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P R O C E E D I N G S

of the

I N S T I T U T E O N M E N T A L D E F I C I E N C Y

Sponsored jointly by the

UNIVERSITY OF MINNESOTA

and the

NATIONAL INSTITUTE OF MENTAL HEALTH

Edited by Reynold A. Jensen, M.D.

Center for Continuation Study

February 2 - 4, 1956

INSTITUTE ON MENTAL DEFICIENCY

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FOREWORD

Judged by the comments of those who attended, the Institute on Mental Deficiency was truly successful. The physicians attending the Institute were stimulated to give serious thought to the problem of mental deficiency. We are sure that they have communicated information gained at the Institute to their colleagues in their home areas. We believe that a pattern has been set for future Institutes in other areas.

We wish to express our gratitude to the National Institute of Mental Health for its generous support of the Institute. In particular the cooperation, interest, and helpful suggestions of Senior Surgeon Seymour D. Vestermark, Chief, Training and Standards Branch, National Institute of Mental Health, U. S. Public Health Service, Bethesda, Maryland, is acknowledged with appreciation.

The success of the Institute was in large measure due to the contributions of the faculty of the Institute and to the physicians who attended it. For each of them attending the Institute meant taking time from other pressing duties and responsibilities.

— Robert B. Howard, M.D.,— Director
Department of Continuation Medical
Education

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INTROOUCTION

The problems of the mentally retarded and their families has, in a comparatively short time, become a problem of local, state, and national concern. This has developed in large measure by the action of local, state, and national parent organizations which have sought to assure better understanding and more adequate provision for this large group in our population which has too long been neglected. Hardly a day goes by that one does not read in the daily paper or in many of our magazines a story about interest and activity in this area. Currently, major legislation is pending in our Congress and in many state legislatures in the interests of the mentally retarded and their families.

Since mental retardation is a medical problem, it is essential for the physician to become aware not only of the current developments taking place, but also of his role and responsibility in this important area of medical practice. It is a medical problem in which rightfully the physician can and should assume a significant role. This has not been the case to date, though there are indications of developing interest by many physicians.

In an effort to stimulate the interest of a group of physicians in the upper midwest, an Institute on Mental Deficiency for Physicians was held at the University of Minnesota Center for Continuation Study February 2-4, 1956. It was the first such institute to be arranged by the Department of Continuation Medical Education of the Medical School. It was made possible by a supporting grant from the National Institute of Mental Health.

It's main purposes was to provide an opportunity for a small group of representative physicians from the Upper Midwest to become acquainted with the developments in the field, the many problems intrinsic to it, and to stimulate

interest in the many possibilities which exist for the physician to increase his effectiveness in dealing with them. The group assembled, thirty in number, came from Nebraska, Iowa, North and South Dakota, Wisconsin, and Minnesota.

Represented was the Northwest Pediatric Society, The Academies of General Practice in the upper Midwest, and the obstetrical societies. Included also were several medical educators.

Since the Institute was to be for two and one-half days, the plan of operation provided for a maximum of group discussion led by physicians eminent in the field. After the first morning, which was devoted to a presentation of the problem and the parents' point of view, but one talk was given at the start of each morning and afternoon session. The remainder of the day was devoted to free discussion in small groups with a final short report session at the close of each day. A final summary session was held the last hour on Saturday morning.

The plan of providing ample time for small group discussion did much to stimulate the interest of everyone and to help clarify some of the issues involved.

We, who helped to arrange this first institute, were gratified at the enthusiastic response of the physicians who attended. Amply demonstrated was the simple fact that physicians are vitally interested in the mentally retarded.

This brief summary is presented in the hope it may serve to remind the participants of the course of two and a half pleasant days spent together. It is also hoped that others may find it useful in furthering the interest of physicians everywhere in the problems of the mentally retarded.

-- Reynold A. Jensen, M.D.

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Program

Thursday. February 2

8:30- 9:00 Registration. Dormitory Desk, Center for Continuation Study
9:00- 9:15 Introduction Fred E. Berger,
Robert B. Howard, Reynold A. Jensen
9:15 - 9:30 Assignment of Groups for Work Sessions
9:30 - 10:30 A Statement of the Problem George Tarjan
-10:45 - 12:00 Parents' Presentation
12:00 - 1:15 Luncheon. Center Dining Room
1:15 - 2:15 Mental Health and Mental Deficiency. Reynold A. Jensen
2:15 - 3:30 Discussion Groups
3:30 - 4:00 Coffee
4:00 - 5:00 Discussion Groups
5:00 - 5:30 Summary

Friday, February 5

9:00 -10:00 Medical Counselling and Genetics. Sheldon A. Reed"
10:15 - 12:00 Group Discussions
12:00 - 1:15 Luncheon
1:15 - 2:15 Physician's Role and Responsibility. Charles Bradley
2:15 - 3:30 Discussion Groups
.3:30 - 4:00 Coffee
4:00 - 5:00 Discussion Groups
5:00 - 5:30 Summary

Saturday. February 4

9:00 - 10:00 What Can Be Done for the Mentally Retarded in the Home, the Com-
munity, and the State. George S. Stevenson
10:00 - 11:00 Discussion
11:00 - 12:00 General Summary of the Institute

INSTITUTE ON MENTAL DEFICIENCY

Faculty

FRED E. BERGER, Director, Center for Continuation Study, University of Minnesota

CHARLES BRADLEY, Associate Professor of Pediatrics and Psychiatry, University of Oregon Medical School, Portland

ELIZABETH CLARK, Program Consultant, Center for Continuation Study, University of Minnesota

MERRILL K. CRAGUN, Course Coordinator, Center for Continuation Study, University of Minnesota

ROBERT B. HOWARD, Director, Department of Continuation Medical Education, University of Minnesota

REYNOLD A. JENSEN, Professor, Departments of Psychiatry and Pediatrics, University of Minnesota

J. M. NOLTE, Dean, General Extension Division, University of Minnesota

W. A. PORTER, Program Director, Center for Continuation Study, University of Minnesota

SHELDON C. REED, Professor of Zoology and Director, Dight Institute, University of Minnesota

GEORGE S. STEVENSON, National and International Consultant, The National Association of Mental Health, Inc., New York City

GEORGE TARJAN, Superintendent and Medical Director, Department of Mental Hygiene, Pacific State Hospital, Spadra, California

INSTITUTE ON MENTAL DEFICIENCY

Physicians Attending

WARREN R. ANDERSON, 600 Security National Bank Building, Sioux Falls, South Dak.

ROBERT BERGAN, Duluth Clinic, Duluth 2, Minnesota

HEINZ H. BRUHL, Minnesota School and Colony, Faribault, Minnesota

JAMES A. COSGRIFF, JR., Olivia, Minnesota

L. R. CRITCHFIELD, 1517 St. Clair Street, St. Paul 5, Minnesota

HENRY FISKETTI, 1029 Medical Arts Building, 324 West Superior St., Duluth, Minn.

MORGAN FOSTER, 1320 - 2nd Avenue S.E., Cedar Rapids, Iowa

J. L. GEDGOUD, 304 South 42nd St., Omaha, Nebraska

JOHN S. GILLAM, Fargo Clinic, Fargo, North Dakota

ROBERT K. GRAU, 366 North Prior Ave., St. Paul, Minnesota

ROY G. HOLLY, Dept. of Obstetrics and Gynecology, University of Nebraska Medical School, Omaha, Nebraska

E. A. KILBRIDE, Worthington, Minnesota

WAYNE LeBIEN, 807 Broadway, Fargo, North Dakota

JOHN F. LOECK, Independence, Iowa

JAMES K. MARTINS, Eleva, Wisconsin

FRANKLIN MELLENCAMP, 1513 E. Capitol Drive, Milwaukee, Wisconsin

HARRY ORME, 807 Broadway, Fargo, North Dakota

BROOKS RANNEY, Fourth St. and Park Ave., Yankton, South Dakota

E. R. SATHER, 527 1/2 Broadway, Alexandria, Minnesota

PHILIP L. SPENCER, Essex, Iowa

JOHN STAM, Worthington Clinic, Worthington, Minnesota

KATHERINE STEWART, 213 Garfield Ave., Eau Claire, Wisconsin

KENNETH W. TEICH, Medical Arts Building, Duluth 2, Minnesota

JOHN B. TOUSSAINT, No. Wisc. Colony & Training School, Chippewa Falls, Wisconsin

M. O. WALLACE, 909 Medical Arts Building, Duluth 2, Minnesota

N. E. WESSMAN, Sioux Falls Clinic, Sioux Falls, South Dakota

A STATEMENT OF THE PROBLEM ON MENTAL RETARDATION

George Tarjan, M.D.

During the next two and a half days, we will hear excellent presentations on specific problems in mental retardation. We will also have an opportunity in the workshop sessions to share with each other our experiences and thereby learn more about the care of these patients. I would like to spend my allotted time in discussing some of the overall issues that confront the physician when he approaches this diagnostic entity.

One may best start out by an attempt to define the nature and the extent of mental retardation in a given population such as that of the United States. The extent of the problem could not be spelled out without first defining the nature of the issue at hand. This focuses our attention on the need to have a clear and concise definition of mental retardation. Unfortunately there is at the present time no generally accepted delineation of this condition. Different definitions can be found in the various books on education, psychology, and social work. Even medical authors vary in their suggested definitions. Similarly, statute books, changing from time to time, vary greatly from state to state. The differences among the definitions of the various disciplines are even greater.

For the purposes of this presentation and so as to help the understanding of some characteristics of our subject group, I would like to offer the following definition: Mental deficiency is a chronic condition that is present at birth or starts during the developmental years and ultimately interferes with the adaptation of the individual to the problems of his daily living. I will use the terms mental retardation and mental deficiency interchangeably. Though this definition can justly be criticized, I think it will serve our purpose.

May I call your attention to some important points in the definition. "Chronic" implies that the condition does not change rapidly. It also implies that it is not completely unalterable. I consider this fact of importance because we find more and more cases where, with our present diagnostic tools, a "correct" diagnosis of mental deficiency is made, but where significant improvement is obtained after careful management of the case. This concept also helps in the elimination of the previously nihilistic therapeutic attitude which is neither productive nor correct in today's light. "Developmental years"⁵ are usually considered to be from birth to the age of 16.

The condition interferes with the adaptation of the personality to the "problems met in day-to-day living." The plurality of "problems" should be emphasized so as to exclude from the diagnostic group so-called single symptom abnormalities often seen in children. Reading, writing, or arithmetical disabilities, even learning disability, as a whole, though at times indications and symptoms of mental deficiency, in themselves do not establish the diagnosis. There are many children with such disabilities who are not mentally deficient. Similarly, difficulty in adaptation to the requirements of social mores also may be part of the syndrome of mental retardation, but in itself may mean a personality disorder rather than mental deficiency. Attention should be called to the importance of the word "his," so as to avoid diagnosing a patient as being mentally deficient by standards applicable only to a different social setting than his own.

May I point out that I have not included in my definition any reference to the "IQ." Impaired intelligence and its mathematical expression on a specific test is an important manifestation of mental deficiency. Categorization of human beings by this numerical term, however, is of very limited practical value and is wrought with inaccuracies. Traditionally, people had

been diagnosed as mentally deficient because their IQ's were below a predetermined cutoff point. The most commonly used cutoff point was 65 or 70, depending upon the test used. Rigid adherence to such concept may label a patient with this diagnosis on the basis of rather insignificant and often infinitesimal difference between him and the next person on the distribution curve.

The location of the predetermined cutoff point also completely alters the prevalence rate of the condition. Limits established at 65 or 70 would likely incorporate about 1 to 2 per cent of the population in our diagnostic group, whereas a limit recently suggested by the American Psychiatric Association (IQ 85) would increase the number to 16 per cent. Among the detrimental results of our over-reliance on IQ should be mentioned a tendency to identify mentally retarded individuals simply by their IQ. Much more important aspects of their personalities become forgotten, and they are viewed as if they were nothing but a "living IQ." It would never occur to any of us to identify brilliant people by their measurable level of intelligence rather than by the production of their brilliance. Nor would we think about two people as if they were at all alike just because both have an IQ of 158. Unfortunately, the mentally retarded have often been considered as if they had no other characteristics but that which is expressed in their IQ.

For some time it was thought that the IQ represented a stable characteristic of the personality. We know today that intelligence as measured on any test varies greatly, particularly so in the mildly retarded. It is not at all uncommon that suppression of IQ is followed by rather rapid rises. We should not think of the IQ as anything but the numerical expression of success or failure at a given time by a certain individual on a specific test.

When making the diagnosis of mental deficiency, we ought to view the individual as a total personality whose pathology is characterized by an early inability to meet the stresses of daily living on a chronically consistent basis.

The extent of our problem could best be expressed by the prevalence of this condition. Most conservative estimates using the most rigid criteria place this prevalence at 1 per cent. This frequency rate has been found to vary at different age levels and is highest in early adolescence.

The extent of mental retardation could also be viewed by examining the frequency with which mental deficiency occurs among the newborn. This is a difficult task to accomplish as children would have to be examined immediately after birth; but only few types of mental deficiency can be readily diagnosed at that age. Conservative retrospective studies, however, point out that about 3 per cent of the newborn will be considered sometime during their life span as being mentally deficient.

Having so examined the nature and extent of our problem, let us now study a representative sample of the mentally deficient. This could most easily be done by assuming that we are looking at a sample composed of 100 patients. In the sample every type, every degree of severity, every age group, and every causative agent of mental deficiency is proportionately represented.

What would we see? We would notice that both sexes are present but that the males outnumber the females.

Several factors could account for this fact. Time does not allow me to go into the details. We would also notice that the age distribution of our sample differs from that of the general population. We would find that though all ages are represented there are very few infants, that there is a preponderance of young adolescents with a diminished representation of adults, particularly the aged. This is because many people diagnosed as mentally deficient in adolescence are no longer so identified in adulthood and also because the life expectancy of the mentally deficient group as a whole is less than that of the average population.

Probably to our surprise we would find that the physical appearance of most is no different from that of others with conspicuous somatic signs present only in some 15 to 20 per cent. Among those with specific somatic signs, we would find the microcephalics, the hydrocephalics, those with other cranial anomalies, the mongoloids, etc. We would notice that almost all the infants show some typical physical abnormalities pointing out that the diagnosis in infancy is difficult without the help of physical findings. Among the adults abnormal physical characteristics would be rare because the life expectancy of those patients with physical signs is shorter even if compared to other mental defectives.

In examining the severity of their condition, instead of categorizing them by IQ, let us group them by simpler and more practical criteria. We find that about 5 per cent of our sample is retarded to such an extent that they require someone's helping protection at all times; otherwise they cannot survive. They cannot differentiate between danger and safety; they cannot separate edible from non-edible; they are unable to satisfy even their minimal hygienic needs; they are not toilet-trained; they have no concept of oral or other personal hygiene; on their own they cannot protect themselves from exposure to dangerous climatic conditions; and cannot verbally communicate their needs. They are as dependent as average children under the age of two. They represent the most severely retarded group. Their life expectancy is the shortest, among them physical characteristics are most common, and superimposed handicaps are most prevalent.

