

COUNSELING PARENTS OF CHILDREN

with

MENTAL HANDICAPS

Proceedings of the 33rd
Spring Conference of
The Woods Schools, held in
Minneapolis, May 2 and 3, 1958

Sponsored *by*

THE WOODS SCHOOLS For Exceptional Children

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Mr. Edward L. Johnstone
President, The Woods Schools



Leon J. Obermayer, Esq.
Chairman, Board of Trustees

Proceedings of the 1958

WOODS SCHOOLS CONFERENCE

Held in Minneapolis

in cooperation with

The University of Minnesota

Friday, Saturday

May 2 and 3, 1958

Mayo Memorial

Auditorium

ABOUT THE PROGRAM

TOPIC:

"COUNSELING PARENTS OF CHILDREN WITH MENTAL HANDICAPS"

The emotional impact of mentally handicapped children in our social community has brought about constructive individual and group action by parents seeking to understand, to live with, and to plan for the problems presented by children who have been denied a normal life experience.

In 1950, the creative force of the first organized parents group, the National Association for Retarded Children, came into being in Minneapolis, Minnesota. This nation-wide parent movement, reinforcing the professional contributions of The American Association on Mental Deficiency, has pioneered for improved community services; it has worked unceasingly for state and federal legislation to provide special education classes for the retarded; it has stressed the need for more adequate national, state and private research funds through which to study this long neglected problem.

Parents everywhere have done a great deal for their handicapped children. However, counseling services for the parents themselves have been sporadic and child-centered, leaving them to struggle with their own mixed feelings about rearing and planning for their child.

The 1958 Spring Conference of The Woods Schools represents the coordinated effort of several organizations dealing with these problems, held in cooperation with the University of Minnesota.

The program deals with the scope and practice of parental counseling from the time of first knowledge of retardation to the time of using community or residential school facilities.

Other agencies participating are the Minnesota Department of Public Welfare, the Mayo Clinic, the administration of the National Association for Retarded Children, the Minnesota State Board of Education, the Philadelphia Child Guidance Clinic and the Sheltering Arms Day School of Minneapolis. The conference topic is keyed to a sensitive interpretation of the relationship between natural parental expectations and the over-all personality development of mentally handicapped children.



MR. LUND



DR. JENSEN



DR. MAYO



DR. ROSE

ON 1958
SPEAKERS'
ROSTER



DR. REYNOLDS



DR. REED



DR. ADAMSON



DR. BLODGETT



THE PROGRAM

FIRST SESSION

MAYO MEMORIAL AUDITORIUM

May 2, 1958

8:00 P.M.

EDWARD L. JOHNSTONE, President, The Woods Schools, *Presiding*

INVOCATION

THE REVEREND DAVID W. PREUS, Lutheran Campus Pastor, University of Minnesota

WELCOME

WALTER W. COOK, Ph.D., Dean of College of Education, University of Minnesota

GREETINGS

CHARLES W. MAYO, M.D., Mayo Clinic, Rochester, Minnesota;
Member, Board of Regents, University of Minnesota

KEYNOTE ADDRESS:

"THE PARENT COUNSELOR—AN EMERGING PROFESSIONAL RESOURCE"

MR. JOHN W. BYSTROM, Hamline University, St. Paul, Minnesota;
President, Minnesota State Board of Education

"FACTORS IN THE DEVELOPMENT OF THE MENTALLY HANDICAPPED CHILD"

JOHN A. ROSE, M.D., Director, The Philadelphia Child Guidance Clinic

SOCIAL HOUR: In foyer of Mayo Auditorium

SECOND SESSION

MAYO MEMORIAL AUDITORIUM

May 3, 1958

9:30 A.M. to 12 o'clock Noon

Miss MILDRED THOMSON, Minnesota Department of Public Welfare; past president American Association on Mental Deficiency, *Presiding*

INVOCATION

THE REVEREND H. A. GUILLEY, Chaplain and Director, Episcopal Foundation, University of Minnesota

"COUNSELING WITH PARENTS AT TIME OF FIRST KNOWLEDGE OF RETARDATION"

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

"GENETIC COUNSELING"

SHELDON C. REED, Ph.D., Director, The Dight Institute, University of Minnesota

"THE ROLE OF PARENTS IN HELPING EACH OTHER"

MR. ALTON F. LUND, President, The National Association for Retarded Children, Salt Lake City, Utah.

THIRD SESSION

MAYO MEMORIAL AUDITORIUM

May 3, 1958

2 P.M. to 4:30 P.M.

WILLIAM C. ADAMSON, M.D., Director, The Child Study, Treatment and Research Center, The Woods Schools, Presiding

INVOCATION

THE REVEREND MICHAEL MCDONOUGH, Chaplain to Catholic Students, Newman Foundation, University of Minnesota

"HELPING PARENTS IN THE COMMUNITY SETTING"

HARRIET E. BLODGETT, Ph.D., Program Director, The Sheltering Arms Day School, Minneapolis, Minnesota

"HELPING PARENTS IN THE PRIVATE RESIDENTIAL SCHOOL SETTING"

Miss MARY F. CARSWELL, M.S.W., Psychiatric Social Worker, The Woods Schools

SUMMARY OF CONFERENCE

MAYNARD C. REYNOLDS, Ph.D., Associate Professor, Educational Psychology, University of Minnesota

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FIRST SESSION

MAYO MEMORIAL AUDITORIUM
UNIVERSITY OF MINNESOTA

May 2, 1958
8:00 P.M.

MR. EDWARD L. JOHNSTONE, president, The Woods Schools, Presiding

INTRODUCTION TO THE FIRST SESSION

CHAIRMAN JOHNSTONE: Ladies and gentlemen, the 1958 Spring Conference of The Woods Schools, in cooperation with the University of Minnesota, will please come to order.

May I ask the Reverend David W. Preus, Lutheran Campus Pastor of the university, to offer the invocation.

THE REVEREND DAVID W. PREUS: O God, whom we address as a person, who became a person for our sake, who is the creator of persons, who does encourage us to love persons, we thank Thee for the personal love that has gone forth in The Woods Schools and all such ministering groups.

We thank Thee for the appointments as carriers of Thy love.

Help us and all men to see beyond exterior strangeness, beyond size and shape, race and nation, ability and guilt, to the person resident in each human body.

Teach us, we pray Thee, to love and honor each person who lives with Thee.

Grant that this conference may help us to this end, through Jesus Christ, our Lord. Amen.

CHAIRMAN JOHNSTONE: On the day after Christmas in 1956, Mrs. Paul Christopherson of Minneapolis detached herself from holiday activities long enough to write me a most beguiling letter. In it she presented a very logical sequence of reasons why The Woods Schools should select Minneapolis as the locale of our 1958 Spring Conference.

Immediately thereafter, distinguished members of the faculty of the University of Minnesota, representatives of the State Department of Public

Welfare, and others wrote enthusiastically urging that we accept no substitute for Minneapolis this year.

The invitation was most flattering. More important, however, has been the cooperation of the Minneapolis local committee in connection with planning the program and in making local arrangements for your reception here.

So, at the very outset, I take this opportunity to express warm appreciation to university officials, to agency representatives and to the interested citizens who have made this Conference possible.

We at The Woods Schools are honored to be identified with the University of Minnesota in this cooperative effort. I shall not take time to name individually all of those to whom we are indebted. However, Dr. Maynard Reynolds, Dean Walter Cook, Dr. Harriet Blodgett, Miss Mildred Thomson, Mrs. Christopherson, as well as University Relations Director William Nunn and his co-workers, Mr. William T. Harris and Mrs. Jean Lovaas, are among the many who deserve the thanks of all of us.

In addition, a word of gratitude is due the public press in this area for excellent newspaper coverage and to KTCA-TV, for the two half-hour programs on the University of Minnesota TV Journal. I might also add that other television and radio stations, including KUOM were most cooperative and helpful.

The foreword in your printed program sets the stage for the content of this series of meetings. It lists a distinguished roster of participants who possess unusual qualifications.

On the platform there are certain people that I would like to introduce at this time and the first that I am going to call upon is Dr. Walter W. Cook, dean of the College of Education, who will welcome you on behalf of that college.

Dr. Cook, a native of Iowa, received his undergraduate and advanced degrees from the State University of Iowa. His biography indicates that during his early career days he was associated with the National Map Company. Obviously, he has been putting places and programs rather prominently on the map for several decades. From public school work, he moved forward to identification with such organizations as the National Advisory Committee on Education; Eastern Illinois State Teachers College;

the universities of Chicago and Pennsylvania and then to the University of Minnesota. Here he advanced from associate professor to full professor and, in 1952, to dean of the College of Education.

In World War I, Dr. Cook served with the 87th Division of the A.E.F. in France. In 1943, the Army Engineers recalled him in a consultative capacity to design buildings, formulate curriculum, and select staff for the Los Alamos schools when the atomic project was initiated there. His membership in professional societies, associations and academies is extensive.

I now present to you Dean Cook . . .

DR. WALTER W. COOK: Thank you, Mr. Johnstone.

Ladies and Gentlemen: It is now more than a year since I wrote to Mr. Johnstone and the trustees of The Woods Schools suggesting that the University of Minnesota be the site of the 1958 Spring Conference on Exceptional Children. An informal group of university staff members and others in our community had suggested the appropriateness of the invitation. We were aware of the distinguished quality of this conference series and were hopeful that we might have its immediate stimulation and rewards for Minnesota in its centennial year. We are most pleased that the conference is now in session on our campus.

We like to believe that Minnesota provides an especially appropriate totting for the conference. Minnesota has always been forward-looking in its programs for exceptional children. At least since the time of the Children's Code of 1917, Minnesota's legislative provisions and its programs for exceptional children have frequently been considered models for the nation. We are particularly mindful and proud, in view of the theme of tin's conference, of the leadership Minnesota has given to programs concerned with mentally handicapped children in the persons of Dr. Fred Kuhlmann, Professor Florence Goodenough, Miss Mildred Thomson, Dr. E. J. Engberg, Dr. Grace Arthur and many others.

In very recent years, our programs for exceptional children have been revicwed and revised. A distinguished group of legislators—under the chairmanship of Senator Elmer L. Andersen—studied programs for exceptional children during the period 1955 to 1957 and succeeded in securing passage of a pattern of legislation which equips us well to move forward in the future.

Indeed, programs for exceptional children are being strengthened on every front in Minnesota. This conference follows by only one week the conclusion of a series of seven Governor's conferences on Exceptional Children at which health, welfare and education officials from all parts of the state have met to consider means by which programs of all types may be pressed forward.

During this past week, plans for a state-supported comprehensive diagnostic and treatment center for disturbed children have been announced. These are some illustrations of the busy Minnesota scene in special education.

We have had especially good opportunity to observe and work with parents of exceptional children. Parents have provided the basic stimulus for much of the improvement and expansion of programs for handicapped children in recent years. As they have formed their various associations, we have witnessed their growing strength, maturity and effectiveness.

We appreciate the fact that they have worked so constructively with us at the university. They have shown much interest in the College of Education, and this is also true of other divisions of the university. Their interest in research and training programs has come earlier than most of us would have predicted.

We congratulate The Woods Schools on its continuing leadership in services to children and especially for the recent development of the new research center. I'm sure The Woods Schools feels a real pride in this program addition. We have also been able to make substantial additions to our own research, training and service programs for exceptional children, under the able leadership of Professor Maynard Reynolds.

Mr. Johnstone, we join with you in presenting this conference at a time when our total state program of special education, including our university program, has promise of important progress.

It is especially pleasing to us that this conference is to be concerned with parents of exceptional children. To be sure, parents need to be better understood and counseled more adequately.

I hope that the parents who are present and those who will later read the proceedings of this conference will interpret the total program as a

tribute to their good work and for the sense of real partnership they have built and are sharing with us in all phases of special education.

On behalf of the College of Education and the local planning committee, I extend to all representatives of The Woods Schools and to all guests of this conference a very sincere welcome.

CHAIRMAN JOHNSTONE: Thank you, Dean Cook, for your message of welcome.

I don't think it has been my privilege to introduce a more distinguished scholar, humanitarian and gentleman than your next speaker.

Though he was born in Minnesota, the states of New Jersey and Pennsylvania (via Hill School, Princeton and the University of Pennsylvania) make certain claims upon him.

Many honors have been accorded this man, both in this country and abroad and, in each instance, they have been eminently merited.

I have been advised that he has been named an Honorary Fellow in the Royal College of Surgeons in England and that he will go to England in July to receive this citation.

The name Mayo is uttered with respect and with esteem. To bring you greetings from the University of Minnesota, I am honored to present a member of the Board of Regents—Dr. Charles W. Mayo . . .

DR. CHARLES W. MAYO: I have always wondered in my own mind just at what point a child is called mentally handicapped or not. Actually, I do not know at what point that is. I am, as the father of eight, a bit suspicious.

I am happy that you have selected the topic that you have, "Counseling Parents of Children with Mental Handicaps", because that really is a broad subject.

As I understand the situation, this takes in about ninety percent of the so-called mentally handicapped—there being only ten percent in institutions.

One might develop a subject for this occasion and perhaps entitle it: "The Mentally Handicapped Child — a Liability or a Parental Asset".

It has been my feeling that those parents who have individuals in their families who have handicaps of some sort, mental or otherwise, and who have accepted it and who have cooperated in every way for the benefit of that individual, find that this family is better because of what has happened. Once adjustment is made, the finest things from the soul of the human being are brought forth into the light, namely tolerance and understanding. Parents who have children of this type are, I think, better citizens because of it, and usually contribute much to their communities in addition to the problems they have as a family.

I believe it was Winston Churchill who said about the United Nations organization, "If we did not have it, we would have to create one." The same thing might well be said about The Woods Schools. What they have accomplished is important in all phases of mental work, in all states and in all countries.

It has been a pleasure to be with you and again my greetings and the hope that this conference will be a stimulating one for each one of you.

CHAIRMAN JOHNSTONE: Thank you, Dr. Mayo, for those encouraging words.

At this point, since there are no trustee members of The Woods Schools present tonight, I would like to convey to the participants and to this audience the very warm greetings of Dr. Leon J. Obermayer, chairman, and all other members of the board of trustees of The Woods Schools.

To keynote this Spring Conference program, we are fortunate in having a man who might well be described as "a rising young man in the field of education". The biographical data which he submitted was modest to the point of being terse. It follows:

Formerly on the staff of the University of Minnesota, John W. Bystrom is presently an instructor in the department of speech and drama at Hamline University, St. Paul. He has served as a director of the Minneapolis Citizens Committee on Public Education and as secretary and director of the Citizens League of Minneapolis and Hennepin County.

Having earned his B.A. and M.A. degrees from the University of Minnesota, he is currently completing work on his doctorate.

He is co-author of "Communication Through Speech", published in

1950 and is a member of several educational associations. He resides with his wife and three sons in Minneapolis.

It is a pleasure to introduce the President of the Minnesota State Board of Education, John W. Bystrom, who will address you on the topic: "The Parent Counselor — An Emerging Professional Resource". President Bystrom . . .

"THE PARENT COUNSELOR— AN EMERGING PROFESSIONAL RESOURCE"

By

JOHN W. BYSTROM

MR. JOHN W. BYSTROM: Thank you, Mr. Johnstone.

Ladies and Gentlemen: Goethe once commented that there is nothing which lends more dignity to man, nothing which ennobles him more than life in a state which is commensurate with his humanity.

In this sense it can be said that Mollie Woods Hare and later the trustees of The Woods Schools have ennobled all of us with their dedication to the problems of the exceptional child. By conferences such as these, they continue to broaden our understanding and urge us on to the day when we can truly say that there are no forgotten folk in our society.

It was in 1851 that the Minnesota territorial legislature delegated to the Judge of Probate Court the care and custody of "idiots, lunatics, and persons of unsound mind."

From that day to the present, we have seen an ever-increasing enlightenment in the approach of organized society to those with mental deficiency.

Although always bound by the attitudes and conventions of the time, we in Minnesota can point to a number of evidences of hospitality to progressive ideas in the area of the mentally handicapped. It was at Fari-bault that Dr. Frederick Kuhlman pioneered in mental test methods in one of the nation's first research programs on mental retardation.

One of the first experiments in public school programs for those of very limited abilities was held in St. Paul. In 1950, the National Association for Retarded Children was organized in Minneapolis, in part because the vigorous activities of local parent groups gained national attention. Both political parties have a history of advocacy in behalf of the mentally handicapped, a tribute to the attitude of our citizens.

In recent years Minnesota has made marked progress in its programs for the retarded and other handicapped children. Notable steps by the state government began with the formation, in 1955, of a Legislative In-

terim Commission on Handicapped Children. This Commission made a detailed study and produced a comprehensive report.

In 1956, Governor Orville L. Freeman expressed his concern over the problems of the handicapped which grew out of the physical rehabilitation which he experienced after being seriously wounded in World War II. He appointed an Advisory Committee on Exceptional Children, under the chairmanship of Dr. Maynard Reynolds of the University of Minnesota.

As a result of these activities, there were presented to the 1957 legislature proposals which embodied a new and dynamic approach to the problems of special education and most of the recommendations were passed.

In regard to the mentally deficient child, four provisions of the laws are notable:

First, it has become mandatory that every public school shall provide special instruction and services for educable handicapped children of school age who are residents of the school district.

Second, a permissive bill has made it possible for every school district to provide special instruction for trainable children of school age who are residents of the school district.

Third, an advisory board on handicapped, gifted, and exceptional children was created, with its twelve members to be appointed by the Governor.

Fourth, within the Department of Education four new positions in special education were approved and have now been filled. In addition to a Director of Special Education, Mr. James Geary, we now have consultants for speech handicaps, for deafness and for mental retardation.

Furthermore, monies were appropriated for the encouragement and development of teacher personnel and a program, centered at the University of Minnesota, is now well under way.

As a result of these new laws, an immediate and pressing problem in Minnesota today has become the proper fulfillment of the legislative intention.

I have observed, from the vantage point of the State Board of Edu-

cation, the development of this new program and have become acquainted in a small way with the problems for the parent and the child which accompany mental retardation. It is within the limitations of this experience that I direct my attention to the subject of this conference—the counseling of parents of retarded children.

My first proposition tonight is that services for handicapped children are less than adequate unless parent adjustment is considered as an integral part of the program and parents are allowed an equal partnership in the struggle to provide adequate services.

To all of you this may seem so evident as to approach triteness. However, the present status of services available to the parent suggests to me that it is still worthwhile to discuss the values gained from involving the parent in a program of services for the retarded child.

It will be my second contention that effective parent counseling is the prime means for tapping the vast resources for good which lie in the frustrations, guilt-feelings, anxieties and hostilities which are often the burden of the parent.

Of course, parent counseling is not to be justified alone by the strength it brings to the service. More important is the contribution it makes to the successful adjustment of the parent and the opportunity it provides for the handicapped child to adapt to his environment. However, consideration of these latter points is on the agenda of this conference and can best be left to the experienced professional for comment.

The recent development of services in Minnesota is one evidence of how the parent working with the professional can improve available programs. It has been made clear that the parent is an important resource in the strategies and tactics by which those partisans of the handicapped seek to construct a society which will actively extend itself to prepare the handicapped child for the road ahead, as well as to prepare a road over which the child can travel.

That is my first reason for stressing the important role of the parent. In a service almost totally dependent on government for its resources, parents are vital in meeting the challenges of political participation necessary to make up for past neglect of the handicapped.

Referring to the new Minnesota program, I once asked one of the

participants in the conference we are now attending: "How did it happen?"

"It would not have happened," he said, "without the parents. The professional would not and could not have done it alone."

It was John Stuart Mill who stated that "in politics, as in mechanics, the power which is to keep the engine going must be sought for outside the machinery."

With this as a guide, let us look at the Minnesota development. It was a group known as the Minnesota Council for Special Education which became the prime striking force, ultimately bringing to bear a vast network of professional organizations, parent groups, and service organizations in the field of the handicapped.

Senator Elmer Andersen, the very effective Chairman of the Legislative Interim Committee on Special Education, once referred to this group as the main instigators of that committee.

There are two characteristics of the council which I regard as important.

