An exploratory study of the services rendered by public health nurses from October 1, 1957 to May, 1960 to ten mentally retarded children and their families included in the Cambridge Service for Retarded Children as perceived by the families and the nurses themselves.

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AN EXPLORATORY STUDY OF THE SERVICES RENDERED BY PUBLIC HEALTH NURSES FROM OCTOBER 1, 1957 TO MAY, 1960 TO TEN MENTALLY RETARDED CHILDREN AND THEIR FAMILIES INCLUDED IN THE CAMBRIDGE SERVICE FOR RETARDED CHILDREN AS PERCEIVED BY THE FAMILIES AND THE NURSES THEMSELVES

By

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CHAPTER I

INTRODUCTION

It is a far cry from the ancient to the modern concept of mental retardation.

Slowly over the years, we have progressed from the primitive concept that the mentally retarded child was possessed by the Devil to a recognition of the fact that "... the mentally retarded child, like any other handicapped child, is first and foremost a child, with all the basic needs for security, for love, for acceptance and for accomplishment."2 This change in attitude has come about largely through the efforts of a few dedicated professional people working individually and through the organized efforts of such groups as the American Association of Mental Deficiency and the National Association for Retarded Children. The American Association of Mental


Deficiency was established in 1876 and its membership is composed largely of physicians, educators, and psychologists. The National Association for Retarded Children, incorporated in recent years, is composed largely of parents of mentally retarded children and has been responsible for arousing public interest in the problems related to retardation, as well as promoting social action on behalf of the mentally retarded child.

In reviewing the literature on the subject of mental retardation, it was found that many books have been written by psychologists, various medical specialists, and educators. Nursing periodicals, however, contained only a very limited number of references on the function of the nurse in the care of the retarded child. Since it was felt strongly that public health nurses are rendering beneficial services to families of retarded children and that the families are receptive to these services, the investigator became interested in studying this concept.

Relevance of the Problem to Public Health Nursing

In 1956, the Congress of the United States appropriated a four million dollar increase in the budget

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1 Levinson, op. cit., p. 47.
of the Maternal and Child Health Services of the Children's Bureau to be used in the field of mental retardation. One million dollars of this amount was designated for use in developing pilot health service programs for retarded children and State Departments of Health were expected to extend and improve their services with funds from the remaining three million dollars. Currently, many State Departments of Health are conducting surveys to determine the number of mentally retarded children in their population, and to evaluate the need for establishing or extending service to this group.

Because public health nurses have assisted families with mentally retarded children as part of generalized programs for some time, and, because they constitute the largest body of professional workers providing Maternal and Child Health Services, it is not surprising that the Children's Bureau looks to this group, within existing agencies, to extend and improve its services to retarded children.¹ Before extension and improvement can occur, it seems important to determine

what functions public health nurses are rendering to
tmentally retarded children and their families and how
families view these functions.

Statement of Problem

During the academic year, 1959-1960, while en-
rolled at Boston University School of Nursing, the
investigator received concurrent field experience at the
Cambridge Service for Retarded Children--one of the pilot
projects which is supported in part by funds from the
Children's Bureau. Upon completion of this program, the
investigator plans to return to Wyoming to act as a con-
sultant nurse to public health nurses who will "extend and
improve" their services to mentally retarded children and
their families. Thus, the investigator became interested
in learning how families with mentally retarded children
perceive the functions of public health nurses and how the
nurses interpret their own functions. Therefore, the
following study was undertaken at the Cambridge Service
for Retarded Children:

This study attempts to compare how ten families
who have received coordinated services in the care and
management of their retarded children perceive the
services of the public health nurses; and how the public health nurses recorded the services which they rendered to these ten families.

Scope and Limitations

The Cambridge Service for Retarded Children was established on July 1, 1957 and is an integral unit of the Cambridge Health Department. This Service was developed as the result of collaborative efforts on the part of local, state, and federal agencies. It has three objectives: (1) provision of adequate health services for retarded children, with particular emphasis on children of preschool age; (2) provision of training facilities for professional personnel; (3) the designing and conducting of studies in the area of mental retardation. Since the project is located in the local Health Department, it is family and community centered rather than clinically centered. The team approach is used to meet the needs of the mentally retarded and their families. 1

The ten retarded children, who were selected for this study had been evaluated physically, socially, and psychologically at the Cambridge Service for Retarded Children and were receiving family-centered follow-up care in their homes by public health nurses.

The public health nurses, who were providing follow-up services for these children were employees of the Cambridge Health Department, an official agency, and the Cambridge Visiting Nursing Service, a nonofficial agency. Also, included in the study was the public health nurse who is a member of the team of the Cambridge Service for Retarded Children.

Limitations of the study included the following:

1. The study was geographically limited to Cambridge and to ten children who were currently receiving continuous, coordinated, and integrated services from the Cambridge Service for Retarded Children.

2. The study was exploratory in nature.

3. The size of the sample was limited to ten.

4. The interpretation and presentation of the findings were dependent on the judgment of the investigator.

5. There was a paucity of nursing studies regarding the problem.
Definitions of Terminology

The following are definitions of terminology used in this study:

1. Mentally retarded child: "any child under twenty-one years of age who has been identified as retarded, or is suspected of mental retardation on the basis of developmental history, poor academic performance, I.Q. score, or social adaptation when contrasted with his age peers."

2. Public Health nurse: any nurse, practical or professional, employed by the public health nursing agencies within the community.

Methodology

Following a conference with the public health nurse at the Cambridge Service for Retarded Children, the investigator decided to self select ten mentally retarded children and their families to participate in this study. She, therefore, reviewed the composite records at the CSRC* to confirm that a diagnosis of mental


*Cambridge Service for Retarded Children.
retardation had been established and to confirm the fact that public health nurses had been involved in providing follow-up services to these children and their families in their homes.

The families were contacted to explain the purposes of the study, and to obtain permission from the parents for interviews in their homes. In the interviews, conducted in an informal manner, the investigator followed a guide which had been prepared for this purpose. Recording was done outside the home immediately following the interview.

Records on which the public health nurses had recorded their services to these ten families were studied to determine the kinds of nursing services that the nurses felt were provided to these families. This information was categorized on a work sheet. After the interviews had been completed and the records reviewed, the data were compared and studied.

The literature was reviewed in order to discover the philosophy which currently prevails regarding the total care of the mentally retarded child.
CHAPTER II
THEORETICAL FRAMEWORK

Review of Literature

Mental retardation, today, is no longer considered an evil curse nor disgrace to a family as it was in the past. Instead, mental retardation is thought to be a condition resulting from a variety of causes. The complexity of the problems arising from the variety of causes requires a multidisciplinary approach for alleviation or solution. This change in attitude which has evolved slowly over the years is not the result of one event in history. Rather, it is the result of increased knowledge and changing concepts in the fields of medicine, psychology, sociology, and education as well as a change in attitude by lay persons.

"Since earliest times, the mentally retarded have been found in all parts of the world and in all classes of society. Plato, who died in 347 B.C., mentioned them and even noted different degrees of retardation." At that

time, the general attitude toward the mentally defective seemed to be one of neglect. With the rise of Christianity, certain religious groups began to apply the virtue of charity and provided a few basic essentials such as food and clothing for the feebleminded. It was during the seventeenth century that society started to build institutions for the infirm and included the mentally defective. St. Vincent de Paul was one of the first to inaugurate such a trend. However, little was done in the way of treatment or education for these individuals.

Undoubtedly, one of the first to be interested in the education of the retarded child was Jean Itard, a French physician who lived between 1774 and 1838; he was inspired by the philosophy of sensationalism in which it was thought that man acquired his knowledge through the sensory processes. Itard attempted to use this method in teaching Victor, a wild boy about twelve years of age, who had been found wandering in the woods of Aveyron and who acted very much like an animal. Although Itard failed to reach the goals which he had established for this boy, his work attracted the attention of the French

Academy of Science. Upon the request of the Academy, Itard wrote the \textit{Wild Boy of Aveyron} which has become a classic in the history of education of the retarded.

Inspired by Itard's slight accomplishments, Seguin,\textsuperscript{1} a physician and teacher, devoted his life to the training and education of mentally retarded children. In 1837, he founded a School for Idiots in Paris—the first of its kind. Later, Seguin came to America where he demonstrated the application of physiological principles to problems of training retarded children. He also helped establish institutions for care of subnormal children. Like Itard, his writings are considered classics. Many of Seguin's principles of teaching by sensory and physiological training are used today in "readiness education at preschool levels."\textsuperscript{2} Seguin was one of the first to observe that "the brains of the retarded were not always diseased or abnormal but were often arrested in development."\textsuperscript{3}

After studying the works of Itard and Seguin, Dr. Deteressa Montessori, a physician in Rome, came to

\textsuperscript{1}Levinson, \textit{op. cit.}, p. 42.

\textsuperscript{2}Kirk and Johnson, \textit{op. cit.}, p. 74.

\textsuperscript{3}Levinson, \textit{op. cit.}, p. 43.
believe that many of the diseases considered by society as medical problems were educational problems so she organized the Orthophrenic School for the Care of the Feebleminded and included a training program for teachers. By use of her own didactic materials, Montessori's program of "self-teaching" was so organized that teachers withdrew and supervised while the children taught themselves.\(^1\)

Although her method of teaching the retarded has been criticized, Montessori became famous for her Casa dei Bambina which were established for young children of working mothers and provided valuable social experience for these children. Her purpose was to combine home and school. "... the greatest defect in her theory is the assumption that there is a transfer of learning from didactic materials to life situations."\(^2\) Her utilization of "self-teaching" the child is still used in combination with other methods.