About 20 per cent of the group are somewhat more self-reliant. They can protect themselves better; they know their basic hygienic and other needs and can communicate them in a simple language to others. In a sheltered environment and under proper guidance, they can learn many tasks and contribute to their own and to their community's welfare in a limited fashion. They are the

moderately retarded or the semi-dependent group requiring primarily a somewhat sheltered environment. Their difficulties become self-evident when they are called upon to communicate by symbols, when they are asked to recognize the meaning of printed words, to understand figures, or to express themselves in a written language.

By far the largest number, about 75 per cent of the total, have much greater capacities. They are the mildly retarded or the semi-independent. They can communicate reasonably well even by means of symbols. They can learn productive tasks though of somewhat simple nature. They can accomplish the ordinary chores of daily living; however, their difficulties become evident when called upon to think in abstractions. During prolonged periods of their lives, they remain indistinguishable from others, but during periods of stress, unless skillfully supported, they falter. In our sample we find very few of this group among the young children because the first stress period that calls our attention to them is their entrance into schools. In this competitive setting where learning ability is at high premium, they are most likely to fail. This is the time when their diagnosis is generally established. Stress recurs to a lesser extent during sexual maturation, entrance into employment or the military, marriage, and parenthood.

Let us now examine our sample more closely. We will find that superimposed physical abnormalities of a congenital or acquired nature such as congenital hearts, cerebral palsy, epilepsy, etc., occur with greater frequency than in the average population.

A close review of each case, with the hope that an accurate etiological diagnosis can be made, would soon point out that only in a small percentage can we pinpoint a specific causative agent such as a given infection, a certain trauma, or a known mode of inheritance. In an additional number of cases physical characteristics and mental retardation can give us at least a good combined, though symptomatic diagnosis; for instance, in cases with cranial

anomalies, in mongolism, etc. In some others clear evidence of the affects of psychological complications may be found, and this fact gives us better understanding of the total picture. In the largest percentage of the cases, however, the best diagnosis which we can make is mental deficiency - undifferentiated,⁵³ meaning that our etiological understanding of the case is quite limited.

Having become acquainted with these basic characteristics of the subjects of our study, we ought now to focus our attention upon their environment, particularly because it exerts a great influence on their growth and development. The mentally retarded child is first a child and only secondarily deviant from others. Environmental factors which influence other children have an important bearing upon them too. The retarded child comes from an environment which may have been identical to others "prior" to his birth. His arrival, however, likely altered this most important environmental unit, the family. The parents, emotionally influenced by his retardation, then further influence his personality growth. In the molding of our future patient, this interplay is of great importance.

In our cultural setting intellectual normalcy or brilliance is a very important expectation of a child. The birth of a retarded child is one of the most severe traumas to parents. Their observed reaction patterns have several common characteristics. An early attitude may briefly be described as follows: "This could not have happened to me! It really didn't! My child is not retarded!" A long trek of diagnostic shopping' begins, aimed toward finding a physician who will I agree with the parents' denial of the facts. The physician who matter-of-factly gives his correct diagnosis is often considered unqualified, rude, or inhuman.

With good professional guidance sooner, without it later, the tragic facts become self-evident. In retrospect, previously consulted physicians are

again often unjustly blamed. They are accused of "not having said" what was really "not absorbed by the parents." The diagnosis of the last physician is finally accepted, and at this moment the "therapeutic shopping" starts. A search is on, at first for a somatic cure. The financial resources of the family are exhausted in hope of finding a tablet, a hormone, or a diet which could restore their child to normalcy. Having failed, they then search for psychological cures, only to be disappointed again.

A phase of "fault finding" then begins. Someone must bear the guilt for the tragedy. Obstetricians, pediatricians, other physicians, social agencies, are high on the list of suspected culprits. Not even the marital partner and his ancestry are spared. This phase is at times followed by a period of crusade. It is society as a whole which seems unfair and unjust. From these crusades of parents has grown important progress in the field of mental retardation. When finally all facts are understood and accepted in a realistic fashion, the parents can look upon the issues with objectivity and make stable and lasting plans for their child.

It is important; for the physician to understand these developments and movements in the thinking and feeling of the parent because one cannot deal with the retarded child without concurrently dealing with his family. Each alteration in parental attitude brings with it a new hope, a new expectation, always to be followed by new disappointments. Each phase of hope brings with it over-protection, each disappointment carries the danger of rejection. An understanding of these dynamic forces can substantially help a physician in his treatment of the total family problem.

Matters are further complicated by the role of grandparents, friends, and neighbors. Planning for the retarded requires an understanding of all these forces including those that work in the community where the patient lives. The availability of good community programs can make a physician's job much

easier. The lack of health, educational, recreational, spiritual, and vocational programs can make his job in helping the family almost hopeless.

We will hear about these aspects in greater detail in succeeding lectures. The last important point to which I want to call your attention is that role of the physician which really begins after the establishment of the diagnosis. All too often we are inclined to consider our contributions closed to a patient when an accurate and explicit diagnosis of mental deficiency has been made. All too often we leave the family with but one alternative - institutionalization. This is not a universally applicable and generally palatable medication. Interpretation of the meaning of the diagnosis, assistance to the family during its most serious emotional turmoil, help to the parents in their crucial period of adjustment, and in long-term planning for a child's life is what determine good medical practice in mental retardation. Until we have discovered methods of prevention, our services in this field will remain one that embodies closest the concepts of good family medicine. It is not only the pathology which deserves the attention of the physician, it is the total living unit with its inter-acting environment that deserves the close attention of the practitioner.

PARENTS' PRESENTATION

Dr. Jensen;

For the balance of the morning, we are going to hear from three parents each with a mentally retarded child. They will tell the story of their experiences as they searched for solutions to their problems. As far as can be ascertained, such a presentation has not been made to a group of physicians. These parents, I am sure we will find, have worked through their difficulties and disappointments in a most remarkable manner. When invited to participate in our program, each one expressed not only a willingness' to be with us, but welcomed the opportunity to meet with us. When they have finished, they will be glad to discuss questions which any of us may have.

Their presentations *are* their own. While it is true, we had a short meeting last week, the only suggestion which was made to them was that they tell their story in their own way in a direct, straightforward manner. In the course of their talks, it may be that we shall be somewhat uncomfortable, since we may see some of our errors in retrospect. However, in the interest of gaining a keener appreciation of what we, as physicians, can do in helping parents more effectively in the future, they will tell us their experiences.

Our first speaker is Mrs. Robert Gunderson, who has a child who is not only retarded, but has convulsive seizures in addition. At the present time, Mr. and Mrs. Gunderson are active in the Minneapolis Association for the Retarded.

Mrs. Gunderson;

I would like to say how much I enjoyed Dr. Tarjan, who has ably defined the various phases we parents go through in our struggles. Our retarded girl is age nine. The cause or causes of her retardation are rather indeterminate. Several contributing factors our obstetrician and pediatrician have considered

to explain the cause of her brain damage are the RH factor, a long labor with high forceps delivery, and a severe Bartholin gland infection which was present during the pregnancy. At the age of three months, she had her first grand mal seizures following a DPT shot. The seizures lasted 20 to 30 minutes and was followed by several hours of semi-consciousness. Other seizures occurred every one to two weeks with petit mal seizures also. Phenobarbital was prescribed, and it was suggested we have our well water tested. Our physician seemed to feel there was nothing basically wrong. Since the seizures persisted, we felt that this doctor had not adequately handled our problem. We consulted another physician, who, after reviewing the case, sent us to a neurologist. At this doctor's suggestion, x-rays were made and an electroencephalogram done. The findings suggested abnormalities on the left side, and the diagnosis of a possible brain tumor or blood clot was made. I can't describe our anxiety and how much we hoped for some miraculous cure. The most difficult part of our problem as parents of retarded children is to stand by and watch our children go through so much and not be able to help as we would like to. However, the results of the bilateral trephining operation and air study was only that scar tissue was found to be present. We were stunned and wondered where we would turn next. Our pediatrician was wonderful to us during this time and gave us much needed help and counsel. Her seizures continued to be frequent and severe and became more of a problem as she began to walk. She was continually falling down and into things. During a period of just a few weeks, she required frequent stitches for lacerations in different parts of her face and around her eyes. For this reason, a succession of drugs - dilantin, tridione, phenobarbital - were tried and discontinued. Finally, masantoin and mebarol were found to give the best results.

Up to this time, we had not realized our daughter was retarded, although we were beginning to note her development was far below that of other children

of her age. We seemed to be driven by the idea that by continuous searching we would find a definite cause which could be treated, and everything would be all right. During a particularly trying time for us, our pediatrician was drafted into military service. He was going through a difficult time of his own, of course, and no doubt felt a little inadequate to help us. Before leaving for service, he told me our daughter would never be able to go to school, and we should consider institutionalization. Needless to say, I was very upset and felt I had been put on the "spot" to tell my husband. My reaction was one of immediate rejection of the whole idea. We just refused to accept his diagnosis. In our despair, we turned to University Hospitals, which was a turning point in our problem. We felt we received excellent counseling both medically and psychologically here. The doctor who helped us most had specialized in convulsive disorders. Although after study of our daughter's case, he couldn't keep her as his patient, he recommended another pediatrician to us. We started keeping a daily chart of everything concerning her habits and reactions, but particularly of the seizures, hoping to find some correlation. We found only that they seemed to follow a pattern or cycle with the seizures more severe at times, lessening at other times. Some days she had hundreds of petit mal seizures and was in a confused state, unable to dress or eat or continue any thought through for any length of time. We continued to search for a drug which would control her seizures. Finally, phenurone was prescribed and tried with no better results. After a period of time, certain personality changes occurred, and her coordination was very poor.

One one occasion, she developed status epilepticus. This continued for approximately an hour and a half before we finally got help from a neighbor, a neurologist who gave her a hypo under our doctor's direction. Gradually, we put her back on mebarol, which had previously given the best results. From that time on, the seizures have been under better control. We were thankful, but as

we look back, we wonder how much brain damage we could have spared her, had the seizures been controllable earlier, and whether it might have modified her retardation to any degree,

When she reached school age, we were aware of her limitations. She tested about 56 at the age of five and had a vocabulary of about 25 words. Her seizures seemed fairly well controlled, though one day out of every five or six she would be in a confused state for several hours in the forenoon from the continual petit mat seizures. Our concern now was her education. We set about to do what we could to find other families in our community with the same problem and to try to get special classes started. It was a slow procedure. We were fortunate enough to get her into a special class in Hopkins, and this year we have our own class in Richfield. Retesting each year indicates improvement in the use of her abilities.

In conclusion, I would like to say we have, as a whole, received good counseling from the various doctors we have consulted. Always they stressed the fact that our child needed great love and understanding, without over-protection, and that we must give her the security of our affection and a happy, serene environment. We, as parents, needed this encouragement and the assurance we were capable of fulfilling this need. Our child has given purpose and direction to our lives; and though we have had some sorrow and disappointment, we have had great satisfaction from seeing the progress she has made. But our greatest joy is the progress being made every day in the whole field of the mentally retarded. I personally am so happy to see the interest shown by you physicians here today. And I should like to commend the medical profession for its growing interest in problems of mental retardation and for their efforts in the area of counseling and guidance. This we parents greatly need. We want so much to increase our knowledge of the field and to help others to do likewise. Each effort made today to help a child will ease the heartache for those to follow.

Dr. Jensen:

Thank you very much, Mrs. Gunderson.

Mrs. Monson, who has a daughter who is mentally retarded, is now going to tell us her story. As with the experience of Mrs. Gunderson, you will note a good many similarities in her experience. Mr. and Mrs. Monson reached a solution to their problem in a different way, which she will tell you about. As with Mr. and Mrs. Gunderson, Mr. and Mrs. Monson are active in the Minneapolis Association for the Retarded. More important, however, is the fact that Mrs. Monson has become so interested in the education of mentally retarded children that she is now a teacher of special education in the Minneapolis Public School system. She is putting her experience to good use, not only with the children in her classes, but also with their parents. I mention this, since it illustrates how parents who have worked through their problems do find ways and means of passing on to others some of the things which have been gained through the struggle that has been resolved. We are very glad that you are here, Mrs. Monson.

Mrs. Monson;

I would like to say first that our case is rather extreme and complicated. It is extreme because of the very nature of the handicaps of our daughter and perhaps because of the nature of her parents.

Thirteen years ago when our daughter was born, we were living in another state in a small town in a rural area. It was the home county of my husband. Upon graduation from college, he had returned to the county seat as a high school teacher and later as principal of the high school. He resigned and went to law school. He became an attorney, and we returned to this town where he started law practice.

I shall relate what happened in our attempts to find an accurate diagnosis of our daughter. And you're going to hear, Dr. Tarjan, a mighty good

example of diagnostic "shopping around."

The labor and birth were long and difficult and when she came, she was quite blue. Immediately our baby was given oxygen and placed in an incubator. It was soon noticed that she had much difficulty in swallowing and so feeding was a very great problem. After being examined and determined that she had no physical malformation, the nurses and doctor suggested that we take our daughter home on the fifth day where we would have more time to work with her during the feeding periods. Upon arrival home, our concern was to keep her alive. It was a matter of feeding her each hour around the clock.

At the end of two-months, my husband came home for a short furlough, It was during the war. We took our baby to a pediatrician in the city because she still had swallowing difficulty and cried much of the time. The pediatrician was extremely busy. We waited for a long time for our appointment. He examined her briefly, pounded his fist on the table on which she was lying, and when she made no response to the pounding noise, he turned to me, and I quote: "You do not have a nervous baby. I think she is developing slowly emotionally." I did not quite know what this meant, but he was busy and had to go on into the next room to see the next child. We went home not knowing whether to feel happy or unhappy.

However, at about four months she began to develop at a somewhat satisfactory rate to us and did develop into a beautiful child. At about one year of age, I woke up to the fact one day that she was not responding to words that I said to her. She simply was not understanding. I well knew what her brother, who was just one year older, had understood at one year. Again my husband came home, and I persuaded him to go again to the city to see a different pediatrician. This doctor was a very warm and understanding man. He and the nurses took our little daughter, who was not walking at 15 months, and examined her for several minutes. When he returned to us carrying our little daughter, he said,

"Why would you think there is anything wrong with this little girl? Certainly nothing could be wrong with a baby so beautiful. She will walk and talk." Then he told us that, in his opinion, this slowness in developing was due to difficult birth but that she would catch up with herself in time. This made us feel better.

However, we were still concerned that she did not understand speech. We decided that perhaps it was because she might be deaf or hard of hearing so we tried various little home-made tests. The results appeared to be inconsistent. She did not walk until she was 22 months old. Her poor coordination would have been observed, I think, by anyone.

At the age *of* three, our county nurse and personal friend, came to us and offered to take us to a clinic in a city because she felt the child was deaf. When we arrived at the clinic, we had a long, tiring wait after a long, tiring, warm drive. The baby cried and screamed and became frustrated and upset. After a long time, someone called for the baby and me, leaving my husband in the waiting room. Inside the small, closet-like room, my daughter was placed on a hard table. A lady doctor came—a large, formal person who appeared far removed from our troubles. The baby continued to cry during a brief examination of a few minutes. Then the doctor said to me, "Your daughter has not developed as she should. I do not believe she will ever be a normal person. I do not believe she will ever develop sufficiently to attend school." That was a horrible experience for me. After saying that she left immediately to go to the next patient, I was forced to find my way back to the waiting room, and I found it very, very difficult to relate to my husband what she had said. It shouldn't have been, so, but for some reason I had a terrific, almost undescrivable fear of telling him her diagnosis. When we related this finding to the county nurse, she disagreed. She then made a second appointment for us -- this time to see a neurologist in the city.