First, the organization represented a joint approach by interests in a variety of phases of special education. All the eggs were put into a single basket marked "exceptional children" — the case for the retarded child along with the rest.

Secondly, the organization represented complete and unreserved cooperation between the professional and the parent.

Successful public services are not created overnight, by a single master-stroke. It requires continued interest. Active concern by the public must be expressed at every point where decisions are made which affect the nature and quantity of these services. In the public school system, in particular, authority is so widely dispersed between so many agents that public concern must be of substantial size to be effective. Here the mature parent of a handicapped child is the principal resource to which the professional must turn.

Among the seven members of the Minnesota State Board of Education, there are two who have had an intimate connection with special education.

One, Mrs. Henry Kramer, had worked as a lay helper with Sister Ann Marie at the Christ School for Exceptional Children in St. Paul.

A second, Mr. Wayne Bassett, is the father of a cerebral palsied child. To him I owe much of my very limited knowledge in this field and I regard him as a kind of prototype of the mature, objective parent about whom I am talking. As a state representative, Mr. Bassett served on the Legislative Interim Committee on Special Education. He was a director of the Minnesota Council and is now active in the development of a multi-county school for the handicapped at his home town of Worthington, Minnesota. I emphasize Mr. Bassett's contribution to point up the significant role of a parent if he allows the tensions of his experience to be released in *action* for the general good.

The presence of these members on the State Board of Education is an assurance of an aggressive concern in matters relating to handicapped children.

It has been said that parents are in the best position to say what help they need and how a program is working. They provide an important sounding board for the alert administrator and a test of the effectiveness of a going program.

I know of one case in which local parents of retarded children, having started a home instruction program in their community, wanted to place it under the aegis of the local school board. They were confronted with a report that an Attorney General's decision stood in the way; and their own superintendent seemed to them to be willing to let matters stand at that. Spokesmen for the group confronted first one and then another responsible official as they progressed up the ladder of command. They became supplicants before the legislature and ultimately they prevailed; but only after many letters and many hours in conference.

It requires high motivation at times to get things done and it is encouraging to observe here in Minnesota that our administrators are aggressively developing channels to the parent, calling him in as a consultant and as a friend and making use of his experiences.

There is also a third point. The mature parent can be a direct aid to the professional by helping in the process of parent counseling.

Mrs. Letha L. Patterson of St. Paul, one of the founders of the National Association for Retarded Children, wrote of a "pro" who was once afraid of a "lay" movement, but now frequently requests "that some mature couple call upon parents who have learned that their child is

retarded." He has found, she writes, that parents who have successfully faced their problems can offer to new families a special kind of help which transcends his own professional services. Further, he has seen the therapeutic effects of parents working together in common cause.

Finally, the parent can help to meet the challenge of interpreting the program to the public. Mr. Geary, our director of Special Education, tells me that in areas of Minnesota where school programs for retarded are being considered for the first time, he has observed that many superintendents begin by encouraging the development of a parents organization. For, in this little understood field where program costs may be high, especially in sparsely populated areas, the official feels the need for advocates who can interpret the program to a large segment of the local community.

Now, when I discuss the contributions which can and have been made by parents, I must hasten to add that I am not referring to all parents of the retarded.

Parents who are to be treated as partners with the professionals and who may be effective agents and spokesmen for extending services for the retarded are persons who have reached a stage of personal development in which they ask themselves the question, "What can I do for others?"

It was Dan Boyd, a New Jersey parent, who described three stages in the growth of a parent of a mentally retarded child.

First there is the stage of self-pity—"Why did this happen to me?"

Next is the concern for family—"What can I do for my child and my family?" .

Finally there is the third stage, when he has attained to a deep desire to help and be of service to others in like circumstances.

These stages are not, of course, mutually exclusive, but they help in establishing our meaning.

So, having noted briefly the benefits which adjusted parents can offer to a total program for retarded children, we must now turn hopefully to the function of parent counseling to secure these benefits.

The way parent counseling is being handled in Minnesota, I suspect, represents the prevailing pattern for the United States. In some places there

are strong programs; in more places there are informal efforts; and at many points parent counseling is provided in theory while, as a practical matter, it is weak or non-existent. In brief, there is no strong pattern or structure for parent counseling within the the state. As one professional put it, the parent must largely "run into it".

However, I feel sure that it is not unrealistic to say that the impact of this conference on local thinking could well set in motion activity which will lead to further development of parent counseling in the state.

We may perhaps conclude, from our Minnesota scene, that the need for parent counseling is recognized but that experience has not been sufficient "to know all the answers" as to the place of parent counseling and the way it should function in a comprehensive program for retarded children.

I would like to point briefly to some developments in Minnesota which have a bearing on the programs for retarded children where parent counseling might best function.

Just last month a report was released by a subcommittee on Trainable Retarded Children from the Governor's Advisory Board. In it the committee recommends "that the lifetime program for trainable retarded be placed under the supervision of the State Department of Public Welfare." This then makes the county welfare board an obvious point to consider for development of adequate parent counseling.

The same report states: "During the time the child is in school, all features of group classes for trainable retarded children—the specifications of class size, entrance requirements, curriculum and other considerations—shall be determined by the Department of Education."

So, while the Department of Welfare has total responsibility for the training of the child, the Department of Education also has an important role which may extend from the time the child is five to the time he is twenty-one years of age.

It is the view of one director of a private school for the retarded, with a strong parent-counseling activity, that once the child is placed in the school, the parent is drawn to the school; tends to look to its staff for leadership and often asks questions as to how particular difficulties with his child are handled.

The public school, then, needs to be considered as a point at which parent counseling may take place.

Finally, the report notes the role of the private agencies which it says have developed "from strong felt needs" and which "frequently pioneer in new areas of need."

It seems to me, at the present stage in the development of parent counseling, that private agencies provide the greatest opportunities for immediate action.

It was Lord Asquith who, it seems to me, most aptly stated the challenge which leadership in our society confronts in our problems with the handicapped: "The test of every civilization," he said, "is the point below which the weakest and most unfortunate are allowed to fall."

In all the comparisons now being made between Russian and American education I have yet to see one reference to the treatment of retarded and other handicapped children.

We, in this country, are only at the beginning. With the help of the parent, with the help of the professional, with the help of The Woods Schools and with the help of those of us who really know very little about the problem, may we continue to commit ever greater amounts of our resources to improving the lot of the handicapped children in our midst. I thank you.

CHAIRMAN JOHNSTONE: Thank you, Mr. Bystrom. In this very stimulating keynote address, you have opened up areas of thought which, I am sure, will be invaluable in promoting the thinking and, we hope, the action of less aggressive communities than this in which you and your co-workers live.

During my own lifetime of service in the field of the mentally, physically and emotionally handicapped, the delinquent, the defective and the socially maladjusted, I have been blessed in having had the encouragement, support and counsel of wise and perceptive friends.

Your next speaker is one of them and this occasion affords me the opportunity to acknowledge his valuable help in many instances. A brief word concerning his career:

John A. Rose, M. D., director of The Philadelphia Child Guidance

Clinic, is also associate professor of Psychiatry in Pediatrics at the University of Pennsylvania. He is psychiatrist-in-chief at Children's Hospital, Philadelphia.

Dr. Rose received his B. A. degree from Rice Institute and his M. D. from the University of Texas Medical School.

He is a member of the Board and Executive Council, Pennsylvania Mental Health Society; charter member of the American Academy of Child Psychiatry; affiliate Fellow of the American Academy of Pediatrics; a Fellow of the American Psychiatric Association, American Orthopsychiatric Association, American Medical Association and Pennsylvania Psychiatric Society.

Dr. Rose is a vice president of the Philadelphia Psychiatric Society. He is also author of many leading articles in the field of medicine and psychiatry.

I am happy to present to you, Dr. John A. Rose, who will talk to us on "Factors in the Development of Mentally Handicapped Children".
Dr. Rose . . .

"FACTORS IN THE DEVELOPMENT OF MENTALLY HANDICAPPED CHILDREN"

By

JOHN A. ROSE, M. D.

Solomon¹ recently stated in reviewing the fluctuations in adequacy of mental hospital programs over the past 100 years that the central problem was one of public morality and ethical belief; that the quality of care of the mentally ill person at any given time was a reflection of the value of individual life and its welfare interests.

The history of advances in child health and welfare seems to have a similar linkage. In the past half century such advances have improved the life expectancy of the child and have also afforded greater opportunity for individual development through augmented social and educational opportunities.

In the medical sciences and in the social sciences while we still pursue the problems of mortality, there is increasing emphasis directed toward the mastery of problems of chronic disease and complicated states of social morbidity. This emphasis leads to programs both of rehabilitation and prevention. In public health language², this has become an attack on the problems of human wastage. In this context we may comprehend the purpose of all efforts in the children's field is to prevent not only excessive mortality but also the conditions leading to complicated states of morbidity and social ineffectiveness. The relative control of infectious disease and other advances in medical science have made us increasingly aware that increased expectancy of survival in childhood is now coupled with an increased expectancy for the discovery of developmental handicaps in those children who survive. It is the particular task of medical science to facilitate the prevention of such conditions or, at least, to promote better and earlier intervention aimed at decreasing the social cost of late rehabilitation; or the greater cost involved in social custody of persons without capacity for positive contribution to society.

It is in this context that this discussion of the factors in the development of the mentally handicapped child is undertaken. The existing body

¹ Solomon, Harry C. in address before Penna. Mental Health Annual Meeting.

² Lemkau, P. in "Elements of a Community Mental Health Program"—Milbank Memorial Fund, New York, 1956.

of knowledge with respect to these factors is marked by scattering and lack of correlation.

Human development is generally believed to be the product of complicated interaction between the basic biological equipment of man and the total forces of the environment—his nature and his nurture. In studying the factors involved in this nature-nurture interaction, scientists are caught in the dilemma of either attempting to study the whole and ending in a kind of global confusion, or of studying a part of the problem intensively and risking the development of isolated or irrelevant knowledge. Currently there is underway in some 13 medical centers a cooperative effort³ at investigation in which we comprehend a major attempt to escape the dilemma imposed by this massive and complicated problem.

In our group, it has been quite stimulating to review the ideas of other groups and to consider various possibilities for the focus of research design. There seem to have been two major trends in the study of morbidity in child development. In one approach, a large number of cases are involved in an epidemiological approach which seeks to establish positive correlations of statistical nature between the variables of antecedent life events and the picture of a given developmental outcome. In the other, a small number of cases, usually of longitudinal mother-child interaction, is studied intensively.

Such studies have usually originated from theory formation which involves interaction as an important variable in the prediction of a certain developmental endpoint. Each approach has different values and different sources of error. The epidemiological study seems to be able to show significant correlations between related previous events and given developmental outcomes; it runs the risk, however, of missing a key variable of importance since high positive correlations are not necessarily interchangeable with etiology.

The most obvious factors are not necessarily the most significant with respect to attempts at prevention and intervention. The longitudinal study is handicapped by the limited number of cases which can be studied and apparently by the fact that necessity for intensive study involves the investigative personnel in such a way that the personnel also become a part of that which must be investigated. The tendency of such studies is to produce many variables and few significant correlations. Prediction has been attended

³ "Collaborative Study of Cerebral Palsy"—Sponsored by National Institute of Neurological Diseases and Blindness.

by little success. There seems to have been relatively more study of intrapsychic change in the child, with the mother viewed as stabilized.

While considering such methodological issues, we were confronted with yet another source of complication in these studies. In the attempt to escape global involvement, particular foci of investigation are developed. At a conference of consultants, we were impressed with the assumption of several persons that a given set of maternal attitudes were most importantly relevant to pregnancy while others were inclined to feel that the same attitudes were more significant for child care than for pregnancy. It seems possible that in attempting to escape the problem of too many mutually dependent variables, there is a resultant attempt to perceive one aspect of the problem as more fixed and constant than can be sustained by intensive scrutiny.

In the studies on factors in child personality development, we were impressed by the common assumption that maternal personality was perceived as a relatively fixed and unchanging quantity versus the perception of the child as differing and varying greatly. Among those studying pregnancy there seemed to be a belief that pregnant women were in a greatly varying dynamic integrative flux; that maternal personality was in a state of change so that a cross section of attitudes might differ from day to day and from early to late pregnancy in quite a significant manner. The same group tended to be little impressed with the relevance of the view that this process might continue into the neonatal period or early years of a child's life.

It is possible that this tendency accounts in part for the history of theory formation and investigative work in morbid human development⁴. Evolution of ideas about mental illness seem related to assumptions which were not sustained with respect to some unchanging aspect of man's nature or nurture. The most recurrent theme has usually been that a given condition was the result of a single variable in nature as more determinative than factors of nurture. Successive discoveries seem to have led to the conclusion that nature is less fixed than was assumed and more influenced by nurture in complicated ways.

At one time the variability in genetic inheritance seemed independent of nurture influences. The danger of radioactive fall-out and indeed of all uncontrolled radiation tells us that nature is again vulnerable to nurture.

⁴ Adolph Meyer was a pathologist but led the study of causation in mental illness to patterns of longitudinal type.

The development of knowledge with respect to the unit of individual development, the gene, increases the uncertainty that any given developmental endpoint has a single cause. The subtle possibilities of interaction between nurture and nature in cellular physiology suggest that human development is the result of endless permutations: that the developmental model has indeterminate probabilities.

Certain children, for instance, are born with an inability to metabolize certain amino acids; others with a similar inability to handle certain carbohydrates. These conditions are often spoken of as if the cause was a completely understood genetic trait and the remedy a simple substitution of a chemical substance to compensate for the defect in nature. We now know that nurture-nature interaction may alter the long range effectiveness of such simple substitution when the yardstick is that of a qualitative developmental endpoint rather than a question of survival. Scientific developments with respect to alteration in genetic structure now permit us to speculate as to whether we even understand the cause or causes of these "simple" conditions.

Early and severe damage to the growing fetus, formerly assumed to have a simple genetic base, has successively been shown to be related to a myriad of infections and metabolic depressants⁵. Such discoveries have increased the existing hope that a single cause of defect will be found. The endpoint of maldevelopment is not the same as the cross-section of fetal damage; it is the product of subsequent interactions between damaged organism and environment. It is possible that such conditions have multiple causes as well as various developmental possibilities. We are not yet certain we understand entirely the machinery of damage.

Understanding the dynamics of causation may be seen as presenting problems both of method and concept. It has seemed to us that the hope of the group approach to study design, while slow, did allow for certain "built-in" safeguards against some of the problems of the past. Possibly the greatest contribution of such group effort will be in the inclusion of more significant variables through a spread of conceptual thinking. Since the core study is to be of epidemiological type⁶ it is quite dependent on

⁵ "Psychopathology of Mental Deficiency in Children" by Clemens E. Benda and Malcolm J. Farrell. Pg. 56 in Psychopathology of Childhood, edited by Hoch and Zubin.

⁶ Reference is made to the cooperative study of perinatal morbidity supported by N.I.N.D.B.

previous clinical and investigative experience if all necessary issues are to be considered and appropriate variables introduced as possibilities.

Group effort also may contribute to the solution of another problem. Studies of factors in child development involve attempts to quantify behavior, attitudes, and emotions along with physical events of more fixed nature. The heterogeneous character of the involved groups will probably assure the detection of inconsistencies and spurious validation of data which are common problems in quantification of these factors.

Conceptually, it has seemed to us that it was possible to avoid the problem of fixity by regarding the mother and child both as changing objects in which the changes are somewhat related to each other and also to influences which are more specific to one than to the other.

Experimental studies in animals and human autopsy findings suggest that the greatest damage to the developmental potential of the fetus occurs when toxic influences are exerted during periods of greatest activity in the development and differentiation of the basic structures of the child's body. In a like fashion, it is generally believed that the greatest damage to the potential for successful personality development occurs in the first months and years when personality growth and differentiation is changing rapidly. Vulnerability is thus related to rapidity of the rate of change. Though maternal growth is relatively more complete, it must be assumed that the rate of maternal personality development is influenced by task of pregnancy and neonatal care; we have added the influence of an "external" pacemaker to the timing apparatus governing maternal change. The imposition of the time-table of pregnancy and child care increases the need to consider the existence of vulnerability of the same general origin, that is, as a function of the rate of change.

There are common examples which may illustrate the derivation of this idea of maternal vulnerability. We are generally aware that social and psychic readiness for pregnancy are not direct functions of physical readiness. Some women are ready for pregnancy but not for child care. A biologically functional breast may produce milk but not be ready to allow nursing. It is generally believed that the social complexity demanded of contemporary adult roles has increased the period of psychic and real dependency of children on families. A woman therefore may arrive at the state of pregnancy and mother role with a considerable disparity between the actuality and the state of psychic and social readiness.

Vulnerability in the mother is likely to appear as a symptomatic manifestation. It is generally believed today that the greater the disparity between psychic readiness for a given task and the demand⁷ for its performance, the greater will be the resultant stress on the homeostatic capacity of the organism. If the resultant tensions exceed the adaptive or homeostatic capacity, we have come to expect that we will see the appearance of symptomatic behavior and/or derangement of body physiology. Pregnancy and the period of early child care are noted generally as being periods of odd behavior, peculiar ideation, and many physical symptoms in women.

If we consider that we are dealing, then, with the study of two organisms whose vulnerability to developmental damage may be concurrent and thus interacting⁸, it becomes important to consider the damage both as separate and as related phenomena.

With respect to the mother, considering pregnancy and child care as relatively fixed states, we may say that she brings certain assets and liabilities to the task. From her past life she will have derived certain ideas as to the value of the roles of woman, wife, mother and adult. She will have arrived at some point of experience in the management of past adaptive crises and will bring to bear on the new experience the expectation with respect to failure or success derived from the past. She will have developed patterns of relationship which on the whole make it easy for her to find support from family, husband and friends; or oppositely, to make it difficult. She will have developed certain typical behavior of regression or disorganization in the face of excessive stress. Her educational experience and socio-economic group will have influenced the nature of her values as to what is satisfying and rewarding in life in general as well as her experience in her own family. To this new experience then she will bring a complicated set of needs for satisfaction and happiness and probably a certain predisposition to fail or succeed in such goals. It would appear probable that one combination of assets and liabilities will predispose more to vulnerability and stress than will others.

We would therefore like to know as much as possible about this past experience and where it has brought the person. In considering such an assay, it is of course important to consider the place of present experience both as a factor in itself and as influencing perception of past experience. Allowing pregnancy or motherhood still to be things apart, we would

⁷ Demand=inner expectation and social expectation.

⁸ Interaction=interpersonal and intrapsychic in both.

need to know of any stresses of current catastrophic nature such as illness, death, or financial and social disasters. It is generally considered that currently overwhelming situations are likely to distort impressions of basic capacity in any person.

Considering the mother with this equipment and experience now in the state of pregnancy or new motherhood, it is readily supposed that at any given time her behavior and ideas will be the result of interaction between past and current experiences. If we can succeed in getting typical samples we should be able to establish the trend of change as more or less favorable to the task. Both physical symptoms and ideas tend to take on either positive or negative qualities and to present a range of values as closer or more distant from a median point of indifference. There are, of course, inherent in this, problems of methodology toward which we are now acting as if these too are "fixed".

To pursue the model, we may now consider the fetus and child in a like manner. We are somewhat handicapped in this because of lack of knowledge of the probabilities of the "past" of the neonate and we have no reliable communication with intrauterine events. For this reason we arrive at the neonatal period with little more than a general knowledge of the past as denoted by changes in size and the beginning of movements and heart beat. X-rays may tell us of abnormalities in structure of bones, of position and of the possibility of multiple pregnancy. Laboratory studies may tell us the fetus could have been affected by maternal infections capable of crossing the placental barrier and also of the existence of Rh incompatibility. Examinations of the mother may tell us of the task imposed on the fetal endocrine system by the endocrine deficiencies in the mother. The mother's general or special health problems sometimes provide clues to silent possible effects upon the fetus. Apart from a few known specific infectious or toxic events this is largely a matter for exploration.