It is interesting to note that the early pioneers who were interested in the education of the retarded child were European physicians. The first to combine medical treatment with education was Gugenbuehl,\(^3\) a Swiss

\(^1\)Ibid.

\(^2\)Kirk and Johnson, op. cit., p. 79.

\(^3\)Levinson, op. cit., p. 43.
physician, who discovered that thyroid extract improved cretinism. After making his discovery, Gugenbuehl treated cretins medically and established a school for them in Switzerland.

In the United States, during the latter half of the nineteenth century, interest in the welfare of retarded children led to the establishment of schools and institutions for their care. In 1848, under the direction of Dr. Samuel Howe the Perkins Institute for the Blind was established. This later became the Massachusetts School for Idiots and Feebleminded Youths. Other states followed this example and, slowly, throughout this country, institutions for the feebleminded, which attempted to combine care and education, were established. During this era, the American Association for Mental Deficiency was organized. This society, which still exists, is composed of psychologists, physicians, and educators. It has helped bring about many changes in the care of the retarded in the past. Today, it continues to attempt to discover the causes of mental retardation by furthering research studies in particular.

In 1890, Dr. Walter E. Fernald, Superintendent of the Waverly State School in Massachusetts, started a new

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Gruener, Jeanette R., Feebleminded Children as a Massachusetts Problem, (Boston: The Massachusetts Child Council, 1941) Report.
trend when he began to parole patients to their communities informally.\(^1\) Meanwhile, other states started unlocking the doors to their institutions and allowing many of the mentally subnormal to return to their own communities for care.\(^2\) At the same time, larger cities began to organize special classes in their schools for these children and private schools such as the Woods Schools in Pennsylvania were established.

Several events, which occurred at the turn of the century or soon after, have fostered the trend which was introduced by Fernald, of keeping the retarded child in his own community if possible, rather than committing him to a state institution. However, this is not to say that institutions have not made their contributions to the care of the retarded child or that they can be entirely eliminated.

In 1905, Alfred Binet, a French psychologist, devised a test by which the mental age of the child could be compared with his chronological age. Binet was interested in assessing the child's learning abilities as well as his learning liabilities.\(^3\) His contributions in the

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\(^1\)Ebco, loc. cit.

\(^2\)Kirk and Johnson, op. cit., p. 82.

\(^3\)Ibid.
area of intelligence testing have had far reaching benefits for the normal child as well as the intellectually handicapped child. Revised forms of his tests are still used.

An important stimulus to providing education which would meet the needs of the retarded came as the result of compulsory school attendance laws which started to be enforced in the early twentieth century. As a result of these laws, educators and society came to realize that there are many in the general population who never function at a mature level of intelligence.

Another important event which had a far reaching effect on the entire field of mental illness was the organization of the National Committee for Mental Hygiene in 1909. This Committee came about as the result of crusading done by Clifford Beers, who had a long history of mental illness. It is now recognized that many children, who appear retarded, are emotionally disturbed. It is known also, that retarded children are often emotionally disturbed.

Changes in concepts regarding the care of the retarded child have paralleled, in many ways, changes in

1 Gruener, op. cit.
concepts regarding the care of the normal child. Because of the great advances in medical science, the physical needs of the child have become of less concern than formerly, as society has begun to consider the total child—psychological, social, as well as physical. The second World War greatly stimulated the growth of psychiatry as a medical specialty and psychology as a behavioral science. The mass psychological testing of military personnel uncovered larger numbers of so-called mental retardates than had been expected. It was obvious that social and cultural factors as well as a lack of educational opportunities were the causes of inoptimal mental functioning among large segments of the group being tested rather than true intellectual deficit. This experience has led to improved methods of psychological testing and an increased understanding of the complexity of the problem of mental subnormality.

In fact, Jarvis has defined mental deficiency as

A condition of arrest or incomplete mental development existing before adolescence, caused by a disease or genetic constitution and resulting in social incompetence. This definition includes both the social concept which stresses the social inadequacy of the defective, and the psychological concept which is considered in the term arrested or incomplete mental development. The biologic view is embodied in the mention of genetic factors and diseases.¹

Thus defined, it is apparent that a multidisciplinary approach is essential in providing comprehensive care to the retarded.

If one uses as the criterion of disability the inability to obtain gainful employment, one can say that, with the possible exception of mental illness, mental subnormality is the most significant handicap in our present society.1

Of the 4,200,000 children born annually in the United States, 3 per cent will never achieve the intellect of the twelve year old, 0.3 per cent will remain under the seven year level, and 0.1 per cent will not be able to cope with their own bodily needs.2

When we consider all the family members involved as well as the retarded themselves, the enormity of the problem is apparent. The impact on the community is emphasized by the fact that only 150,000 persons, most of them severely retarded, are institutionalized.3

This leaves the majority of the retarded residing in local communities with their own families.

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2Ibid.

The value of keeping the child in his home with his parents has been pointed out by Bowlby in his studies regarding the effects of maternal deprivation in which he states that

To insure optimum physical growth and personality development, the infant needs a continuous intimate relationship with a warm giving mother (or permanent mother substitute).\(^1\)

Farrell, among others, has pointed out that early institutionalization of the retarded child has effects as adverse as those on normal children.\(^2\)

Professional workers have come to realize that in services directed at helping children, treatment necessarily includes the parents.

Treatment of mentally retarded children has to be primarily aimed at reduction of secondary difficulties and in improvement of tolerance of the condition and in ability to handle it on the part of the person carrying responsibility for the child. The problem of retardation is always a family problem and diagnosis has therefore to be a family diagnosis focused on the total situation.\(^3\)


It is evident from this statement that services to retarded children must of necessity include parent counseling.

Authorities agree that before parents reach the stage of acceptance in coping with their retarded child's handicap, they usually experience fairly typical reactions. First, there is a period of shock, when parents begin to suspect that their child is atypical. This is usually followed by a period in which they refuse to believe their own suspicions regarding their child's intelligence or, if they see a physician during this time, parents are inclined to disbelieve his verdict. A period of shopping among medical practitioners is likely to occur. Unfortunately, some parents never pass beyond this stage of frustration. However, more and more, parents are arriving at a stage of acceptance and intelligent inquiry in which they seek professional guidance in caring and planning for their child.

Parents, in their desire to help their retarded children to attain the maximum of their limited potential, joined together to form the National Association for Retarded Children, incorporated in 1950. This organization has been responsible for stimulating public interest in problems related to retardation, and in promoting social action and legislation. Professional interest coupled with parental interest has led to the development of the
professional team approach in meeting the problems of mentally retarded children and their families. In the past, such teams have been effective in assisting the physically handicapped child and the emotionally disturbed child.

Although the number of clinical facilities for the mentally retarded is still limited, their number is increasing. As mentioned in Chapter I, Congressional appropriation of funds for the mentally retarded was made to the Children's Bureau as late as 1956. As a result of this appropriation, approximately forty demonstration projects have been established throughout the country. Some of these projects are located in State Departments of Health, while others are associated with hospital facilities. The Cambridge Service for Retarded Children is the only pilot project located in a local health department and serving a single community.

Procedure in these diagnostic centers involves a comprehensive evaluation of the child's capacities and limitations utilizing a multidisciplinary approach. Future planning for the most effective use of special facilities such as counseling, education, and rehabilitation is based on this evaluation. Repeated clinical appraisals are considered to be of fundamental importance in meeting the child's changing needs and in assisting
the parents plan for his present and future care.

In doing this comprehensive evaluation, Slobody stresses the importance of remembering that conditions "other than a primary deficiency of intellect may interfere with the child's ability to accumulate experience and to learn, and can, therefore, simulate mental retardation."\(^1\) Impairment of hearing, vision, and motor coordination may limit the child's intellectual accomplishments if they go uncorrected. Often, children exhibiting hyperactivity from brain damage are considered retarded when, in reality, there is no intellectual deficit. Emotional problems often simulate retardation if not carefully differentiated. Environmental factors, too, can hinder a child's progress. Thus, it is apparent that in making a differential diagnosis and in planning for the care of a retarded child, assessment of the child and his family by the physician, psychologist, social worker, public health nurse and, often, other skilled workers is essential. If the child is of school age, his teacher will also contribute valuable information.

The treatment of the child as a whole requires careful attention to his special educational and

\(^1\)Slobody et al., op. cit., p. 669.
vocational needs, to his emotional health, and that of his parents, and to his physical health.¹

Society's concept of the slow child has, indeed, changed from the era in which he was considered feebleminded and thus institutionalized to the era in which he is considered an exceptional child and retained in the community in his own home. The trend, today, appears to be that only the severely retarded are institutionalized. It is realized, however, that because of his special problems, the retarded child has additional needs above and beyond those of the normal child.

In reviewing the literature, on the functions of the public health nurse in mental retardation, it was apparent that a paucity of information existed. Although Hormuth has written on The Public Health Nurse in Community Planning for the Mentally Retarded and Flory has written articles on Training the Mentally Retarded Child, the investigator feels that current trends in the philosophy of care have greater implications for the nurse than are described to date. It is anticipated with an increased awareness of the contribution of the nursing profession to the problems of the mentally retarded child that there will be additional literature on the subject in the future.

