

# THE EVALUATION AND TREATMENT OF THE MENTALLY RETARDED CHILD IN CLINICS

Proceedings of a
training institute co-sponsored by
New York Medical College and the
National Association for Retarded
Children, Inc.

NATIONAL ASSOCIATION FOR RETARDED CHILDREN, INC.
99 University Place, New York, N. Y.

# The Evaluation and Treatment of The Mentally Retarded Child in Clinics

Papers given at a professional training institute, March 14-17, 1956

New York, New York

co-sponsored by New York Medical College and the National Association for Retarded Children, Inc.

\$1.25 per copy
10 or more copies: \$1.00 per copy

NATIONAL ASSOCIATION FOR RETARDED CHILDREN, INC.
99 University Place, New York City

# **Contents**

PA	GE
FOREWORD.	.1
I. FACTORS IN THE EVALUATION OF MENTAL RETARDATION	
ETIOLOGY AND PATHOLOGY OF MENTAL RETARDATION	
Herman Yannet, MD.	3
PSYCHOLOGICAL CHARACTERISTICS Seymour B. Sarason, PhD.	8
SOCIAL FACTORS—FAMILY AND COMMUNITY	
Howard R. Kelman, M.S.W. 1	1
EPIDEMIOLOGICAL ASPECTS Paul V. Lemkau, MD. 1	6
II. PROBLEMS IN THE DIFFERENTIAL DIAGNOSIS OF MENTAL RETARDATION	
PSYCHIATRIC ASPECTS Arthur M. Meisel, MD. 2	8
PEDIATRIC ASPECTS. Meyer Perlstein, MD. 3	5
PSYCHOLOGICAL ASPECTS. Herbert G. Birch, PhD. 4	0
LABORATORY DATA AND THEIR SIGNIFICANCE George Jervis, MD. 50	0
III. TEAMWORK IN THE TREATMENT OF MENTALLY RETARDED CHILDREN	
MEDICAL TREATMENT Joseph Wortis, MD. 5	3
PHYSICAL MEDICINE Jerome S. Tobis, MD. 60	0
PSYCHOLOGICAL TREATMENT Harold Michal-Smith, PhD. 6.	3
SPEECH THERAPY Doris T. Leberfeld, Ed.D. 66	5
EDUCATIONAL GUIDANCE	3
SOCIAL WORK SERVICES Winborn E. Davis, M.S.W. 7	1
THE ROLE OF THE PARENT /. Clifford MacDonald 75	5

# IV. FAMILY AND ENVIRONMENTAL FACTORS IN TREATMENT

PARENT COUNSELING Leo Kanner, M.D.	78
HOME TRAINING	84
INVOLVING COMMUNITY RESOURCES Alfred H. Katz, D.S.W.	90
V. CLINICS IN A TOTAL COMMUNITY PROGRAM FOR THE RETARDED	
Salvatore G. DiMichael, Ph.D.	97
DISCUSSANT	106
DISCUSSANT	109
VI. CASE PRESENTATIONS	
SUMMARY OF DISCUSSIONS	113
VII. ADMINISTRATIVE AND ORGANIZATIONAL PROBLEMS IN CLINICS	
SUMMARY OF DISCUSSIONS.	.114
CONFERENCE PROGRAM	.130

# *Foreword*

THESE PROCEEDINGS ARE ABSTRACTED from the Training Institute which was held from March 14-17, 1956, in New York City.

For more than two years prior to the Institute there were many requests received for information regarding clinic facilities for the mentally retarded. These inquiries, together with a perception of need for such facilities, prompted the National Association for Retarded Children to approach the New York Medical College about co-sponsoring the Institute. The suggestion was accepted without hesitation because the New York Medical College shared N.A.R.C.'s belief in the potential value of the proposal. We prepared our plan and submitted it to the National Institute of Mental Health of the U.S. Public Health Service which had long realized the need. They approved the plan, and made a grant to cover most of the expenses.