At the second appointment, I first related the complete history to an intern. I think I was honest in telling everything. My husband and I were both called into the examination room with our daughter. The neurologist came in. I am sure he had previously read the history I had given. He placed the child on a long table and was going to examine her, but she scooted down to the other end. She did not want him to touch her. She was extremely hyper-active. After a few minutes, and I can't over-emphasize the shortness of the time, he turned to my husband and said, "Your child is feeble-minded." That was the worst shock we could possibly have had. My husband attempted to speak, but the words did not come out; and after a while in a very -shaky voice, he asked the doctor a question to this effect: "Are the symptoms of feeble-mindedness similar to the symptoms of deafness?" The answer: "Possibly so." And then the neurologist said to my husband that we would be ready to institutionalize her in about a year's time. There are no worse words for a parent to hear. We dressed our child, walked down the long corridor alone, drove home saying very little. Our world had dropped out from under us.

For several days we could not relate our experience to anyone. Finally, one day my husband left his office and walked over to our family doctor—the one who had delivered our daughter. He had never talked to us about our child. He had not made the referrals, you remember. In attempting to relate our experiences and the results of the diagnosis, my husband completely broke down. The family doctor's remark was, "I never dreamed that this was the case."

However, another doctor friend of ours in another town found it difficult to accept the diagnosis and made arrangements for us to visit a fine audiologist in the city, because he felt she was deaf. This audiologist was in private practice. We were greeted most cordially upon our arrival. We told our story completely again. He suggested that we leave Royce Ann with him and the nurses while we went out for awhile. We were away an hour and a half while

they were testing and observing our daughter. Upon our return, he told us that he disagreed with the others because he felt that the handicapping factor was deafness. He had some explanation for the poor coordination. He told us that our problem was an educational one and stated that if he had a deaf daughter he would leave a small town and get to a city where there would be educational facilities. This remark we never forgot as you will discover later.

We read much about deafness. We came upon an article written about aphasia. Aphasia seemed to us to fit our daughter. We learned that a school in a far away city had a department where these aphasic children were being taught. We decided to go there. Royce was given a psychological test of a non-verbal type. In our interview, we were told that the test results were not too good, but that at this time, it did not look like a hopeless case. They felt sure there had been some brain damage but stated that the only way one knew how much was to start on a definite educational program. It was determined that I should go down to the school with Royce Ann for a few weeks and that I should take some training to teach her. After doing this and teaching her for several weeks at home, everyone felt encouraged with Royce Ann's accomplishments.

Remembering the audiologist's statement, my husband felt that we should get located in a city. Eventually, we were located in Minneapolis, and at four and one-half years of age, Royce Ann was enrolled in the Louis Agassiz School for the Deaf. She had passed the tests for admittance here. From the very first day on through the weeks and months, she made a very poor adjustment. She was extremely upsetting to school room and acted entirely different than anyone else the teachers had. There were things she could do. She could take a word and match it with the picture if she were not crying or screaming.

The principal suggested to us, at the close of the first year, that we go to the University for a complete diagnosis. This we were glad to do. At the end of a four or five-day stay in the hospital, we had an interview with the doctor. We were told that she was perhaps deaf but that she did have a low IQ and was a retarded child. By this time my husband had reached the place where he neither believed nor disbelieved a diagnosis. In our own mind, we had to prove that she was a retarded child. We fully recognized that she did not do the things she should, but she did not fit into our prior concept of a mentally defective child.

Royce Ann went back to school the second year. Her behavior was not improved. In fact as the months passed, her adjustment became worse. She was studied by the Child Study Department in our public schools. Before the beginning of the third year of school, we were asked to withdraw her because the school people felt that she was not gaining any help from school, and she was a hindrance to the other pupils.

Then several people offered suggestions of people we might go for help. Our minister asked us to take our daughter to a personal friend of his. This doctor became interested in Royce Ann and decided that he would like to have a team of doctors study her for awhile. The audiologist in his doctor team was firm in his belief that she was not a brain-injured child as such, but that the handicapping factor was deafness. The team decided that our daughter could benefit from individual instruction, hoping later to make the adjustment in group. They secured for us a wonderful teacher of the deaf who for one year gave her private lessons. I was to carry on these lessons during the intervening days. The teacher was extremely satisfied with the progress Royce Ann made and sent a report to the school administration.

In the meantime, my husband and I were reading whatever we could find on brain-injured children, on retardation, and on deafness. We could easily

find evidences - almost daily evidences of brain-injury. I should say evidences of behavior which is characteristic of the brain-injured child. She learned to recognize words very readily, but I discovered it was a rote type of learning. There was much hyperactivity; there was impulsiveness; there was much unevenness in development; there was non-conformity; perseveration; catastrophic reactions almost every day. It seemed that every day she was growing farther away from a normal child.

Then the public school people phoned and suggested that we enroll her again which we did. The first month of school went fine, but as school progressed, the pressures and tensions mounted, and soon the catastrophic reactions occurred again in the school room. At the end of the first semester, we withdrew her from school at the request of the school.

Again we sought the advice of the team of doctors. She was again tested. This time they gave us some very direct counseling. They reminded us that ten years had passed and that all our efforts to keep her in group situations had failed. They pointed out the possible effects, of having her continue in the home, upon the other children. They recommended state commitment and placing her in Owatonna, a state school for those with IQ from 50 to 80. This was the procedure and decision we had fought against for ten years; but three months later, she was committed to the state and in a few months placed in school in Owatonna. The school situation again was too much pressure for her to withstand, and the psychomotor disorders were more extreme. She was transferred to the State Hospital in Faribault where she has now been for about three years. She has gradually become quite happily adjusted, and the catastrophic disturbances are much less frequent. We see her every two weeks. She is happy to see us, but she is just as happy to go back to her friends, the first friends she has ever had.

I think it is evident to everyone that the shopping around indicates that we did not attack the problem in an intelligent manner. However, the very fact that there was an unevenness of development and that there were differing and conflicting diagnoses were possible factors that encouraged us to continue our search. You will note that in the early days, we had no counseling. We had diagnosis, but not until we came to the audiologist did we have counseling and that was "I'd move." Our family physician was a very fine man; but if he recognized any difficulty, he somehow found it impossible to talk to us about it. He was a personal friend of ours, and he knew that I was worried about our daughter.

After the diagnosis, parents need to have an opportunity to sit down with the doctor and talk about their child. We recognize that time is limited with the busy doctor; and yet perhaps it doesn't take too much time to be somewhat warm and understanding. Such an attitude and personality on the part of the doctor can ease the parent's suffering a bit. Parents need to be told where they can go for further help. They need educational information. They need all sort of referrals to agencies, individuals, and parent groups. It is desirable in most cases for a parent to be referred to another parent who has already met some of these problems and learned to live with them. Care must be taken that the experienced parent is one who is reasonably intelligent, has made a reasonable adjustment, and who is reasonably socially mature and stable.

The mental health of the entire family is at stake. Perhaps the doctor is the only one who can observe this and can somehow save a lot of emotional stress and strain within the family.

We would like to say that we are very happy with the interest that has been shown in this area by the doctors in the field of mental retardation. We would like to encourage you to continue your study.

Dr. Jensen:

Thank you very much, Mrs. Monson.

Our next speaker is Mr. John Halahan. Mr. Halahan is head of the Division of Research at General Mills. His story may be a bit unusual. As you would expect of any researcher, he has kept running notes, particularly of his own reactions since he was first aware of his son's deficiency. In our conference the other day, he was encouraged to give us the benefit of these recordings. You will find them interesting, since he will indicate that the passing of time does bring changes in parents, particularly as they relate to change in feelings and attitudes. As with so many parents who have worked through their difficulties, they make very real contributions in other ways. Being trained in research methods, Mr. Halahan has made a most comprehensive survey of the mentally retarded which is most useful for planning purposes in our state. We're glad that you're here, Mr. Halahan,

Mr. Halahan:

It is a pleasure, as my two dear friends have indicated, for us to be here to speak before you. One of the bonuses that comes with having a retarded child is that you get into the parents movement as the three of us have, and then meet so many splendid people. We often say in jest that unless people have retarded children, we aren't interested in associating with them. Our involvement in the parents' movement has been so complete that by now our friends, both social and extra-curricular wise, invariably are other parents. We have had vacations together. We go over to each other's houses frequently. Perhaps the greatest single factor accounting for the adjustment which Dr. Jensen says that we three have made is the association we parents have with each other. In market research we have what we call assets and liability studies. There are, no doubt, many liabilities attendant to having a retarded child; but if you look at it in the right way, there are assets to be had also. One thing we

would like to urge you doctors to do and that is to encourage parents to associate with each other so that they may gain these tremendous benefits. Parents need to get out and find that they aren't alone and that there are lots of other people in the same boat.

Now to talk about my child, Peter. Many of the things I will tell you have been abstracted from notes that I started keeping soon after Peter was born. The impressions I will give you are those I had at the time the notes were written. These impressions and ideas were not laid down as impassionately or as judiciously as I might state them today. But for your purpose, I believe you want examples of how patients feel during the critical times, not some thirteen years or so later.

Our child is now thirteen years old. He was born in Akron, Ohio, where we were living at the time. At that time all of the girls in our circle of young married couples were having babies. The girls would get together and discuss this obstetrician and that obstetrician, and finally as a matter of sifting through the evidence they generally gravitated towards one fellow, a Dr. C, who was regarded as the leading specialist in Akron at the time. His practice was quite vigorous, to say the least. He was delivering about 125 babies a month. The girls raved about him because he was brusque and tough with them and stood for no nonsense. We fellows were essentially neutral about this, feeling that what happened from now on was strictly a matter between the doctor and the girls.

Our son came into the world rather reluctantly after a 36-hour period of labor. From the very beginning, he seemed to be a pretty baby, well-formed, and nicely colored. On the fourth day after the delivery, I asked my wife if she had ever seen the baby with his eyes open, I hadn't. She said that she had and assured me that all was well. She mentioned, almost as an afterthought, that his eyes were a little cloudy. But that was nothing to worry about. New

babies are like that sometimes, but it clears up in a few days. So I let the matter drop too.

My wife was due home on the tenth day. On the ninth day, when I came in to see her, she burst into tears and told me that Dr. C. and an eye specialist had been in to see her. The eye man had told her that something was wrong with Peter's eyes. Just what, he couldn't say for sure, but indicated something about congenital opacity of the cornea. I gave my wife what comfort I could and then hurried to call Dr. C. since she told me that he wanted to talk to me. When I reached him on the phone, I said, "Hello, Dr. C. This is Mr. Halahan. I understand you're concerned about Peter's eyes." "You're dam right I'm concerned about him," said Dr.C., with the style that the girls thought so highly of. "You've got something to worry about, but I want you to get one thing straight. It's not my fault. The delivery was perfectly normal, and the condition has nothing to do with what I did.'

Although having heard about the man for the last seven months, I had never seen him or talked to him. And now, here he was, in my most critical moment, on the defensive absolving himself of a blame J had no intention of casting on his shoulders, seemingly oblivious to the vital problem - my baby's eyes. His lack of tact and consideration brought out the same in me.

"Listen, Doctor." I said, bristling immediately, "I'm not the least bit concerned about whether Peter's eyes are your fault or not. All I want to know is what the trouble is and what can be done about it." "Well," said the Doctor, "I suggest you stick with the eye specialist. He's the best eye doctor in town. I called him on the case right away as soon as I spotted the trouble. He'll tell you all about it- Keep me informed. I'd be interested in hearing about the Case." "Like hell you will," I thought and hung up without answering him. We paid his "bill and that's the last we ever had to do with him.

We then put the child in the hands of a pediatrician who kept the child healthy and who was concerned about the eye condition. He tried a little medication for them but generally felt that the condition was beyond his power to cure, and, indeed, it was. The eye doctor in the meanwhile kept observing the child, feeling that this was the wisest thing to do. He did give us some rather good counseling, and according to my old notes, he said this, 'There is no hurry about treating this eye condition. Mother Nature is the best doctor for fit. All I can do is observe what Mother Nature is doing. Sometime, however, when you go, back home to Minneapolis, I want you to take Peter to another eye man, but when you do I want you to go to a top man. I insist upon it. I am the only doctor in Akron who has earned his living exclusively off eye cases for the last thirty years, and I don't want my opinions kicked around by just any doctor you might go to.' (Apparently the medical profession doesn't show the same high regard for all their fellows as they publicly claim to.) "Once you have seen this other specialist, please accept our opinions and don't spend a lot of time and money chasing all over the United States trying to find someone who can help Peter. In my opinion, nature is the only doctor who can do Peter any good.

This advice was good and sound and essentially we followed it. This doctor, however, never did give us a complete description of Peter's condition.

On our next trip back to Minneapolis, we took the child to Dr. Bu. in St. Paul. Dr. Bu. looked at Peter, much as the Akron eye doctor did, and then said he couldn't tell us much without taking the child to a hospital, anesthetizing him, and observing the child when quiet. This was done. Dr. Bu. then took us into his office and explained to us exactly the whole problem. He rendered the explanation clear by drawing us a sketch of the eye and then pointing out the parts that were congenitally malformed. He also outlined the possible operations that might be performed, the risks involved, and the poor chance of the

operations doing any good. Without saying so, he actually advised us against any operations, and from that time on we never considered any.

On returning to Akron this information was passed along to the eye specialist, who oddly enough seemed a little miffed. He had told us to seek out an expert, and yet on hearing our report made, the rather odd comment, "Well, I could have told you all that too if I had taken him to a hospital and did all of that!"

When the child was sixteen months old, we moved to Princeton, New Jersey, as part of my Navy training. Dr. Bu. had urged us if ever we were near Philadelphia to take Peter to a colleague of his there. This we did. It involved the same hectic trip situation that Mrs. Monson has just described. Upon arrival we were ushered into the doctor's office. He spent about five minutes looking at Peter, checking his eyes, his hearing, and his reactions. He told us nothing. We then took the three-hour trip back to Princeton. Sometime later we heard from him in the form of an invoice. We paid it and never heard anything more from him either. Again my notes state that Peter was probably regarded as a rather interesting specimen to be exhibited to as many medical men as we could be persuaded to visit. However, I kept bearing in mind the advice of the Akron doctor stating, "It's no use going all over the United States hoping for a cure. It probably won't do any good." So we were disinclined at that point to do any further searching.