¹Slobody et al., op. cit., p. 676.
Freeman has said that

Nursing has achieved a significant place in the modern public health movement. The concept of public health nursing has broadened and deepened with scientific, social, and educational advances. It has drawn from psychology, sociology, medicine, education and nursing the basic ingredients from which has been fashioned a potent, flexible and unique contribution to human welfare.¹

It is obvious that the public health nurse has a professional contribution to make in the area of mental retardation in both primary and secondary prevention as well as treatment.

CHAPTER III

SETTING AND METHODOLOGY

Description of the Community

Cambridge has been described as a typical New England town having been settled in 1630. It is often referred to as "University City" because of the large college population, although it has 500 industries. In fact, Cambridge ranks third in number of industries among New England cities. This city has a large number of official and nonofficial agencies to assist its citizens who have problems with which they need professional help.

The 1950 census of Cambridge revealed a population of 120,740. Predominating nationality groups were: English, Scotch, Irish, Italian, Portuguese, Polish, and French-Canadian. Native born population was 78,000 and foreign born was 33,000. The total white population was 115,000 and the non-white population was listed as 5,672. The population excluding college students was 112,343.\(^1\)

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\(^1\)Manning's 1954 Cambridge Directory, p. 2.
Description of the Cambridge Service for Retarded Children

The Cambridge Service for Retarded Children,* which is an integral unit of the Cambridge Health Department, was established July 1, 1957. This project and approximately forty other projects for retarded children throughout the country have been aided through grants-in-aid and consultative services from the Children's Bureau. However much of the success of the Cambridge project is due to the efforts of state and local agencies—both official and voluntary.

Although the aims of CSRC are chiefly concerned with service, it incorporates study and training objectives. The criteria for admission to the Service are that the child be a resident of Cambridge and that he or she be known to be or suspected of being mentally retarded.

The professional staff of the CSRC includes a study director—who acts as coordinator, a pediatrician—who acts as clinical director, a social worker, a clinical psychologist, a nursery school teacher, and a public health nurse. The part time services of a speech therapist and public health nutritionist are available. The CSRC, also,

*Cambridge Service for Retarded Children will be referred to as CSRC as it is commonly called.
utilizes the existing community agencies to provide services not available in the clinic setting.

Following referral to the CSRC by a parent or other interested person, a typical evaluation of a child consists of an intake history which is obtained by the social worker. Parental permission is obtained at this time to obtain information from other agencies which have examined the child in order to secure as accurate and complete a history as possible.

The public health nurse then makes an evaluative home visit. Although she maintains a focus on the retarded child, she is equally interested in assessing the health of all other family members. In addition to attempting to assess the developmental, health, and nutritional history of the retarded child, she utilizes the opportunity to observe family relationships and the general atmosphere of the home.

After the social and nursing evaluation have been done, the child receives a complete physical examination by the pediatrician. If further diagnostic evaluation is necessary, referral to a cooperating hospital is made at this time. Testing of the child's emotional health and intellectual function is then carried out by the clinical psychologist.
Following this evaluation, appropriate plans for care are formulated at a staff conference which is attended by the entire staff. If personnel from other agencies have contributed to the evaluation, or if it is thought that they can contribute to the follow-up care, these professional workers are invited to participate in the conference.

After the staff conference, both parents are invited to come to the CSRC to discuss with a staff member, usually the pediatrician, the results of the total evaluation and to discuss recommendations for follow-up care. In all instances, the CSRC attempts to arrive at realistic and realizable plans that will be acceptable to the parents and meet the needs of the retarded child.

Public Health Nursing Service

Because this study is primarily concerned with the functions of the public health nurse in mental retardation, a further interpretation of her function is included.

One public health nurse is employed full time at the CSRC.

Her duties include developing an inservice training program in mental retardation for the public health nursing staff of the Cambridge Health Department and Visiting Nursing Association; working out methods
of involving both nursing staffs in case finding and follow-up, and providing necessary nursing service at weekly clinics. An additional duty is that of devising methods for aiding parents in the habit training and home management of retarded children. She consults with the Regional Nursing Consultant from the Children's Bureau, the Chief Supervisor of the Public Health Nursing section, State Department of Public Health, and confers regularly with the Director of the Nursing Division, Cambridge Health Department.

To avoid duplication of nursing services, the Director of the Cambridge Visiting Nursing Association has agreed that when a nurse from that organization is visiting a family whose retarded child is included in the case load of the CSRC, the nurse from the Visiting Nursing Association* can provide nursing supervision for the retarded child. To insure continuity of care, this nurse will continue to provide nursing follow-up for the retarded child, regardless of the original purpose of the referral. Obviously, since the CSRC functions administratively as a unit of the Cambridge Health Department, the larger number of cases are the nursing responsibility of the official agency.


* Visiting Nursing Association will be referred to as VNA--as it is commonly called.
Selection of the Sample

After obtaining permission from the Director at the CSRC to do this study, a conference was held with the public health nurse at that agency. At the request of the investigator, the staff nurse suggested the names of ten families with retarded children who, in her judgment, would meet the criteria of this study. The criteria of choice were that the child be retarded or suspected of being retarded and that a public health nurse was providing follow-up services to the child and his family in their home.

The ten composite records, on which each member of the professional staff records, were reviewed to insure that the criteria, which had been established for selection of the sample, were met.

Permission was then secured from the Director of the Cambridge VNA for the investigator to review the nurses' records on two families who were being followed by nurses in that agency.

The investigator realized that there were many variables in the study. However no attempt was made to control these as the most important criterion for this study was felt to be the nursing service which was provided the families. In order to prevent a certain amount
of bias, an effort was made to select families who had been visited by nurses from the staffs of the Health Department, the VNA and the CSRC.

**Tools Used to Collect Data**

**Data Categorized from Nurses' Records**

A work sheet, * which included family-centered as well as patient centered care, was devised in order that the services recorded by the nurses could be categorized. In recording on the work sheet, no attempt was made to distinguish which of the three agencies concerned employed the nurse. Nursing records were reviewed and nursing services categorized on the work sheets before families were visited. This sequence was followed as it was felt that it would be easier to establish rapport and comprehend the statements of the mothers if the investigator were familiar with the services which the families had received.

**Guide With Open-ended Questions Used in Interviews**

A short questionnaire** with open-ended questions was prepared to use as a guide in conducting informal

*See Appendix A  **See Appendix B
interviews with the mothers of the ten retarded children. Since the guide appeared to elicit the information desired the first time that it was used, no revisions were necessary. Questions, which were asked of the mothers, attempted to discover what families expected to receive in the way of nursing help regarding their retarded child; what nursing service they felt they had received; what was most helpful; and what did not help.

As it was felt that much of the nurse's time was devoted to such mental health activities as listening and offering reassurance, a question was included which attempted to ascertain whether or not the mothers recognized this activity. Since the nurse functions as a team member at the CSRC and often acts as a liaison person among workers of several community agencies and an integrator among staff members, a question was asked to find out whether or not mothers felt that any other person or agency had provided them with assistance in the care of their mentally retarded child. Because public health nursing is family-centered as well as patient-focused, a question was asked to see if mothers recognized this family-centered approach or if all their attention were directed toward the retarded child.
Procurement of Data

A telephone call was made to eight of the ten families studied to explain the purpose of the study and to obtain permission for the investigator to interview them in their homes. The seven mothers and one father who answered were most agreeable. Since the remaining two families had no telephone, a home visit was made for the purpose of explaining the study and to make an appointment to return at a later date. One mother immediately invited the investigator into her home for the interview. In the other family, a sibling of the retarded child, arranged for the interview with her mother at a later time.

The interviews were from one to two hours in duration. Following the interviews, the information gathered and the observations made were recorded at the first convenient location outside the home in order that the recall would be immediate. This technique was preferred rather than risk the distraction of recording in the home.

The data from both sources were then compared individually and collectively.
CHAPTER IV

PRESENTATION OF THE DATA AND DISCUSSION OF THE FINDINGS

Description of the Sample

Five of the children included in the study were male and five were female. The ages of the children on admission to CSRC ranged from six months to sixteen years. Age ranges at the time the study was terminated (May, 1960) were from two years-four months to sixteen years-seven months. The length of time the children were known to CSRC ranged from six months to thirty-one months. Nursing visits made to the families of these children ranged in number from seven to forty-nine. All of the children had two or more siblings. In five of the families more than one child is included in the CSRC case load.