The Institute was intended as a training program for professional workers in the fields of medicine, psychology, social work and other professional disciplines—an occasion for team training—and thus, to foster, through clinic centers, increased and improved services for the mentally retarded.

The specific guiding purposes were: (1) to broaden and extend professional understanding of the best team methods in rendering clinical services to these children; (2) to bring together in one forum the best available knowledge and techniques on diagnostic and treatment centers for the mentally retarded; (3) to provide a training experience in this field for competent, skilled personnel in the pediatric, psychiatric, psychological and social work disciplines who could transmit the knowledge and skills derived from the Institute to members of their professions and those in training; and (4) to publish the proceedings with the intention of making a contribution to the field of clinic services for the retarded, since it would be the first comprehensive manual of its kind yet to appear.

It will be up to the serious reader and the student to decide for himself whether our purposes have been achieved. The responses from the "trainees" have been uniformly good and give us reason to believe the Institute and this publication probably have attained their goals.

A perusal of the agenda in the appendix, and a study of the successive papers in the body of the book will show the plan for the Institute. On the first day, the tours of clinical and training facilities were arranged to provide a brief concrete view of some specific settings in which the retarded are served. The second day was devoted to broad theoretical knowledge on comprehensive evaluation and differential diagnosis. The third day dealt with the contributions of various team workers in treatment, and also with the important considerations of family and environmental factors in treatment. The last day was devoted to specific cases, in the study of which the trainees actively participated, and the final afternoon was given to practical questions in planning, establishing, and administering clinics.

We describe the development of this Institute in the hope that it will serve

as a source of ideas to others. It is obvious to us that training institutes of a somewhat similar kind should be conducted in other regions and states.

The proceedings are complete, except for the "question and comment" periods following each didactic session; the study of the actual cases on the fourth day also are not included. These omissions seemed necessary because of the difficulty in reporting such sessions, the factor of cost involved in printing a lengthy transcript, and the informal teaching character of "question and answer" periods.

We are deeply grateful to each of the "faculty" members for his contribution and permission to print his paper. We also wish to acknowledge the excellent stewardship for the arrangements and conduct of the Institute of Mr. Howard Kelman who was at the time Consultant in Community Services for the National Association for Retarded Children.

SALVATORE G. DIMICHAEL, Ph.D.

Executive Director

National Association for Retarded Children

LAWRENCE SLOBODV, M.D.

Chairman, Department of Pediatrics

New York Medical College

New York, April 24, 1956

# Etiology and Pathology of Mental Retardation

HERMAN YANNET, M.D.

Medical Director, Southbury Training School

IT IS THE PURPOSE of this presentation to briefly summarize the more important pathological cerebral mechanisms and clinical syndromes that are basic to the problem of mental retardation. While confining ourselves at this time to what may be considered the "organic" determinants of intellectual inadequacy, we do not intend to minimize the importance of psychogenic or environmental factors in the over-all problem. These will be covered by the other contributions to follow.

Well over a hundred different etiologies, diseases and syndromes have been described in which mental retardation represents a more or less important symptom. Most of these, however, are extremely rare, some to the point of being considered medical curiosities. About 20% are encountered with sufficient frequency to have practical importance, and it is this group to which we intend to confine our attention at this time.

They can be classified, most effectively, into three large groups, depending on the period of life during which their causative mechanisms are established; namely, (1) the prenatal; (2) the natal and paranatal; and (3) the postnatal.

### I. PRENATAL MECHANISMS

a. Hereditary factors: the importance of genetics in the causation of mental retardation has been variously estimated to cover from 5 to 75% of the problem. This discrepancy may be because of the failure to differentiate the two distinct groups which are included. In the first group, to which the term familial or sub-cultural retardation is applied, the genetic determinants might properly be called "physiological," in that they represent a part of the genetic pool which determines the hereditary transmissions of normal intelligence. Intellectually inferior individuals in this category inherit from their parents those genes, undoubtedly multiple in nature, which determine their position in the lowest levels of the normal distribution curve of intelligence. These represent our intellectually marginal population whose social adequacy will be closely related to the nature and complexity of the society in which they live at the moment. Their problem is basically sociological, and their numerical magnitude will depend on the efforts of society to meet their special needs. There is no reliable data to indicate their extent in the general community at any one time. However, some concept of the importance of this group is indicated by our Southbury

statistics in which they represented approximately 40% of our total inmate population covering over 2,500 admissions.