The Navy then sent me to Boston to complete my radar training. We were put in the hands of another pediatrician. My wife took Peter to him at his request every two weeks over a four-month period. Peter was then nineteen months old. This pediatrician never mentioned the possibility of retardation during these visits. My wife and I suspected, however, that something was wrong, and we discussed it often among ourselves and mentioned our concern to the pediatrician. At the time we knew nothing, absolutely nothing, about retardation; the word, the terminology, anything about it. We just felt that Peter wasn't

coming along as fast as other children we had noticed. The pediatrician's examinations were casual, and he seemed to confine his activities to watching the child's diet and general health. Finally, at our urging, he did make arrangements to have the child taken to Boston's Children's Hospital for three days for observation. The pediatrician reported back that the findings were inconclusive and didn't indicate lack of normal development one way or the other. True, Peter was developing more slowly than normal, but this condition could be due to the handicap of poor vision.

During the last visit to the pediatrician which my wife made alone with Peter, she told the doctor that I was being transferred overseas and that she was returning to Minneapolis. The doctor then opened up in a rather sharp and decisive fashion. He told my wife that Peter was low in mentality, that he would never develop normally. He advised her to stop chasing around to doctors and expecting anything much from Peter. She came home greatly distressed, somewhat disinclined to accept the advice. An interesting point here. Peter had a profusion of pretty auburn curly hair, and she rushed out of the doctor's office to take him to a barber shop and had all the curls cut off. Giving him a butch haircut somehow made her feel better. Then she came home and reported what the doctor had told her. After his report had sunk in awhile, we both were inclined to accept it as being essentially correct. His overall evaluation coincided quite well with what we had observed about Peter's slow development. Again in my notes I wrote that it now seemed-obvious that the doctor had suspected mental retardation from the very beginning. We felt that he should have told us sooner, at some point towards the beginning or the middle of our visits. But instead he told us at the last hour. Had he told us sooner, we would have been spared a great deal of inconvenience. I realize now that he probably had my wife coming back every two weeks in order to check out what he was suspecting. This was o.k., but he certainly should have taken more time and been more tactful when

he finally told her the bad news. The fact that he told her only when he knew we were about to leave town the next day indicated to us some reluctance on his part to discuss the matter.

We returned to Minneapolis and from there I went overseas. My wife then had Dr. Be. as our pediatrician. Dr. Be. is a good friend of ours. He went along pretty much with the mental retardation evaluation, but to make sure Dr. Be. had my wife go and see Dr. Jensen. Dr. Jensen placed Peter in University Hospitals for observation, and then told my wife that he, too, thought Peter was mentally retarded. He, however, didn't let it go at that. He practiced what Dr. Tarjan was preaching before you today. Dr. Jensen gave my wife a long explanation as to what mental retardation was, what it meant, and what might be our various alternatives for handling Peter's case. He also wrote me a long letter telling me much the same thing. His final advice was that my wife need do nothing until I returned home from the war. He felt there was no need for her to rush into anything before then.

When I returned to Minneapolis, we again went over to see him. This time he also had a psychologist give Peter an intelligence test. - This established Peter's IQ at around 30. Dr. Jensen again explained to what extent Peter might develop, what mental retardation was, and what we might look forward to. He told us about the state institution in Faribault, urged us to go down there sometime and look the place over. He explained what commitment proceedings were all about. At the time we weren't even aware that there was such a thing. He told us how to undertake the commitment action by working through the Hennepin County Welfare Board. He said we should look upon commitment as an insurance policy - if anything happened to either of us that we would be assured at least of Peter's future because the state would be responsible for him. Until such time as we actually wanted to put Peter in an institution, there would be no obligation for us to do so.

We felt then, and we still do, that Dr. Jensen did an excellent job for us. He told us what was wrong with Peter; he explained what mental retardation was; he told us what was done with mentally retarded people in our own community; he suggested a plan of action that we might follow. He was kind, considerate, and understanding with us. We never felt at any point that we were under any pressure to get out of his office or that we weren't welcome to come back again to talk about the problem as long as we wanted to. When we left his office for the last time, we felt for the first time since Peter's birth as though we knew what we were up against, and what we had to do to cope with our problems.

A period of three years elapsed from this time until the time when we actually placed Peter in an institution. During the three-year period, we had ample time to confirm Dr. Jensen's evaluation of the child.

After leaving Dr. Jensen's office, and with his explanations still fresh in our minds, we then proceeded, post haste, as it were, to find out all we could about mental retardation. We joined the parents' group and became active in the affairs of the organization. This put us in touch with the professionals in this area who were working with the mentally retarded. We learned much from them. We also asked around for books on the subject. I spent several days at the Public library going through everything they had on the subject. I also joined the American Association on Mental Deficiency and subscribed to their publication, "The American Journal of Mental Deficiency."

During this same period, another of our parent members, Mrs. Gladys Bierne, a graduate librarian, undertook to compile a bibliography on "Mental Retardation," slanted to the viewpoint of parents. MARC mimeographed this bibliography and sent a copy to everyone of its members. The national parents' group, NARC (National Association for Retarded Children) has subsequently taken

over this project and now has printed the bibliography. Copies can be obtained from them.

Looking back now, on all of the reading I have done, I would say that the following books were of the greatest help to me:

"Mental Deficiency" by Tredgold; published in London by Bailliere, Tindall, and Cox

"Vocational Rehabilitation of the Mentally Retarded" edited by Dr. Salvatore DeMichael; published by the Federal Security Agency, Rehabilitation Service, Series No. 123, U.S. Government Printing Office; 1950.

"The Biology of Mental Defect" by Dr. L.S. Penrose; published by Sidgwick and Jackson, Ltd., London, 1949.

Perhaps the best speech I ever heard on the subject was one given by Dr. Abraham Levinson at the NARC convention in Grand Rapids, Michigan, in 1951. Dr. Levinson developed the doctor-parent relationship in great detail, and gave excellent advice which both parents and physicians would do well to follow to their mutual advantage. Dr. Levinson has since published a book, which I haven't read, but which probably contains this good advice and more.

"The Mentally Retarded Child" by Dr. Abraham Levinson; published by John Day Company; 1952.

Looking back now at my own experiences and having listened to many other parents relate theirs, these things stand out:

First of all, we parents do not take kindly to doctors who are brusque, short, and unsympathetic with us. We feel quite strongly, as Dr. Tarjan has just told you, that a doctor's obligation doesn't stop with the evaluation of the child. It really begins at that point.

Secondly, we are puzzled and resentful of doctors who told us nothing or withheld information from us. In our vanity, perhaps we feel that those of us who possess some degree of intelligence can be told things without going to pieces over the information, or using it subsequently in a very imprudent fashion.

Thirdly, we feel that doctors ought to explain something about mental retardation to the parents, so that the parent can begin to follow through and acquire the additional help and information he will need. Obviously the more the doctors can tell parents about resources and conditions in his own community, the easier it will be for the parents.

In view of what I now know about mental retardation, it seems that my wife and I went down a long, long trail before we finally came to the end of it. The Monsons went down an even longer one. The Gundersons *are* still marching down theirs.

I realize now, as my friend Dr. Be. has told me, that a doctor has to be very sure of his evaluation before he can break the news to the parents, If a doctor has to make mistakes, Dr. Be. feels they should be made on the side of caution. I fully agree with him on this.

However, I still feel, that if we had to go through our problem all over again, I would want to get to someone like Doctors Be. and Jensen a lot sooner than we did.

MENTAL DEFICIENCY AND MENTAL HEALTH

Reynold A. Jensen, M.D.

It may seem unusual to discuss the subject of "Mental Deficiency and Mental Health," since the question may arise, "is there any relationship between these two large areas of medical practice?"

Careful inspection does substantiate a close relationship. First and foremost is the large number of persons involved. Dr. Tarjan ably pointed out this morning that the mentally retarded population constitutes the largest single group of individuals in medical practice. Yet, until recently, it has not been accorded its rightful place in medical practice. The reasons for this are many and, no doubt, some of these will be clarified for each of us before these sessions are over.

Because many of us have been unmindful of the mentally retarded for too long, there is a general lack of understanding of the many unmet needs in this large group. Hence little has been done in the way of medical planning for their care and management. This in itself carries with it mental health implications. Retarded persons are human beings whose basic needs must be reasonably met if they are to be assured of a chance to live as satisfying and happy a life as possible.

But there is a much closer relationship between these two fields than mere numbers. Each mentally retarded person belongs to a family. The influence of such a child in the family can be very threatening as was pointed out by the parents who met with us this morning. The many concerns, anxieties, tensions, and frustrations which too often are associated with mental deficiency influence the stability and often the integrity of the home and family. The desperate struggle which many parents encounter in their efforts to find help in the resolution of

their dilemma further complicates the situation. Many parents, striving for assistance, practically deplete their economic resources to find help and that too adds further tensions.

But most important is the persistent agony which parents of mentally retarded children experience unless they are fortunate in finding help in the understanding of their child and in resolving the many problems associated with his deficiency. It is in this area that a close relationship exists between "Mental Deficiency and Mental Health." Helping parents understand the basic difficulty which their child presents, what its probable explanation may be, what can be expected for the future, and what possible plans should be considered in the interests of all, does much to restore and conserve their "peace of mind" and hence mental health.

It is in this area we can do a great deal to promote mental health of parents and their children.

To be effective requires an understanding of what we as physicians can do when a child is mentally retarded. At the present state of our knowledge, there is little that can be done to correct the child's basic deficiency. This we must accept for it will reduce our own feelings of uneasiness. We can do something, however, and that is to help parents accept the child's deficiency, and we can help them deal more effectively with their frustrations, doubts, and uncertainties. It is in this area that much can be done to enhance the mental health of parents and their children.

Parents with retarded children are anxious. It is seldom that they recognize the sources of their anxiety. It was implied this morning by Dr. Tarjan and in the presentations made by the parents. In brief, it stems from the dreaded-question, "If I've brought a defective child into the world, what's wrong with me?" It does seem every human being has a notion of perfection.

Anything which tends to jeopardize that notion creates tension. In illustration, I remember a medical student who nearly went into a tailspin when, on his first chest x-ray, it was noted he had a congenital anomaly involving the union of one or two of his ribs with the sternum. Ridiculous, to be sure, but it illustrates the point. Second is the dreaded question, "What are other people going to think about us and our child?" This involves, of course, relatives, friends, and neighbors. The third source of tension stems from the dreaded question, "If I have a defective child, what is it that I have done that I should be so punished? There is often an unconscious effort to relate the birth of a retarded child with an unrelated incident which may be many years in the background." If we recognize some of these sources, and there are others, we are in a strategic position to help parents handle their dilemma.

With this as an introduction, I should like to offer a few suggestions which may be helpful. To do this requires that we clearly define our roles and responsibilities and develop our skills and techniques in dealing with parents. It is acknowledged that one such as myself, who sees parents and children as a consultant, may function differently from one in everyday practice. However, some of the lessons distilled out of many years of trial and error may be useful to each of us.

What is our primary task? Since it has been my observation that most parents, particularly mothers, know intuitively that something is wrong with their child, what they want most is confirmation of their doubts. What is wrong? What is the cause? What can be done about it? These and many other concerns are uppermost in the minds of most discerning parents. True there are some parents who, when the child is young, may not yet be mindful of their child's deficiency. In such cases it is possible to raise a question now and then concerning the child's growth. But here, too, it is well to wait until the

parents themselves express concern.

It is essential to assure parents of our interest in their child and their questions or concerns. This requires patience and a willingness to devote the necessary time to determine the child's potential and to answer, to the best of our ability, the many questions parents have. Too often what is obvious to us is not to the parents. We handicap our efforts when we are too direct in expressing an opinion and not following through with full explanation. Each parent this morning mentioned their disappointment in this regard.

We can strive for thoroughness in the study of each situation. In no problem is careful detailed history so essential. Careful physical study is also indicated with particular attention being accorded to the child's hearing. And if, after we have done our best, most parents will welcome the suggestion of consultation.

We can be helpful by disciplining ourselves in the choice of our words and the manner of presenting our findings and impressions. It is helpful to eliminate words such as "moron," "imbecile," or "idiot" substituting instead such words as "mentally retarded," "slow developing child", or "backward child." In discussing possible plans of action, one never talks of "sending the child away. This implies a threatening kind of finality. One can suggest "placement" which carries a bit different connotation. It is possible to suggest in the case of a severely retarded child that parents may wish "to take advantage of the facilities which the state provides for a child who is unable to manage successfully for himself." It is a difficult exercise to train oneself in this way - but it is rewarding.

Helpful also is to differentiate and understand our responsibilities and what those of the parents are. It is our responsibility to confirm their doubts, to explain the factors responsible for it, and to suggest possible plans of action for future planning. It is the parents' responsibility to make the

final decision as to whether the child is to remain in the home or is to be placed. They will make good decisions when we have helped them in understanding the child's limitations.

In this connection, we could be more accepting of the mother's intuition concerning her child. And also we can be more accepting of parents' resiliency. Difficult as it is parents do want to know and are capable of accepting the reality of their situation when given time and support. If we will perfect our techniques in dealing sympathetically with them and their feelings, a disagreeable task will be a bit easier and a bit more comfortable.

Parents should be seen together when we discuss our findings and impressions. This is important not only to prevent misunderstanding when one spouse tries to tell the other what the doctor said, but also to help parents in coming to grips with their common problem. By seeing parents together, we do help them strengthen their interpersonal relationships in many instances.

The realization that, in moments of doubt, they can call on us is likewise helpful. As they and we work together in the resolution of their troubles, they learn what they can expect of us and we of them.

One more thought. Recognizing the threat which a mentally retarded child has to many parents, they often become angry at us. Not one of us enjoys having anyone angry with us. It may, however, be important for parents. We can avoid complications by accepting this as an essential part of the process and by trying not to be too much threatened by it. At times this is difficult.

As was mentioned earlier, parents welcome the encouragement to associate themselves with other parents who have faced similar problems. By our knowledge of parents who have retarded children or of parent organizations such as the Association for the Mentally Retarded, we can introduce them to other sources of help and support.

At best, trying to help parents with a retarded child is a difficult task. However, if with patience and understanding we can help them in their dilemma, we can do a great deal to preserve their mental health and the stability of the family.

MEDICAL COUNSELLING AND GENETICS

Sheldon A. Reed, M.D.

The Dight Institute, as Dr. Jensen said, was established by a former physician of this city who had great intellectual brilliance. He was far ahead of the thought of his times, and many of the concepts that we accept today as being ordinary public health facts he understood at a time when they were still generally unknown. He realized at once, as soon as the Mendelian laws of heredity were discovered, that they were important to people, to the extent that their lives were determined by their heredity.

Dr. Dight realized that people who had problems concerned with their heredity would want to know the answers. They always had wanted to know the answers. They had asked their friends and enemies for answers to these questions, and if the friends and enemies had no information, they still probably gave answers, so what we hope to do is upgrade the kind of over-the-fence answer that you get, so that it's a little closer to what has been established scientifically. So Dr. Dight stipulated in his will that a center be established where people could come to get information about heredity, to find out what was known. Also, research was to be done in the field of human heredity and some course work was to be presented. His stipulations have been fulfilled to the best of our ability, with the rather limited funds which we have.