The stress imposed upon an infant by the birth process is far from clear. Even the time when a child will be born is related to a highly complicated interaction between fetus and mother; maternal machinery is currently considered as dominating the onset of the birth process with maturity of the fetus a secondary factor. The tendency of mothers to spontaneous abortion and premature delivery will probably be related to an infant's "past" history as a function of maternal attitudes and feelings. Beyond this we know that severe trauma in the birth process can injure the brain as can states of oxygen deprivation. There are few ways to measure

the severity of insult; often considerable damage may have occurred and is manifest for a few days after birth by signs of non specific nature. The later failure of motor sequences signals the appearance of developmental handicap of relatively severe nature. The problem we can begin to see in the history of the infant is in its uncertain equipment for life.

We may see that some babies are active and alert and some are difficult to rouse and relatively low in activity. Many consider that there are significant variations in sensitivity to stimuli as well as in energy output. For the most part this too is an area for exploration as to what is actually intrinsic to the infant apart from the mother.

It is from the neonatal period on that we are less uncertain of the factors influencing the developmental potential. The dilemma in this may be comprehended from the fact that we are already uncertain with respect to the outcome (in other than a gross sense) of previous interaction between nurture and nature as manifested in the new-born infant. As previously mentioned, one of the most significant determinants now becomes the attitudes and feelings which enter into infant care. Actually it appears that infants in the first six months are much less vulnerable to the trauma of disease or even to surgical intervention than to problems in the mothering climate. This is not to deny the existence of a number of specific conditions which may exert a severely crippling effect upon the infant, if not producing death. Certain congenital defects, severe infectious diseases, chronic metabolic diseases and hereditary neurological diseases are well established causes of severe morbidity. The unanswered question even in these cases is the degree to which the mother's development and hence mothering capacity is also affected as a function of the total outcome.

The literature of child development⁹ has placed great stress on the tremendous importance of the contribution of parental attitudes and feelings to child development. Deprivation of maternal care during the early months of life may lead to inanition and death; at a later period it has been linked to developmental lag and shallow character formation. Oppositely, over-stimulation has been related to sleep disturbances and irritability. Tensions of fear and anxiety in the handling of babies seems to give rise to a variety of biological dysfunction appearing as symptoms in the gastro-intestinal tract, respiratory tract and skin during early months; later there may be deviation in the developmental sequences involving muscular skills and failures of walking, talking, playing and

⁹ Brody in "Patterns of Mothering" lists some 335 titles bearing on this point.

habit training. Past the age of two years, severe developmental disorganization may appear as psychosomatic disease or beginning psychosis. Less severe states are manifested by impulsive and hyperactive behavior. The common factor in such states is the inability of the child to bear stress or stimulation. Since the purpose of maturation is to allow for more complicated states of organization and goal-directed behavior, the ultimate failure is in this area.

To state it differently—in order to learn and to perform in the first place, the parent-child relationship must act as a buffer against excessive disorganization. If the relationship is ineffective totally, the later learning function is all but lost. If the relationship is inconsistently effective, the child is vulnerable to disorganization, and stress of varying degrees results in regression to more infantile states. Thus, a child may ultimately handle more complicated states of development such as peer relationships and school except that this competency is liable to disruption by greater or lesser stresses. Perhaps more importantly, maturational failures in a child are accompanied by impulsive and often hostile provocative behavior which is not only incompatible with learning but also alienates relationship with any significant adult. The latter point is relevant to the focus of this discussion. It is clear in such situations that the behavior of such a child produces disturbed feelings in almost any adult. It is less clear that even infant behavior may have the same effect. In our group we have observed babies who could alienate student nurses in a group. Similar experiences have been reported from other groups¹⁰.

It is possible that these data illustrate a basic point—the idea that various states of child development not only disturb significant adults, but are actually able to influence the maturational progress of those individuals in constant contact with the child. Much has been discovered with respect to the effect upon the child of parental behavior but relatively little about the counterpart experience with respect to parental maturity.

The problems of evaluation of this effect are complicated in a way by the fact that parental maturation processes are less total than that of the child. The impact of the child upon that development may affect only the handling of that child or that of other children. There are no doubt radiations of this process into the total machinery of the satisfying and dis-

10 Wessel, M. A., Cobb, J. C., Jackson, E. B., Harris, G. S. Jr., & Detwiler, A. C: Paroxysmal Fussing in Infancy, Sometimes Called "Colic". *Pediatrics* 1954, 14, 421.

satisfying aspects of life but the effects are less specific and difficult to distinguish in a unique form. Frustrations in child-care may, for instance, impose strains on the husband and wife relationship but the manifestations may or may not differ greatly from financial hardship strains, etc.

From a clinical viewpoint the most impressive evidence of actual increase in maternal maturity may be seen in the differences between experience with first and second children. It has been our impression, for instance, that parents are almost uniformly less tense in the care of second children than of first ones. They seem to have learned "how to do it". As a usual thing, we are accustomed to hearing that the second baby has just been "allowed to grow" and seems more relaxed and less anxious with respect to developmental tasks.

The ability of a child to reward and satisfy a mother seems to arise partly from what he is as a real creature and partly from the values engendered by imagination and creative perception. In this sense we may see that the unreward of a mother from a child may arise primarily from her original perception; primarily from the difference between what he is and what he should be, or primarily from a mixture of the two attitudes. In the latter case it is possible to see that if tensions arise from original perception and affect the development of the child, there will inevitably be variations between what the child should be (as a satisfying object) and what he really is. This allows for a type of circular interaction in which a mother feels continuously less adequate and a child is really less rewarding.

In a sense, then, what a child is may influence what he becomes developmentally no matter what the primary origin of the "what he is". In clinical child psychiatry and in pediatrics where there exists responsibility for adequate intervention, we are necessarily interested in the principal primary origin or origins as different foci for intervention.

In study design we have problems originating in the difficulties of determining the "cause" or principal "causes". Even if we succeed in arriving at a study design which delineates the significant variables, the problem of relative values remains. The more important variable may be determined from subsequent studies; it may yet be less important from the clinical point of view with respect to the problem of intervention.

We may illustrate the clinical problem by several examples. If infantile disorganization is the major cause of maternal disorganization, as exempli-

fied in states of gastro-intestinal upset and irritability, the best point of intervention may be to isolate the infant sufficiently to restore homeostasis. By changing what the child "is" to a more gratifying state, we may interrupt the circular interaction since presentation to the mother of the different "is" may find her with greater solution of her original tension problem. In other situations where the developmental deviation of both appears to be more related to problems of original perception of role, the developmental deviation in the infant may only be managed by treating the perceptive problem of the mother directly, i. e., she may not be able to perceive the need of the infant except by alteration of her original perceptual distortion. The assumption is that the infant cannot become what he needs to be without this alteration.

It may be seen that clinical management depends in quite a degree upon being able to establish with some clarity *why* an infant is as he is and even to have some idea as to what he can be under given conditions.

This somewhat lengthy preamble now enables us to approach the factors in the development of the mentally handicapped child since it should be readily perceived that such development is complicated in almost all possible ways. It may be related to interference with potential in fetal life or to birth injury or to post-natal interaction. It is obvious that the more total the damage the easier it is to establish clinically what the child "is". This becomes a factor of central importance. If prenatal damage has been massive, the matter is least complicated. States of lesser prenatal damage and post-natal damage become involved in ever more complicated transactions which make diagnosis and adequate intervention quite difficult.

It has been suggested that what a child "is" objectively, may be perceived by the mother both realistically and symbolically. Any deviation between the "is" perceived and that perceived as "should be" is reacted to with guilt, as if something willfully bad had been done against one's parents or society. Life patterns of management of one's misdeeds are invoked and in the subsequent interaction, it becomes extremely difficult to decide as to whether what the child "is", is perceived more realistically or more symbolically.

This tendency in the adult to react with guilt and perceptual distortion not only accounts for the general problem of determining objectively what a child "is" but, even more importantly, must be handled, if further distortion of the developmental potential is not to occur. The comments most

frequently encountered in discussions about the emotional problems of children with relatively simple intellectual defects are—"The parents expect too much and the child tries too hard and so becomes nervous."—"The parents have never been able to accept the nature of the handicap—they shop constantly for other medical opinions."—"The mother overprotects this child so much that he is much more infantilized than he should be."

Such comments, of course, suggest that different types of the parent-child interaction are generally perceived as interfering with the child's developmental capacity. In some cases physicians can be quite clear even though the parent is not; in others there has already been such massive interaction in the nature-nurture area that diagnosis of developmental capacity has become a major task of clinical practice.

Children with various degrees of brain destruction or injury have inherently less capacity for independence and more complicated states of goal-directed organization. The failure of such competence to develop is associated with the retention of infantile traits and inadequate controls over impulsive behavior. It is assumed that defective cognition is the larger factor in the inability to learn and profit by experience in such cases. The distortion imposed by and upon parental attitudes and feelings in transactions with brain injured children introduces diagnostic confusion in the individual case; the child's failure in maturation may be considered to have emotional and structural interference to cognitive function.

The problem of evaluating the relative importance of factors with respect to interference of cognitive function leads to problematic generalizations. The studies of Pasamanick et al¹¹ are those of a series revolving about the hypothesis that all behavior disorders of children are one end of a continuum in which severe brain injury is at the other. This hypothesis has the virtue of seeming to establish what the child "is" and "can be", independent of parental attitudes and feelings. The clinical effect of such a formulation seems to illustrate its intrinsic fallacy. When the

¹¹ Lilienfeld, A.M.: Pasamanick, B.: Association of Maternal and Fetal Factors with Development of Cerebral Palsy & Epilepsy, *Am. J. Obst. & Gynec.* 70:93-101 (July) 1955;.

Pasamanick, B., and Lilienfeld, A.M.: Association of Maternal and Fetal Factors with Development of Mental Deficiency: I. Abnormalities of Prenatal and Perinatal Periods, *JAMA.* 159:155-160 (Sept. 17) 1955.

Pasamanick, B.; Rogers, M.E.; and Lilienfeld, A.M.; Pregnancy Experience and Development of Behavior Disorder in Children, *Am. J. Psychiat.* 112:613-618 (Feb.) 1956.

potential of the child is basically indeterminate and when physicians and parents feel unable to influence child development, the net effect is corrosive to the parental developmental process with the consequences previously discussed.

Recently, as we began a follow-up study¹², we were presented with some quite pertinent findings bearing on this point. The purpose of this study was to review the development of the children in some 500 cases in which Rh incompatibility was a complication in pregnancy and the neonatal period. During the past few years the utilization of exchange transfusions in infants has seemed remarkably effective in protecting them against severe and formerly inevitable neurological damage. The procedure was of such clinical value as to give rise to the impression that damage was preventable in 100% of the cases, providing there was sufficiently early diagnosis and intervention. These cases had been managed and followed through the first few months of life by one physician who is currently an investigator on the larger study to which this one is ancillary. It was hoped that a more formal follow-up study would produce confirmatory evidence as to the protective value of the procedure. Since the clinical impression was that almost no gross neuromuscular symptomatology would be found, the study was designed with a view to establishing the presence or absence of more subtle neurological defect and/or intellectual deficit. The children were to be seen at around five years of age.

This study is continuing and as yet so few cases have been reviewed that it is not possible to draw any conclusions from the material developed. One aspect of the study has already become so impressive, however, that it seemed appropriate to discuss it as a series of clinical impressions which must be further substantiated to be of real value.

In past clinical experience, we have been impressed by the impact of uncertainty with respect to damage in a child as a cause of considerable disturbance in both parent and child. This has seemed true whether the uncertainty arose as a parental fear with no significant reality stimulus, or whether it was derived from contact with a physician and/or the infant himself.

In several instances we have seen cases in which the fear that defect exists in the child has been so strong as to be almost delusional in character. In one case the eventual effect upon the child was breath

¹² A sub-study of the N.I.N.D.B. is the study referred to.

holding to the point of syncope. In the other, while no gross change had yet appeared in the infant, the intensity of maternal fear was of such character as to lead a pediatric resident to administer an aminophyllin suppository to an infant in whom no objective signs of asthma existed.

The relatively rapid impact of pregnancy and child care on the personality integrative process of the mother seems to increase the probability that such ideas will appear with varying frequency and intensity during these time periods. Fortunately they do not often appear with the same intensity as in the cases cited. They are, however, likely to be sufficiently in evidence as to be triggered into activity by apparently slight stimuli. This phenomenon is frequently overlooked by physicians and because of the omission creates immediate and long range complications in care. Some mothers who seem disproportionately anxious when illness is mild or after symptoms are under control, may actually be perceiving the infant as critically ill or at death's door. A variant of this situation occurs when an inconsequential remark of a physician with respect to a child's condition is construed as having a value referring to gravity of prognosis. Such impressions have led us to stress with pediatricians that care should be exercised in the conduct of neonatal examinations of both well and sick children to avoid burdening the parent with irrelevant professional uncertainties. (Obstetricians should observe similar precautions in prenatal examinations.)

We have been impressed with the fact that serious uncertainty and consequent anxiety is rather readily introduced both by objectively appropriate and inappropriate stimuli. Once introduced it seems to acquire a life of its own, continued by all the mechanisms discussed and able to endure despite the passage of time and the pressures of other life events.

It has seemed to us that the parents of premature babies continue with great uncertainty as to ability of the child to survive long after the child is established in a healthy and relatively physically normal existence.

Clinical experience of this nature has led us to speculate that the uncertain complex of feelings and ideas, while most often set in motion by objective events, will exist with an intensity more related to previous life experience than to either the original stimulus experience or the continuing objective problems in a child's performance.

It was for this reason that we became so interested in the remarks

made to us by parents being interviewed in the study. In almost all cases interviewed, the parents' retrospective impressions of disturbance triggered by the interpretation of the infant's condition was more total than perceived by the physician at the time. The intensity and duration of the uncertainty disturbance seems to have been little affected either by reassurance from the physician or the real immediate improvement in total prognosis with respect to survival or major neurological disaster. The objective focus of the uncertainty has seemed little or only tangentially related to realistic possibilities of complication as understood intellectually by the parents. One mother, for instance, who had seen her best friend's child develop severe muscular involvement (from a like cause) was not afraid of this but was deeply concerned over the possibility of mental defect.

It is our impression that there exists a tendency for the uncertainty to become fixed to symptoms in the child of widely varying type and in our experience more linked to maternal tension than to complications of the original problem. One mother described herself as exercising perpetual vigilance in observing her child's stools following bowel movement. This dated from a severe diarrhea of apparently functional nature which had resulted in bleeding from the bowel at age 4 months. The child at five years had never experienced any subsequent gastro-intestinal problem of grave nature, though she had recently been troubled by pinworm infestation. For another mother the fixation was upon a croupy wheezy breathing in sleep which was first noted at nine months of age. She has taken the child for care repeatedly without satisfaction but continues to do it persistently despite the absence of significant physical findings.

In some instances the uncertainty is manifest in a magical mechanism. Several mothers have entertained vague ideas that exchange transfusions may cause the infant to acquire the personality characteristics of the donor¹³. In one instance the mother's fear is stirred if the child gets anything yellow on his hands, an apparent association with the original jaundice (which is the striking feature of the Rh baby when the condition is developing). Several mothers discussed in some detail conflicts over extending love to their babies; in one instance as if it would have increased the risk for the baby if love had been fully granted. In another, the mother related more frankly the intolerable tensions

¹³ The child in fact does lose some of the immunity common to infants, in the first 6 months.

which might exist in herself consequent to loving the baby fully and then losing it.

These latter points seem to correspond to the impressions we have that these mothers tend either to move anxiously closer to their babies or to withdraw and allow their own mothers, husbands and friends to invest in the minutia of care of the infants.

It is our clinical impression that this group of children are disturbed. It would appear that there is little or no neurological damage and that intelligence is good. If these impressions are confirmed in the study, we may well find that a very high correlation exists between perinatal morbidity and the subsequent appearance of disorganization tendencies in the developmental patterns of these children. It may be that as a group, the emotional crippling will be sufficiently great to make for a guarded and uncertain future unless there is adequate intervention.

In summary, the problems of understanding the relative importance of the factors in the development of mentally handicapped children have been reviewed. There is hope currently that a group approach to this problem will make an important contribution to our knowledge. Some of the conceptualization of our group has been presented. The focus of the ideas and clinical evidence has been related to damage of the parental maturation potential by reinforcement of uncertainty with respect to a child's developmental potential. It is our conclusion that this factor is sufficiently important to warrant much more intensive study.

Thank you.

CHAIRMAN JOHNSTONE: I think, Dr. Rose, when word of the content of this address gets around, that the demand for copies of the proceedings is going to threaten The Woods Schools budget. I thank you for a very stimulating presentation.

Before adjourning, I would also like to ask three gentlemen to stand and be identified when I call their names:

The first is Dr. Dale Cameron, director of Medical Services, Minnesota State Department of Welfare.

The next is Dr. Edward Engberg, superintendent of the Faribault School.

The third is Mr. A. Whittier Day, director of the Youth Conservation Commission of the State of Minnesota.

When we leave here we will be entertained in the foyer by a group of Minnesota hosts and hostesses. I would like to thank all of them in advance for their careful preparations in setting up the period that will follow.

(The meeting adjourned at 9:50 p.m.)

SECOND SESSION

MAYO MEMORIAL AUDITORIUM

May 3, 1958

UNIVERSITY OF MINNESOTA

9:30 A. M.

Miss MILDRED THOMSON, Minnesota Department of Public Welfare;
past president American Association on Mental Deficiency, *Presiding*

PRESIDENT JOHNSTONE: Ladies and gentlemen, I welcome you on this beautiful May morning to the second session of this annual conference.

I should like to make two or three brief announcements before calling on your presiding officer.

First, there is a gentleman from Toronto—representing the Ontario Association for Retarded Children—Mr. Harold Lobb. Will he kindly stand and identify himself?

We are also very pleased to have with us Dr. Frederick L. Richardson, who currently is from the Department of Pediatrics at Johns Hopkins Hospital. He comes from Birmingham, England and has served a number of years in the Children's Hospital in London. Will Dr. Richardson kindly stand for a moment?

I am sure that many of you from this vicinity know Mrs. Letha Patterson and are aware of her fine activities in connection with the national and local associations for retarded children. She serves on the editorial staff of "Children Limited" and has been an active member of the National Publicity Committee of the NARC.

Also from this local area, a person of distinction in this field, the president-elect of the American Association on Mental Deficiency—Frances M. Coakley.

We are most happy to have all of you with us at this conference.

Your presiding officer this morning is a very dear friend of mine. She has been a consistent leader in the field of endeavor which we represent.

A native of Georgia, Miss Mildred Thomson, was graduated from Agnes Scott College, a girls college in Georgia, and received her M.A. degree at Stanford University, California. She later did further graduate work at Columbia University and for the past 34 years she has served ably with the Minnesota Department of Public Welfare.

She is past-president (1949-1950) of the American Association on Mental Deficiency, and past-president of the Twin City Chapter of the American Association on Social Work.

Miss Thomson was chairman of the first committee (Liaison Committee) established by the American Association on Mental Deficiency to work with the National Association for Retarded Children, when it was first established.

I am happy to give you your presiding officer for this morning's session, Miss Mildred Thomson.

CHAIRMAN THOMSON: Thank you very much, Mr. Johnstone, for asking me to be the chairman this morning.

First we will have an invocation by the Reverend H. A. Guiley, chaplain and director of the Episcopal Foundation, University of Minnesota.

THE REVEREND H. A. GUILLEY: Almighty God, our Heavenly Father, who has blessed us with the joy and care of children, we beseech Thee to have mercy upon all who suffer mental handicaps and upon all who love and care for them, that they may have such strength of mind and cheerfulness of spirit in both health and sickness. Also, within the limitations of their impairment, grant us grace to continue our efforts to discover the ways to help these and all other people to live and become Thy children.

Accept our thanks for what we are learning and discipline us into using our discoveries to Thy glory and in the comfort of Thy children.

Prosper the aims of this conference that all who participate in it, that all who share, with Thee, the concern for the well being of children may secure an awareness of Thy love and the assurance of Thy guidance and protection; we pray in Thy name and service. Amen.

CHAIRMAN THOMSON: I have been provided with biographical data on the speakers this morning. Some of it I am going to read and then I'll add a bit, because it happens that I know each one of the speakers personally and have enjoyed working with them over the years.