The second group in our hereditary category represent an entirely different mechanism. The genetic factors involved in these patients are truly pathological in that they determine abnormal cerebral structural and metabolic manifestations. These conditions which are fortunately few in number, although diverse in nature, are due, as a rule, to single, mutant genes. They may be discussed most conveniently, from four aspects. First are a number of diseases which have been called "inborn errors of metabolism." The responsible genes determine either the absence of, or the interference with, a specific enzymatic activity. They are represented in each of the various metabolic processes involving proteins, carbohydrates and lipids. Of the more important conditions represented here are:

- (1) Phenyl-pyruvic disease, which involves a defect in protein metabolism, specifically, the absence of the enzyme system which determines the metabolism of phenylalanine.
- (2) Galactosemia, involving a defect in carbohydrate metabolism, and specifically affecting the metabolism of galactose.
- (3) Glycogenosis, also involving carbohydrates, specifically affecting the metabolism of glycogen or animal starch.
- (4) The Tay-Sach's group of cerebral lipoidoses in which the intracellular lipid metabolism of the brain cells is abnormal.
- (5) The white matter or myelin degenerations also called the cerebral scleroses, a lipoidal defect.
- (6) Gargoylism, a disease of a complex nature probably involving more than one metabolic system.

The importance of this group of metabolic disorders lies, not in their frequency as compared to other causative mechanisms since they are rare; or basically in the eugenic implications of their recognition, important as this is. It lies in the relatively recent advances in our understanding of the mechanisms by which the respective metabolic disorder injures the brain or interferes with its growth and function, and the development of methods to circumvent this injurious activity. It thus represents a new and hopeful approach to the medical management of genetic disorders, namely the prevention of the clinical expression of the genetic factor. So far two of these have yielded or seem to be yielding to this technique, namely, galactosemia and phenyl-pyruvic disease.

A second group of genetically determined conditions have in common the fact that in addition to the cerebral defect, the disorder also results in a maldevelopment of the skull by which the condition can be recognized, and properly categorized. These include primary microcephaly, craniostenosis or premature cranial suture closure, and hypertelorism. It should be stressed that not all children with these skull defects show cerebral abnormalities. Conversely, in practically all of these cranial anomalies there is no obligatory cause and effect relationship between the distorted cranial shape and the cerebral dysfunction, if present. Thus, surgical procedures designed to prevent or ameliorate

the cranial anomaly, as for instance in the craniostenoses, may have little or no effect on the underlying cerebral defect, and prognosis should be guarded.

A third group of genetically determined conditions have in common a cellular dysplasia that may include many organs of the body in addition to the brain. Three such conditions are recognizable, but with so many similarities and overlapping of clinical features and familial genetic expressions, that a unitary genetic mechanism is suggested. These clinical syndromes, commonly called, the congenital ectodermoses, include tuberous sclerosis, neurofibromatosis and cerebral angiomatosis. One of the most striking features of this group is the almost unbelievable variability of expression of the responsible gene or genes. A parent carrying the genetic factor involved may have as the only clinical expression, a small skin lesion, of no practical importance to his social status. Yet, his offspring may be completely devastated by the cerebral dysplasia and other organ defects. When we have learned which factors, genetic or otherwise, are responsible for such a variability in the clinical expression of an inherited condition, we may have another key to the possible by-passing of undesirable genetic traits in addition to that applicable to the metabolic disorders previously mentioned.