Table 1 illustrates the above statistical information and includes the diagnoses of the children on admission to CSRC. Note is also made regarding correction of physical defects, and treatment after initial contact through CSRC recommendation. Case numbers correspond to the alphabetical order of the child's name and are the same as those listed in the case studies which are
<table>
<thead>
<tr>
<th>Case No.</th>
<th>Sex</th>
<th>Age on Adm. to CSRC</th>
<th>Level of Retardation</th>
<th>Associated Physical Handicaps</th>
<th>Physical Defects Corrected or Treated Since Admission to CSRC</th>
<th>Length of Time Known to CSRC</th>
<th>Number of Nursing Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Fe</td>
<td>5 2/12 yrs.</td>
<td>Dull normal intelligence</td>
<td>Post poliomyelitis. 30% conductive hearing loss Strabismus.</td>
<td>Corrected by tonsillectomy and adenoidectomy. Corrective eye surgery.</td>
<td>15 mos.</td>
<td>11</td>
</tr>
<tr>
<td>2</td>
<td>Fe</td>
<td>1 8/12 yrs.</td>
<td>Moderate retardation - both physical and mental.</td>
<td>Severe mal-nutrition. Anemia Septic hip following otitis media</td>
<td>Was hospitalized for further evaluation. Receiving iron medication and vitamins. Infection has cleared.</td>
<td>8 mos.</td>
<td>30</td>
</tr>
<tr>
<td>3</td>
<td>M</td>
<td>2 6/12 yrs.</td>
<td>Diagnosis deferred. Functioning at a retarded level.</td>
<td>None</td>
<td>----------------</td>
<td>7 mos.</td>
<td>15</td>
</tr>
<tr>
<td>4</td>
<td>Fe</td>
<td>3/12 yr.</td>
<td>Mongolism</td>
<td>Asymptomatic congenital heart disease.</td>
<td>Under regular medical supervision.</td>
<td>20 mos.</td>
<td>15</td>
</tr>
</tbody>
</table>

(Continued on next page)
<table>
<thead>
<tr>
<th>Case No.</th>
<th>Sex</th>
<th>Age on Adm. to CSRC</th>
<th>Level of Retardation</th>
<th>Associated Physical Handicaps</th>
<th>Physical Defects Corrected or Treated Since Admission to CSRC</th>
<th>Length of Time Known to CSRC</th>
<th>Number of Nursing Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Fe</td>
<td>8 10/12 yrs.</td>
<td>Mild retardation.</td>
<td>Left spastic hemiplegia.</td>
<td>Corrective orthopedic surgery to leg. Physical therapy to hand. Glasses obtained</td>
<td>24 mos.</td>
<td>14</td>
</tr>
<tr>
<td>7</td>
<td>M</td>
<td>9 9/12 yrs.</td>
<td>Mongolism.</td>
<td>Strabismus.</td>
<td>Glasses obtained.</td>
<td>31 mos.</td>
<td>31</td>
</tr>
<tr>
<td>8</td>
<td>Fe</td>
<td>2 4/12 yrs.</td>
<td>Severe retardation.</td>
<td>Demyelinating Disease</td>
<td>Institutionalized for care.</td>
<td>24 mos.</td>
<td>49</td>
</tr>
<tr>
<td>9</td>
<td>M</td>
<td>16 yrs.</td>
<td>Dull normal intelligence</td>
<td>Delayed adolescence</td>
<td>Had endocrine evaluation. Receiving vitamins and nutrition instructions.</td>
<td>7 mos. office 6 home</td>
<td></td>
</tr>
</tbody>
</table>

(Concluded on next page)
<table>
<thead>
<tr>
<th>Case No.</th>
<th>Sex</th>
<th>Age on Adm. to CSRC</th>
<th>Level of Retardation</th>
<th>Associated Physical Handicaps</th>
<th>Physical Defects Corrected or Treated Since Admission to CSRC</th>
<th>Length of Time Known to CSRC</th>
<th>Number of Nursing Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>M</td>
<td>2 11/12 yrs.</td>
<td>Moderate to severe retardation. Both physical and mental.</td>
<td>Severe malnutrition. Anemia.</td>
<td>Was hospitalized for further evaluation. Now receiving iron medication and vitamins.</td>
<td>6 mos.</td>
<td>15</td>
</tr>
</tbody>
</table>
presented later in the chapter.

Residences of the families were located in the eastern section of Cambridge which is very crowded in terms of population and housing. Certain sections are social "problem" areas, while other sections are characterized by strong civic pride, nationality loyalties and strong church affiliations.¹

Nine of the ten children were Roman Catholic. The tenth child was Protestant. Nationality backgrounds included: Irish-American, Italian-American, Portuguese-American, French-American, and Scotch-English-American. There were also combinations of these nationality groups in addition to Mexican and Japanese.

Salaries of the fathers of these children ranged from forty-four dollars per week to one-hundred dollars per week. Two families were receiving Unemployment Compensation, and one mother was a recipient of Aid to Dependent Children. The fathers were common or semi-skilled laborers.

One child was from a broken home and one girl was being adopted by a family who had taken her in their home.

as a foster child from the Division of Child Guardianship.

The religious, cultural, and social backgrounds of the families will not enter into the interpretation of the data except in isolated cases. It is recognized, however, that these factors had a strong bearing upon the attitudes and feelings expressed in the interviews.

Presentation of the Data

Data from the interviews and nurses' records are presented in condensed case study form. The format is as follows: an introductory statement; an outline of the nursing services rendered as perceived by the mother and as recorded by the nurses; and a statement of comparison and summary. Unnecessary wordage has been eliminated so that the data could be more easily listed in the columns.

Most of the headings used in the outline are self-explanatory. Two pairs of side headings which may require further explanation are: (1) Future Problems and Plans; and (2) Others Who Helped and Referrals. In the first instance, mothers were asked if they would think to call CSRC should any problems arise in the future regarding their retarded child. To validate this response, they were asked if they had called recently. The nurses' plans for
future care were considered an appropriate parallel for this question. In the second instance, mothers were asked if they had found anyone else especially helpful to them in the care of their retarded child. This information was recorded under **Others Who Helped**. If the mothers responded that other staff members at CSRC had been helpful, this was recorded as a coordinated activity of CSRC under **Referrals**.
CASE NUMBER I

Introduction:

Sex: Female
Age on Admission: 5 years 2 months
Time Known to CSRC: 15 months
Number of Siblings: 6
Family Income: $100 per week

Presenting Problems: Slow physical growth; slow in school work; hoarse voice.

Diagnosis: Dull normal mentality, post-polio myelitis; 30% conductive hearing loss; strabismus.

Current Status: Attends regular classroom; hearing loss corrected following tonsillectomy and adenoidectomy. Strabismus corrected by surgery; receiving speech therapy at CSRC.

Interview with Mother

Summary from Nurses' Records

Regarding the Care of the Retarded Child

Expected:
Received more than expected.
Knew only of bedside service.

Received:
Explanation of everything that would happen to her daughter.
Help with arrangement for surgery.

Services Rendered:
Details of procedures explained when appointments were given.
Appointments and referrals were discussed on eight visits. Many telephone calls made to complete these arrangements.

Nurse talked to child directly before surgery—this gave child "faith" in nurses and understanding of what would happen.

One visit devoted to preparation for surgery. Mention not made that counseling was done directly with the child.

Total Number of Visits Made: 11
**Interview with Mother**

<table>
<thead>
<tr>
<th>Most Helpful:</th>
<th>Summary from Nurses' Records</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother given &quot;hope.&quot;</td>
<td>Evidence that reassurance was given.</td>
</tr>
<tr>
<td>Child profited most by direct contact with nurse.</td>
<td>Direct contact with child not stressed.</td>
</tr>
</tbody>
</table>

**Future Problems:**

| Has called the agency when problems occurred and will call again. |
| Others Who Helped: |
| School nurse. |
| Speech therapist. |
| Hospital nurse. |

**Plans:**

| Informal contacts in the office when the child receives speech therapy. |
| Referral made to hospital through CSRC for correction of strabismus, and tonsillectomy and adenoidectomy. |

**Regarding Nursing Service to Family**

**General Comments:**

| Helped with emotional problems of a foster child living in the home. |
| Change in Feelings: |
| Given "hope" that progress could be made. |

**Mental Health Aspects of Visits:**

| Evidence of listening and giving reassurance on seven visits. |

**Other Health Problems:**

| None at present time. |

**Plans for Other Health Problems:**

| None required. |

**Comparison of Results and Summarizing Statements:**

Although visits have been extended over fifteen months, this mother recalled many of the visits in detail. Analysis of the records would in no way reveal the "hope"
this mother has realized. The records did not give evidence of the direct counseling with the child before hospitalization which the mother considered to be the most important contribution.
CASE NUMBER II

Introduction:

Sex: Female
Age on Admission: 1 year 8 months
Time Known to CSRC: 8 months
Number of Siblings: 3
Family Income: $44 per week

Presenting Problems: Slow development; poor eating habits; severe generalized rash.

Diagnosis: Moderately physical and mental retardation; mal-nourished; anemic; septic hip developed following otitis media soon after initial evaluation.

Current Status: Weight gain; walking; less irritable.

Interview with Mother

Summary from Nurses' Records

Regarding the Care of Retarded Child

Expected: Help with arrangements for medical care
Received:
Help with appointments and transportation.

Services Rendered:
Clinical appointments were discussed on three visits. Several telephone contacts made to other agencies. Transportation arranged. Sample vitamins were provided because of malnutrition and limited income.

Visits twice a week to help care for child while she was "sick in bed."

On instruction from physician, mother was instructed in care of child while in traction at home. Demonstrations of exercises were given. Intensive nutrition teaching on six visits following consultation with nutritionist.
<table>
<thead>
<tr>
<th>Interview with Mother</th>
<th>Summary from Nurses' Records</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Most Helpful:</strong></td>
<td></td>
</tr>
<tr>
<td>Directions for taking child to CSRC and what to do for her.</td>
<td></td>
</tr>
<tr>
<td>Vitamins—&quot;when you have nothing to do with, it's hard.&quot;</td>
<td></td>
</tr>
<tr>
<td><strong>Future Problems:</strong></td>
<td></td>
</tr>
<tr>
<td>Has called in the past and will call CSRC in the future.</td>
<td></td>
</tr>
<tr>
<td><strong>Others Who Helped:</strong></td>
<td></td>
</tr>
<tr>
<td>Hospital in Boston.</td>
<td></td>
</tr>
<tr>
<td><strong>Plans:</strong></td>
<td></td>
</tr>
<tr>
<td>Receiving follow-up visits at regular intervals.</td>
<td></td>
</tr>
<tr>
<td><strong>Referrals:</strong></td>
<td></td>
</tr>
<tr>
<td>Referrals made to service clubs by the nurse were not mentioned by the mother.</td>
<td></td>
</tr>
</tbody>
</table>

**Regarding Nursing Service to Family**

<table>
<thead>
<tr>
<th>General Comments:</th>
<th>General Services Rendered:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Didn't feel any help was given.</td>
<td>Nutrition stressed on three visits.</td>
</tr>
<tr>
<td></td>
<td>Appointment made to have check-up on mother's cardiac condition—not kept.</td>
</tr>
<tr>
<td></td>
<td>Children were referred to Well-Child Conference for physical examinations and immunizations—begun but not completed.</td>
</tr>
<tr>
<td></td>
<td>Mother received two ante-partum and two post-partum visits at birth of child; two neonatal visits were made.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Change in Feelings:</th>
<th>Mental Health Aspects of Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helped &quot;to talk.&quot;</td>
<td>Records indicate as much specific information was given as listening or reassurance.</td>
</tr>
</tbody>
</table>
| Helped "to know that someone would help." | }
Interview with Mother

Other Health Problems:
Mother has none now.