Dr. Jensen is a native Minnesotan. A very interesting thing, I think, to those of us who have worked with Dr. Jensen is that he started out to be an educator. He taught rural school in the early Twenties and also attended a teacher's college. After four years of YMCA and church work, he turned to medicine. So he has an unusually good background to work with social workers and most certainly with teachers.

He was graduated from the University of Minnesota Medical School in 1935. After that, he took graduate training in three centers and came back to Minnesota about 1938. He has been at the university hospital since that date and in 1952 was appointed to his present position as Professor of Psychiatry and Pediatrics, University of Minnesota Medical School.

He is a fellow and member of a number of state, regional, and national associations. And, of course, I think that we can take it for granted that he is a member of all of the associations that he works with. In addition, I do have a little information which may be of particular interest to this group.

Those who have worked with the mentally retarded for years know that prior to the last ten or twelve years, it was not easy to find people who were interested in the mentally retarded. This was true of the medical profession as well as of other people.

From the time Dr. Jensen came to the university in 1938 until today, he has been a person who has been vitally interested in the problems of the retarded. We could always go to Dr. Jensen and know that he would help us.

Dr. Jensen also took the lead in trying to get more psychiatrists interested in the mentally deficient. He worked actively toward getting a committee organized in the American Psychiatric Association for this purpose. Others joined in his efforts and I believe this committee now exists.

There is another first which I think must be credited to Dr. Jensen.

For several years he has asked parents of retarded children, as well as parents of other handicapped children, to talk to groups of medical students so that the young doctors have some idea of what they are going to deal with when they leave the university and are working with parents.

And still another first—about three years ago Dr. Jensen set up for practicing physicians in Minnesota, a three-day institute on mental handicaps.

So — today Dr. Jensen comes to you as a person who has taken the lead in trying to bring the medical profession and the parents and others working with the mentally deficient much closer together. Therefore, it gives me great pleasure to present to you, Dr. Reynold A. Jensen, professor of Psychiatry and Pediatrics, University of Minnesota Medical School, who will speak to you on, "Counseling with Parents at Time of First Knowledge of Retardation". Dr. Jensen . . .

"COUNSELING WITH PARENTS AT TIME OF FIRST KNOWLEDGE OF RETARDATION"

By

REYNOLD A. JENSEN, M.D.

DR. REYNOLD A. JENSEN: Counseling with parents at the time of first knowledge of their having a retarded child is a strenuous, arduous and exacting task. It is a task that is not always done too well. But, in view of the many changes now occurring, it is my hope that it will be done better by more people in the future.

It is difficult not only for the parents who, for the first time, come to an understanding of their problems and are required to come to grips with the realities of the situation, but also for the counselor who must, during the process, be one with the parents in their struggle.

Difficult as that task is, it has been even more difficult for me to formulate this presentation. It was only last night that I finally realized why it has been difficult. It is because I am trying to describe a process. However, I shall do the best I can.

What I have to suggest for your consideration today will be in three parts.

The first is to share with you an excerpt from Gibran's "The Prophet". In speaking of children, he said:

"Your children are not your children—they are the sons and daughters of life's longing for itself.

"They come through you but not from you and though they are with you, yet they belong not to you.

"You may give them your love but not your thoughts, for they have their own thoughts.

"You may house their bodies but not their souls, for their souls dwell in the house of tomorrow, which you cannot visit, not even in your dreams.

"You may strive to be like them but seek not to make them like you. For life goes not backward nor tarries with yesterday.

"You are the bows from which your children, as living arrows, are sent forth.

"The Archer sees the mark upon the path of the Infinite, and He binds you with His might that His arrows may go swift and far.

"Let your bending in the Archer's hand be for gladness; for even as He loves the arrow that flies, so He loves also the bow that is stable."

With this as a background, I would like to review very briefly, and perhaps in a little different way, some of the basic principles which were delineated for us last evening. This I do because it becomes important as we come to consider the third part of this presentation.

We must be clear in our own minds that the goal for every child is the same. Briefly, it is to help him to develop to the fullest extent his own individual potential so that, insofar as possible, he lives happily and productively with others.

In this process we must make every effort to help the child to appreciate and accept not only his strengths (and most every child has strengths) but also his shortcomings. And who is there among us who does not have both?

Recognition of the simple fact that living together is a reciprocal process of giving and taking is also essential. We can measure adult maturity by how close we come to achieving this goal of mutual giving and taking easily and smoothly and freely.

We must also remember that an important ingredient in the maturation of the child is the development of healthy attitudes toward himself, toward others and toward whatever daily tasks must be undertaken.

Important also for us to keep in mind is the fact that goals of living vary with each successive stage of maturation.

For the infant the primary goal is full gratification of all needs—physical, social, psychological and emotional. As a child leaves the scene of infancy and enters into childhood, the goal, of necessity, will shift toward developing an increasing capacity for independence and the assumption of responsibility. Then, in the final struggle before adult maturity is achieved, the adolescent must achieve complete emancipa-

tion from all of the dependencies of the home and must develop his capacity to assume now the responsibilities of the mature adult.

Every individual, whatever the potential he is born with, is a product of three interacting sets of forces. The first is his own potential or capacity, which is changed, shaped and directed by the basic attitudes demonstrated toward him by his parents or parental surrogates. These attitudes, in turn, will be largely influenced by the culturally determined child practices—that is, the accepted manner in which basic needs are gratified and modified during each successive stage of maturation. In some instances, an unusual life experience may also be important in the individual's later development. An accident or severe infection early in life may alter significantly the developmental process and necessitate changes in what is to be expected of him.

Every human being is born with a certain heritage and potential. The process of growth—physical growth, intellectual growth, emotional growth and social growth—is a continuous process of differentiation and integration.

This process is an orderly one in which sequence follows sequence in a time relationship. It takes time to mature. While it is true that norms have been established for children born into our culture, we must always bear in mind that each child develops in accordance with his *own* pattern and his *own* time.

This simple factor of time is important and of special significance in the case of the child who is retarded.

Since growth is a process, it cannot be forced nor can it be delayed without causing difficulty for the child and those who are responsible for him. This simple fact is of paramount importance as we think of the maturation of the handicapped child.

Every child is born with the ability to perform a few simple tasks for himself. However, if he is to survive and grow, he must have steady and supporting help from others. Maturation is a slow but steady process of change from dependency to independency and self-sufficiency in accordance with the individual's potential.

Success or failure in achieving self-sufficiency will depend not only upon the gratification of the child's basic needs but upon how he is

helped to learn about himself and others and how he develops his skills for increasing independent action.

Most children grow up in families with a mother, father, brother and sister. While it is true that because of the sweeping changes in our social order the character and the structure of the family today is different from that of yesterday, the essentials involved in child rearing remain the same.

It is still in the home that the child discovers for himself and consolidates his own opinion about himself and about others. It is here, in accordance with his basic potential, that he develops his skills in managing his interpersonal relationships and learns what is expected of him and what, in turn, he can expect of others. It is here that he learns and must learn the basic lesson of obedience to authority, which is so essential to all of us if we are to live in a satisfied way. It is in the home that he develops his skills in meeting new people and adjusting to the ever-changing scenes and, in accordance with his capacities, learns the primary lessons of competition, the acceptance of criticism and blame and praise, in preparation for the unavoidable struggle of the future.

In the secure home setting, the difficulties of growing up can be, or at least should be, tempered always with tolerance and patience. It is here in the home that the child secures the much needed sense of belonging that is so important to all of us.

How does the child learn these primary essentials?

First and foremost—by being accepted and loved for himself alone and not for what someone expects of him or wants him to be. The handicapped child who is accepted and loved for what he is will grow up to be—without the feeling that he is too much different from others—will thereby have a better chance to develop his capacities to the full.

The term "love" is used synonymously to express feelings and attitudes toward one another as well as toward children. Every individual has his own definition of it. For our purpose here, the word "love" implies a warm, affectionate acceptance of the child as he is, tempered by a firm yet tolerant support of his efforts to achieve his goals by the development of an increasingly independent technique.

In addition to acceptance and love, which are so necessary in this

process of growing up, it is important that the child's basic needs be gratified.

I would call your attention to the term "gratified", since it is used here to imply more than mere satisfaction. It is satisfaction with pleasure.

We are all aware that children have physical needs, such as an adequate diet, sleep, and activity geared to age and experience. However, they also have emotional and affection needs, and it is in connection with these latter needs, which are so often not gratified because parents and others of us lack appreciation of what is required, that the child encounters difficulty. Dr. Rose in his address last night pointed this out to us very clearly.

While the goals of living change from year to year, each individual needs the opportunity to exercise his capacities for independent action insofar as he is able. This the child does when he is permitted to assume responsibility consistent with his age and experience and ability.

Every child, insofar as possible, should be accorded the opportunity to make decisions when he is ready to do so. He at times should be permitted to make mistakes so that, along with the rest of us, he may learn from error. He needs to learn not to fear failure, but to deal effectively with its sources or causes.

At every point along the way, he should be accorded the opportunity to have that pleasure which comes from doing things and making things and he should have the joy of sharing his achievement, whatever it is, with others.

He needs also to learn to master frustration, which comes from denial. Early in life he needs to learn a fairly well circumscribed set of limits within which he can operate without too much interference. In moments of failure and doubt, he requires the protection and the encouragement to try again.

A child reared in accordance with these simple but basic principles should eventually achieve the development of his full potential and should be able, ultimately, to learn to live happily, securely and productively with himself and with others.

Now, to consider the third part of this presentation—dealing with and helping parents who have handicapped children.

Parents with retarded children are troubled people. They often feel uncertain, harassed and frustrated. These feelings complicate life, not only for themselves, but for the child as well.

As was mentioned earlier, these troubled people often do not get the kind of help and support which is so important in the resolution of their difficulties.

The sources of their concern are varied. "Why did this have to happen?" "Why did this happen to us?" "What was wrong with us—what might we have done?"

At times their difficulties spring from the careless and thoughtless remarks of others. Someone in the family or a relative may question their capacity to be adequate parents. Whatever the source of the problem, if one is to be reasonably successful in counseling with parents, it is important to keep a few simple precepts in mind.

First and foremost, one must have an appreciation of what parents are searching for. I believe that there are at least four things which they seek. During the years in which I've tried to help parents, I have always been impressed by the fact that when parents come for help, they know that something is wrong with their child. Therefore, those of us who counsel with parents, must accept the fact that, when they come to us, they come for confirmation of their doubts and of their anxieties.

It is not necessary to tell parents something they already know but, in my experience, they are forever grateful for a confirmation of what they have known, probably from the time the child was born.

Secondly, once the fact of the child's retardation has been established, it is important to determine, if possible, the degree of retardation. How much is it—a little, a moderate amount—is it serious?

Thirdly, once the "how much" has been determined, every effort should be made to interpret to the parent what this means.

Lastly, we must help parents plan at that time for the future, being content at this juncture to realize that a process has been initiated which in time will work itself out.

If we are to give parents some of the answers they are searching for,

it is most important that we study the child carefully and make as accurate a diagnosis as possible. At all costs, every effort should be made to avoid error. It is possible to avoid error if the total study is done carefully in successive steps.

The initial point of departure is, of course, a detailed and accurate history of the child's developmental pattern obtained from the parents, who live closest to the child.

It has been my observation that when one accords to parents an opportunity to relate their thinking and their feelings about the child that they do so willingly and, for the most part, accurately.

It is essential to do careful physical and neurological studies and such other special studies as may be indicated. Other handicaps should be ruled out—the lack of hearing, the lack of sight—to mention only two.

When the child is old enough, he should have the benefit of a thorough psychological evaluation, done by a competent psychologist. There should also be time allowed for clinical observation of the child in a setting away from home, preferably in a hospital.

If, after a careful study of this kind is done, there is a common core of agreement, one can be fairly sure as to what the actual state of affairs is. Then it is time to sit down and discuss the matter with both parents.

Of course, the point of *both* parents is made here because both parents have a common interest and concern about the problem. Also, by sitting down with both parents it is possible to avoid misinterpretation or misstatement when one spouse reports to the other.

Even more important is the fact that as one begins to present the total situation to the parents it is possible to initiate a process of mutual sharing and a give-and-take, which is important in the ultimate resolution of their dilemma.

It has been my experience over the years that most mothers know their child is handicapped and are willing to accept it much more easily than the fathers. Therefore, if there is to be any opportunity to initiate full and free discussion between the parents, it is necessary to have both parents present.

When a decision has been made, it is important to present the facts

of the case in a direct and forthright manner, making as clear an interpretation of the study as possible—the cause, what may be expected, and possible plans for the future.

Stress is laid upon the fact that the parents must come to an acceptance of the reality of the situation—must come to an acceptance of the child as he is—and emphasis is then placed upon what best can be done in meeting **the** basic needs of the child. Focus is directed to the needs of the child since the parents, henceforth, must plan for the lifetime of their child.

It is also important to recognize the fact that the parents will have the responsibility of making the final decisions. For the most part, they will make good decisions when they have an understanding of the total situation.

A good decision is a decision that the parents have come to after most careful consideration.

With respect to plans for the future, it must be recognized by the counselor that there is no standard plan for every child, for each child and each family has its own peculiar problems, which may change and shift with the passing of time. Also, available resources vary from one community to another.

Before a family finally decides on a plan that may be right for them, it is necessary to point out that the child will continue to grow physically. And as the child grows physically, with the persistent lag in social and intellectual maturation, peculiar problems will arise which must be planned for.

The parents should also be urged to consider not only the needs of this one child but the total needs of every member of the family in order that nobody will be overlooked and neglected. This is particularly true for other children in the family who might, because of greater endowments, make better use of what the parents have to offer.

It is also important to call to the attention of the family that when mothers and fathers do consider and plan for the needs of their child, they are basically discharging the fundamental responsibilities of parents. This point is emphasized with a dual purpose. It is an effort to encourage the parent to think about their child's needs so that he may derive as much satisfaction from living as possible, and also to plan for his future.

Finally, parents must be accorded the opportunity to ask questions. On many occasions when parents bring up their own questions, it is then that much good can be accomplished in the shaping of attitudes and in clearing up misinterpretations.

Two more points: I would like to mention very briefly the attitude and the role of the counselor, for so much depends upon it.

To be effective, the counselor, whoever he is, must himself have worked through his own feelings about handicapped children and he too must have learned to accept and love them for what they are. This is essential in order that the counselor may bring a certain objectivity to the task at hand.

The counselor also needs to know what he can and what he cannot do. He has to be quite content in the knowledge that there are some things that he cannot do.

For example, with very few exceptions the counselor can do nothing about changing the potential of the child. Therefore, accepting this fact frees him to act more directly and definitively in helping the child, through the parents.

As he moves directly toward discussions with the parents, he must enter into a process of turmoil since he must be one with them. Through it all, he must be gentle, thoughtful, considerate and yet firm in what he knows he can do and what he must do. He must never be hostile, never aggressive, never punitive. This is sometimes difficult because the counselor must accept the fact that at times he may need to be a whipping post. This role may be necessary if he is to help the parents work out their disappointments, conflicts and guilt feelings. All of it is a part of the counseling process.

Finally, he must stand ready to offer continuing support to those whom he serves. He must know the resources of the community. He must encourage parents to follow through, using help that is available.

When this has been accomplished he can be reassured that his responsibilities have been discharged. In the process, the responsibility for final decision has been placed where it rightfully belongs—with the parents.

CHAIRMAN THOMSON: I am sure that those of you who have not known

Dr. Jensen in the past realize his place of leadership in Minnesota in helping parents and others who have responsibilities in planning for the retarded.

We are now going to hear about these responsibilities from a different angle.

Dr. Sheldon C. Reed was born in Vermont and was graduated, in 1932, from Dartmouth College.

He received his Ph.D. degree in 1935 from Harvard University. He was at McGill University for a time and later served as an assistant professor at Harvard.

Dr. Reed came to Minnesota in 1947. Because of his studies in genetics, he has been interested in the mentally retarded. With his wife, Dr. Elizabeth Wagner Reed, he is presently at work on a follow-up study on the mentally retarded who were in residence at Faribault School and Colony (Minnesota) some fifty years ago. This study, sponsored by the Minnesota Human Genetics League, involves contacts with thousands of relatives of these former patients and, from it, it is hoped a better understanding of family structure and problems will be obtained.

Over the years, Dr. Reed has counseled with parents of retarded children, as well as with parents whose children have anomalies other than retardation. Some of this extensive experience has been included in his text, "Counseling in Medical Genetics". He has been both secretary and president of the American Society of Human Genetics, is a life fellow of the British Eugenics Society and is presently serving as secretary of the Minnesota Human Genetics League.

I will say that Dr. Reed is a person who does a great deal of work through the Human Genetics League and has made it a force in Minnesota today.

He has been greatly interested in the retarded and has given much time to addressing groups of parents and others. Few states have this genetic counseling service, and I am indeed glad to introduce to you, Dr. Sheldon C. Reed, Director, the Dight Institute, University of Minnesota, who will speak to you on, "Genetic Counseling".

"GENETIC COUNSELING"

By

SHELDON C. REED, PH.D.

DR. SHELDON C. REED: Thank you, Miss Thomson. My greatest personal interest in the field of human genetics lies in the area of heredity and mental health. To be sure, the problems associated with heart diseases and cancers are of obvious importance because these two groups of illnesses result in the death of seventy percent of our population. However, we must all die sometime and a heart attack is a merciful way in which to terminate one's old age.

The prevention or postponement of death is a most worthy field of effort but, to me, the mental health of the living far transcends in importance the problems involved in prolonging old age. The general public does not behave as if it understands this simple distinction between the needs of mental health and those of simple physical well being. Just think of the progress that could be made in helping the mentally ill if the money now being invested in bronze or stainless steel caskets for the dead were devoted to the health of the living.

You may wonder why I spend time on these morbid invidious comparisons. Self-diagnosis is not expected to give accurate answers but this much is clear to me: my contacts with the mentally retarded and the mentally ill have been many, and my compassion for their plight is sincere and real.

For the past ten years my wife, Dr. Elizabeth Reed, and I have devoted considerable time to the study of families of the mentally retarded. The work was started by others, some fifty years ago, with a genealogical and psychological study of the patients in the Faribault State School and Colony at that time. We have considered it most instructive to follow-up the patients and their relatives for the two or three generations which have elapsed since that unique and priceless study was initiated by our foresighted predecessors.

Information contained in the data from the past makes it clear that in some families the patient was the victim of infection and had no retarded relatives, either then or now. In other families the mental retardation was clearly of genetic origin and behaved in strict Mendelian fashion.

In the majority of the families it is impossible to determine the cause of retardation in the original patient, or in his retarded relatives who were born in more recent years. It is crystal clear, however, that every family with a retarded member is in some way different from every other family and their problems must be considered individually. There is no single solution to all problems of mental retardation and there is no reason to think that there ever will be.

It is natural to expect, as a by-product of our study of the families of the mentally retarded, that there would be referrals, to the Dight Institute, of parents with one or more retarded children. Such parents are particularly concerned with genetic counseling because the diseases of mental retardation are usually congenital, often genetic in origin, and always a matter of distress to them. The parents have the deepest and most sincere desire to learn anything they can about their problems. They find satisfaction in trying to help other parents and in furthering scientific research in the whole field of mental retardation.

What is it that the parents of the retarded child wish to learn from the geneticist?

In the first place they want to know whether the child's retardation has a predominantly genetic or environmental basis. Regardless of the cause, the parents are also acutely interested in the chances of a repetition of the anomaly in each subsequent pregnancy. Some parents have decided that they do not wish to have any more children, regardless of the causation, and inquire about acceptable methods of prevention. Parents are also interested in the chances that their normal children might have retarded offspring. These four questions are appropriate ones which the geneticist can answer with varying degrees of accuracy and satisfaction. These are questions in genetics and presumably the geneticist is best qualified to answer them.

A good counselor in human genetics speaks from his heart but he is also a scientist and must speak the truth as it is accepted at that time. No counselor is clairvoyant, and none can predict the scientific discoveries of the future. The counselor cannot make decisions for the parents but he can give them facts they need in order to make decisions themselves. These decisions may not be perfect ones; they may even be sinful to some people. However, the social worker learned long ago that the hasty judgment of others is often false righteousness. This lesson of "not throwing the first

stone" was clearly explained by Jesus and by many others with insight long before Him. Fortunately, quite a few people in every generation learn and practice the withholding of hasty judgment.