For the formal part of the talk, I will commence by borrowing an old story which you probably have heard before. But this story is important to our consideration of what is to follow. This story goes that on hearing about Darwin's theory of evolution a lady cried, "Descended from the apes? My dear, we will hope that it is not true. But if it is, let us pray that it may not become generally known." To her it was terribly degrading to be related to an

ape even if it was millions of years ago. But the news did become known, of course, and most people have grown reconciled to the idea that many millions of years ago they had primate ancestors who were not developed intellectually to the state that we are today. Whether they had a little more fur or a little less isn't important. It's probably the intellectual difference between the apes and us that makes the comparison invidious. That is, we may recognize the fact that we are related to these early primate forms, but we still do not enjoy this thought particularly. We recognize the biological continuity of the heredity with the changes that came about as time went on, but we don't appreciate that particularly. We have the same sort of thing in counseling in human genetics. People are not anxious to acknowledge all of their heredity. Some parts of it they are interested in; for instance, everybody that can claim descent from some obscure passenger on the Mayflower points this out with great pride, but this obscure passenger who was not known to the world at that time, therefore, becomes one of their important ancestors whereas they neglect the other three or four thousand ancestors that they had in that generation, some of whom might have been much better known as witches or pirates or other notorious characters of the time, who did not come over on the Mayflower.- But we are not so interested in tracing our ancestry back to those individuals as we are to those who came over on the Mayflower, so I usually think of this misconception about the importance of our various ancestors as the Mayflower myth. People point with pride then to traits which they assume they got from somebody whom they look back to with interest and approval, and do not take much trouble to acknowledge their relationship to some cut-throat or other ancestor they had who wasn't generally socially acceptable. They tend to have somewhat the same idea about their heredity. They are willing to acknowledge heredity for types of noses or eye colors or things which really have no fundamental importance.

Everybody has some kind of colored eyes and generally most people are fairly satisfied with their eye color, whereas they're not so interested in acknowledging the fact that they might have inherited the gene for Huntington's chorea, for instance. We find that in doing research on deleterious traits you get pretty good information from the in-laws about the affected members of the family, but the blood relatives are not quite so free with the information. Now why is that? It's obviously due to the fact that those who are likely to get the trait deplore the situation and are not telling. They're not free agents in this respect.

We find that clients at the Dight Institute do not really wish to learn that their problem has a hereditary or genetic basis. For instance, they want to be told that their albino child is just an exaggerated Scandinavian or some rationalization which takes off the sting of the fact that the albino has a tittle different heredity from that generally found in the population. If you have a straightforward pedigree of say three generations of congenital cataracts, you'll find that then the client wishes that the heredity be of the recessive type rather than the dominant. They will argue for this because they feel that the chances of their children being affected are less if it's a recessive in its heredity than if it is a dominant. So you see that the counselor in genetics has a psychological problem right away in that his clients really do not want to accept the idea that heredity has something to do with the situation. And I might say that my experience in general is that the people who are the most resistant to the idea of heredity probably are the parents of the mentally retarded. The social stigma which goes with mental retardation is very considerable and they feel that if there is a genetic background for mental retardation, it classifies them as being part of a Jukes or Kalakak type of family. It is a condition which they would deplore; they do not want to be a

part of such a family and do not wish to accept the idea, even if they actually belong to a family with many cases of retardation in it. I suppose that probably among physicians the group which find it hardest to accept the concept of heredity - that is, the concept that the cells of the brain have something to do with the person's actions - would be the psychiatrists, for two reasons; first, that it is difficult to show an association between the cells of the brain and the actions of the individual. The physiology of mental reactions is still not at all well known. And secondly, because they might think that if genetic, there would be no way of curing a mental disease or mental retardation. That, of course, is not so. The acceptance of genetics does not decrease at all the need for psychiatrists or other physicians who are curing the ill that the individual has. What the basis of the disease is, is important in the diagnosis and the methods of cure, but you still have to treat the patient whatever caused his difficulty.

On the other hand, we occasionally come in contact with some relatives, perhaps some of the in-laws, who are very much in favor of genetics. They really believe in it one thousand per cent. Now when you get such vigorous enthusiasm for genetics, it ought to be somewhat suspected. It may be that their love of science in this case is merely a camouflaged weapon for internal family warfare. It may not have anything to do with the actual position of science in their thinking.

Supposing that we accept the idea that the client in general does not want to accept the idea of heredity being related to his problem, what effect does this have on the counselor? The person comes to see the counselor and tells him what the problem is, and the counselor naturally wants to make the client feel at ease. He wants to make the client go away happy, and at the same time to impart whatever information is necessary. So the geneticist will

try to find some way of relieving the client of the heredity aspects. In other words, he will look for an environmental explanation of the abnormal child or whatever it is that is bothering the couple who came to see him. The people come entirely voluntarily. They are referred by their physician or have learned about the Dight Institute through the newspapers or in some way or other, or by talking with other people, so that we get a constant stream of people coming to the Dight institute. They want to talk about their problem, but they don't, certainly at first, want the suggestion that the situation is genetic. They want to be told that it is environmental. And in many cases, of course, you can do that -which is a very fortunate situation.

In many cases, of course, we have a clear indication that there was birth brain damage or something of that sort and can immediately be helpful to the client by pointing out that this is not genetic, that Weismann showed sixty years ago that mutilations of anything other than the gene itself would not be passed on to the offspring. That is, you can circumcize for two thousand years, and still it has to be done over again in every generation. It has not become hereditary; it has not in any way affected the germ cells. We can point out to the couple that the problem is a result of an infection, if that happens to have been the case, and that no repetition of their misfortune would be expected. We always try to get all the medical information that there is. Usually it comes with the referral; if it doesn't, we send them back for it if there ever has been any, or make them go get it if there hasn't been. Thus we can help out by immediately dismissing the idea of genetic transmission if it seems clear that no genetics is involved. However, if it is doubtful as to whether genetics is involved or fairly certain, then we have a different situation. We have to have the conference come to some kind of a happy ending, but without denying the role of heredity. We have to bring in the educational

aspects. We don't tell them brutally that they have transmitted a gene to their child which is causing the difficulty, but we have to somehow or other impart that idea and let them know what they have come to ask, that is, what are the chances that they will have another child with the same difficulty. Now we could, of course, always tell them that, "No, there is nothing hereditary about this. Go and have a dozen children, and every last one of them will be normal." However, if you go too far in that direction, you may get into a very unfortunate fix, because they may take your advice very literally and produce not a dozen children, but enough so that you'll get a repetition of this same abnormality, and lightning having struck twice in the same way and in the same place, they will no longer consider you to be one of their friends. You should have told them the truth in the first place. Unfortunately, things like rubella and automobile accidents, do not occur a second time at exactly the right time to account for the second abnormality. Now if the trait is a Mendelian one and the chances of the repetition of the trait are one-half as it would be with a dominant showing good penetrance, or one-fourth for each subsequent child for a recessive trait, there is a very strong probability that the clients will be back with a second affected child, particularly if they carry out the pediatrically approved spacing of a child every two years. They will have enough children soon to fulfill the Mendelian ratio with a second affected individual. Now it's my impression-that thirty or forty years ago there was a rather different attitude than there is today about the reproduction of the family after an abnormal child has appeared, and I think that most of the literate families a generation ago generally refrained from further reproduction after they had had an abnormal child. I don't mean that all families did, but those who were educationally advanced, I think, were worried about the reappearance of an affected child after they had had one, and stopped having children at that point. Today the young

Americans seem to have accepted very literally the philosophy that every married couple should have a family. If the couple is infertile, then fertility can *be* provided at the fertility clinic. There isn't any limit on the number of children you can have, as long as they are spaced and as long as they are wanted. So that we have had, as you know, a very sharply rising population since the war and today's young couples reproduce with joyous planned abandon which I think is a good description of what happens in veterans' villages. Now whatever the reasons for this seeming increased compulsion to produce a family, the lot of the genetic counselor becomes somewhat harder, because if they are certain that they should have a family regardless of what abnormalities might appear in it, it is much more difficult for the counselor to, without telling them what they should do, educate them in what they might do. Let me give you a recent counseling case which is not concerned with mental retardation, but which illustrates very clearly this compulsion which most couples have to produce a family. In this couple, the wife had been blind since she was a small girl. She had had both eyes enucleated because of congenital glaucoma. Her husband has very poor vision because of congenital cataracts. They have had one child, and this baby is the third generation with the congenital cataracts. First, the ophthalmologist thought the baby had glaucoma too, but it didn't, fortunately, so that while the baby's prognosis for vision is poor, it none the less isn't as bad as if it had had glaucoma too. Statistically speaking, that is according to the Mendelian expectations, this couple has at best an even chance of producing a normal child at each subsequent pregnancy; that is, if they had very many pregnancies, they will certainly produce more blind children. And the couple was worried about the production of subsequent blind children. They didn't want to have any more blind children. On the other hand, they had no inhibitions against producing normal children. They did not feel that they were particularly handicapped, in spite of the fact that the mother could see nothing whatsoever as her

loss of vision was absolutely complete, but they were worried they might have more effected children and so had come to see me on the referral from their obstetrician. I was rather curious about the attitudes of this couple as they seemed to think that they could do as good a job as anybody else who has normal children. They just wanted to be free of the genetic defect and not transmit their genes for abnormal vision, but that was their only problem. I tried to point out to them - I usually do not go that far with the clients - that they had another problem, that if they had a normal child, this child might feel that itself was abnormal, being a member of a blind family. We have other cases where such has occurred; that is, the normal child feels that it is the abnormal member of the family because it's not like the rest of the members. Within a family, what is "normal" is a matter of relativity.

This problem of how far the counselor should go in advising parents should be considered. I think that in all of the heredity clinics which we now have in the United States, that the conduct is absolutely uniform, or very close to being uniform. We do not try to sell anybody anything, that is, we are not telling them they should have zero or twelve children. We are not trying to persuade them to do anything. They come voluntarily in the first place, and we realize that we have no commission from anybody to try to convince them of anything, but that our job is purely that of trying to answer their question which they have come to ask, and the question that they ask is, "What are the chances of the repetition of the abnormality?" You see, this is not really counseling, it's not really medical, and it is not entirely genetic. But the geneticist is the one who will know, if anybody does, what the chances are of a repetition of a congenital or genetic abnormality. And even if it is not genetic___that is, if it is due to hormones of the mother - the geneticist is still the one who collects that information about the environmental factors concerned and tries to

evaluate them. Thus we can tell them what the chances are of a repetition even if it is not genetic, because we have the insurance risk figures, that is, the empiric risk figures which show what has happened in exactly this sort of case on a large scale in the past. We try to educate and not to force upon or compel the family to do anything in particular about their subsequent reproduction or lack of it. We merely try to answer their question of what the chances are, and one of the most important functions is to teach them what a chance is. You would be amazed to know the people who are so interested in the Irish Sweepstakes and all other kinds of gambling have so little concept of what chances are. They don't oftentimes distinguish between one chance in four and one chance in one hundred. It's all the same to them so that with many intelligent people you have to explain to them enough statistics so that they have some concept of what is happening when the gametes segregate and separate in meiosis. and when they combine to form the zygote as the fertilized egg.

Now, finally to come to mental retardation, we have had many cases which are most bizarre. The one that I will tell you about shows the kind of problem that we get; it shows the value of a correct genetic appraisal; and it shows how physical and mental traits are correlated and dependent on each other. Most of the cases that I will tell you about are those that I had first because since then I have had time to go back and establish contact with the family again to find out what they did. We do not prescribe for them what they should do; we do not inquire of them at the time of the conference what they are going to do because they don't know. They're still confused, and it takes them awhile to simmer down after they have had their education and figure out what they do wish to do in the future. But we do take their address at that time and later re-contact them, and we have never yet had a refusal to supply information when we went back to them. They have always welcomed our inquiry as to how they were

making out. Now this case concerned a couple who had a baby six months old at that time with microphthalmia, one very small eye, the right eye. They had no thought concerning mental retardation when they came to see me. No one had mentioned the possibility to them. They came to see me about the probability that they might have another child with this same defect. Now it would have been very easy to relax into the environment and say, "This is just an accident; it hasn't anything to do with heredity. It's a developmental accident; it hasn't anything to do with genetics." But unfortunately I could not do that with a clear conscience because there is a large monography by Sjogren and Larson in which they have studied all of the cases of microphthalmia and anophthalmia in Sweden, and it was quite clear that this was a genetic defect and behaved as a recessive. The two normal parents would carry the gene for it, and you could expect some proportion, maybe up to a fourth, of their children to have it. Well, I explored this with them, and I also knew from this monograph that fifty per cent of the children with microphthalmia were mentally retarded and severely so. I felt that it was perhaps time that they should get a hint, at least, that the child might not develop mentally in the proper way. So I raised the point with them, 'Had they ever thought that a defect in the head like this might also affect the development of the brain and that the child perhaps wouldn't be able to keep up with its companions and peers of the same age?' And they said, "No, the thought had never occurred to them." It was a horrible thought, but none-the-less they realized that it was relevant. The physician they had was the next person I heard from, and he wrote me and said that it was so, that the child was very badly retarded as a matter of fact, and that the parents had decided that institutionalization was a possibility and that he, of course, would be called upon as a witness in the probate court when guardianship proceedings would take place. This did not mean that the child

had to go to an institution right away; it merely meant that if the state assumed guardianship, the child would be on a waiting list and then the parents can make their choice when a place comes up (which doesn't come very fast). As you know, we have a long waiting list in Minnesota for commitment to the mental retardation institutions which we have located at various places in the state.

They got state guardianship and kept the child at home for some time, in fact, until the age of six, and that was just this fall when they finally took the child to the new institution at Cambridge. Now I'll read you a letter which I got from the father after that time. He says, "As I think back on our experience, I think we would have been glad if someone before you had told us what we might expect rather than the 'she'll outgrow it' and 'children develop at different rates; don't be concerned' line. And you might be interested in knowing that our little girl was admitted to Cambridge Tuesday of this week."

That isn't the end of the story. The letter was stimulated partly because this individual had discovered that he had an in-law, his wife's second cousin, who had just produced a child with exactly the same thing. In fact, the microphthalmia was even of the same eye, on the right side. And their cousins were going through the same trials that they had. They had no idea whatsoever that there might possibly be mental retardation. The first individual referred the cousins to the Dight Institute, and they came to see us. Now it's quite clear and easy to see that the wives being related might have the same recessive heredity for the ocular defect. How is it, though, that the husbands could be carrying it when they were not, as far as they know, related? Well, that is not as extraordinary as it might seem. One of the things which I really would like to emphasize is the high frequency of the carrier of heterozygous recessive traits. For instance, any rare trait like albinism is a good teaching example. Albinism appears in one out of every twenty thousand births.

That's rare. But the person who carries the recessive gene for albinism is present in one out of every seventy people. There may very well be among us here a carrier of albinism. You will never know it because, in order to produce an albino, you have to marry another carrier, so your one in seventy chance of being an albino times the one in seventy chance that your wife will be a carrier also makes roughly one in 5,000, and then times the one-fourth affected (according to the Mendelian rule) gives you your one in 20,000 that actually appear. But the difference between one in 20,000 of the homozygotes, as we call them, the people who are albinos, and the one in seventy people who carry the gene is very considerable, you see. So that even for the rarest traits, the carriers of the recessives are not rare. They are everywhere. They are very frequent, and it has been estimated that every one of us carries on the average (this is an average, you realize) eight genes which are severely deleterious; that is, lethal, kill the embryo or damage it severely when present in the double dose that you get when both of the parents carry it. Now the reason that we don't have more abnormal children, of course, is that the eight deleterious genes that I have are different from the eight that my wife has. So we don't get together on these, fortunately, and have children that have the same defect in the double dose which would then show. While the chance is still small, of course, that both of these men would be carrying the gene for microphthalmia, it is not out of the realm of probability, and it is very large compared to the idea that it was just coincidence that this very rare thing happened in these two related families.