Summary from Nurses' Records

Plans for Other Health Problems
Investigator later learned that mother is pregnant. Routine nursing visits will be made.

Comparison of Results and Summarizing Statements:

Although health guidance was included in many home visits, this was not mentioned as helpful. This mother does not seem to recognize the value of prophylactic care as she mentioned only the very tangible services as being helpful. Financial burdens, family responsibilities, and her own cardiac condition appear to have overwhelmed this young woman.
CASE NUMBER III

Introduction:

Sex: Male
Age on Admission: 2 years 6 months
Time Known to CSRC: 7 months
Number of Siblings: 2
Family Income: $72 per week

Presenting Problems: Little speech; not toilet trained; temper tantrums.

Diagnosis: Deferred; child functioning at a retarded level.

Current Status: Toilet training accomplished; slight increase in vocabulary.

Interview with Mother

Summary from Nurses' Records

Regarding the Care of the Retarded Child

Expected: Total Number of Visits Made: 11
Help with toilet training
and getting child to
talk earlier than his sis-
ter did. (This sibling
is in CSRC Nursery School.)

Received:

Services Rendered:
Directions for toilet training.
Toilet training was discussed on six visits.
Help with getting child to talk instead of
point.
Speech development was dis-
cussed on five visits.

Most Helpful:
Specific directions for fol-
lowing a schedule in
"Routine, Repetition, and
Relaxation" was stressed.

-Chamberlain and Moss, The Three R's for the Retarded.
<table>
<thead>
<tr>
<th>Interview with Mother</th>
<th>Summary from Nurses' Records</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Future Problems:</strong></td>
<td><strong>Plans:</strong></td>
</tr>
<tr>
<td>Called nurse because children had mumps recently. Would feel free to call any time.</td>
<td>Home visit made in response to call and instruction given.</td>
</tr>
<tr>
<td></td>
<td>Receives home visits at regular intervals.</td>
</tr>
<tr>
<td><strong>Others Who Helped:</strong></td>
<td><strong>Referrals:</strong></td>
</tr>
<tr>
<td>Social worker at CSRC.</td>
<td>Part of coordinated services at CSRC.</td>
</tr>
<tr>
<td>Nursery School teacher at CSRC with older child.</td>
<td>Older child attends school regularly and has developed some speech.</td>
</tr>
</tbody>
</table>

**Regarding Nursing Service to Family**

**General Comments:**
- Helped with admission of older sister to CSRC when she was having difficulty in school.
- Nurse has suggested ways of encouraging daughter in school performance.

**General Services Rendered:**
- Sibling evaluated and is not retarded.
- Praise, teacher conferences, et cetera urged.

**Change in Feelings:**
- Felt nurse was really interested in helping with this child. (son)

**Mental Health Aspects of Visits:**
- Since the mother was seeing the social worker regularly for her own problems, nurse did focus her attention on this child. (son)

**Other Health Problems:**
- None at present.

**Plans for Other Health Problems:**
- None required.

**Comparison of Results and Summarizing Statements:**

This family received regular coordinated services from CSRC. The mother was aware and appreciative of the
help. This mother is an emotionally and educationally deprived person, who does not want her children to suffer these deprivations. She found very specific details of home management for her son the most valuable service.
CASE NUMBER IV

Introduction:

Sex: Female
Age on Admission: 3 months
Time Known to CSRC: 20 months
Number of Siblings: 5
Family Income: $75 per week

Presenting Problems: Mongolism.

Diagnosis: Mongolism; asymptomatic congenital heart disease.

Current Status: Learning to walk.

Interview with Mother

Summary from Nurses' Records

Regarding the Care of Retarded Child

Expected:

Hoped nurse would help her care for her child at home. Mother had a definite need to tell the investigator that the physician who delivered the child said that she would have to be "put away." Mother said she couldn't do this.

Received:

Developed "confidence" that she could care for this child the same as for any other.
Help with care during illness as pneumonia.
Help with discipline.
Help with teaching child to sit and walk.

Services Rendered:

These activities are all recorded--except for giving "confidence."
Future Problems:
Has called CSRC frequently and will continue to do so.
Knows that nurse will help her with toilet training and entering this child in nursery school when she is ready.

Plans:
Records reveal that nurse observes for child's readiness to learn which infers that visits are fairly frequent—about every six weeks or as need arises during acute episodes of illness.

Others Who Helped:
All the staff at CSRC.
Hospital in Boston.
Speech Development Clinic.
Boston Association for Mentally Retarded Children.

Referrals:
Coordinated services of CSRC.
Referrals made to these agencies by CSRC.

Regarding Nursing Service to Family

General Comments:
Arranged for a tutor for an older daughter with school-learning problems.

General Services Rendered:
Sister referred to CSRC and evaluated.
Tutor obtained through CSRC.
Follow-up care for father encouraged as he has a history of mental illness.

Change in Feelings:
Had "hope."

Mental Health Aspects of Visits:
Much evidence that nurse listened and gave reassurance.

Other Health Problems:
None at present time.

Plans for Other Health Problems:
Not necessary.

Comparison of Results and Summarizing Statements:
This mother recalled the content of several nursing visits and explained the demonstrations in detail. Encouragement of the father to return for follow-up care at
a mental health clinic was made on several visits but this was not mentioned by the mother. However, this has been accomplished. Obviously, the record cannot express the feelings of "hope" and "confidence" which the mother described.
CASE NUMBER V

Introduction:

Sex: Female
Age on Admission: 8 years 10 months
Time Known to CSRC: 24 months
Number of Siblings: 7
Family Income: ADC

Presenting Problems: School learning problem; physical problems due to left spastic hemiplegia.

Diagnosis: Mild retardation; cerebral palsy; strabismus.

Current Status: Has had corrective surgery to leg; is receiving physical therapy to hand; is in special class at school; has obtained eyeglasses.

Interview with Mother

Summary from Nurses' Records

Regarding the Care of Retarded Child

Expected:
Help with care of "crippled" hand.
Help with "adjustment" at school—other children "picked on" her.

Received:
Help with arrangements for hospitalization and surgery.
Help with getting child into summer camp.
Nurse talked to child directly. This made her feel better after others "picked on her."

Total Number of Visits: 14

Services Rendered:
Many telephone calls were made in order to make these arrangements.
## Interview with Mother

### Most Helpful:
* Help given child herself so she knew what to expect before surgery.

### Future Problems:
* Has called and will continue to call CSRC when she has special problems.

### Others Who Helped:
* School Nurse
* Physical therapist
* Staff at summer camp
* Cerebral Palsy Association

## Summary from Nurses' Records

### Conversations with child are not recorded. However, pediatrician and nurse from CSRC accompanied mother and child to hospital on initial evaluation for admission for orthopedic surgery.

### Plans:
* Arrangements have been made which allow the child to receive follow-up clinical services of CSRC although the family have moved. Being followed by VNA in new place of residence.

### Referrals:
* Coordinated service of CSRC.
* Referrals made by CSRC.
* Also, referred for orthopedic surgery and ophthalmologic examination by CSRC.

## Regarding Nursing Service to Family

### General Comments:
* Help with a son who has epilepsy.

### General Services Rendered:
* Health guidance was offered in relation to "well" children also.

### Mental Health Aspects of Visits:
* Evidence that many visits were concerned with listening as well as giving reassurance.

### Change in Feelings:
* Felt that her daughter would now get help with her learning problems and other problems caused by cerebral palsy.
### Interview with Mother

<table>
<thead>
<tr>
<th>Other Health Problems:</th>
<th>Plans for Other Health Problems:</th>
</tr>
</thead>
<tbody>
<tr>
<td>None at present.</td>
<td>None required at present.</td>
</tr>
</tbody>
</table>

#### Comparison of Results and Summarizing Statements:

This mother repeated that the most helpful service given by the nurse was direct counseling of the child regarding her handicap and in preparation for surgery. The records did not reveal that the child herself was encouraged and reassured. The mother did not mention that health guidance was provided for the "well" children.
CASE NUMBER VI

Introduction:

Sex: Male
Age on Admission: 9 years 6 months
Time Known to CSRC: 24 months
Number of Siblings: 2
Family Income: $62 per week

Presenting Problems: Child not in school.

Diagnosis: Mongolism; sub-luxation of patella; strabismus.

Current Status: In sub-special class at school; obtained eyeglasses.

Interview with Mother

Summary from Nurses' Records

Regarding the Care of Retarded Child

Expected:
"Have struggled so long by myself that I didn't expect much."

Received:
Help with obtaining special schooling for child.
Help with obtaining eyeglasses.