Please do not think that genetic counseling includes sermons. I am merely trying to explain to you that it is a helping process and is thus a type of social work.

The parents of the handicapped child are helped by teaching them the biological facts and the expectations associated with the particular kind of mental retardation which has appeared in their family.

Let me illustrate some of the ways in which the geneticist can be helpful to the perplexed parents of Mongoloid children, in three different situations. In none of these cases does the geneticist solve any problems of finances, nor does he have new cures or management techniques. He merely supplies comprehension of one small part of the total problem. Indeed, he may consider his assistance to be of such intangible value that he charges nothing for his services.

The first illustration is a simple question which could easily be resolved. A war veteran student had just become the father of his first child, a Mongoloid. He had received evasive answers to his main question before coming to the Dight Institute. His sexual outlets during his army experience had been restricted to masturbation, against which he had been strongly conditioned. His question was, "Is my Mongoloid child a result of some hereditary peculiarity of my wife, or due to the masturbation?" It was easy to explain that there was no reason whatever to think that the sex practice had anything to do with Mongolism. It was pointed out to him that on his right hand he had a transverse crease, a peculiarity found more often in Mongoloids and their blood relatives than in the general population. When it became clear to him that there was some kind of a biological background involving him, his attitude toward the problem eventually became matter of fact and his reproach of his wife and his own feelings of guilt disappeared.

A second and more frequent situation involving Mongolism demonstrates that, even after the production of two affected children, a couple may complete the family with normal children without too much psychological trauma.

A 23-year old mother gave birth to a Mongoloid boy, then to a normal

girl and at age 29 to her third child, a Mongoloid girl. Before the birth of her second Mongoloid, the mother had been assured by two physicians that there was no danger of a second Mongoloid. Without warning the second abnormal child was presented to the mother with resulting psychological trauma, the mother having made the diagnosis herself. After a period of adjustment to this shock, the couple appeared for counseling.

Upon examination of the hands of the couple, the husband showed a striking transverse crease of the left hand and a less pronounced evidence of it on the right hand. Both could see this clearly. The wife's hands were normal.

Request: "What are the chances of our having a third Mongoloid child?"

Reply: The transverse creases on the hands of the husband suggest there is something more than accident in the production of the rather uniform entity of Mongolism. Consequently, there is a small chance (thought to be about four percent) that a third Mongoloid child might result from another pregnancy. If another pregnancy is to be attempted the couple must prepare for the small, but real, chance of a third Mongoloid child.

Follow-up: Since the counseling, another child has been born. The parents, though prepared for the worst, had an uneventful pregnancy. Both were relieved and delighted that it resulted in a normal boy.

Second follow-up: The couple now have their fifth and sixth children, and both of them are normal. The two Mongoloid children have been institutionalized and the family is much as it would have been without this distressing experience.

A third situation regarding Mongolism is likewise unique in my experience. A family of four children grew up and three of the four produced one daughter each and the fourth had only two daughters. This makes five girls who are all first cousins. The first of the five girls produced one normal daughter, two miscarriages and a Mongoloid child. The second of the five cousins produced one Mongoloid child at age 21. The third gave birth to two normal children and one Mongoloid child, and had two miscarriages. The fourth girl has had three normal children; and the fifth cousin has had one normal child and four miscarriages. This adds up to seven normal children, eight miscarriages, and three Mongoloids from the five cousins.

Naturally, all five cousins wonder what is the matter with their reproduction. It is the kind of question which baffles the experts. One might see some kind of dominant heredity factor manifested in the reproduction failures of four of the five girls, or they could be sheer coincidences. No firm decision can be made in such a case. The cousins are most concerned with the problem of explaining the situation to their normal children when they are old enough to understand it; how to guide their thinking about marriage and reproduction when that time arrives for them.

The advice for the normal children can only be optimistic with our present knowledge, or rather lack of it, about the causes of Mongolism. We seldom get affected nephews and nieces of Mongoloids and predict that such will be the case in this badly shaken family. Guess work is certainly involved here, but the fears in this family already exceed the worst scientific expectations so that optimistic counseling is clearly justified.

The three situations involving Mongolism all rest upon rather small chances of a repetition of this disability. Therefore counseling should always revive flagging spirits and instill hope for better luck with future pregnancies.

It is not known what part, if any, genetics plays in Mongolism. With some types of mental retardation the genetic expectations follow the Mendelian laws and the probabilities are a little more sobering. We know, for instance, that the retardation and eventual death in Tay-Sach's disease and in Schilder's disease behave as Mendelian recessives. In these diseases, both parents carry the trait concealed by a normal gene partner. One quarter of the children of such a couple will get two genes for the trait and will die as a consequence. The brighter side of the coin is that three quarters of the children will be as normal as can be. A frustrating aspect of the whole picture is that there is no way of predicting whether the affected children will all come at the beginning or will be interspersed with normal siblings.

Probably the most distressing counseling case I have had resulted from the successive appearance of three children in a family with Schilder's disease. After the birth of the second affected child, I had emphasized the optimistic prediction that there was a three-fourths chance that the next child would be normal. Mendel's rule worked otherwise. This couple will have no more children, ensured by a hysterectomy, and they have eased the losses of their three children by adopting a baby boy. They will

not forget the troubles they have had but they are developing a new happiness with their adopted family.

At this point you must think that genetic counseling is a morbid occupation indeed. In a sense, it is. Fortunately, most families do not have such unhappy experiences as those I have described. But even with the worst turns of fate the parents of the retarded children are helped greatly by an understanding of how Mendel's laws work and what to expect as a result.

If the retardation is not due to genetic causes, the counseling is a great pleasure. If retardation resulted from an infection of the mother, one can predict that present day antibiotics will help protect the mother from any subsequent infections.

Our final, largest, and most puzzling group of mental retardates are those where there is no evident physical disability. At birth the child seems to be perfect. The mother has had a happy healthy pregnancy but the child never learns to talk well and is incapable of school work. Since there has been no warning of retardation the child becomes established in the home and, later, the idea of institutionalization is usually unacceptable to the parents.

The following case represents the dilemma faced by some of the parents of the undifferentiated mentally retarded. This particular couple has a nine-year-old retarded girl and a five-year-old retarded boy at home. Both are handsome children but with little mental capacity. No one has been able to state the cause of the retardation though the children have been seen by a large number of specialists. The father and mother decided to have no more children because they have no desire to produce another defective child; nor could they see any merit in producing a normal child, who would have to adjust to the two older mentally deficient siblings. Recently the mother discovered that their contraceptive technique had failed in some way and she had her pregnancy confirmed. Her physician referred the couple to me with the hope that I could dissuade them from their insistence upon a therapeutic abortion.

I not only failed to dissuade the couple but was converted to their point of view. As this couple absolutely refused to subject a normal child to the hazards of the home environment which they could foresee through the years ahead, one could not expect that quoting a favorable genetic ratio would convince them that they should have more children—and it

didn't. A correct decision for this family is by no means the correct one for other families. It must be made on an individual basis always.

I have exceeded my allotted space in describing for you a few ways in which the geneticist can help parents of the mentally retarded. The purpose of this conference is to record procedures through which parents can be helped by many kinds of specialists and how they can help each other. I consider it an honor to have been invited to give you this somewhat incomplete picture of heredity clinics and to show how they can contribute something to help parents of the handicapped, regardless of whether their child's difficulties are mainly genetic, environmental, or undifferentiated.

CHAIRMAN THOMSON: Thank you, Dr. Reed.

We now come to a third phase of counseling. The next speaker is one whom I have known for several years. Mr. Lund was born in Salt Lake City, Utah, and has lived there all of his life. He and his wife have two children. Incidentally, Mrs. Lund is present and those of you who have not met her should plan to do so today.

Their son Mark, aged 19, attends the State Training School in American Fork, Utah, and their daughter Jean, aged 16, attends high school in Salt Lake City.

Mr. Lund's interest in the parent movement for retarded children began many years ago when he was asked to organize the first association for retarded children in the state of Utah. He served as the Association's first president for two years and has been on the advisory board ever since.

A director of the National Association for Retarded Children since its inception, he was named second vice-president in 1954 and first vice-president in 1956. He now serves as president of this nationwide organization.

By profession, Mr. Lund is an attorney, specializing in real property law. He was graduated from the University of Utah in 1930 with a degree in sociology and from the University of Utah, College of Law, in 1932.

Mr. Lund is one of the parents whose breadth of vision has helped make the National Association for Retarded Children the force that it is in this country today. I heard a government social worker, who travels through many states, say yesterday that there has been no move-

ment in the whole history of the United States which has spread so rapidly.

Mr. Lund identified himself with the NARC at the very beginning and moved up steadily in the national organization, as well as in his state organization—which meant accepting more and more responsibility, and giving more and more of his time. Too much cannot be said in commendation of these parents who have given such long service to the national movement despite the fact that they have to earn a living for their own families.

Therefore, I am happy to present to you, Mr. Alton F. Lund, president, the National Association for Retarded Children, who will speak to you on the subject, "The Role of Parents in Helping Each Other".
Mr. Lund . . .

"THE ROLE OF PARENTS IN HELPING EACH OTHER"

By

ALTON F. LUND

MR. ALTON F. LUND: Thank you, Miss Thomson.

Ladies and gentlemen, it is indeed a pleasure to be here and to participate in this conference. First, I would like to pay tribute to Miss Thomson because, as Mrs. Letha Patterson has so often said, she rocked the cradle of the NARC. She has been to every convention except one and those of us who attend these conventions always look for her. We look for her guidance, her support and, of course, her wise judgment. On behalf of the National Association, Miss Thomson, I want to thank you for your untiring help to our organization.

It is indeed an honor to represent the National Association for Retarded Children at this conference and, on behalf of the Association, to bring you greetings and best wishes.

On this program my colleagues have been discussing with you various elements in counseling. I, as a parent and a layman, would like to discuss the role of the parent in the past, his present-day role, and perhaps a few ideas for the future.

Not long ago I had two experiences which brought home to me the irony surrounding the relationship of the retarded child and his parents. My daughter, who is wonderfully normal in all respects, was taken ill. Suddenly we found ourselves face to face with a serious illness—a ruptured appendix. But everyone was wonderful—the doctors took over with all of their tremendous skill, the neighbors were most helpful and proffered every aid. Afterwards, when everything turned out for the best, my wife and I had a warm feeling indeed for these neighbors and friends.

The second experience involved our other child—our retarded boy. That we were not prepared for the devastating realization that our child was retarded, goes without saying. Seventeen years ago no one, with some rare exceptions, was prepared for such a happening and the parents found themselves alone. That was our experience and while I will not attempt to recite the emotional upset, the shock and bewilderment, I do want to point out the ironic contrasts in the two situations.

In the one, people, armed with knowledge and understanding, stepped in and were able to give efficient and skilled help. Tragedy was averted and the best elements of society came out. In the other—bogged down by ignorance, misunderstanding and fear, we *all* groped for help.

I do not resent this difference because the years have taught me that we were all in the same boat and my family, my neighbors, and my associates simply did not have the answers, or the knowledge, to cope with the situation.

In my position I talk with literally hundreds of parents in all areas of the United States. I would like nothing better than to report to you that all of the past records of ignorance, cruelty, superstition have passed—and that we no longer face these situations. When I see progress being made my hopes rise. Then, just as I am in a complacent mood, things happen which bring me down to earth.

Not more than a month ago, I was at home on a Saturday afternoon when the phone rang. It was a woman begging for help. It seems that her sister-in-law was retarded and had been in an institution. She had been released because she was an excellent worker and could easily find employment. However, she was the victim of one designing person after another until her life had become nothing but a morass of immorality, crime and debauchery. This woman asked me what help was available. But when I undertook to get some of the facts, she became very evasive. It finally came out that she was appealing for help over the strong objections of her entire family. The mother of the girl flatly refused to permit the matter to be discussed by the family. The girl's conduct did not seem to bother the family nearly as much as the terrible danger that people might discover she was retarded. That disgrace they could not face! Since she would not identify herself so that I could make an appointment with people who could help, I did get her to promise she would take the matter up with the proper authorities. She also promised to come to some of the meetings of our unit in Salt Lake City. When such a case comes to my attention I wonder just how far we have come in ferreting out the cases in the back rooms, basements and the like.

While I am sure that we have made tremendous progress, there is still a vital role for the parent to play in helping fellow parents with this problem. I would like to discuss some phases of this role with the hope that the position of the parent may be made a little clearer.

Recently I had the pleasure of sharing a television program with the noted American actor, Mr. Walter Abel. In his opening remarks Mr. Abel stated, "It is our duty as parents to see to it that no couple should be unprepared for the birth of a retarded child." I believe this very clearly expresses that desire to help other parents which is so basic to the entire parent movement today.

Since accepting this invitation to speak to you today, I have conducted an experiment, asking several parents what other parents can do to help them and how they had been helped by other parents. You will be interested to know that every single parent stated, almost without hesitation, that he or she had been helped most *by finding out that they were not alone.*

I recall vividly the letter, written by a parent and published in the newspapers, in which she stated that she was the parent of a retarded child and would like to meet with others with the idea of finding out what could be done. What an indictment that she had to resort to the public press to even find other parents. This took courage on her part and it well illustrates the type of parent who is responsible for the parent movement today.

In any consideration of this subject, we must first answer the question as to why there is such a need for one parent to help another. Social problems are rarely solved by individual action but rather by concerted action on the part of all society to rid our civilization of a blight or problem. Of course, individuals through discoveries in medicine, social science, and the like sometimes make possible some solutions, but society itself must act if the solution is to be widespread and effective. In most fields we are very advanced in this type of social action. Why then in the field of mental retardation are we some fifty to seventy-five years behind?

The reasons for this social phenomenon would warrant a vast study in itself. I believe there is no single cause but a multiplicity of them. Such factors as the change in our economic set-up with the advent of the machine age with its premium on skilled labor; false theories of heredity; universal public education; medical advances which have greatly prolonged life among all members of our society; developments in the fields of psychology; and many other factors have had a great deal to do with the whole problem of the mentally retarded child and his inability to adjust satisfactorily to modern day social patterns. Such changes have brought the entire problem to the forefront. While consideration of all of these

factors would be most enlightening, it is to the question of the attitude of the parent that I would like to address myself. In that attitude lies the key to help. It is only in understanding that attitude that one parent will be able really to help another.

I return, then, to the comment made above that parents were helped by finding that they were not alone. They were not glad that others were in the same predicament but rather that this was not something that had befallen them particularly. In other words, there were many parents involved. This discovery is most important psychologically. It is the key which opens the door to cooperation and action.

What has resulted? As victims of a stigma placed upon them and their children by society with false theories of heredity and old wives tales, they found that they and their retarded children were without programs or help. So they began to look around and make inquiry. This led to organization—and the parent movement of the twentieth century was born!

This all seems so simple and basic that it is indeed puzzling that the movement was so slow in starting. But it is a fact that the parent movement, as we know it today, is less than twenty-five years old.

It is interesting to note that this discovery of not being alone, with its therapeutic value to the parent, does not result at first in a program for the child. The parent is still in the stage of thinking about himself. Further development in his attitude is essential. He must come to see that his child needs help not only from him but from others as well. He then begins to make comparisons. He compares his child with others. He sees that they are not all alike but are as different and varied as all children. He begins to see the many problems which face retarded children. But at this stage, he is very much wound up in the problems of his own child.

Unfortunately I must admit there are many parents who never get beyond the "my child" stage. Too often parents are interested only if their own child is involved. Sometimes these very parents are most active if the activity revolves around a facility or program which encompasses their child. But they are indifferent if their particular child is not involved.

There is one very important step in the development of a wholesome attitude—and that is the acceptance of the child as he actually is. By this, I do not mean that the parent must give up all hope and quit, but he must

realize that his child has limitations and needs help; that even with help he may be far from a normal child. I have heard it said many times in our association work that nothing really happens until the parent does accept this fact and give up false notions and wishful thinking. He is then ready to help other parents and other children.

The ideal lesson for the parent to learn is: He helps his own child most by working for all children. This does not lessen interest in his own child, but his perspective changes. He sees that a truly worthwhile program, which will build a community in which his child may function to the best advantage, can only be accomplished when that program encompasses all children. Although his child may not be particularly benefited by a particular program, other children will benefit and thereby build up a program in which his child can eventually participate. He must sometimes wait his turn.

For example, most school districts are now beginning to accept educable children readily and form classes for them. Would a parent of a trainable child be justified in ignoring a program for educable children because his child could not participate in the classes? I think not. Such a parent must come to realize that with such a program he is just that much closer to a broader program which will eventually help his child. I know this is sometimes difficult but parents must work to help others understand that a program for all children should be their goal and not a narrow specific one which includes only a few children.

In my own community the parents who worked so hard for the establishment of school classes are now realizing that they should have taken a much greater interest in workshops and other similar programs to help their children after they leave school. We, who have learned such lessons, can help by passing along this type of information.

Now here is a word of caution. The fact that we have been through the mill does not qualify us as amateur psychiatrists and sage counselors especially where new parents are concerned. The many emotional involvements in this problem should make all of us wary, and the old statement that fools rush in where angels fear to tread is very pertinent. But through our organizations and units we should stand ready to offer the helping hand and make it possible for new parents to take part in, a program for their children. There is great consolation in being actively engaged in such efforts.

Another word of caution—psychological development takes time and we cannot rush it. An unwise or foolish remark can often shut the door on the very thing we are trying to accomplish. It may take months and years to see these wholesome attitudes develop, but they are worth waiting and working for.

No discussion of parental attitudes and the role of parents in helping each other would be complete without some discussion concerning attitudes toward public institutions for the retarded. Because of public apathy, a number of unfortunate incidents, and downright public neglect, there are some disheartening situations existing with reference to public institutions for the retarded. Long waiting lists, overcrowded conditions, economy drives and so on—have resulted in all institutions of this nature, both good and bad, being looked upon as a last resort. I have actually heard parents say, and this is very recently, that they would rather die than place their child in an institution. In this way, we have actually "created" a stigma on children in state institutions.

We sometimes forget that these are the same children as those within the community. Their problems do not differ. They have the same limitations, they have the same feelings—the same desires to be loved and wanted. Fortunately things in the past few years have taken an about-face. In most areas, with the development of community programs, there has come an over-all change for the better. We, as parents, are becoming better acquainted with our public institutions and their problems.

The stigma I mentioned can be removed. We, as parents, must continue to stress that a public institution is a public responsibility. It cannot and must not be shirked. The public institution must not be considered a "last resort" but rather a definite part and facet of a larger problem. While the private school and residential home can care for some of our children, it is clear that we must also have our public institutions.

Therefore, I say to parents who are critical of state institutions and to parents who place their children there, please shift from the negative to the positive side. If your institution warrants criticism and needs help to bring it up to standard, you should do all you can to see that this information is brought to the attention of the proper officials, legislators, and to the public generally. Urge upon them the necessity for action to correct the situations.

I am not urging placement of children in institutions. That is a ques-

tion which must be the decision of each parent, consistent with the needs of each child. My appeal to you is to consider the public institution in its rightful place—a needed place for some children and also a place which we can take pride in because we have done our duty as citizens in making it so.

So far we have concerned ourselves with a discussion of parental attitudes towards this problem and our relationships with other parents. But there are additional ways in which we can help. We can urge all new parents to affiliate with parent units and show them that there is much satisfaction in working in these units and in an organized program.

In our local units, our state units and our national organization there is a progressive program at all three levels. It would take more than my allotted time to give you even a brief description of the vast program which is now being carried on by parents all over this nation. We have more than 550 separate units in our National Association for Retarded Children, all dedicated to helping retarded children. And this has happened in less than eight years.

To the parent who is worried about what may become of his child when he is no longer here, we say: "Get in touch with the Guardianship Advisory Committee of the national and of your state organization. We have far reaching plans for making provisions by way of wills, insurance, trusts and other arrangements. We are constantly studying this very question and are actively investigating many phases of it. We may not have all of the answers but we can certainly help you."

To the parent who does not know where to go or what to do for help:

"Contact the Parent Guidance Committee of the national association. This committee will not only help you but will put you in touch with people in your local area. Contact these people on your local level. They are parents with the same problems and they will help in many ways."