Finally in our genetic survey. We have a group of conditions, probably variable in nature, and more disturbing to us than those mentioned above, since they cannot be recognized as yet as being genetically determined except through the birth of a similarly involved sibling. In other words, unlike the abovementioned inherited conditions, there are no recognizable associated disorders, and the only presenting symptom is the intellectual defect which is non-specific. The dilemma which such a condition presents to the medical counsellor is at the present time insurmountable. Fortunately, these conditions making up this last group are relatively rare, and such a category was diagnosed in only  $^3/_4$  of 1% of our Southbury admissions.

The total incidence of inherited conditions due to pathological or mutant genes (not including Mongolism which may have a genetic component in its etiology) represented about 5% of our total admissions.

Other prenatal conditions aside from those genetically determined and mentioned above have an incidence of about 10% in our series. These include a number of relatively rare conditions like:

- (1) Prenatal infections of which we recognize at least three, namely, congenital toxoplasmosis, maternal rubella, and congenital syphilis. Cytomegalic inclusion disease, may represent a fourth, but its relationship to the mental retardation problem has yet to be established.
- (2) Prenatal maternal pelvic irradiation, a causative condition not uncommon in the early 1920's or before, is practically never seen at present, as knowledge of the dangers involved in irradiating pregnant females became widespread. Its present importance stems from the increasing use of atomic energy and therefore needs mentioning.
- (3) Kernicterus, a cause of mental retardation, is a disease of the neonatal period resulting from high levels of bilirubin in the infant's blood due to various mechanisms. While rightfully not belonging in the prenatal category, it is placed here, since the most common clinical condition responsible for its development is erythroblastosis fetalis due to maternal Rh immunization. An

appreciation of the importance of the hyperbilirubinemia as the etiological mechanism, and the development of techniques to combat it (exchange transfusions), have reduced the incidence of this condition almost to the vanishing point in certain clinics.

(4) Endocrine disorders are quite common among the mentally retarded. Basic cerebral injuries of one type or another may involve the nervous connections of the pituitary gland and various factors affecting the brain at certain periods of prenatal life may conceivably also adversely affect other endocrine glands. However, the only hormone for which a reasonably acceptable cause and effect relationship with mental retardation can be established at the present time is the thyroid. It is also becoming more apparent that the cerebral abnormality resulting from complete absence of this hormone may well be established at the time of birth or quite soon thereafter in many of the cases. This probably explains the relatively poor prognosis encountered even in cretins treated within the first month of life.

Finally among the recognizable conditions prenatally determined, we come to Mongolism, established as a syndrome almost 90 years ago, and whose complete etiological story remains to be told. While undoubtedly advanced maternal age is accepted by all, and implies an environmental causative mechanism, there is also strong evidence to implicate some type of genetic mechanism as well. As yet, the nature and mechanics of expression of this genetic factor has not been established. The incidence of Mongolism in our Southbury data is about 8%.

A total of about 90% of our admissions were classified as either genetic or otherwise prenatally determined. If we add up the conditions already discussed, we are left with a prenatally determined group of unknown etiology representing about 35% of the total. This is a substantial number, that bears strong witness to the limited nature of our knowledge of causation, and the great need for continued research in this area. Studies of pregnancies resulting in abnormal children, including the mentally retarded, have shown a significant incidence of such conditions as early maternal bleeding suggesting imperfect placental attachments and toxemias of pregnancies including eclampsia and prematurity. The nature and importance of the role these abnormal conditions play are still being evaluated.

# II. CEREBRAL INJURY DUE TO FACTORS ASSOCIATED WITH THE BIRTH PROCESS

In our Southbury survey, mental retardation due to cerebral birth injury, neonatal asphyxia, or other mechanisms associated with the process of birth was diagnosed in about 3% of the admissions. A high incidence of associated neurological abnormalities like cerebral palsy and convulsive disorders was found in this group.

# III. POSTNATAL CONDITIONS

Approximately 6% of our admissions could be related to postnatal conditions of various kinds. The most common included inflammations of the central nervous system like meningitis and encephalitis. The next most common cause was cerebral trauma as a result of various accidents in infancy. Occasional mention is made of accidental poisoning like lead, carbon monoxide and coal

tar derivatives. It was also somewhat disconcerting to find at least two cases resulting from vaccination against pertussis and one after smallpox vaccination.