At the Dight Institute we have tried to provide adequate information for physicians and the couples themselves about many different types of mental retardation. There isn't time to take up these problems, one by one. The best

that I can hope to do is to invite you to think about mental retardation as a series of separate diseases with some genetic background. In some cases environmental variations are of great importance and in others of less significance. The interaction between heredity and environment is a basic certainty in all cases.

Thank you very much for your interest in the subject of mental retardation and in human genetics counseling as evidenced by your attendance at this Institute and at this morning's session.

THE PHYSICIAN'S ROLE AND RESPONSIBILITIES

Charles Bradley, M.D.

In thinking of the physician's role and responsibilities, I think we must keep in mind the particular function he serves and his particular opportunities. If he is the family physician, he is usually the first professional person whom the parents consult about their retarded child. In addition, he has a fund of medical knowledge which does apply to the parents' problems. He cannot, however, be all things to all people. He can perform his own function but must be ready and willing to refer families to other sources of information in special fields, such as those of education and social work, where parents can obtain other special knowledge of which they are in need.

In regard to children who are mentally retarded, it is well to keep in mind that the physician is primarily going to be of service to the child through the agency of the parents. In some ways he is dealing more directly with the parents than with the youngster. This assumes special importance when we realize that if the physician is to be of service to the parents, he must be able to communicate with them. This not only implies that he must tell them certain facts but that he must also present these facts in such a way that the parents can understand them and in such a way that they will be acceptable to the particular parents with whom he is talking. Each of us communicates with other persons in our own special ways, and I do not believe that we can necessarily imitate the language and gestures of someone else in getting our particular points across. In general, of course, we should use terms which are clearly understandable to parents who do not have a medical background. We must also be ready to adapt the use of these terms to the particular parents with whom we are attempting to communicate, and this will vary markedly in individual instances.

The particular information which parents seek from physicians can be divided into three aspects. One has to do with an accurate diagnosis, a second has to do with whatever medical treatment is indicated, and a third has to do with planning for the special problems of the retarded child. This last item is primarily involved with education and training.

Diagnosis

I think it is generally understood that mental retardation is not a disease. As applied to individual children, it merely means that they differ from the bulk of the population in terms of the intelligence with which they are endowed. If a child is retarded, it is, of course, important for the physician to help the parents understand this. However, a mere statement of retardation is not the answer to what most parents seek. The degree of retardation is far more important.

When we are speaking of retardation, we are speaking of a personal characteristic which is more or less permanent for the individual to whom it applies. In most instances mental retardation has existed in the past for a particular child, it exists in the present, and will continue into the future. Fortunately for the understanding of both physicians and parents, the degree to which a particular child is retarded, as compared with his more fortunate fellows, remains fairly constant. We can, therefore, ascertain this degree of retardation by learning something about the child's past, by estimating his present capacities} and, on the basis of what we determine, can give the parents a realistic outlook for the future.

There are four areas of inquiry which are particularly valuable in helping the physician ascertain the degree of retardation. Two of these are based on information obtained from the parents; one is based on the physician's own observations; and the fourth is derived from data which can be supplied by the

psychologist who is proficient in psychometric examination.

In obtaining a history from-parents, I believe it is always helpful to talk with one parent alone, and this should be done not in the presence of the child or other members of the family. The mother is the individual who usually has the most extensive information about the child, and ordinarily she is selected as the one from whom the physician obtains a history. From her one first inquires as to the past development of the retarded child. Information in this category has to do with the ages at which he first began to do specific things as compared with children who are not retarded. One inquires as to the age at which the retarded child held up his head, sat up, pulled himself to a standing position, walked, first used speech, either in individual words or short sentences, acquired toilet training, and the like. If one is inquiring about an older child, one also requests information as to the age at which he first began to use table utensils, to dress himself, to be able to go on errands alone, as well as the progress he has made in various types of formal education. By comparing the rate of his development relative to other children, we begin to get a picture of the degree to which he is retarded.

The second item about which we inquire has to do with his present level of functioning as compared with other children. One requests information about his play interests, his ability to take care of himself. In general, one tries to get a clear picture of his day-to-day activities and make a rough estimate of how they compare with the similar activities of children who are not handicapped. If he is ten years of age but his capacities seem to be those of a child of five, we are justified in assuming that, on the basis of this particular information, he may be functioning as a child of about half his age. If we couple this with the information obtained as to the rate of his earlier development, we begin to get an even clearer picture of his relative degree of retardation.

A third item, which has to do with the physician's own observations of the child in the office, is subject to serious limitations. Most children do not perform in the office as they do in their day-to-day life. However, the physician who is accustomed to examining many children can draw some conclusions about the age level at which the child is functioning. The physical examination is, of course, important, though in many retarded children it contributes very little to an understanding of the degree of retardation.

Data obtained from the psychologist is most important. The single essential laboratory test for most retarded children is a psychometric examination. In the case of infants, of course, it is not as accurate as in older children. However, in the hands of a competent psychologist who can properly motivate children to perform at their optimum capacity in the test situation, the information he can gain is invaluable.

By putting together the various items we have learned from the child's past development, his present functioning, what we see in the office, and the results of the psychological examination, we can in most instances come up with a very clear picture of the degree to which the child is retarded and transmit this information, to the parents.

One complication which can be confusing to both physician and parents is the reaction of the child who has suffered from some organic impairment of the central nervous system. The popular term for this is brain injury, although it is a crude expression and must be used with genuine consideration of the parents' feelings. Children who have suffered from illnesses or injuries which damage the brain tend to differ from their uninjured brothers and sisters with a very definite pattern of behavior, whether they are retarded or not. In general, the brain-injured child shows much more variability in his disposition than the average child. He has good days and bad days. He learns better at certain

times than he does at other times. Moreover, he is apt to be more active than other children of comparable ages and abilities. His attention span is usually shorter. A particularly characteristic symptom is his tendency to react to frustration or other irritating situations in what has been termed catastrophic manner. This implies that he "goes to pieces" emotionally and overreacts to such situations. One additional evidence of brain injury in certain children who are not too seriously intellectually impaired is their relative lack of proficiency in arithmetic. No one of these items, of course, is diagnostic of brain injury, but when one sees the general picture of this symptomatology and, in addition, can couple it with a history of past illness or other event which might have resulted in brain injury, the diagnosis is justified.

Organic impairment is a complication of mental retardation in that it seriously interferes with the function of the retarded child beyond the degree of his retardation alone. An excellent book for parents on the behavior of brain-injured retarded children is "The Other Child" by C. S. Lewis, written a few years ago by the parent of a brain-injured child and published by Grune and Stratton.

Making the diagnosis of the degree of retardation and ruling in or ruling out the complicating factors of organic brain injury is a particular function which no one but the physician can carry out and must, therefore, be taken with real seriousness.

Etiology

In the case of a permanent impairment such as mental retardation, etiology is really a matter of academic interest as far as the physician is concerned. It is, however, far more important than that to parents who may have

many misconceptions as to the cause of their child's retardation. This is particularly important for them if they are concerned with hereditary factors or blame themselves for some particular event which they think caused the child's retardation. We cannot determine with any accuracy the etiology of more than about half the retarded children whom we examine. However, when some definite event has occurred which presumably caused the retardation, it is important to communicate this to the parents, as it will usually contribute greatly to their peace of mind. In certain instances illness of the mother during the first trimester of pregnancy, in other instances illness of the child in infancy with asphyxiating disease or with infections which directly impinge on the brain, such as meningitis or encephalities, appear as definite etiological factors. While, as has been pointed out, genetic factors are certainly important in individual instances, they are not conspicuous in the majority of children seen in office or consulting practice. One possible source of brain injury must be considered carefully and conservatively. It is only natural that many parents wonder whether or not some injury may have occurred at the time of birth. The tendency to blame most injuries and insults to the central nervous system on the circumstances of birth has certainly been overemphasized in the past. There is little to be gained from erroneously putting too much emphasis on this particular experience, especially as it often implies to the parents some criticism of the obstetrical measures used.

Medical Treatment

In the majority of instances medical treatment per se has little to offer most retarded children. If examination shows a complicating medical condition, such as impaired vision or hearing, various motor disturbances, or evidences of endocrine deficiency such as occurs in cretinism, of course, the treatment is self-evident. However, the vast majority of retarded children do not suffer

from these complications, and the physician has little to offer accordingly.

With the advent of new medications popularly known at the present time as "tranquilizing drugs," the physician has a good deal to offer in terms of easing the adjustment of certain retarded children. If a child is particularly irritable or overactive or suffers from some of the complications mentioned in the category of brain injury, some of the newer drugs are most helpful. The amphetamines, including benzedrine and dexedrine, are most helpful in many brain-injured children. They act by apparently channeling energy and ambition so that the child keeps busy with appointed tasks and is less distractible. In the case of seriously retarded children, these are not helpful because the child lacks the capacity to keep productively busy. Some of the newer drugs, including thorazine and reserpine, are being used effectively in certain disturbed retarded children. Anything that can be done to ease the parents' problem by helping the child become easier to live with is certainly a step in the right direction.

Education

The focus of really effective treatment of retarded children lies in the area of training and education. Planning for this effectively depends on an accurate knowledge of the degree to which the child is retarded, and the physician performs an important function in ascertaining this. However, most physicians are not in a position to make detailed and specific recommendations as to training and education per se. A recently published book by Kirk, Karnes, and Kirk entitled "You and Your Retarded Child" is a very valuable source of such information for parents and physicians alike and can be enthusiastically recommended. In general, the physician best fulfills his obligations if he knows the sources to which he can refer parents for the training and education of their retarded children. A knowledge of the available special schools and

special classes available to such children helps the physician make such suggestions effectively. In recent years parents have formed associations for retarded children; and if the physician is aware of such groups and can direct his patients to them, he will find that many parents derive a great deal of useful information and can obtain a great deal of constructive advice by talking with other parents who have faced similar problems with their children.

I have mentioned one or two books which are helpful to some parents. In our office we have a mimeographed list with the titles of four of the better books on mental retardation which may be useful to parents, and each parent receives a copy of this list and is encouraged to purchase whichever books are most pertinent to his particular problem. These books in general have to do with training and education, and some of them contain directories of special schools. They are useful as sources of information beyond what the physician can in most instances adequately discuss with parents in the office.

Relieving Parents' Anxiety

The last function of the physician, which I would like to discuss briefly, has to do with relieving parents' anxiety. There is a great deal of folk lore and many misconceptions about mental retardation, and these contribute to a great deal of unhappiness for many parents. Since planning for the retarded child calls for clear judgment and at times decisive opinions, it is important to relieve the parents of unnecessary anxiety as much as possible. It is impossible to discuss in general all the potential sources of anxiety for individual parents. However, giving each parent a chance to discuss the particular things for which he blames himself regarding his child's condition may often be helpful. Most young parents have misgivings about having additional children and may be too bashful to inquire of the physician as to what is implied. As a matter of practice, one can often make quite definite statements about this which will be of great help to the parents in the future.

In summary, the physician best fulfills his function when he is able to successfully communicate to the parents information derived from his particular sphere of activity. He should be able to make a clear-cut diagnosis of retardation, a fairly accurate estimate of the degree of retardation, and on the basis of this predict what the parents may look forward to in the future. He should attempt to determine the etiology and, if it is definite, give the parents the satisfaction of knowing what probably contributed to their child's retardation. If specific medical treatment is indicated, this is certainly a particular responsibility for him. Although he may not be able to give the parents information regarding details and training and education which they will require, he should be in a position to direct them to sources of such information and assist them in providing adequate training and education for their children. Finally, if he can fulfill his various functions with sympathy for the feelings of the parents, do what he can to relieve unnecessary anxieties, and welcome further inquiry, he is performing a service which, within its own limits, can be obtained by parents nowhere else.

WHAT CAN BE DONE FOR THE MENTALLY RETARDED
IN THE HOME, THE COMMUNITY, AND THE STATE

George S. Stevenson, M.D.

It is the task of the doctor, not only to deal with a patient who is mentally deficient and his parents, but, in addition, as a citizen to give leadership in his community.

There are two essential elements in mental deficiency. First, the mentally deficient person is socially insufficient. Second, this insufficiency is due mainly to a deficiency of intelligence. Deviation in intelligence, per se is no more a sign of a disorder than is height. People can be dwarfed intellectually by genetic or accidental causes. Their capacity for abstract thinking may as a result be too limited to carry them through the ordinary demands of life. They must, then, depend upon others to think for them.

The social criterion of mental deficiency is not a fixed one for it varies with the demands of society, still it serves well except at the borderline. At that level a shift from city to country, from single to married life, from childlessness to parenthood may throw a person of limited intelligence below the borderline of social sufficiency. Mental deficiency accordingly denotes a disability due to a discrepancy between the demands of society that are reasonable for most people and a limited intellectual capacity. Well below the borderline the intellectual defect may, however, be so great that even the most favorable life situation cannot balance the defect.

Sometimes a person of slow development may be falsely classified as mentally deficient, especially at the borderline. Late maturing or a spurt in the teen years may upset predictions that have been based upon previous slow progress. It is hazardous, therefore, to classify a person as mentally deficient until his growth potential is known.

Sometimes the school may force the slow child into a special curriculum for the mentally deficient, even though later he may become socially sufficient.

Less than two per cent of the population are mentally deficient. Most of these are concentrated just below the borderline, the prevalence decreasing as the deficiency increases. Because of this concentration of cases at the borderline, small shifts in the social demands may, therefore, seriously alter the count of cases.

According to Gibson, a deficiency of intelligence is found in some seventy different diseases. Some such as mongolois are practically always mentally deficient. Others, such as the cerebral palsied, may have good intelligence. Each medical diagnostic category has its own causes, peculiarities, outlook, and treatment. This means that generalizations ere apt to be unsound.

Mild cases are more likely to come from families which themselves *are* not highly endowed intellectually, whereas the moderate and severe cases tend to come from families that ere fairly representative of the whole population. Since three quarters of all mentally deficient are mild cases, early recognition by the family is infrequent.

The use of the term "mental retardation" is confusing because it includes children who are slow in school, but not mentally deficient. The change merely of the word tends to obscure temporarily the unpleasant connotations of mental deficiency, but does not correct them.

There are, however, real signs of progress. It is no longer believed that a mentally deficient person could propagate only the mentally deficient, or that permanent custodial care is the only answer. However, many professional persons will *treat* the mentally deficient as/they were not subject to the same emotional forces as affect other people and the same prospect of psychotherapy.

The mentally deficient are a life-long concern of society. There is need for prevention before conception, better prenatal care, early case finding, diagnosis and treatment, training and education during the period of growth. The concern continues into the adult vocational life and ends in dealing with the dependency that comes in old age. Success in each period depends upon a concern for every other period. For example a school serves the child better when it takes his adult prospects into account.