Services Rendered:
Social worker and nurse worked together to arrange this through school system.
Nurse reinterpreted referral for ophthalmologic examination, assisted mother with instillation of eye drops in preparation for eye examination, and made suggestions for getting child to wear glasses.
Dental care has been strongly urged and arrangements made for this care—not accomplished.
Interview with Mother

Summary from Nurses' Records

Most Helpful:
Help with preparing child for and entering him in school.

Future Problems:
Has called CSRC and will call as problems arise.
Does not feel that the family will proceed with surgery on child’s knee which has been recommended as a result of CSRC referral.

Others Who Helped:
A nun.
Family physician.

Plans:
Plan visits at fairly long intervals for present.
Nurse has reinterpreted reasons why surgery was recommended and arranged for family to talk with pediatrician at CSRC regarding the orthopedist’s recommendation.

Referrals:
Arrangements were made by CSRC pediatrician for child to be examined by an orthopedic surgeon but this was not mentioned.
Referred for ophthalmologic examination.
Referred also to Recreational Program for Retarded Children.

Regarding Nursing Service to Family

General Comments:
Encouraged medical help for daughter.

General Services Rendered:
Tactfully suggested psychiatric care for daughter’s "nervousness." This has been obtained.

Change in Feelings:
"I know now that there was a person whom I could always call for help."

Mental Health Aspects of Visits:
Appears to have spent much time being a listener.
### Comparison of Results and Summarizing Statements:

Mother recalled how she had struggled for years with the trial and error method of caring for her child before help was finally obtained. This mother stressed the need for nursing help while the child is small. The nurses' record indicated that this mother had talked about her problems at length but "talking" was not mentioned as helpful by the mother. The nurse has encouraged dental care and corrective orthopedic surgery for the child, but the family appear to respond only to crisis situations—not prevention.
CASE NUMBER VII

Introduction:

Sex: Male
Age on Admission: 3 years 9 months
Time Known to CSRC: 31 months
Number of Siblings: 3
Family Income: $62 per week

Presenting Problems: Not toilet trained; temper tantrums.

Diagnosis: Mongolism; strabismus.

Current Status: Toilet training accomplished; attending CSRC Nursery School; obtained eyeglasses.

Interview with Mother

Summary from Nurses' Record

Regarding the Care of Retarded Child

Expected:
Had been referred to CSRC by nurse at Well-Child Conference so expected help with toilet training and help with admission to CSRC Nursery School.

Received:
Many suggestions were made in regard to toilet training.
Arrangements were made for admission to nursery school.

Most Helpful:
Specific suggestions in regard to toilet training.

Services Rendered:
Suggestions regarding toilet training were made on eight visits.
Help with arrangements for admission to nursery school were made and help with preparing child for this experience was given.

Very specific recommendations were made.

Total Number of Visits: 31
<table>
<thead>
<tr>
<th>Interview with Mother</th>
<th>Summary from Nurses' Record</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Future Problems:</strong></td>
<td></td>
</tr>
<tr>
<td>Has always called CSRC when a problem regarding her children has arisen.</td>
<td></td>
</tr>
<tr>
<td><strong>Others Who Helped:</strong></td>
<td></td>
</tr>
<tr>
<td>Nursery School teacher. Nurse at Well-Child Conference for making referral to CSRC.</td>
<td><strong>Plans:</strong> Received regular visits. <strong>Referrals:</strong> Coordinated services. Ophthalmologic examination arranged by CSRC pediatrician.</td>
</tr>
<tr>
<td><strong>Regarding Nursing Service to Family</strong></td>
<td><strong>General Services Rendered:</strong></td>
</tr>
<tr>
<td><strong>General Comments:</strong></td>
<td>Ante-partum guidance, especially in relation to existing toxemia, was given on ten visits. Bath demonstration of twins given at request of mother. Five visits made in relation to care and prevention of spread.</td>
</tr>
<tr>
<td>Received information before and after birth of twins. Visited frequently during staphylococcus infection in the family.</td>
<td><strong>Mental Health Aspects of Visits:</strong> Discipline and sibling relationships discussed on many visits. Nurse often listened to mother discuss &quot;in-law problems&quot; in relation to rearing her retarded child.</td>
</tr>
<tr>
<td><strong>Change in Feelings:</strong></td>
<td>Plans for Other Health Problems:</td>
</tr>
<tr>
<td>Felt &quot;better.&quot; Began to realize that her retarded child had to be disciplined and treated as a normal child in many respects.</td>
<td>None required at present.</td>
</tr>
<tr>
<td><strong>Other Health Problems:</strong></td>
<td>None at present.</td>
</tr>
</tbody>
</table>
Comparison of Results and Summarizing Statements:

This mother appears to have been aware of both the patient-centered and family-centered care. However, as might be expected due to the element of recall, the nursing record includes a few areas of nursing service not mentioned by the mother. These include arrangements for ophthalmologic examination for the retarded child and the concerted effort made by the nurse and social worker to help the family obtain improved housing.

This was the only mother who felt free to mention the service she considered least helpful; the suggestions made to get the child to wear his glasses.

The mother did not mention feeling better after just "talking" although it was evident from the record that the nurse had listened to this mother discuss "in-law problems" in relation to interference in the methods the family was using in rearing the retarded child.
CASE NUMBER VIII

Introduction:

Sex: Female
Age on Admission: 2 years 4 months
Time Known to CSRC: 24 months
Number of Siblings: 4
Family Income: $52.50 per week

Presenting Problems: Obesity; not sitting.

Diagnosis: Demyelinating disease.

Current Status: Institutionalized.

---

Interview with Mother

Summary from Nurses' Record

Regarding the Care of Retarded Child

Expected:
Nurse came because of ante-partum referral.
Mother did not expect any help for this child.

Received:
Referral to CSRC for examination of child.
Help with child while still at home.
Explanation about the child's condition.
Help with getting child into State School.

Services Rendered:
Child discussed on ten visits prior to being seen at CSRC.
Diet, physical handling of child, care of rash discussed. Reinforcement of CSRC's findings provided.
CSRC staff arranged for admission to State School and nurse explained procedure.

Total Number of Visits: 49

Most Helpful:
Sending child to CSRC clinic. In the ten visits before child was seen at CSRC, it was apparent the mother did not understand the gravity of the situation.

"The hospital where she had been seen was no help."
<table>
<thead>
<tr>
<th>Interview with Mother</th>
<th>Summary from Nurses' Record</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Future Problems:</strong></td>
<td><strong>Plans:</strong></td>
</tr>
<tr>
<td>Would call about the</td>
<td>Siblings seen at regular</td>
</tr>
<tr>
<td>other children.</td>
<td>intervals at CSRC.</td>
</tr>
<tr>
<td>No need to call about</td>
<td></td>
</tr>
<tr>
<td>the retarded child,</td>
<td></td>
</tr>
<tr>
<td>&quot;as she is well-cared</td>
<td></td>
</tr>
<tr>
<td>for now.&quot;</td>
<td></td>
</tr>
<tr>
<td><strong>Others Who Helped:</strong></td>
<td>Referrals:</td>
</tr>
<tr>
<td>All the staff at CSRC.</td>
<td>Coordinated services.</td>
</tr>
<tr>
<td>State School staff,</td>
<td>Referred by CSRC pediatrician</td>
</tr>
<tr>
<td></td>
<td>to hospital as in-patient</td>
</tr>
<tr>
<td></td>
<td>for diagnostic work-up.</td>
</tr>
<tr>
<td></td>
<td>Referral made by CSRC to</td>
</tr>
<tr>
<td></td>
<td>State School.</td>
</tr>
</tbody>
</table>

**Regarding Nursing Service to Family**

**General Comments:**
Received care before and after the new babies were born. Mother described in detail the visits, including such items as blood pressure, diet, and cord care.

**Change in Feelings:**
"It was good to talk to someone who knew about her condition and where to find help."

**Other Health Problems:**
None at present.

**General Services Rendered:**
Ten ante-partum and five post-partum visits were made in relation to one pregnancy.
Four ante-partum visits and two post-partum visits were made in relation to second pregnancy.

**Mental Health Aspects of Visits:**
It was obvious that the nurse listened, reassured, and interpreted care.

**Plans for Other Health Problems:**
Two other children are being seen at CSRC for observation.
Comparison of Results and Summarizing Statements:

This mother was certainly aware of the family-centered and patient-centered care she had received. In fact, she mentioned nearly all the services which were included in the chart. It was readily apparent that the decision to institutionalize her child was a very difficult one for this mother to make. The fact that an honest explanation of the child's prognosis was given by the CSRC pediatrician seemed to be appreciated by this mother. The family visits the child at regular intervals and the mother repeated several times that the child was "getting good care."
CASE NUMBER IX

Introduction:

Sex: Male
Age on Admission: 16 years
Time Known to CSRC: 7 months
Number of Siblings: 9
Family Income: Unemployment Compensation

Presenting Problems: Cannot read; very small in stature; at home with no employment.

Diagnosis: Dull normal intellect; delayed adolescence.

Current Status: Slight weight gain; employed.

Interview with Mother

Summary from Nurses' Records

Regarding the Care of Retarded Child

Expected:
Mother said that she had looked for help for years so "didn't expect much."

Received:
Help with referring son to Vocational Rehabilitation.
Boy himself received help from nutrition instruction.

Most Helpful:
Nurse talked to son directly in her office. "This made him feel important as a person."

Total Number of Visits: 4 Home visits; 6 Office visits.

