
Date: July 25, 1972.