This society seldom does. There is no over-all design for these cases in the community, in the states, or in the country as a whole. Instead each agency works in isolation. Society, providing poorly, has not been able to raise its head above the problem long enough to get a better perspective on it. As a result the agencies designed to serve the mentally deficient need a thorough rethinking, replanning, and overhauling based on the functions to be performed.

The first service to the mentally deficient is prevention. Prevention is postnatal, prenatal, and preconceptual. Hereditary cases are prevented by preventing conception. Mild cases are harder to prevent because the deficiency goes unrecognized by the family. It is a problem that is complicated, not only with technical, but with moral and religious positions.

Prenatal prevention is concerned with a quite different group of cases such as rubella and cerebral palsy.

The first need of the mentally deficient child after birth, as of every child, is a thorough medical and psychological examination and evaluation. This is often delayed because parents find it hard to accept the possibility of mental deficiency and because doctors have too little training in diagnosing and helping the mentally deficient. The proper place for this is a baby's hospital.

The family can often fulfill its obligation to the child if it has the guidance of a special worker who can visit the home and give parents the counsel and support which they need. The medical evaluation is often the first step in preparing parents to accept their problem and deal wisely with it. Wisdom during the first few years can do much to insure success for those who try to help the child later. However, the family of the mentally deficient may squander its resources by seeking a cure, only to find itself unable to provide for the child later. The most promising trend in many decades has been the organization of associations of parents of mentally deficient. Hand in hand they are able to face their own problems more realistically, plan for better service, and promote better legislation.

Child guidance clinics often refuse to accept the mentally deficient as untreatable. Still the Pacific State School in California has shown that psychotherapy increases the rate of discharge.

To meet the numerous demands of life, the mentally deficient need to use every bit of their intellectual potential. Their meager talents must be identified and developed, and the emotional matrix from which the intelligence is inseparable must be kept as healthy as possible.

Because the mentally deficient live in a world of normal expectations, they are under constant emotional stress. Even the best understanding home cannot fully buffer the cruelties of the outside world. He is trapped between the distorting effects of an unsympathetic world and the stunting effects of isolation at home. A nursery school can help the younger child.

Of all the mentally deficient from birth to death, only some 15 per cent are schooled in their communities. Many are not identified as such, but the identification is better in larger communities. Many schools really do not accept the mentally deficient child. Instead they seek his admission to a

state school. Still the great majority of these children will grow up and must work in the community. The school can help them to adjust there.

Accepting a child in school means more than giving him a seat. It means that he will receive whatever the science of education has to offer him. Sometimes there are formal provisions, but often, especially in rural schools, they depend on the individual teacher. Consultation by experts from a state department of education can do much to help such teachers. Some teachers colleges prepare teachers for the less severely deficient. However, almost no training exists for teachers of low grade pupils.

Some schools provide special classes wherein there is a specially designed program and equipment and relief from competition with normal children. In 1933 L. Pierce Clark pointed out the importance of following the child's own tempo rather than that of the normal. There must be slow advance and constant review. But above all, love must be given by the teacher and won from the child in order to broaden his identification. The special classes for the mentally deficient are not designed to meet well clarified adult needs. Furthermore, since work and home life varies greatly from time to time and from community to community, specific goals must change.

Few of the severely deficient ever go to school. New York City has only thirty special classes for them. Ohio had about 80 classes by 1954 in 22 counties. Also they are often equipped with castoff furniture. They need, in fact, different sizes of furniture in keeping with the greater ranges of age.

Many less severe cases are excluded from school by the failure of the school to meet their needs. Truancy results. The educator, perhaps wisely, may make no issue of this provided the child's time is spent profitably. But this is hazardous since truancy is too often an entree to delinquency. When the child leaves school to work, he is subject to child labor laws. He, then, is a concern of both state and federal labor authorities.

The more seriously mentally deficient are usually excluded from school as uneducable, even though they are educable in that their behavior can be bettered through carefully designed experience. While the teaching profession must share the blame for this, the failure means that society values them as dispensable. They are a burden. Still the cost of special provision is small compared with the cost of neglect as shown by Buell-1/. The issue is: Is the school a service to the school age children of the community, or is it simply an academic instrument?

One large piece of this scattered jigsaw puzzle of needed service to the mentally deficient is the state school. The state school tries to perform three technically different functions and does none of them satisfactorily. It tries first to be a medical agency whose job it is to evaluate the patient to diagnose him, to afford him maximum medical benefit including preventive service, and to determine the residual disability. Thus his education and work life can be planned within his limits.

Secondly, the institution tries to be a school. It must determine the educational potential and achievement of the pupil and bring him maximum educational benefit. It should prepare him for a satisfying and productive institutional or community life.

And thirdly, the institution tries to be a benevolent neighborhood and sheltered industry in which life is enjoyed and useful work is done- There is little scientific foundation for this task. Still it crowds both medical and educational functions.

All three functions need research and personnel training. Should these schools be directed by one or another professional person? It is clear that, to date, no type of director has brought these functions to full realization.

1. Buell, Bradley, and Associates. *Community Planning for Human Services*; Columbia University Press; 464 p., 1952.

A new pattern seems to be needed.

Some measure of the scientific lagg is found in annual reports. These schools record no medical diagnosis in over half their cases. The failures in the educational function of the state school are analyzed by Levine.² Recreation is neglected. There is no overall program into which the various services fit. Research is inadequate. The public is uninformed. There is insufficient community service.

The negligent attitude of the public is abetted by the isolation of the state schools. In fact, the public likes them to be out of sight. Isolation, however, hampers the return home of patients and militates against the school's securing good personnel.

State schools serve about one-tenth of the mentally deficient. Most are severe cases for whom the psychiatric and educational potentials are more limited. Many more of their cases would probably be returned to the community were they well equipped and a part of a grand plan.

The mentally deficient are admitted to the state school by legal process,. But unlike the mental hospital, many state schools restrict their intake and maintain a waiting list. By this delay valuable opportunity is lost. However, some patients meanwhile make an adjustment spontaneously within the community. Some states give educational and medical service to those who are waiting.

When return to the community is indicated, the school should provide supervision or arrange for it through local agencies. The local agency should be subsidized for this purpose, the social service of the state school serving as advisors and consultants to these local agencies instead of trying to visit the case once a year.

2. Levine, Samuel: Educational Problems in State Institutions for the Mentally Retarded. American Journal of Mental Deficiency, 58 (3): 406-407, Jan. 1954.

The report of a special commission in New Jersey reflects most of the points I have stressed. The findings would be repeated in most other states. They have recommended two more conveniently located institutions, better salaries, opportunities for promotion and living conditions for employees, training scholarships for employees, expansion of home training, responsibility for education in the community by the state department of education and in institutions shared by the department of education and the department conducting these institutions, a central state registry for all cases, a state supported research program and a state coordinating agency.

In the effort to achieve these advances, I don't think I can over-emphasize the influential position of pediatricians, obstetricians, and general physicians based upon their professional authority and their opportunity to speak as citizens in their communities.

SUMMARY OF INSTITUTE

A major emphasis of the Institute on Mental Deficiency was to provide ample time for group discussion. Those in attendance were divided into three groups, each with a discussion group leader. The aim was to provide an opportunity to "get at" the problems and concerns of the physician confronted with the problem of mental retardation.

At the close of each day, the three groups assembled to report the topics covered. On Saturday morning each group presented a summary of the four sessions spent together. All of these were recorded and transcribed.

This summary is an attempt to present in an organized way the topics covered, the needs defined, conclusions arrived at, and suggestions which emerged from the several groups. Study of the transcriptions reveals a striking degree of similarity of, ground covered in the three groups. This has been helpful in its organization.

A. Complexity of the Problem.

There was a consensus of all concerning, that mental retardation is not only one of our biggest unsolved medical problems, but also is one of the most complex. Considerable time was devoted to this latter point. "We do not have the answers to the common problems insofar as the parents of the mentally retarded children are concerned.... Therein lies a source of considerable confusion...." is the way one group reported.

What were these "common problems" referred to which are intrinsic to the complexity of the problem? Briefly they are -

- a. The problem of diagnosis. This was of immediate concern to all.

How does one make a diagnosis - differentiate from other deficiencies? There seemed to be a real need for further exploration of this area alone.

b. "What are we to do about telling these families that we suspect a child is retarded?" "What is the proper technique?" "What can we do?" The problems of excessive anxiety of the parents and how to deal with it, how to prevent diagnostic shopping, and how to prevent it were also considered. Out of the discussion in this area were developed the following suggestions: The importance of the physician's attitude in dealing with area was, emphasized as well as the need for patience and time in helping parents come to a full realization and acceptance of the child's limitation. It was proposed that "we have longer and more thorough conferences with the family, that we try to arrange time and be more patient, gentle, and kindly toward them." Likewise it was suggested that much confusion could be avoided by "having parents together whenever a child is suspected of being mentally handicapped." It was also agreed that, whenever indicated, either from the physician's point of view or that of the family, a referral for more comprehensive study be arranged.

c. What should be considered in the best interests of the child? It was the consensus that every possible corrective measure should be provided for the child in an effort to help him mobilize and develop his potential to the utmost. The child should be provided with hearing aids when needed, as well as glasses, dentures, etc.

d. Much time was devoted in all groups concerning the question of whether the child should remain in the home or be placed. There was agreement on the following: (1) That as many mentally retarded as possible should be maintained in the home and community,

(2) That if a child is ultimately to be placed, this decision should be made by the parents who should be given adequate help as they consider the interests of all concerned, and (3) That the time of placement is best arranged when all other plans have been unsuccessful.

B. Relationship to Others Actively Engaged with the Mental Retarded.

This logically led into a consideration of the need on the part of the physician to recognize and to know the interests and concerns of others in the community who also are vitally interested in the welfare and management of the mentally retarded. Involved were the following:

- a. The Schools. One group summed it up this way: "We came up to the problems of schools and the problem these children have in the schools" The question of special classes was also considered. Such questions as - "What are special classes going to lead to; what is the national picture regarding special classes; what are the aims of special classes" - were considered along with the need for more adequately trained teachers in the field of special education.
- b. Other Community Resources. Mention was repeatedly made to the need for establishing better understanding and means of communication with county welfare boards and other social agencies as well as the parents' groups now organized in many communities. This suggestion was offered for the primary purpose of "getting advice as to the proper channels to direct parents'" for additional help.

It was further suggested that, since there will be an increasing number of lay groups interested in this problem, we must accept this development and "stimulate their formation" and work with them whenever possible.

While it was generally recognized that the physician may not be actively engaged in the operation of the schools, community agencies, and parents' groups, he is in a strategic position to assist them by serving on boards, as a consultant, and by his general interest in being willing to participate in community planning at whatever level may be indicated.

c. National Organizations: The group attention was called to the existence of several national organizations interested in the mentally retarded about which physicians should know. These are: (1) The American Association on Mental Deficiency which membership is composed primarily of professional persons (physicians, psychologists, social workers, teachers, etc.). Its address is P.O. Box 96, Willimantic, Connecticut. It published a monthly journal, The American Journal of Mental Deficiency. (2) The National Association for Retarded Children sponsored by parents. Its main office is located at, 129 East 52nd Street, New York City 22, New York, and it publishes "Children Limited." (3) The International Council for Exceptional Children, an organization composed primarily of educators. Its headquarters are located at 1201 - 16th Street Northwest, Washington 6, D.C., and it publishes "The Journal of Exceptional Children." For further current reading in this field, "The Training School Bulletin" published by the Vineland Training School located at Vineland, New Jersey, is recommended.

C. Research.

Each group emphasized the importance of research in the field of retardation if answers to such questions as the following were to be found: The cause of prenatal and neonatal deaths. What is the influence of excessive anesthesia and analgesia during labor? What are the risks in vaccination reactions?

Should mothers be immunized during early pregnancy? Is there a higher percentage of mental retardation among children born to parents suffering from infertility than in the general population? What is the influence of abnormality during pregnancy on the child? These and others questions were asked with no definitive answers obtained.

Of most importance in this regard was the emphasis on "the unique position of the practitioner for doing clinical research" in this important area. Careful observations and recording of case by case can be a rich source of research material for those interested.

The increasing attention accorded basic research in all aspects of mental retardation by the Research Advisory Board to the National Association of the Mentally Retarded, as well as that of National Institutes of Health, the Dight Institute, and others, was called to the attention of the group. It is hoped that these developments will someday provide answers to the many unsolved questions.

D. The Physician's Role and Responsibility.

As might be presumed, the physician's role and responsibility in the field of mental retardation was considered at some length during the Institute. One group put it succinctly: "What is the role of a physician? What can he do? What can't he do?"

With respect to professional leadership in this area of medicine, one group felt "the medical profession has not assumed proper leadership (in the field of mental retardation), that we've lagged (to the point) people in search of help often turn to others for advice, counsel, and leadership." There was a difference of opinion, however, for another group reported there is "a certain warmth inherent in all physicians, but that certain things prevent it from coming out" (in the field of mental retardation). In explanation, it was

suggested that most physicians are burdened with tremendous case loads. For this reason, often little time is available to deal effectively with each case suspected of mental retardation. Also mentioned was the dilemma many physicians face in understanding the complexities of the field and, therefore, not dealing effectively with the pertinent needs.

Other searching questions considered were (1) How can parental anxiety be best dealt with? (2) How can one avoid parents' misinterpreting the physician's analysis of the case and his interpretation to them? (3) How can one correct or at least reduce the parents' "heartaches, confusion, and resentment" of the problems they face? (4) How can one prevent parents from shopping around excessively?

A careful review of the reports indicated there were areas of agreement which emerged in answer to some of the pertinent questions. Some of the areas of agreement are as follows:

1. In but the rare instance, the physician can do little to alter the child's mental retardation. The acceptance of this simple fact is of great importance to every physician, for it enables him then to direct his attention to what can be done.

2. What can the physician do? There was a general consensus that the primary responsibility of the physician is to give aid and support to the parents by helping them clarify their own thinking and feelings and disappointment about having a mentally retarded child. Such help would do much to maintain the family's integrity and stability. Two groups reported direct statements. It is necessary for the physician to consider "the family in our culture, the importance of the family and what problems it can carry, and the special problems which develop when the integrity of the family is not maintained." Another group summed it up this way: "Each

situation must be evaluated in terms of determining the developmental potential of the child, the home, the family, and the facilities available in the community and the state."

With respect to this point of view, it was pointed out that community attitudes toward those who are mentally retarded vary considerably. The problems and difficulties encountered in rural areas would be quite different from those encountered in crowded urban areas. Here again is emphasized the point there is no one solution to the problem of mental retardation. Also, there is further evidence of the intrinsic complexity of the problem, since the standards, the philosophy, and the pattern of thinking of each community requires consideration.

What can the physician do in helping parents accept the fact of the child's handicap? The attitude of the physician himself toward the total problem is extremely important. If he has a real interest in it, if he has an understanding of the complexities of the problem, and if he has developed for himself a notion of what he can do, he can be helpful to the parents.