Services Rendered:
Referral made to Vocational Rehabilitation.
Youth comes to nurse's office for instructions regarding adequate nutrition. Vitamins are provided.

Nurse allowed youth to take responsibility to call her for appointments.
### Interview with Mother

**Future Problems:**
Indicated that she kept in touch with CSRC regularly.

**Others Who Helped:**
Settlement House worker

### Summary from Nurses' Records

**Plans:**
Continued counseling of this youth.

**Referrals:**
- Settlement House worker participated in staff conference.
- Referred to Division of Vocational Rehabilitation.
- Referred to Adolescent Endocrine Clinic at nearby hospital and to Speech and Language Clinic by CSRC.

### Regarding Nursing Service to Family

**General Comments:**
Nurse referred a younger son to CSRC for evaluation. "She knows all the children."

**Change in Feelings:**
She has felt so much better that she has referred two or three other parents with similar problems to CSRC.

Mother is concerned that others, who might need this kind of help, do not know that the service is available.

**Other Health Problems:**
Husband is going to have back surgery.

**General Services Rendered:**
One child with epilepsy was discussed at length. Another son was evaluated at CSRC but is not mentally retarded.

**Mental Health Aspects of Visits:**
Evidence that nurse has listened to mother discuss her problems is obvious.

**Plans for Other Health Problems:**
Family seems to have contacted appropriate agencies. Nurse will help as indicated.
Comparison of Results and Summarizing Statements:

This mother referred to CSRC as a "haven" which she had found after years of searching. Services recorded by the nurse were recalled in detail. The mother expressed concern regarding the fact that CSRC might not be getting enough publicity. She emphasized the importance of direct contact with the child on the part of the nurse.
CASE NUMBER X

Introduction:

Sex: Male
Age on Admission: 2 years 11 months
Time known to CSRC: 6 months
Number of Siblings: 5
Family Income: Unemployment Compensation

Presenting Problems: Slow--not walking, talking, nor eating well.

Diagnosis: Moderate to severe mental and physical retardation, severe malnutrition on admission.

Current Status: Was hospitalized for further evaluation; is receiving iron for anemia; appetite improved; walking; and partially toilet trained.

Interview with Mother

Summary from Nurses' Records

Regarding the Care for Retarded Child

Expected:

Didn't expect to receive so much help in her home. Thought nurse worked just in the clinic.

Received:

Help with transportation to CSRC clinic.
Help with getting child hospitalized to find out what was wrong.
Help with feeding the child--booklet, special spoon, and what the nurse said "all helped."

Total Number of Visits Made: 15

Services Rendered:

Arranged for transportation through CSRC funds.
Nurse helped make arrangements for admission.
Nutrition instruction included on ten visits. "Yummy spoon" and appropriate literature provided. Nurse consulted with nutritionist for suggestions.
<table>
<thead>
<tr>
<th>Interview with Mother</th>
<th>Summary from Nurses' Records</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received (continued):</td>
<td>Services Rendered (continued):</td>
</tr>
<tr>
<td>Received vitamins which</td>
<td>Sample vitamins provided.</td>
</tr>
<tr>
<td>the family could not</td>
<td></td>
</tr>
<tr>
<td>afford.</td>
<td></td>
</tr>
<tr>
<td>Most Helpful:</td>
<td></td>
</tr>
<tr>
<td>Getting the child into the</td>
<td></td>
</tr>
<tr>
<td>hospital.</td>
<td></td>
</tr>
<tr>
<td>Future Problems:</td>
<td>Plans:</td>
</tr>
<tr>
<td>Has called and will</td>
<td>Regular visits.</td>
</tr>
<tr>
<td>continue to call.</td>
<td></td>
</tr>
<tr>
<td>Others Who Helped:</td>
<td>Referrals:</td>
</tr>
<tr>
<td>All the CSEC staff.</td>
<td>Coordinated services of CSEC.</td>
</tr>
<tr>
<td>Doctor and nurse at</td>
<td>Referred by CSEC pediatrician</td>
</tr>
<tr>
<td>hospital.</td>
<td>to hospital as in-patient</td>
</tr>
<tr>
<td></td>
<td>for diagnostic tests.</td>
</tr>
<tr>
<td></td>
<td>Referrals made on behalf of</td>
</tr>
<tr>
<td></td>
<td>family to service clubs</td>
</tr>
<tr>
<td></td>
<td>were not mentioned.</td>
</tr>
</tbody>
</table>

Regarding Nursing Service to Family

<p>| General Comments: | General Services Rendered: |
| &quot;Appreciated&quot; the nurse's | Mother is nearly seven months |
| interest in the whole | pregnant so ante-partum care |
| family. | has been urged. Nurse called |
| | hospital to arrange appoint- |
| | ment—not kept. Nurse |
| | referred children to Well- |
| | Child Conference for physical |
| | examinations and immuni- |
| | tations—not followed. Nurse |
| | has visited during acute |
| | illness. |</p>
<table>
<thead>
<tr>
<th>Interview with Mother</th>
<th>Summary from Nurses' Records</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Change in Feelings:</strong></td>
<td><strong>Mental Health Aspects of Visits:</strong></td>
</tr>
<tr>
<td>Felt better knowing &quot;someone was interested and could do something.&quot;</td>
<td>It is evident that nurse had listened to mother discuss her problems with this child and with finances. Nurse has secured help, offered reassurance, and praise.</td>
</tr>
<tr>
<td><strong>Other Health Problems:</strong></td>
<td><strong>Plans for Other Health Problems:</strong></td>
</tr>
<tr>
<td>An older son is having visual trouble in school.</td>
<td>Referred to school nurse.</td>
</tr>
</tbody>
</table>

**Comparison of Results and Summarizing Statements:**

The mother reviewed the help given the retarded child in detail. She "appreciated" the health guidance but has not followed through on the suggestions. This family appear to seek medical help in times of crisis only.
Discussion of Data from the Interviews

Patient-Centered Care

It has often been said that the public health nurse is "a guest" in the home of her patients. The investigator felt like an "honored guest" in several of the homes which she visited. In five instances in which an appointment time had been arranged by telephone, coffee and dessert were served on arrival. All of the mothers, in their own way, indicated that they were happy to share any information which would be helpful to nurses and to other mothers with problems similar to theirs. It was apparent that many of the answers given in reply to the questions asked regarding nursing care reflected the coordinated efforts of the CSRC staff and were not the unique contribution of the nurse. However, since the nurse functions as an integral member of the team, it was considered impossible to separate certain functions and shared responsibilities. The home visits made by the nurse seemed to be one of the services which engendered very positive feelings on the part of the mothers as expressed by such comments as, "she knows all the kids," or, "she seems like one of us."
Five mothers stated that they received much more help from the nurse than they had expected. The mother of one of the more severely retarded older children and the mother of the oldest child in the study related how they had looked from one source to another for years without avail. The six mothers who made positive statements in relation to the question regarding expectations of nursing service, were families in which the case-finding had been done by a nurse. Thus, these families had been given an interpretation of the functions of the public health nurse and of the functions of CSRC. In these six instances, the services which the families had expected to receive related directly to the presenting problems of the child. For example, if one of the presenting problems was that the child was not toilet trained, then, help with toilet training was the nursing service which the mother expected to receive.

Replies to the questions regarding the nursing service which had been received by families for their retarded children can be placed in the following five categories:

1. **Case finding**—in which families said they had been referred to CSRC by the nurse.

2. **Help with problems of habit training and home management**—reported by mothers of pre-school age children.
3. **Liaison activities**—in which mention was made that the nurse assisted with referral to other agencies, such as hospitals, school and camp.

4. **Supportive care**—as evidenced by such replies as the nurse gave me "hope" or the nurse gave me "confidence."

5. **Counseling of the children themselves**—which was considered very important by three mothers of school-age children. In two instances, counseling was in relation to hospitalization and surgery.

The nursing services which were considered most helpful by the mothers appeared to be in relation to the presenting problems, age of the child, and financial status of the family. Responses to this question were as follows:

1. Three mothers of pre-school age children considered assistance with home management problems most helpful.

2. Three mothers of school-age children considered the direct counseling of the child as most helpful.
3. Four mothers considered referrals as most helpful. One referral was to CSRC; two were to hospitals by the CSRC pediatrician for further evaluation following admission to CSRC; and one was to the school system.

Only one response was made to the question, "What did not help?" The mother of one of the children, who exhibited the stigmata associated with mongolism, felt suggestions made in regard to teaching her son to wear glasses were least helpful of all the recommendations.

All the mothers stated that they had called CSRC in the past when a problem arose regarding the care of their retarded child, and all indicated that they would not hesitate to call in the future should a problem develop.

Other staff members of CSRC were considered especially helpful in the care of the retarded children by the ten mothers. In addition, six mothers of children, who had been referred for further evaluation and treatment, found the medical and nursing personnel at those institutions of much assistance. Other sources of help which were mentioned were: a nun, a family physician, a settlement house worker, the Cerebral Palsy Association, and the Boston Association for Retarded Children.
Regarding Family-Centered Service

Nine of the ten mothers stated that the nurses had helped with the health problems of other family members. The mothers tended to recall nursing service rendered at the time of acute illness or in the cases of chronic illness more than health guidance. Two mothers, however, described in detail ante-partum and post-partum guidance visits. The one mother who failed to recall that an appointment had been arranged for her at a cardiac clinic had not kept this appointment. This young mother appears harassed by family and financial responsibilities.