To the parent who is concerned about legislation—both federal and state:

"Your national association maintains an active legislative committee which is in constant contact with the Washington situation and furnishes materials and information to Congressmen and other governmental departments. The present interest and large appropriations of the present

day were spearheaded by your national association in cooperation with state and local associations. Perhaps we are not entirely responsible for this change but it is interesting to note that it has all come about since our organization and activity. On the state level we are setting up a new committee to coordinate state commissions and legislative activity, and to exchange information. This interest in national and state legislation affects every citizen and any parent concerned with this problem should interest himself and become active in this area."

To the parent who is concerned with research (and what parent is not?):

"Your national association has established the Grover F. Powers Chair of Research at Johns Hopkins University under Dr. Robert Cooke and we are in the process of setting up others. These research projects will concern themselves with basic research into causes, prevention and the other phases of mental retardation. We are establishing a research fund to finance this work and in this we must have help. Every parent and interested person is vitally concerned here."

To the parent who is concerned with his child who is in an institution:

"Our Public Institutions Committee, with state correspondents in most of the states, is constantly working on problems concerning institutions. We have completed a fee study to bring public attention to this whole question and to show the inequities and differences which exist. Programs concerning the operation of state institutions, such as education and recreation, are being studied by this committee. Such parents should get in touch with this committee for certainly a program to help their children is underway."

To parents concerned with income tax questions and social security provisions:

"Your Legal Advisory Committee has succeeded in having many of these regulations clarified and has sent the information to all units. These provisions now offer great help to parents and guardians, who should keep in touch with their national, state and local associations concerning such regulations."

Similarly we have programs in the fields of recreation, education,

vocational rehabilitation, and in publications. All are coordinated by a professional staff in our national office in New York City, and no request is ever ignored.

These matters are constantly discussed and reported in our national newspaper, "Children Limited" which goes to all members of the national association. No parent should be without this paper. It is the concrete and dramatic story of a dynamic program now going on in behalf of retarded children—and it stems from this desire of one parent to help another and his child.

These are methods by which one parent has helped another and they illustrate better than any words of mine what can and must be done.

It is the parent who has filled the role of the catalyst in this vast social structure of ours in bringing about this change. He has, by his pilot projects, proved his point that the retarded child can and should be helped—and in his various activities, he has succeeded in bringing about what amounts to a social revolution in the public's treatment of one of its great problems. And this is not a parent's problem alone, for the cost to the public is staggering and the public must be made to see that it has a basic responsibility here.

We have come a long way but we have truly only scratched the surface. If I had to name one element essential to our success, it would be enlightened public opinion. When the American people understand the needs of these children and the scope of this problem, I have absolute faith that they will act not only to help the children living today, but will establish a research program which will insure that tomorrow's children will be born, live and grow beyond the limits of this shadow.

As we ring down the curtain on a past era of ignorance, prejudice and misunderstanding, we raise it immediately on a new era dedicated to hope, understanding, and realistic evaluation—to the end that our children may attain their rightful heritage. We must bestow upon our mentally retarded children that respect, that human dignity, that real importance which is their birthright.

(The meeting adjourned at 11:50 A. M.)

THIRD SESSION

MAYO MEMORIAL AUDITORIUM
UNIVERSITY OF MINNESOTA

May 3, 1958
2:00 P. M.

WILLIAM C. ADAMSON, M.D., Director, The Child Study,
Treatment and Research Center, The Woods Schools, Presiding

PRESIDENT JOHNSTONE: Ladies and Gentlemen, you may be interested to know that the entire proceedings of this conference is being tape-recorded by Radio Station KUOM and, in time, will be rebroadcast in sections, appropriate to the station's program schedule. This is another indication of the unusual activities of the very excellent local committee on arrangements.

This afternoon I take pride in presenting to you the Director of the Child Study, Treatment and Research Center of The Woods Schools and the director of all professional services, Dr. William C. Adamson.

Dr. Adamson came to The Woods Schools January 1, 1956 from the Community Guidance Center of Austin, Texas where he had served as director and administrative head for the preceding four years. His psychiatric experience in the problems of child behavior and development eminently fit him for the responsibility of directing our great new center.

Following his graduation from Swarthmore College and later from the University of Pennsylvania School of Medicine in 1943 (and after a period of service from 1944-1946 in the U. S. Army Medical Corps), Dr. Adamson received postgraduate training at the Delaware State Hospital and at the Institute of Pennsylvania Hospital for Nervous and Mental Diseases. He later served for two years as a Fellow in Child Psychiatry at the Philadelphia Child Guidance Clinic.

From 1950 to 1952 he was a consulting psychiatrist for The Woods Schools prior to his challenging appointment as director of the newly formed Texas center.

I would like to add that Dr. Adamson and I personally became acquainted during his period as consulting psychiatrist to The Woods Schools when I, at that time, was also serving as a consultant. Dr. Adamson has brought to The Woods Schools a warmth and a sensitivity to human beings.

He has brought to The Woods Schools a relationship among the staff, among the children, and among the patients which has greatly furthered our objectives. I am now happy to present to you, your presiding officer, Dr. William C. Adamson.

CHAIRMAN ADAMSON: In responding to the introduction, I would like to acknowledge my own appreciation for all that Mr. Johnstone and the Board of Trustees of The Woods Schools have entrusted to me as director of the Center and to thank them for the continued support which they have given to the staff and to me.

At this time I would like to ask The Reverend Michael McDonough, Chaplain to Catholic Students, Newman Foundation of the University of Minnesota to lead us in our invocation.

THE REVEREND MICHAEL McDONOVGH: May God support us all the day long. Direct, O God, our actions by Thy Holy inspiration and carry them on by Thy gracious assistance, that every prayer and work of ours may begin with Thee and, by Thee, be happily ended, to the same Christ, our Lord. Amen.

CHAIRMAN ADAMSON: This afternoon we will hear first about the need for helping and counseling parents in a community resource to which parents may turn when the retarded child reaches the pre-school or school age.

This presentation will be given by Dr. Harriet E. Blodgett, program director of The Sheltering Arms Day School, Minneapolis, Minnesota.

A native of Lyndonville, Vermont, Dr. Blodgett received her B.S. degree from Tufts College, Massachusetts, and her graduate degrees from the University of Minnesota.

After earning her master's degree in 1943, she served as state psychologist with the Bureau of Psychological Services of the Department of Public Institutions, State of Minnesota, working with county welfare boards, public schools, state institutions, and private agencies throughout the state. In 1946, she was named instructor and later assistant professor at the Institute of Child Welfare, University of Minnesota.

After receiving her doctorate in 1953, Dr. Blodgett served as clinical psychologist with the Genetic Research Project of the State of Minnesota

at the Rochester State Hospital. In 1955, she was appointed program director of The Sheltering Arms Day School, Minneapolis, Minnesota. She is especially interested in problems relating to psychological diagnostic techniques and ability measurements and family counseling.

A consultant assistant professor in the Child Clinical Psychology program at the University of Minnesota, Dr. Blodgett is a member of the American Psychological Association, Executive Council of Minnesota Psychological Association, the American Association on Mental Deficiency, Advisory Board of the Minnesota Council for the Gifted. She also serves on the advisory board of the Elliot Park Special Day Care Center, conducted for mentally retarded children.

The title of her talk today will be: "Helping Parents in the Community Setting". Dr. Blodgett . . .

"HELPING PARENTS IN THE COMMUNITY SETTING"

By

HARRIET E. BLODGETT, PH.D.

DR. HARRIET E. BLODGETT: Thank you, Dr. Adamson. In common with other local people, I would like to express my particular pleasure that The Woods Schools Conference was held in Minneapolis this year. We sincerely appreciate the opportunity of cooperating in such a purposeful series of meetings.

In looking at the field of mental retardation, one thing which is most impressive is the change which we have seen in recent years. Whenever we are in a period of very rapid change, we use words such as "revolutionary"—an impressive term—and sometimes I suspect that these terms may only cover the feeling of confusion that many of the workers in the field have experienced.

Because facilities are new, because attitudes are changing, we find a tremendous variety of professional viewpoints, as well as of lay viewpoints. People simply do not stay the same when they continue working in a field in which there has been such dynamic motion in recent years. Because of the rapid changes, it is only fair to say that the current attitudes, which we might consider the best, may be out-dated by tomorrow. Of course, this is good at our present stage of knowledge if we can continue to make evaluation of progress and learn from our mistakes.

Before discussing the problems of parent counseling, it is only fair to warn you that I will be drawing heavily on our experiences at The Sheltering Arms.

Sheltering Arms is a relatively young program. It is now in its third year. We have a joint cooperative effort with a partnership between Sheltering Arms, which is a private organization, and the Minneapolis public school system. The public school system furnishes teachers and supplies; Sheltering Arms furnishes other staff and fills in any chinks in connection with budgetary needs.

We have three classes for trainable children, ranging in ages from six to fourteen, with ten children in each group; and also one class of educable

children, from eight to eleven years of age, with sixteen children enrolled in this group.

Our staff, aside from four teachers, includes a full-time social worker, a business manager, a research assistant, plus a program director, and also stenographic, secretarial, and maintenance people. Volunteers provide much valuable extra help.

In order that this moment of glory in connection with Sheltering Arms be fully shared, I would like to ask my staff if they would stand up. They are here in the front row.

(At this point nine members of the staff arose and were applauded.)

In considering major problems in connection with the parents of mentally retarded children, one of the first and biggest is lack of information.

Most parents have not planned on having a retarded child; they have not taken courses in school to learn how to cope with this possibility. Even professionally trained parents have not considered this as something that would be likely to affect their personal lives. Parents do not have information about the meaning of mental retardation, the meaning of degrees of mental retardation, what limitations are implied for school learning, for behavior learning, for terminal level of ability, or for ability in life adjustment.

Particularly, parents are usually not aware of the influence of intelligence on behavior organization and behavior learning. The first and most common interpretation that they receive is that the mentally retarded child will not be able to make adequate school progress. Many times, the parents will say, "Well, school isn't everything. If he can do other things, does it really matter if he cannot make an adequate school adjustment?"

What is not made sufficiently clear is the tremendously important part played by intelligence in the organization of all behavior—behavior controls, ability to adapt, ability to conform, ability to see the points of view of the other person, and to make adaptations for social living. Parents do not recognize, without some special help, the importance of intelligence in such areas as motivation, as persistence, as measuring work to be done and the importance of making an effort to do it. They may not understand that the total personality of the child is closely tied to his intellectual endowment which governs the pattern of his future development.

Therefore, the first area of parent counseling should be concerned with giving information of an intellectual sort or a factual sort, if you will, on which parents can base their own thinking about their own problems and their own child.

There is still another kind of information which parents typically lack. That is information about community facilities. Here is an area where the professional needs to be well informed concerning the facilities and also well informed as to current sentiment. At least he should know what the situation is and what it may become in the future.

Therefore, the professional has a real obligation to "keep up", to keep posted, to know what the new things are. It is not enough to say to parents: "Somewhere in town there is a nursery school that might give your child some group experience. I think the name of it is Elliot Park, so why don't you call them and see if your child might be eligible." Parents, in the early stages of educational planning, do not have the confidence or clear enough understanding to know what plans they should make. They need to know specifically if there is a chance that their child will be eligible. This means that the counselor must be informed about community facilities; about age limits and intelligence limits; who can be accepted; distribution of types that can be accepted; admission requirements; geographical restrictions—things that are part and parcel of the detail of running our own facilities but which, wrapped up as we are in our own work, we may not take the trouble to look into.

Parents need specific help. They need to know the name of the person to contact. It is better if you can also give them the phone number. This type of information helps the parent to move ahead. One of the problems we face in working with the parents of retarded children is to get them into suitable and appropriate programs.

We also need (and this is something that sounds like an ideal rather than a practical possibility) improved ways of correlating our efforts. Parents need to plan ahead for retarded children. This is not the usual way parents bring up a family. Normally, you do these things one step at a time and you think, perhaps wisely, that it is wrong to plan too far ahead for a normal youngster; that he should have a hand in shaping his own destiny; that many decisions as to where he might like to go to school, what course of study he might pursue, should wait until maturity gives him a rightful share in decision making. Unfortunately, this is not the case with the retarded child.

While our facilities remain limited and we do not have enough of anything to go around, it is most important for parents of retarded children to plan ahead, to see where they are going, to see what might be the case in five years from now, not just for tomorrow. In order to help parents look to the future, we need to be pretty clear as to the things we can predict, the things we cannot foresee—as well as being completely honest with the parents in connection with which things are which.

It is true that we cannot always blueprint the entire future of a retarded child but, in many respects, we can draw the rough outlines of suitable plans.

For example, we know that for most children at the trainable level, at least the strong likelihood of later institutional placement should be considered. We know that this is also true for many educable children, particularly if they have other kinds of handicaps in addition to restricted abilities.

Another reason why parents may find it hard to plan ahead for retarded children is that the child very frequently make it difficult for us to think of him as growing older. We call them "little kids" long after they have moved into the middle childhood range because that is how they act. This is also true in connection with parents—the fact that children require their care makes them seem younger, at least in the eyes of the parents.

So much for the informational area—which is detailed, complicated, and involves a continuous on-going process. It is quite an assignment but, without question, the emotional area with which we must also deal is more important, more difficult, and of greater significance to the family.

Parents have certain emotional problems in common as they face the situation of a retarded child but we do not deal with problems in a vacuum. We deal with problems in people, and people come with all sorts of variations. They also come with all sorts of psychological traits as well as physical traits.

We see these parents at different stages of emotional maturity, with different degrees of ability to comprehend their individual problems. We see them at different stages of acceptance. In our discussions it is very easy to point out extremes of attitude—the very cooperative parent or the very resistant parent. We need to focus our attention on the range in between

these extremes—the parents who are somewhat cooperative but also somewhat resistant.

We must remember that people do not stay the same, even from day to day. Their attitudes are undergoing gradual shifts. We must deal in day to day, week to week growth processes, maturational processes, attitude changes, increases in understanding. So, unless we pay attention to these differences, we will be doing our counseling job at less than full potential.

Early diagnosis of children is desirable for this long-range planning. However, it is at the earlier ages of their children that parents can be expected to have the most resistance to accepting the facts about them. They may still be hoping that there is some other explanation than mental deficiency in connection with the deviations of their child.

At the beginning of the counseling process a characteristic of parents, which is most frequently mentioned, is the tendency to reject an interpretation given them by either the psychologist, the medical expert or the team of people who have studied the child. Again I think that this is oversimplification. We are not dealing with the total rejection of interpretations. We are dealing with stages of being able to accept, and these stages start at rather minimal points. It has already been pointed out that one of the most basic principles which counselors have to grasp is the fact that parents come to them for help. This in itself indicates that they are confused, puzzled and alarmed, and that they want some clarification. Therefore, a clarification of the facts, even though the initial reaction appears to be rejection, is most important.

When we look at the continuing process of reactions which parents may show, we are overwhelmed by the variety of them. Any attempt to put them into categories is artificial and may lead us further astray in our direct procedures.

We find that parents may move in the direction of intellectual acceptance of the problem but that their acceptance may be only on a factual level and not on a feeling level. If it is on a factual level, our problems are not solved. What that implies is that parents will not be able to make the attitude changes which are important if the child is to have appropriate goals set for him and appropriate techniques for helping him reach them.

The parent, who is intellectually accepting but emotionally unaccept-

ing, cannot honestly see the child the way he is. Emotional acceptance for many parents takes a long time but it must remain one of our primary counseling goals.

One reason for being concerned about emotional acceptance is that many of the practical management problems which children present are created by parents, certainly not on purpose, but out of their efforts to move the child along into a more acceptable behavior pattern.

Another major reason for early work with parents is that the parents themselves are growing and changing, as we also hope we are. For all of us the life process is a process of change and hence must be viewed in a time framework.

One thing that may happen to parents, who do not receive early counseling attention, may be described by what we call "circular dependency". Normally, parents expect that they will take total care of their baby because that is what the baby needs. Normally, however, the babies themselves call a turn on this procedure by their own development, their growth and independence, their ability to get around by themselves, to communicate, to assume charge of some aspects of their own lives. However, with a retarded child, this does not happen. He stays in the dependency stage longer and he grows out of it unevenly. Parents, in the very course of taking care of the child, continue to meet needs on an infant level much longer than they do with their normal children.

We suspect that the only way parents can do this without too much frustration is to force themselves to enjoy it. In the process of forcing themselves to enjoy it, they may become dependent on this need.

I think that this is a background for many of the reactions that we see. For example, when a youngster is placed in an institution at the age of twelve or thirteen, the child has little trouble adjusting to his new environment. However, the parents may have a great deal of trouble adjusting to his absence. They find that they and the child were linked together by bonds tighter than were intended.

These are major problems. I fear that they have somewhat of a theoretical slant. We are talking about long-range plans. We are talking about long-range attitudinal changes. We are talking about emotional growth. And now, I think, we should turn our attention to some of the day-to-day essentials.

As far as parents are concerned, the things which are a source of anxiety to them are the daily behavior problems which must be handled as they happen. The questions parents ask, either openly or hiddenly, are like these: "What do we do with this child who is so hyperactive? What do we do with this child who is so destructive, who cannot communicate, who cannot seem to get toilet trained, who cannot get along with other children, who cannot sleep at night, who has temper tantrums and aggressive outbursts—what can we do? How can we cope with it all? How do we manage him?" Unless we can look at these problems from the point of view of the parents, I feel that this mutual rejection of each other as resources will widen.

Tied to these behavior-management problems, there are many less visible but perhaps equally important aspects of family living. There is concern for normal children in the family. What price are they paying for having the handicapped child at home? There is the concern for family living patterns. There is the concern for the social, professional and personal contributions that the parents, as adult citizens, make to the life of their own community. In what ways is this jeopardized or even completely destroyed?

We have to be concerned about the neighborhood situation. How are other children being affected; what about the attitudes of other adults in the community?

We have to be concerned about all of these problems. However, there has been relatively little scientific study of them because it is difficult to generalize about such situations. This is an area where individual differences are many—and important.

All of which brings us to the processes of parent counseling. We think that the emphasis in such counseling should be put on content rather than on method.

Our own parent group, which meets once a month, has made use of every technique we could think of for imparting information. We have used lectures, discussions, panel discussions, questions and answers, parent panels and occasional outside speakers. We also invite written questions from parents which we look up in reference books in order to report back to them. We are beginning to use our own research material to make information more clear to parents.

We have used teacher-parent conferences, social worker-parent conferences, home visits, psychologist-parent conferences. We have used all three of our professional people, plus information from our medical consultants, in order to convey as many aspects of the problem as possible. We have also made use of a social hour following our serious meetings. We find this is a time when parents can let down the bars a bit, talk with each other, exchange experiences, and talk with the staff.

We have made use of classroom meetings, in which parents have an opportunity to see the work their children have done and to compare it with that of the other children.

It is one of our basic rules that each one of us must, in every conversation with a parent, be aware of the possibility of holding out unrealistic hopes, without intending to do so. When you are working with retarded children you also become involved with them. You become proud of each bit of progress that is made and, subjectively, the accomplishment of the child is very much tied up with your efforts. So, it is very easy for the teacher to say that the child is doing well. It is equally easy for the parent to read into this the fact that the child is going to turn out to be normal. This, we must truly guard against. We must say that he is doing well—for his present mental capacity. We must explain it further, in specific areas—he is doing well in contact with other children; he is less aggressive, more friendly, a little more cooperative. It requires more work to be specific but it is far more rewarding.

In our group meetings with parents, we have attempted to give them as much information as we have available. In our meetings we have discussed causation, state facilities, community programs, why we think a research approach is important—in fact, our parents now think that research is just as important as we do and they are pushing us for results of our most recent medication study.

We have also tried to discuss behavior development and behavior problems; what to do and what not to do.

In short, our content has been everything that you might hope to find in a fairly complete, up-to-date and thorough textbook on mental deficiency but that is not all. We think that it is basically important for parents to reach a better understanding of themselves.