Concerning the development of techniques in helping parents, the following were suggested: (1) A thorough history must be taken on each case. This history would include not only the usual items in the medical history, but also would include a careful survey of the developmental aspects of the individual life. In other words, what was the developmental pattern of neuromuscular maturation pattern, of the speech pattern, of the play pattern, and so on. (2) In each case, inquiries should be made as to how the child behaves in the home. If other children are in the home, it is often useful to encourage parents to draw comparisons between the child suspected of being retarded and the others. If a child is an only child, other children of approximately the same chronological age known to the parents could serve to draw comparisons. (3) Careful

observation of the child's behavior, either in the home or in the office, by the physician is important. The observations of the physician's nurse or receptionist of the child's choice of playthings, how the child plays, the kind of speech used, and how the child develops his interpersonal relationships while in the waiting room or in the office may also be helpful. (4) If psychological services are available, special studies such as psychological testing should be done as a part of the total study. (5) In case of doubt on the part of either the physician or the parents with respect to the child's developmental status, the physician can suggest consultation. One point that was emphasized is that parents do not resent the suggestion of consultation in such cases. The general experience is that parents welcome such a plan.

One group mentioned that in some instances hospital admission is desirable. Hospital admission has many advantages, in that it provides for a period of observation of the child removed from the family. It permits more thorough physical studies. Also, there is the psychological advantage of having the child separated from the family for a few days. This is often very helpful and useful to the parents, as well as the physician.

The matter of differential diagnosis was considered. If a child is suspected of mental retardation, the differential diagnosis should include a consideration of any possible physical handicap, such as deafness. In the older child, the physician should also consider the possibility of a specific learning difficulty, now known to occur among school children. To be considered also are the possibilities of an emotional disturbance of such severe character that the child, who is of adequate potential, is behaving immaturely. Early infantile autism or schizophrenia also requires consideration.

Everyone was in agreement in the fact that once a diagnosis has been made, there should be no procrastination in dealing with the reality of the

situation. One group put it this way: Parents should be informed "as soon as one is reasonably sure that the child is mentally retarded. It seems quite a mistake to withhold information if one is really sure of the diagnosis of mental retardation. There is no exception to that." Another group emphasized that, every physician should "appreciate the importance of being direct and forthright with parents about findings. Also, every physician should be considerate of other doctors if an error has been made."

Once the diagnosis has been made, parents wish to be enlightened as to the possible cause of retardation. Also parents wish help in determining what they might expect in the future. Consideration of possible plans for the child's welfare as well as that of the family, including themselves, is essential.

Placement of the child was considered at length. As the discussion proceeded, it became increasingly clear that placement of the child requires much thought and preparation. Before deciding on a placement plan, parents should think through and decide on answers to the following questions: (1) What is to be in the best interests of the child and his future? (2) What will be in the best interests of the family? Should the child be maintained in the home or should the child be placed? (3) Will placement satisfy the needs of all better than any other plan?

Before parents decided on a placement plan, they should be accorded ample time to think through to their satisfaction all the issues which require consideration. They should be encouraged to visit the school being considered. Visiting during active session is important not only because it provides parents with an opportunity to see, but also to meet the school personnel who shall have responsibility for the care of the child.

Physicians can be helpful to the parents by introducing them to parents' groups interested in and concerned about the mentally retarded. Referral

to such a group does much to help parents since they have an opportunity to think and talk with others who have faced problems similar to theirs. This is good therapy.

Concerning the lay groups now being organized in the interest of the mentally retarded, "it was felt that there is to be an increasing number of these in the future and that their importance and significance will increase. Therefore, we physicians must accept that end should stimulate their formation." The suggestion was also advanced that where there are groups already organized, physicians serve on their advisory boards or occasionally address a meeting of the association.

Other areas of interest which might be of concern to the physician were considered. Apparently some recognized the shortcomings of their own medical school days, for the need of teaching medical students in this area was stressed. Many suggestions were offered. The students should be introduced to the technique of interviewing. He should have clinical experience in seeing handicapped children. He should be introduced to techniques of study and observation. Whenever possible, he should have clinical experience with a case. He should visit the state schools provided for the care of the mentally retarded and other handicapping conditions.

(It may be of interest here to suggest that the medical educators participating in the Institute had lunch together on Saturday for the purpose of considering what is being taught currently and what should be taught. It may be heartening to know that every medical school represented does some teaching in this field.)

Recognizing the magnitude of the problem and the many needs, the suggestion was made that much could be done through the several medical societies. One group suggested "This should be brought to the attention of the several

societies, that it may form a definite part of the subject matter of their meetings." Another pertinent suggestion was offered that medical societies consider the development of a committee to the organization "which would deal with lay groups having a medical interest." Through the development of such a committee, the medical societies might establish and maintain more satisfying liaison relationships with others who have an interest in the mentally retarded. In time, this could help resolve many difficulties.

There was a consensus that a great need today was in the field of public education. To meet this need, "physicians and society should strive to help in the education of the general public with respect to the development of more adequate teaching programs in the public schools and the development of more adequate facilities locally and statewide."

One group came up with an unusual suggestion. Recognizing the many complexities intrinsic to the field of mental retardation which need study and clarification, there is a great need for endowing a chair at some university in mental retardation. The establishment of such a chair would do much to stimulate research so important in this field and would help promote a program of education which would help "to bring this whole problem into a proper focus."

The medical profession has often been criticized for its lack of interest in the field of mental retardation. If the group assembled at the Institute could be considered as representing a cross-section of medical practice, it would appear that the physician is not indifferent to or unwilling to assume active leadership and responsibility in this important area of medical practice. Rather, the experience of the Institute suggests the physician often struggles with his own dilemma which stems from the enormous complexity of the problem. However, as was so convincingly illustrated, when an opportunity presents itself to clarify issues, roles and responsibilities the "certain warmth inherent in all physicians" does emerge in the field of mental retardation as in other areas of medicine.

Findings, Reactions, Recommendations

E. Reactions to the Institute.

All groups reported favorably on the worthwhileness of the Institute. "The first point we'd like to make is that, for our group, interest in this particular problem has been heightened." "Our group felt it was a great stimulation, not only from a professional standpoint, but also a social stimulation very enlightening." "The members of our group felt very grateful to those who put on this Institute and to the leaders who have come from a distance to be with us." Such favorable expression attests to the simple fact that physicians are interested in an area of medicine such as mental retardation which heretofore has not been accorded proper emphasis.

Commenting on the manner in which the Institute was arranged, it was felt that the technique of small groups and their continuance under one leader throughout the course was excellent. The length of the program and the balance of time between lectures was felt to be fine. A general consensus prevailed that further such institutes should be arranged since "over the last three days, we have only hit on about ten per cent of the problem, and we didn't completely discuss the ten per cent." If further institutes were to be arranged, "it would be better to have only doctors as participants."

More diagnostic aids such as information of psychological testing; emphasis on the emotional problems, prevention, classification, and etiology of the mentally retarded, delineating further other services available to parents and others were suggested items for future consideration in a similar Institute or in others.

FINAL REMARKS

Last Thursday, a group of thirty physicians from six different states gathered here, by invitation, to consider the broad field of mental retardation and its relation to medical practice. The rapid developments over the past two and a half days leaves one almost breathless. The keen interest and enthusiasm which has evolved is most reassuring to us who helped arrange the course.

This Institute was a long time in planning. The major reason was the reservation on our part that physicians might not be interested in the area of medicine which we've just considered. To assure against disappointment, it was decided to arrange this first Institute by invitation. The vigor and enthusiasm demonstrated here during these past two and a half days has been convincing evidence that physicians are interested in the many problems of the mentally retarded and wish to do whatever they can in the resolution of the many problems associated with them. In this regard you have been of great help to us and others.

Out of this Institute has developed a greater appreciation of how complex the problems associated with mental retardation are. As yet, little is known of its causes. Most of us are unsure of ourselves in dealing with the child and his parents diagnostically and therapeutically. We lack knowledge of trends developing in the field and the many resources which can be helpful to us. These and others require further exploration if solutions are to be found. There is much work ahead for all of us.

While no definite solutions were found here, it does seem that each of us did begin to clarify our roles and responsibilities and how we might more adequately help parents and children. The importance of diagnoses has been emphasized. The development of skill and techniques necessary to deal effectively with distraught parents has been mentioned time and again. The need to get better acquainted with community resources and to establish more satisfying

lines of reference with others interested in the field has been stressed. Out of this Institute has developed the recognition of the interdependency of everyone interested in the mentally retarded if solutions are to be found. The physician has a part to play, the parents, the social worker, the school teacher - and many others. All in the community need to work together. This awareness of this need and the defining of our several responsibilities will make for progress.

More specifically, you have pointed out very clearly several pressing needs.. To mention only a few - the need for more research and the need to give more attention to this field in medical education on all levels. Important also is the need for each of us physicians to continue clarifying our own roles and responsibilities.

In these two and a half days together, more problems were raised and left unsolved than were solved. However, as each of us returns to our respective communities, it is our hope that the interest and enthusiasm developed here will permeate through our local communities and our respective professional societies which will eventually be helpful in resolving satisfactorily one of our biggest and most troublesome medical problems - mental retardation.

- Reynold A. Jensen, M.D.

SOME READING SUGGESTIONS FOR PARENTS OF MENTALLY RETARDED CHILDREN

Throughout the Institute, requests were made for a bibliography in the field of the mentally retarded. In response to this request, the following books are suggested for reading, not only by the physicians, but the family as well. The books suggested have been drawn primarily from a list made up by the U. S. Department of Health, Education, and Welfare.

General

New Hope for the Retarded Child by Walter Jacob. Public Affairs Pamphlet No. 210. Public Affairs Committee, 22 East 28th Street, New York 16, N.Y.; July 1954. 22 pp. 25 cents.

The causes and types of mental retardation, and what parents, schools, and communities can and are doing to extend and strengthen services and facilities for the mentally retarded are summarized briefly.

The Mentally Retarded Child - A Guide for Parents by Abraham Levinson, M.D. John Day, 210 Madison Avenue, New York 16, N.Y.; 1952. 190 pp. \$2.50.

In simple language Dr. Levinson discusses many-phases of mental retardation including medical and psychological factors, how a diagnosis is reached, and some ways in which the child's chances for physical, social, and educational growth may be enhanced.

The Retarded Child in the Community by Katharine G. Ecob. New York State Society for Mental Health, 105 East 22nd Street, New York 10, N.Y.; 1955. 22 pp. 35 cents.

Practical suggestions for the care of the mentally retarded child in the community are briefly and concisely stated. The author discusses some of the common misconceptions surrounding mental retardation, the factors affecting the care of the child in his home, his schooling and employment, and institutional care.

Personal Experience

The Child Who Never Grew by Pearl S. Buck. John Day, 210 Madison Avenue, New York (16), N.Y.; 1950. 64 pp. \$1.00. (Originally published in The Ladies' Home Journal. May 1950.)

A mother tells the story of her struggle to secure help for her mentally retarded child and of her final decision to enroll her in a residential school for the mentally deficient.

My Son's Story by J. P. Frank. A.A. Knopf, 501 Madison Avenue, New York 22, N.Y.; 1952. 209 pp. \$3.00.

Perhaps nothing is more comforting to the parents of a mentally retarded child than to learn how other parents have courageously faced and adjusted to both their emotional and practical problems.

The Three Stages in the Growth of a Parent of a Mentally Retarded Child by Dan Boyd. National Association for Retarded Children, 99 University Place, New York 3, N.Y.; 1950. 6 pp. Single copies free.

The evolution of a father's thinking and feeling from the first shattering realization that he was the parent of a retarded child to a philosophy that has broadened and enriched his life.

Training and Education at Home and in School

You and Your Retarded Child: a manual for parents of retarded children by Samuel A. Kirk, Ph.D., Merle B. Marnes, Ed.D., Winifred D. Kirk, M.S., Macmillan Co., 60 Fifth Avenue, New York 11, N.Y.; 1955. 184 pp. \$4.00.

Incorporating the ideas, techniques, and suggestions that grew out of their experience in examining, diagnosing and teaching mentally retarded children, and in counseling with their parents, the authors answer many of the questions inevitably asked by parents. The discussions include, among other subjects, how parents can estimate the level of retardation of their child and ways to help retarded children become more independent, to play, to eat, and to overcome behavior problems.

The Handicapped Child - A Guide for Parents by Edith M. Stern with Elsa Castendyck. A.A. Wyn, 23 West 47th Street, New York 19, N.Y.; 1950. 177 pp. \$2.00.

Because this book covers in individual chapters, eight specific types of handicaps, including mental retardation, parents of multiple handicapped children will find it of special interest. Basic mental health principles are emphasized in the discussion of parents' feelings and attitudes and in the practical suggestions for day by day care and training.

Deciding What's Best for Your Retarded Child by Katharine G. Ecob. New York State Society for Mental Health, 105 East 22nd Street, New York 10, N.Y.; 1955. 14 pp. 35 cents.

Most parents of a mentally retarded child are faced at some time with a difficult decision: Shall we place our child in an institution or residential school or shall we keep him at home? The author discusses some of the values to the child of care in an institution and in his own home and how parents can be helped in arriving at a decision.

For the Parents of a Mongol Child. Anthropolosophical Press, 211 Madison Avenue, New York 16, N.Y.; 1953. 20 pp. 50 cents.

The matron of a home for backward children in England describes vividly and sympathetically the growth and development over a period of more than seven years of three typical mongoloid children ranging in age from infancy to early manhood.

The Other Child - The Brain-Injured Child by Richard S. Lewis with Alfred A. Strauss and Laura E. Lehtinen. Grune and Stratton, 381 Fourth Avenue, New York 16, N.Y.; 1951. 108 pp. \$2.50.

Parents and others are generally more familiar with the type of brain injury that causes motor disturbances than with the type that results in disturbances in perception, concept formation, language, and emotional behavior. This book is for parents of children in the latter group, some of whom may also be mentally defective. It explains the pathology that causes bizarre behavior and offers helpful suggestions about the management and education of such children.

The Forward Look - The Severely Handicapped Child Goes to School by Arthur Hill, Ph.D. Office of Education Bulletin No. II. Superintendent of Documents, Government Printing Office, Washington 25, D.C., 1952. 54 pp. 20 cents.

Community school services for severely retarded children are a relatively new field of service. This booklet considers many aspects of organizing and conducting such services and provides much general information of value to parents.

Curriculum Adjustments for the Mentally Retarded by Elise H. Martens, Ph.D. Office of Education Bulletin No. 2. Superintendent of Documents, Government Printing Office, Washington 25, D.C., 1950. 100 pp. 35 cents.

Although written as a guide for elementary and secondary schools and addressed primarily to educators, many parents will find this publication helpful in its discussion of goals and ways of working with the mentally retarded that are applicable to day by day training in the homes.

Periodical

Children Limited - Quarterly newspaper. National Association for Retarded Children, 99 University Place, New York 3, N.Y. Annual subscription \$1.00.

The national organization of parents and friends of the mentally retarded reports what is being done nationally and by state and local groups of parents to promote the general welfare of retarded children of all ages, in their homes, communities, schools, and institutions.

The American Journal of Mental Deficiency. American Association on Mental Deficiency, P.O. Sox 96, Willimantic, Connecticut.

The Journal of Exceptional Children. The International Council for Exceptional Children, 1201 - 16th St. N.W., Washington 6, D.C.