All of the mothers indicated that they felt "better" after talking to the nurses. In fact, several of the mothers mentioned this before the question was asked. In describing their feelings, the mothers used such emotionally-descriptive words as "hope" and "confidence." They appeared to gain comfort and security from knowing that the nurse and the CSRC were always ready to help them with the problems of their retarded child.

Observations made during the interviews and information gained apart from that which was solicited will be presented briefly. The mother of the child, who has been institutionalized, repeated several times that her daughter was receiving "good care" as if seeking
reassurance that she had made the right decision. One mother was concerned that CSRC was not getting enough publicity. Two mothers mentioned that they had each referred two families to CSRC. The mother of the eleven year old child, who exhibited the stigmata associated with mongolism, stressed the need for assistance when the child is an infant. One mother deeply resented the physician, who following delivery, said that her infant would have to be "put away." Another mother resented the fact that she had not been told of her child's poor prognosis for normal development during a period of hospitalization prior to admission to CSRC.

Discussion of the Data from the Nurses' Records

In analyzing the nurses' records, it became apparent that the services rendered by public health nurses in the area of mental retardation encompass the same types of services as rendered by public health nurses in any generalized program.

As emphasized throughout the study, the nurse functions as a team member at CSRC and thus has an opportunity to share in planning the follow-up services for all children who are evaluated by the agency. This statement implies that any nurse involved in follow-up care attends the case conference on her patient. Because the services
of CSRC are so closely coordinated, it was difficult at times to isolate the functions carried out solely by the nurse from functions in which responsibilities were shared.

Nursing services which centered around the retarded children seemed to encompass four broad areas and included the following: (1) case finding; (2) liaison and coordinating activities; (3) integrating mental health aspects of care in the visits; and (4) helping with problems of home management.

Unfortunately, the investigator failed to include a category for source of referral on the work sheet which she used so this information is not available to her on all the children included in this study. However, under the column, Other, she has noted that six of the children were referred to CSRC by the nurse. Two of these children were found while making ante-partum visits to mothers, two were referred by the school nurse, one was found as the result of follow-up on a birth certificate, and one was referred by a nurse in the Well-Child Conference. It was shown in the case studies presented that the nurse assisted with the referral of six siblings to CSRC for evaluation. Thus, it was felt that case finding is an important function of the nurse.
It can readily be noted from the case presentations that the nurse acted as liaison agent and integrator between families and community agencies. Nine of the ten children had physical defects associated with their mental subnormality. Many of the referrals, with which the nurse assisted, were in relation to correction of the physical defects. Inasmuch as the ultimate goal of CSRC is to help the child to reach the maximum of his limited potential, one would expect to find this activity. In addition to helping arrange appointments for the children, the nurse explained the procedures that would be carried out. Often transportation was arranged. Besides referrals of a medical nature, contacts were often made to social agencies and service clubs on behalf of families because of the economic problems which existed in so many of the homes.

In the pre-school age sample, teaching of habit training appeared to be a service frequently rendered by the nurse. Two mothers were assisted with toilet training their children. The mother of the youngest child in the sample is being assisted in teaching her child to walk. Two mothers were helped with problems in relation to feeding and nutrition.

It was very evident in reviewing the nurses' records that a large proportion of the nurse's time on
home visits was spent in being a good listener. Often the mothers repeated the same problems on several occasions. Frequently, the nurse offered reassurance and praise to the mothers. In discussing the care of the retarded child, she stressed the fact that this child had the same needs as the so-called normal child, particularly in relation to discipline. Another topic relating to mental health, which was frequently discussed, was sibling relationships.

The oldest child included in the sample is receiving direct counseling from the nurse. Regular office visits are scheduled in which the nurse counsels this youth on his nutritional needs and discusses his eating habits with him. Another function of the nurse occasionally alluded to in the records is that of assisting in clinics. Mention was sometimes made that the child would be seen on his next clinical visit.

In family-centered care, health teaching and health guidance have long been considered high priority functions of the public health nurse. In the case studies presented, these activities were frequently mentioned. For example, four of the mothers have received ante-partum guidance—one mother for two pregnancies. It follows that post-partum and infant health supervision was provided. Several preschool age children were
referred to Well-Child Conference for physical examinations and immunizations. In an attempt to prevent further illness or complication, one mother was referred to a cardiac clinic and one father to a psychiatric clinic. Referrals for dental care were also made. In the area of health teaching for the entire family, nutrition was the subject most frequently discussed.

Nursing visits were made in response to requests from mothers when acute illness existed. The extended services provided in the case of the child with a septic hip were, of course, made by a nurse from the VNA.
CHAPTER V

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Summary and Conclusions

This exploratory study attempted to compare how ten families, who had received coordinated services in the care and management of their retarded children in their own home setting, perceived the functions of public health nurses who provided part of these services; and how the public health nurses recorded the services which they had rendered to these ten families.

The Cambridge Service for Retarded Children, an integral unit of the Cambridge Health Department, was the setting for this study in which the Cambridge Visiting Nursing Association provided certain of the nursing services as well as nurses from the Health Department. The ten families of mentally retarded children, who participated in the study, were receiving continuous, coordinated and integrated services from the CSRC.

Data were obtained from informal, guided interviews with the mothers of the ten retarded children and from a review of the public health nurses' records. The activities
which the nurses had recorded were categorized on work sheets designed for this purpose. The data from both sources were compared and studied individually as case presentations and collectively from the point of view of the mothers and public health nurses.

Because this study was limited to ten families of mentally retarded children, who were receiving coordinated services from the CSRC, broad generalizations cannot be made from the findings. In some instances, it was impossible to separate the unique functions of the nurse from functions in which responsibilities were shared with other staff members at CSRC.

There was a striking similarity between the way in which the families viewed the functions of the public health nurses and the way in which the public health nurses recorded their services. The main functions appeared to be:

1. Case finding and interpretation of CSRC and nursing services.

2. Supportive care—listening and reassuring.

3. Assistance with problems of home management such as, toilet training, and feeding of preschool-age children.
4. Direct counseling of children in the school-age group.

5. Reinterpretation of referral to other agencies--mainly for correction of physical defects. Included in this function were liaison activities with workers in other agencies and interpretive services to the parents of the children.

6. Direct nursing service during illness.

7. Health guidance for the individuals and the total family.

8. Other--as nursing service rendered in the clinic.

There appeared to be two slight discrepancies in perception of services rendered. Although the public health nurse had helped directly to prepare two school-age children for surgery, her recordings did not reveal that the counseling had been done directly with the children; and the mothers, in many instances, failed to recall certain health guidance activities such as, referral to Well-Child Conference or discussion of adequate nutrition.
Recommendations

On the basis of the findings of this study, the following recommendations are made:

(1) That this study be developed into a longitudinal study with the same ten families as this original sample to discover the differences in focus of content in the nursing visit as the children grow older, the increased or decreased need for public health nursing services, and whether or not there is a change in attitude on the parents' part towards the problem of mental subnormality.

(2) That a similar study be carried out to include a larger sample in which an attempt is made to control certain variables, such as age of the child and severity of the retardation.

(3) That further consideration be given by nurses to counseling school-age children individually as well as working with the parents.

(4) That the nurses and staff of CSRC utilize all available opportunities to interpret their services to the community.

(5) That inferences be made from the data in this study in planning in-service education programs for public health nurses.
(6) That inferences be made from the data in this study in integrating care of the retarded child in basic nursing educational programs.

(7) That a method, similar to the one used in this study, be developed as an evaluative tool to be used at designated intervals in the follow-up care of mentally retarded children and their families to help determine if their nursing needs are being met.

(8) That in the future, a time study be conducted to determine the amount of nursing time spent on the average home visit to mentally retarded children and their families, the amount of office time used in carrying out liaison and referral activities, the amount of time spent in supportive care, and the amount of time spent in other traditional activities of family-centered care and health guidance.
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Helping Parents Understand the Exceptional Child.


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ARTICLES AND PERIODICALS


REPORTS


UNPUBLISHED MATERIAL


APPENDIX A

Sample Worksheet Used in Analysis of Nurses' Records
**Worksheet for Review of Nurse's Records**

<table>
<thead>
<tr>
<th>Case No.:</th>
<th>Religion:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Employment of Father:</td>
</tr>
<tr>
<td></td>
<td>Private Physician: Yes — No</td>
</tr>
<tr>
<td>Census tract:</td>
<td>Birth date:</td>
</tr>
<tr>
<td></td>
<td>Date of adm. to ESRC:</td>
</tr>
<tr>
<td>No. of siblings:</td>
<td>Age on adm. to ESRC:</td>
</tr>
</tbody>
</table>

**Presenting Problems, as seen by parents, on adm. to ESRC:**

**Diagnosis:**

**Recommendations following staff conference:**

<table>
<thead>
<tr>
<th>No. of visit</th>
<th>Date of visit</th>
<th>Family-Centered Care</th>
<th>Patient-Centered Care</th>
<th>Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Patient:**

**Remarks:**

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APPENDIX B

Sample Interview Guide
Interview Guide

What kinds of help did you expect to receive from the public health nurse?

In what ways did she provide this?

What other kinds of help do you feel the public health nurse gave you with the care of (name of child)?

What sort of information or help that the public health nurse provided did you find most helpful?

How did you feel after talking to the public health nurse about (name of child)?

In the future if you have a question regarding (name of child), would you think to call the public health nurse?

Have you called her within the past three months?

Was there anyone else that you found especially helpful in the care of (name of child)? Who?

Did the nurse help with the health problems of any other members of your family? How did she help?

Are there any other problems with which you feel the nurse could help?