We rarely have a meeting without something coming up about feelings

of guilt, responsibility, self-punishment, attitudes of other people—either on the surface or not very far hidden. We have discussed these things quite openly in our parents' meetings. We have tried to help parents feel that we not only understand these feelings, from the book approach, but that we share them from our own experience.

We are quite open in admitting to parents that we have problems with their children. School is not a bed of roses. We have many difficult situations and many bad days. We also have many good days. In discussing these things with parents, we believe we can take away some of the separation of the professional-parent barrier which may otherwise operate.

I am quite sure our parents do not think that we think we know all the answers. They do think, I hope, that we are willing to work on their problems with them.

We feel that a sense of humor is pretty important. We laugh at our children and with them, and they laugh at us and with us. We try to help parents take a slightly lighter point of view—this is a retarded child; this is a life situation; it can be met and handled as we handle other life situations.

To all of this, there is no standard answer. There is no standard solution, nor should there be because there are no standard people. And, certainly, there are no standard retarded children. However, these problems can be tackled openly, honestly, without too much influence of guilt and punitiveness. And parents can be helped toward a better state, a more mature state of acceptance and problem-solving attack.

We feel we must also turn the attention of our parents to the welfare of their normal children. We do this in a number of ways. One way is by studying the brothers and sisters of our retarded children. Sometimes because they too have problems and sometimes because they do not.

If they do not have problems, we want to know why, so that we can pass on this delightful information. We occasionally ask a parent to write us a week-end diary about a normal child instead of the routine one in connection with the retarded child. We encourage all-family participation to help diminish the excessive involvement that the parent may feel with the retarded child alone.

We try to neutralize the parents' feelings of protectiveness. One step

in the right direction, of course, is in having the child come to school. The parent who can let his child be away from home for several hours a day has taken an important step toward both his and the child's emancipation. By having a child away for part of each day, the mother, for instance, has time to think a thought or two apart from the child.

Certainly, too, a measure of objectivity results from comparison with other children at the school. As parents come to know each other and come to understand something about the other children, they are bound to make comparisons which help in the more realistic viewing of their own youngster.

We think that parents also benefit through observing the relationship which is developed between children and staff. We are fond of our retarded children; we are tolerant of them. We accept them as they are and we are affectionate with them. At the same time, however, we are realistic about them. We do not expect things from them which they cannot do. We try them out in many things but our expectations are guided and modified by the child's performance. This is something that parents, in watching and observing, often carry back into the home in order to modify their own feelings and expectations and standards.

Further, all of us must recognize that families have other problems than the retarded child. Many times, in thinking about counseling processes, we forget about unhappy marriages. We forget about poverty and emotional conflicts between the marriage partners; we forget difficulties with other children; we forget school failures, neighborhood rejections—all of which may not have anything to do with the retarded child. We may also forget unemployment, salary problems, the cost of living, difficulties of housing, even the minor but irritating effect of families not having a telephone. If we are not able to take a broad view of counseling and look at the family situation broadly, then much of our pin-pointed effort is going to be wasted since it does not take into account all the problems that may be involved.

As far as possible, we try to give help that is practical. Parents come to us and say, "What shall I do with Johnny?" "What shall I do with Bill for he will not go to sleep?" "What shall I do with Susie for she will not eat her vegetables?"

These are things of concern. You can say, "Don't worry about it, it

is unimportant. This is one stage and it will go away." But this is not very helpful.

We make our suggestions; we make them honestly, realistically and with no guarantee of success. We usually make more than one suggestion so that the parents can select the one that seems to fit their own situation the best. If it is a discipline problem, we say isolation works in some situations, that sometimes there is nothing like a good spanking to clear the air. Further, to deprive a child of privileges which are important to him will sometimes help. We ask them to try one of these suggestions and see what the results may be.

Part of the problem parents have is in wanting very specific answers to a particular difficulty. Part of the professional problem is having enough strength of ego to admit that there are lots of answers that we don't have and probably lots of answers that we may never develop.

To try to sum up our philosophy, I suppose you might call it "a philosophy of individualized realism." We attempt to take into account differences not only among children but among parents. We say that we try to meet the children as they are, particularly in their emotional reactions. We try to do the same thing with parents, without establishing a preconceived level which they must reach before we accept them into our group. We try to have something to meet their needs at any level of development. We believe that the general principle of "facing up" to life problems applies to problems of retarded children as well as to other life situations.

We attempt to help parents find these principles, to understand them and to apply them to their own lives. We also attempt to help parents make compromises, because the long-range view of mental retardation is a process of successive compromises in many, many ways.

We also do not expect that parents can be completely successful in one week. Change takes time. We try to comprehend and visualize the family pattern and to appreciate what the problem means to each family. A major goal of parent counseling, in our view, is to assist parent understanding and adjustment in as many ways as we can so that life for all our families may turn out to be generally more satisfying. Thank you, very much.

CHAIRMAN ADAMSON: I feel, Dr. Blodgett, that you have highlighted

for us very capably several of the major areas in counseling work with parents of retarded children. I thank you.

The second paper this afternoon deals with recent efforts to help parents use a residential school in a constructive fashion for their handicapped children, rather than having the feeling, either consciously or unconsciously, that they are putting their child away.

Mr. Johnstone has pioneered this point of view for both public and private residential schools. He has urged a closer relationship between school and home. At The Woods Schools he has encouraged a flexible plan for parental visiting; secondly, he has continued to stress a policy of monthly letters (and sometimes more frequent ones) to the parents of our students—and these must be forthright, honest letters about the progress, the lack of progress, or a special problem that the child is having. Parents frequently say to us, "We expected your letter to be sugarcoated, glossing over some of the things that go on at school. But when the little personal things that were happening were described to us, as well as the big problems, we knew that you were talking about our Jimmy."

Thirdly, I am happy to say that our President and the Board of Trustees have fully endorsed the program of parent counseling now underway at The Woods Schools. It is this program which Miss Mary F. Carswell, director of our current counseling services, will describe to you.

Miss Carswell joined the professional staff of the Child Study, Treatment and Research Center, The Woods Schools, in 1956, as psychiatric social worker and parent counselor. She had previously served in similar capacity at the Community Guidance Center in Austin, Texas.

Miss Carswell, a native of Gorham, Maine, was graduated from the University of New Hampshire, and studied at the School of Social Work of the University of Pennsylvania where she earned her Master's degree and Advanced Curriculum Certificate. She served as a staff member of the Akron Child Guidance Clinic in Ohio, and as Senior Psychiatric Social Worker at Harrisburg, Pennsylvania, before assisting in the organization of the Texas Guidance Center at Austin in 1952.

She is a member of the Psychiatric Social Work Section of the National Association of Social Workers.

I am happy to present Miss Carswell, who will talk to you on the subject, "Helping Parents in the Private Residential School Setting".

"HELPING PARENTS IN THE PRIVATE RESIDENTIAL SCHOOL SETTING"

By

MARY F. CARSWELL, M.S.W.

MISS MARY CARSWELL: As Dr. Adamson pointed out to you, I will discuss how we help parents in a private residential school setting.

Our society places great emphasis upon intellectual status and achievement. That, in itself, can contribute to great concern and upset for parents of handicapped children. Many parents feel they have failed in the most important aspect of human creativity—the producing of normal offspring. The feeling aroused by this sense of failure may take many forms. It may reach into various facets of their own lives, as well as affecting the natural growth of their children. We cannot deny that this is a profound personal tragedy, but we hope we can offer a helping hand.

At best, the natural growth process is not a smooth, easy one. It is not without accidents, distortions and disturbances. There are many internal and external forces which influence the nature, rate and quality of the human growth process. There is also inherent in each human being a self-directing capacity and a potentiality to use his resources to the fullest. It is my conviction that every child, including those with multiple handicaps, has within himself the capacity for growth and change.

This presentation is concerned with the role and function of the social caseworker (parent counselor) as a helping person in a private residential school for mentally handicapped and emotionally disturbed children. It will outline three areas of social casework practice which have been developed during the past two years and which are gradually being integrated into the overall programs of The Woods Schools for Exceptional Children at Langhorne, Pennsylvania.

The Woods Schools has been serving the needs of mentally retarded children since it was founded by Mrs. Mollie Woods Hare in 1913. The subsequent refinement in psychological evaluations, with the rising tide of emotional disturbances in young children, has served to extend this traditional function to include a psychiatrically oriented residential treatment program for children with or without mental retardation. The six semi-autonomous school units under a central administration allow for the

therapeutic placement of children according to their physical, mental, social and emotional needs. Currently, approximately 40% of the 400 students are borderline to above average in intellectual ability. Their ages range from 3 years to 30 years. They are benefitting very fully from the residential treatment program. The remaining 60% of the students (with ages from 3 to 50 years, plus), are functioning with varying degrees of mental retardation. They are placed in the long-term socialization program which allows for special education, vocational development and training, and individual or group psychotherapy, according to the degree of handicap or potential which each may reveal during residence in the Schools.

Refinement and definition of this newer program has been under the leadership of Doctor William C. Adamson, director of professional services for the Child Study, Treatment and Research Center at The Woods Schools.

Additional professional personnel from the fields of psychiatry, clinical psychology and social work were added to the staff of the Center to carry out this comprehensive program which emphasizes individualized services to the emotionally disturbed retarded child and to his parents. In this development, the introduction of social casework in The Woods Schools was an indication of the awareness on the part of the administration for more intensive work with parents of the children enrolled in The Schools. This professional work with parents was conceived as the special responsibility of the social caseworker.

Such casework services are now available to parents of children during a pre-admission evaluation process and as a part of both the residential treatment and the long-term socialization programs. In the latter, the casework is focused upon helping parents recognize the nature of this long-term plan for their child and to help them come to terms with this reality. This service provides for regular appointments with parents of children receiving psychotherapy and will be discussed more fully later in this paper.

The social service program of The Woods Schools is still in the process of growth and development, yet much has already been accomplished. I would like to share with you what is now the core of this program of services to parents.

ADMISSION (INTAKE) SERVICE

Placement of a handicapped child in a residential school begins with

the parents' asking The Schools to help them and their child by accepting him for the special education program and residential living offered by The Woods Schools. This move toward separation is of their own choosing. It may have in it the feeling of "putting away", however thoughtfully the decision is reached. Separation, even with purposeful intent, is unnatural and traumatic for both parents and child. Helping parents and child meet this painful experience, by breaking up the totality of feeling through partialization, is an appropriate function of the social worker. (Partialization is that process of sorting out or breaking up the whole experience into smaller parts—or pieces—thus allowing parents and child to cope with these experiences, rather than to be overwhelmed by so much at one time.)

Before social casework services were available, a genuine effort had been made to make placement of the child easy and painless for both parents and child. In reality, we know this is not completely possible. Presently a parent counseling service is available to all parents seeking to enroll their child in The Woods Schools. It is an integral part of The Schools' present admission process.

The purpose of this admission process is: To evaluate as skillfully as possible the nature and degree of the problem in the child whose parents are seeking placement for him;

To accept for residential care and treatment only those children who appear able to make maximum use of the program and services offered by The Woods Schools;

To plan for the kind and quality of care best suited to the individual child's need. (Unit placement, classroom placement, and special services such as psychotherapy, speech therapy, physiotherapy, remedial reading, special arts and crafts instructions);

To give parents an opportunity of working closely with The Schools at the time of admission (through relationship with the social caseworker) in order to establish a continuing relationship with them throughout the child's placement in The Schools. The social caseworker's focus, at this beginning step, is seen as helping parents with the decision as to whether this residential plan is one they wish for their child. If it is, the worker helps them in supporting the child's beginning use of The Schools program.

To set such a process in motion, and to allow it to proceed in partial

steps so important to the psychological experience of separation, a Four Step process is suggested to parents.

STEP I: An orientation visit. If it is possible, parents should plan to visit The Woods Schools without their child to gain first-hand knowledge of the program. In cases where distance and expense make this prohibitive, parents should inquire about the Schools' Registrar visiting the home to see the child, and to inform them about our program.

STEP II: Medical summaries. Parents should ask the consultants who have studied their child to forward medical summaries to the Registrar's office as soon as they become actively interested in enrolling their child.

STEP III: Pre-admission evaluation. When parents have made a decision to enroll their child, they should ask the Registrar to schedule a pre-admission evaluation visit with the Child Study and Treatment Center staff. These are usually scheduled on a Monday or a Friday. Such visits are helpful both to parents and child since they anticipate this new and partial separation from one another.

STEP IV: Enrollment. Application for enrollment is completed by filling out the needed forms and completing the \$50 application fee (which is credited to the first month's tuition when the student enters The Schools).

Parents seeking to place their child in The Woods Schools make the initial inquiry through the Registrar. In some instances it is possible for the Registrar to visit the parents and child in the home prior to their coming to see The Schools. If they are interested and do want to visit, they have opportunity to see the residences, classroom facilities, the new Child Study, Treatment and Research Center, and also the students with whom their child may be living. They may meet the unit supervisor, teachers, housemothers and others serving on the staff. During such a visit, parents not only see the physical set-up but have an opportunity to gain better insight into the atmosphere of The Schools. In some instances, the child accompanies the parents during this first visit.

If the parents are ready to take the next step toward enrolling the child and, if reports of previous psychological and medical studies received from referring physicians and consultants indicate that the child may be eligible for admission, an appointment with the social caseworker and a concurrent psychiatric interview for the child are offered them. This pro-

vides opportunity to evaluate the nature of the child's problem and to decide whether or not The Woods Schools can meet his individual needs for social, emotional and intellectual growth.

The social caseworker's part in this exploratory pre-admission service is focused on a beginning engagement with the parents around a very specific social reality; making appropriate plans for their child, who is different, and on discovering whether this is the best possible plan they can make for him. A substantial part of this interview is concerned with obtaining background and history. Reliving with another person what it means to be the mother or the father of a multiply-handicapped child is not easy. The social caseworker must be sufficiently sensitive to the parents' feelings so that what may appear to be merely information and fact-gathering is, in reality, the engagement of human beings concerned about another human being. What is communicated in feelings, in understanding, and in affirmed respect for one another can be a very real helping experience and the initial part of a continuing casework program.

An important phase of this exploratory pre-admission service is the joint conference with the parents, social caseworker, and the psychiatrist who represents the final medical authority. At this time, there is a mutual sharing of significant information which the parents have given concerning the child's early growth and development, and their feelings **and** attitudes about his handicaps.

The psychiatrist shares with the parents his tentative impressions (as he has seen it in his evaluation) and describes the program which he feels will best meet the child's needs. This may be The Woods Schools' program or he may recommend another agency or another institution which may serve the child's needs. Some exploration of the degree of financial indebtedness the family may be undertaking will be introduced at this point. Our staff holds that this discussion must be a realistic one to make sure that no family becomes obligated out of proportion to goals for the handicapped child, goals for the other siblings living at home, or **out** of proportion to the family's ability to meet such expenses. Currently, The Woods Schools is seeking to build a Scholarship Fund in response to the many worthy requests for financial assistance from families who would like to have their children benefit from Woods Schools programs. Until such funds become available, the professional staff attempts to help families find treatment and care services, suited as nearly as possible to the needs of their child.

When it is possible for parents, in terms of time and distance, to have

additional interviews with the social caseworker, such interviews are arranged—to help them talk about how they may prepare the child for admission and to help them with their feelings about separation and all it holds for the child, for them, and for The Woods Schools.

If the child is eligible for enrollment, the Registrar then arranges for his admission to the specific unit suited to his needs, at a time mutually acceptable to the parents and the Schools.

If the child is not eligible for admission, a responsible referral elsewhere is undertaken.

CASE ILLUSTRATION OF THE PRE-ADMISSION SERVICE

The parents of a six year old child were referred to The Woods Schools by the family physician. The parents had already taken the first two steps in the admission process.

After meeting the child and parents, the Medical Director helped the child separate from the parents for the psychiatric evaluation while the parents talked with the caseworker. This interview represented Step III for parents, child, and Center staff. The highlights of this interview were:

Exploration of the role of the social caseworker on the staff. When parents were encouraged to discuss their feelings about taking this step, they poured out their problems about the child at home, at school and in the community. These were accepted and acknowledged as very real and hard to bear.

The nature of the problems was explored more closely. Parents were self-critical and self-accusatory. The caseworker attempted to help them partialize this total guilt, hurt and blame. Their family physician had recommended placement for the child. Such a decision was not an easy one nor could it be made in haste. The caseworker supported the parents in their two sides of feeling; namely, they wanted placement for their child, yet they were afraid of it.

The early history and development of the child was reviewed fully—including the parents' discovery of a hearing defect in the child. This was not found until after a good many distortions had begun to

appear in the early parent-child relationship and in the communications between them.

It was brought out that the child's inadequate speech led to difficulty in verbal expression, with subsequent violent explosion of feelings, often triggered off by a series of minor incidents. The ensuing discussion gave the parents an insight into why a child often acts out strong feelings in a destructive manner.

It seemed clear, at this point in the counseling hour, that the parents had begun to regard the caseworker as a friend and helper as well as a representative of The Schools. They had not yet discussed the softer, more positive feelings they had toward their child. These came easily and freely, and it was apparent that they did not see their child as "all bad".

The caseworker undoubtedly helped these parents become aware that much of their child's handicap was within the child, and not entirely of their creation. Yet it was made clear that their active support was essential throughout the period of the child's residence in The Woods Schools. They could provide the opportunity for specialized help, but the child himself would have to carry some of the responsibility for how he used the help available.

Reassured by their previous visit to The Schools these parents then discussed with the child the possibility of enrollment in a special boarding school. These parents had made a real beginning in helping their child sense their love for him and also their constructive desire to help him with his handicaps.

This initial casework interview, in the admission process, is geared to help parents understand the residential program more fully and to support their child's beginning use of it.

Without the cooperation and support of the parents, the child's ability to use the program may be lessened. When parents are helped to realize their vital role in the child's new living experience, even though they are separated from him physically, the child becomes free to use more constructively the special help they made available to him. It is the parents' readiness to turn over to others the day-by-day care of their child that requires the greatest degree of faith and trust. It is The Schools' responsibility to honor that trust.

PSYCHOTHERAPY

The emotionally disturbed retarded child, or non-retarded child, living apart from his parents, often needs the specialized psychological assistance offered by the professional staff of the Child Study, Treatment and Research Center of The Woods Schools. The philosophy underlying these services is traditional in most child guidance clinics—the collaborative team approach. This team includes the psychiatrist, the psychologist and the social caseworker, working together. Individual and group psychotherapy is provided on a weekly or twice weekly basis depending upon the individual child's need.

The counseling service to the parents of children receiving psychotherapy includes regular monthly interviews with the social caseworker. In some cases, parents are seen more frequently.

This service is available to those parents who wish to participate as actively as possible in supporting the child's use of treatment and to strengthen their own relationship with the child. In interviews, parents are helped to understand the growth and change in the child which may result, with the hope that the child may ultimately be able to return to his home and community.

CASE ILLUSTRATION OF PSYCHOTHERAPY SERVICE

This case material is summarized from the initial interview with the parents of a ten year old girl, suffering from a number of severe handicaps. While our studies suggest an intellectual potential within average limits, her severe visual handicap, three years of academic retardation as well as severe emotional problems, give her the appearance of a mentally retarded child. She has been receiving psychotherapy once a week since the fall of 1957 to assist her growth both socially and emotionally. It appears that her emotional problems have interfered with her normal intellectual achievement.

Both parents were very responsive to the parent counseling service offered to them. They had expressed their need for help. For instance, how could they meet the situations that arose during their daughter's regular monthly visits home? To help with this problem, appointments with the social caseworker were set up prior to each home visit.

I began by discussing with the parents how we might best use

our interview time. I described my role as parent counselor in relation to the overall program and to the psychotherapy program, in particular. We reviewed their reasons for placing the daughter in The Schools. This family had been referred to The Woods Schools with the hope that, in a year or two, she might be able to return home to attend the public schools.

I described their child's behavior as we at Woods Schools saw it. The parents agreed that it was similar to her behavior at home. I suggested that one of the necessary things in helping her grow up was a feeling of consistency in her relationships with the significant grown-ups in her life. They, as her parents, were the most important people in her life. Since they had chosen to place her in The Woods Schools, they had delegated her care to other adults while she was away from home. In reviewing with them how they had prepared their daughter for placement, it was clear that they had placed the greatest emphasis upon academic learning. What I felt was missing was their frank expression to her that placement in The Schools was a constructive, responsible decision which would help her become a happier and better satisfied child.

We talked about how they might, even now, convey this feeling to her; to assure her that it is not because she was "bad" or a failure that they had chosen the school for her, but because they loved her.

I asked the parents to share with me the things that concerned them most in their relationships with their daughter. It was not until I recognized that she could be difficult to live with, that they discussed this point freely. Once they felt they could trust me and came to realize that I was not critical of them as parents, a flood of experiences and episodes poured out. Each parent censured the other's way of handling the daughter. When I pointed out that this opened up a gap through which she could play one parent against the other, the mother and father began to reflect upon this point and to discuss it with me.

We explored how and why communication of feelings between parents and child breaks down, particularly as a child tests parents' strength in a multitude of ways. I pointed out how she needs to feel the trust and security that represents both the "allowing" and "not allowing" of certain expressions of feeling. Only when she has experienced this with her parents will she be freer to use her energies

toward positive growth rather than to continue to use it negatively. We talked about how their daughter was using the hours with her therapist, testing him at every turn. Out of this weekly experience with him, she is learning, by partial steps, to handle her part in a relationship. I pointed out how our counseling interviews in a sense, parallel the therapy hours as we all work together toward helping her grow up socially and emotionally.

These parents, we hope, are being helped to stand steadfast in their roles as mother and father to a little girl who needs to have security and trust defined to her. Such definition can take place only through healthy interacting experiences between parents, teachers, child case workers, psychotherapist and the child—through which she learns to accept the positive giving, affectionate, "I love you" side of life, as well as the more painful, yet realistic negative withholding, partially frustrating, "no, you can't have that" side of living.

We are all familiar with the many mixed feelings which parents of retarded or disturbed children express—feelings of guilt, reactions of denial, projection or withdrawal. These represent their attempts to cope with what seems to them an intolerably frustrating and painful situation.

Parents need to have the opportunity to talk about themselves, to talk about their experiences in living with, and caring for their handicapped child. They need someone to listen to them, someone who is sensitive to their feelings and attitudes. They need someone who understands their need for support in their role as parents of a child who has added distortions to the usual parent-child relationship as well as distortions in the whole family relationship, by virtue of his handicap. In their interviews with the social caseworker, they can share their feelings of self-blame, anger, and discouragement as they seek direction and guidance toward a new and better understanding of their child.

LONG-TERM SOCIALIZATION PROGRAM

The third casework area we would like to discuss is The Schools' long-term socialization program. Children in this program are functioning with varying degrees of mental retardation. Many parents have difficulty in adjusting to this long-term need.

Casework service to such parents is relatively new. Child guidance clinics offer diagnostic studies and limited help to parents. Sheltered work-

shops offer vocational services to mentally retarded young adults and limited counseling programs for parents. Most schools and institutions providing care and training for the mentally retarded offer intake services. A continuing casework service to parents of mentally retarded children in residence at The Woods Schools is still in the early stages of definition and development. A beginning has been made, which points to the genuine value of this direct service to parents and its indirect service to children.

The extent to which parents may be ready to involve themselves in a helping situation may reveal their deep feelings of hurt and frustration. This is natural. In some instances, it is easier to deny this personal tragedy, than to attempt to understand and to handle these feelings. In many instances there is anger toward themselves which is projected and acted out in many facets of daily living with the child or the family.

It is not uncommon in our experience at The Woods Schools to find that a mentally retarded child, who has created havoc in his own home for years, becomes a very different person after a period of residence at The Woods Schools. When parental pressures and unrealistic expectations are removed from his daily life, he begins to find support and contentment in stable routines. This change in the child is sometimes not easy for parents to bear, yet it is the ray of hope. Such a shift in the child may provoke parents to press the school staff for more academic progress or it may reinforce their own self-doubts and their sense of failure as parents. Whatever the parents' reactions may be, the caseworker supports them in recognizing that the child needs them as parents, not as special education teachers or miracle workers.

LONG-TERM SOCIALIZATION CASE ILLUSTRATION

This eight year old mentally retarded student was enrolled in The Woods Schools in June 1957 following a pre-admission evaluation. A casework interview with the parents, prior to enrollment, was arranged to help them prepare the child for coming to The Schools.

This student was a brain injured child, one of a family of several normal children. The parents were a young couple who were very concerned and distressed about the problem of their child.

Casework interviews over a period of time were focused on helping parents move gradually toward recognition that the child

could not be expected to grow and to achieve the pace they had set for him. They projected their negative feelings to teachers, house-mothers and others working closely with the child. They were understandably critical and they pressed for evidence of academic progress during the early months of residence.

These parents needed and used the opportunity to work with the caseworker who held firmly to the reality against which they were struggling.

The child made very good use of the program. He became less tense when he found he could trust the "new" adults in his daily life at The Schools. He developed more independence and self-assertion. With casework help, the parents also began to organize their strengths differently.

The caseworker met with these parents following the staff conferences held to discuss the nature of the child's problem and use of program with them. It was important at these times for them to have an opportunity to bring back to the caseworker their reactions to the reports they had heard from the staff.

The parents were helped to understand why the child might slip into earlier babyish ways following his home visits. It was not easy for them to accept the fact that although they felt no pressure had been put upon the child during these visits, the child seemed to sense their need for something to be different in him. As a result of the child's sensitivity to such covert pressure, earlier patterns of infancy would emerge.

Many parents need such counseling support over a long period of time. They need the opportunity to run the gamut of feelings about what has happened to their child and to them. Indeed, some parents need to test the strength and skill of the caseworker (The Schools) at every turn until they find within themselves the strength to face and to acknowledge the reality of their roles as parents of a mentally retarded child.

The caseworker recognizes how inevitable the course of some children may be and how this ties into the parents' dilemma. The goal of the caseworker is to hold parents to a step by step process out of which they may find new strength and understanding. They must be helped to see their

handicapped child as he (she) is and to understand that The Schools' program is designed to help their child grow and develop to the full limits of his capacity.

SUMMMARY

In summary, this paper has presented the three areas of casework with parents now being developed at The Woods Schools:

1. Social casework help for parents seeking to enroll their child in The Woods Schools is an integral part of the admission process. It has enabled parents to make better and more meaningful use of this beginning period for themselves and their child.

2. Social casework service offers parents continuing help through which they may learn to support their child in psychotherapy and come to a more understanding relationship with him.

3. Social casework service is available to parents of children placed in the long-term socialization program of The Schools. The service here is focused upon helping parents recognize the nature of the long-term plan and to help them, insofar as it is possible, come to terms with its reality.

I feel the philosophy of counseling services is essentially this: first, that few of us who are not parents can truly know how it feels to be the parent of a handicapped child. However, we can be well aware of the search they have made, within themselves and without, to find the answers to their dilemma. Second, it is asking a great deal to expect these parents to accept totally the fact that their child is handicapped. Yet, they can be helped in varying degrees to "come to terms" with this reality. Eve Mayer, a caseworker in the New York State Association for the Help of Retarded Children, has put it well in this statement: "Real acceptance lets a person make his particular situation part of himself. In coming to terms with a problem, he allows it to live with him, lets it co-exist with him, but does not truly internalize it. The awareness of this difference needs to be underlying any sound professional approach toward helping parents of retardates".

CHAIRMAN ADAMSON: Thank you, Miss Carswell. Now, before we call on Dr. Reynolds to summarize this conference, I believe Mr. Johnstone has a question about The Sheltering Arms program.

PRESIDENT JOHNSTONE: During this session, I have heard a number of

people comment about Sheltering Arms' use of volunteer services in then programs. It seems to me that this is one of the very important aspects in Schools of this nature and of all day school programs which have sprung up in so many communities. I wonder if Dr. Blodgett would care to comment on this, because I believe that here is a great opportunity for successful use of volunteers, or a tremendous loss of potential manpower which could be dissipated by poor use of them?

DR. HARRIET E. BLODGETT: Yes, we do have a volunteer program and we could not live without it.

The chief reason that it is successful is that we have excellent teachers, who cannot help teaching, whether it is the children in their classrooms or the volunteers assisting them.

We have been rather informal in our recruiting of volunteers and we think that this pays off. We think that to have a very specific drive for people to do volunteer work is not the best way to do it. We think it is better to use the ones already at hand.

We use volunteers in two basic way—as assistants to the classroom teacher in preparing materials and in handling individual children's problems. They also assist in supervising the lunch-time period and the free-play-time following lunch at which time our teachers are off duty. The children, then, in turn, are supervised by the remaining members of the professional staff. Our school volunteers (we have an average of two or three a day) are, for the most part, people without specific professional training. We do not give them a formal indoctrination course although we do give them printed materials and a good deal of discussion about the role of the volunteer. We tell them what we need them for and how they can meet these needs.

We try to be flexible in deciding when a volunteer is good and when a volunteer isn't—because people progress at such different paces in their understanding of this kind of program.

Our teachers are very different from each other and a volunteer who doesn't work out in one classroom may turn out to be a "gold mine" in another classroom. We attempt to help the volunteer find a place in our program where she is the most comfortable, to share with her our knowledge, to help her make use of it. We treat her very much like a professional member of our staff—with the exception, of course, that she doesn't get paid.

CHAIRMAN ADAMSON: Thank you, Dr. Blodgett, for that very clear definition of the use of volunteer services at Sheltering Arms. And, now, ladies and gentlemen, I am pleased to introduce to you Dr. Maynard C. Reynolds, associate professor of Educational Psychology, University of Minnesota. Dr. Reynolds has been chairman of the local arrangements committee for this conference and he is also functioning as the analyst who will summarize this meeting.

Dr. Reynolds was graduated from Moorhead State Teachers College and received his M.A. and Ph.D. degrees from the University of Minnesota, the latter in 1950. From 1942 to 1945 he served with the U. S. Armed Forces.

He was named teaching assistant at the College of Education, University of Minnesota in 1946 and later became an instructor in Education and Psychology at Iowa State Teachers College. From 1948 to 1950, he was research assistant at the University of Minnesota; then served for a year on the staff of Long Beach State College, Long Beach, California. In 1951, he returned to the University of Minnesota as assistant professor of Educational Psychology.

He is a member of the International Council of Exceptional Children and serves as a member of its Governing Board and Editor of Special Publications. He is also a member of the American Psychological Association, American Association on Mental Deficiency, National Education Association, and National Rehabilitation Association.

It is indeed a pleasure to introduce to you Dr. Reynolds, who will now give you the summary of our conference.

SUMMARY OF CONFERENCE

By

MAYNARD C. REYNOLDS, PH.D.

DR. MAYNARD C. REYNOLDS: We have been able to speak of progress on many fronts at this conference. Many of the things said in these two days could not have been said at an earlier time. It has become the mark of The Woods Schools Conferences on Exceptional Children that attention is focused on recent and current developments.

In the keynote address of the conference, Mr. Bystrom spoke in prideful terms of Minnesota's history in serving mentally handicapped children. His major emphasis, however, was on certain recent developments. He stressed the real partnership which exists among parents and professional workers in this state and which has been essential to recent progress.

Parents take many roles in the kind of progressive social action Mr. Bystrom has spoken of. They play a really indispensable role in helping to assess current programs and in determining needs for future development. Beyond this, the parents have become perhaps the most effective agents in securing social action.

The illustrations which were given you, of Minnesota's activity and progress are, I am sure, typical of what many of you observe in other states and which has been made possible through the cooperative work of parents and professional workers.

Dr. Rose has done a very helpful thing for us in structuring certain aspects of the climate of feelings and attitudes which seem essential to adequate child development. He has reminded us that our knowledge in this regard, even for normal children, is incomplete and that it is even less complete in the case of handicapped children. It seems clear, he pointed out, that problems of the handicapped child are often compounded by negative or non-constructive feelings of parents and others who care for him. The point that the child is himself an active agent in creating these feelings and the broader aspects of his environment is important. It reminds us that parents are also developing organisms and that they are vulnerable to problems particularly at times of such rapid change as are associated with the production and early care of a child.

Dr. Rose mentioned an important study now in progress on a co-

operative basis in thirteen medical centers, a study which is concerned with causes of mental handicaps. The design and scope of this project is unique. It gives much attention to factors of interaction of parent and child and promises some possible insights into these complex matters.

Dr. Jensen, speaking from experience probably as extensive as that of any other physician of our time, has assured us that counseling with parents of children with mental handicaps is a difficult and exacting task, particularly at the point of parents' "first knowledge". The parents' stress at this point is often very great and too often the counseling provided them is inadequate.

Dr. Jensen was able to suggest to us a number of guiding principles to be considered in the helping process "at the time of first knowledge."

He indicated, first of all, the importance of learning to know the kinds of information and help which parents are seeking. Parents of handicapped children often come to clinics, he reported, for confirmation of what they have already suspected to be the problem. Beyond this, one finds they are frequently seeking information as to the severity of the problem and its likely course of development in the future. Parents need to be helped in interpreting the meanings of the problem and in making plans for the future.

Dr. Jensen suggests that in order to be helpful, we must, of course, begin with adequate child study. Both parents and counselors must enter into the counseling process with the assurance that the child is adequately understood.

In the way of counseling procedures, Dr. Jensen encourages a direct and full statement of the facts concerning the child to the parents.

I suspect that many of us responded favorably to the view expressed in Dr. Sheldon Reed's address, in which he stressed the importance of enhancing the mental health of the living, as against giving attention too largely to mere reduction of morbidity.

Dr. Reed described for us the role of the geneticist in this helping process. Parents of retarded children have many questions and in trying to answer these, the geneticist has a vital role.

It happens that parents often ask the kinds of questions which geneti-

cists are best qualified to answer, One of these concerns causes of retardation. Such a question may take the form of asking for the probability of repetition of defectiveness in future pregnancies or, "what are the chances of our children having defective children?"

Dr. Reed stressed the importance of giving parents biological facts, Decisions reached on the basis of information provided—must be made by the parents.

Dr. Reed's own work at the Dight Institute and the type of leadership which he has given in work with parents of handicapped children, needs to be extended to all parts of the nation.

Marked progress is now being made in overcoming ignorance, superstition and misunderstanding in the field of mental retardation. Mr. Lund's presentation was optimistic in this regard. He also indicated, however, that there is little reason for complacency. There are still too many of these negative attitudes with us. Parents will have a vital role in ferreting out and assisting other parents who have need of more enlightened views and attitudes.

How does parent help parent? Most profoundly, Mr. Lund suggests, by simply making it apparent that no parent is alone. From this simple feeling of togetherness may grow readiness to plan for the child more realistically and to participate in building a community in which the handicapped child may function. The adjusted parent, one who has gone "through the mill", is often in position to turn to help another. Through these contacts with other parents and through continuing work in parent associations on local, state and national levels, really encouraging progress can be made.

Dr. Blodgett has given us a glimpse of the important work which can be done at the community level in helping parents.

Her more-or-less formal analysis includes needs for three types or stages of counseling: first, of an information-giving type; secondly, helping in long-range planning; thirdly, counseling with parents in regard to attitudes and feelings.

Dr. Blodgett believes this kind of framework is helpful to professionals but that it does not indicate the kinds of day-to-day problems which parents raise. The counselor must be prepared for a degree of rejection if

she or he is not equipped to deal with these practical problems of management which parents bring to the counselor. The high degree of assessability of counseling services provided in such settings as the Sheltering Arms, gives promise of development of a detailed knowledge and skill essential to this demanding counselor role.

Miss Carswell has outlined Ways by which a remarkable degree of communication is maintained with parents even from a residential school of national character.

Casework services have been introduced at The Woods Schools to assist parents who are considering placement of a child in a residential school and at the time of actually enrolling the child in the school. In addition, casework services are a phase of continuing help to parents and an integral part of the professional service to children while at the school.

Now, I would like to insert here just a couple of summary statements.

We have been reminded that the incidence of a mental handicap in a child usually brings a serious threat and problem to parents.

Parents of handicapped children must make basic decisions about their children and this process is difficult. We have been encouraged to believe that parents generally will make wise decisions if they are given adequate information.

It is one of the functions of the professional person in his counseling role to give parents information in a forthright, direct and honest fashion.

However, the counseling process involves more than information giving. The parents themselves must be understood and it must be realized that every family situation is different. Our concern is not just for aiding the handicapped child but to assist the parent in attaining an adequate adjustment for himself.

It has been noted frequently in this connection that many parents are now reaching the point where they are able not only to handle their own plans and problems very well but to go beyond this to assist other parents and to undertake leadership in broad social planning and action.

Although we have stressed the importance of counseling with parents of handicapped children, I think it would be agreed that we have not been

able to describe the whole process of counseling with complete satisfaction. This complex process is too little understood to make it a precise research tool or a process that can be easily taught. We have been helped in our understandings by persons wise and experienced in this field, but I am sure you will agree that we must look forward to further studies and conferences on this important topic.

In closing my remarks I must take time for a brief expression as chairman of the committee on local arrangements.

I shall not have time to name all of the members of the local committee and the many volunteers who have assisted in the presentation of this conference. I must express special thanks to Mr. and Mrs. Paul Christopherson for their generous aid and leadership. Beyond this, let me simply but sincerely express my appreciation to all of you who have participated in local planning and management. I am sure that all of the members of the local committee and the volunteers would want me to take these remaining few moments to express appreciation to Mr. Edward L. Johnstone, President of The Woods Schools, to the Trustees of The Woods Schools, and to the staff members of The Schools who have joined with us in this conference. We have enjoyed the conference and we have been richly rewarded by it.

My special thanks go to Mr. Johnstone and Mr. Jack MacDonald. It has been a real pleasure to come to know you gentlemen and I look forward to opportunities for growing friendships with you.

We also thank each of the program participants. We are very proud of our local people and we are most grateful for the presentations of Dr. Rose, Mr. Lund, Miss Carswell, Dr. Adamson and the others who came to our city for this conference.

We appreciate the interest of all of you who have come to our city and to our campus for the conference. It has been good to have you here.

CHAIRMAN ADAMSON: Thank you, Dr. Reynolds, for writing into this 1958 Spring Conference both the question mark and the exclamation point. I now turn our meeting back to the president of The Woods Schools, Mr. Johnstone.

PRESIDENT JOHNSTONE: All of you may be interested to know that a check of the registration reveals that in addition to a large delegation from

this state, there are also representatives present from Wisconsin, Iowa, North Dakota, Illinois, Indiana, Montana, Nebraska, Utah, Missouri, Maryland, West Virginia, Louisiana, Colorado, Oklahoma, New York and Pennsylvania. I think that this is a real tribute to the hospitality of the Minneapolis area and it certainly bears repetition to express once more our very deep and sincere appreciation to the chairman and members of the local committee; to the participants in this program; to the hostesses; the ushers, and to all of you interested and dedicated people who have made this 1958 Spring Conference such a decided success. It is perhaps appropriate to close on an oft-quoted portion of the Scriptures: "Inasmuch as ye have done it unto the least of these, My children, so also have ye done it unto Me."

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NOW AVAILABLE

We are pleased to make available to you this year a printed copy of the proceedings of the 1958 Spring Conference on "Counseling Parents of Children with Mental Handicaps," held at the University of Minnesota, Minneapolis, on May 2 and 3.

Since 1934, The Woods Schools has published clinical studies and scientific information on problems of the exceptional child. Although many of the two-score earlier studies are no longer available for distribution, they can be found in most major libraries and also in college and university libraries.

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The 1958 workshop, held in early June, was so successful that another is scheduled for 1959, sponsored jointly by the Special Education Department of Teachers College, Columbia University and The Woods Schools.

This year the conference and practicum have been designed particularly for residential school administrators as well as public school administrators who have responsibilities for programs in special education. Organization, personnel, medical care, finance, housing, pupil and staff welfare, building maintenance, pupil evaluation, curriculum development, and program supervision will be considered.

Participants will observe and work with Woods Schools staff members while the program is in operation. Observation opportunities include psychotherapy, speech and hearing evaluations, parent counseling, and staff conferences.

Dates of the Work Conference and registration information can be obtained after January 1st by writing to: Dr. Frances P. Connor, Department of Special Education, Teachers College, Columbia University, New York.

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