To summarize the brief survey of etiologies we may say that the causes of mental retardation are many and greatly varied. Only 10% of our cases could be related to conditions occurring during birth or in the postnatal period. Of the 90% that are related to prenatal conditions, either in whole, or in part, at least one-half are genetically determined. Of the remaining one-half of the prenatal conditions our knowledge is, as yet, too incomplete to etiologically classify more than a very small percentage.

# Psychological Characteristics

SEYMOUR B. SARASON, PH.D.

Professor, Department of Psychology, Yale University

FOR SEVERAL REASONS, I am not going to attempt to describe in any detail psychological characteristics of the mentally retarded. First, as was clearly indicated in Dr. Yannet's paper, there are so many different etiological factors in mental retardation—so many different kinds of conditions—that it is difficult to make generalizations about psychological characteristics. Second, whatever generalizations could be made would not be very illuminating. Third, I have come to the conclusion that our knowledge of the psychology of the retarded individual is scanty and superficial, a reflection of the fact that we have very few intensive studies on a respectable number of cases to which appropriate clinical psychological and psychiatric procedures have been applied.

It may be helpful if I expand briefly on the last point. When we attempt to understand the behavior of an individual, we generally ask ourselves the following questions:

- 1. What is the relationship between the individual's overt behavior and internal thought processes, feelings, and attitudes?
- 2. What is the relationship between the correlations discerned in "1" and the individual's interpersonal experiences and environmental milieu?
- 3. How adequate or realistic is the individual's conception of reality? Does he perceive and interpret the external world on a basis similar to ours?

We ask more questions than the three above but they are sufficient to make the point that we do not study the retarded individual in a way so as to get at least partial answers to such questions. If one were to compare the routine clinical psychological or psychiatric studies of the retarded with those of non-retarded individuals coming to a psychiatric clinic, the point I am trying to make would be clear.

My conviction in this regard has been strengthened as a result of a project which I am conducting for the NARC. The project, which I am doing in collaboration with an anthropologist (Dr. Thomas Gladwin), concerns the status of the evidence about the role of psychological factors in the etiology of mental retardation. In going through a rather vast literature I have been struck by the relative absence of clinical psychological or psychiatric case studies, let alone systematic studies of series of cases. Let me illustrate by a special kind of individual, namely, the idiot savant. Over the years a fair number of such cases has been described, in some instances the articles describing these cases

<sup>1.</sup> The medical aspects of the problem are under the direction of Dr. Richard Masland of the Bowman-Gray School of Medicine, Winston-Salem, North Carolina.

have been rather lengthy. However, in no instance was there a serious attempt to understand the individual the way we would attempt to understand a paranoid or a handwashing compulsion or severe stuttering. The interest in these cases has exclusively been on *how* the individual does what he does and not on *why* he does it—the *psychological* significances of the activity. For example, why does the unusual level of performance in a particular activity so frequently involve memory and numbers? Why are the great majority of idiot savants males? What is the significance of the fact that in many of these cases there are reported hallucinations, delusions, and other psychotic features? Although idiot savants have been described many times over the years, these questions can only be raised by us today—we have nothing approximating an answer which would be other than gross speculation.

Let us cite another example. Several people have noted and described psychotic-like reactions in individuals of the idiot level—individuals who presumably never operated on a higher level of functioning. In these cases, institutional ones, the individual's behavior was not noteworthy until he began to manifest such characteristics as mutism, posturing, senseless laughter, and violent rage reactions. These characteristics might subside for a period of months only to reappear again. I think you will agree that this is strange and unexpected. I also think that you will agree that this phenomenon is worthy of study, involving as it does the question of the internal and external conditions which give rise to such psychotic-like behavior. What accounts for the periodicity of the behavior? Why should such an individual become mute when he hitherto has not been so? But these phenomena have not been studied and we have no answers. That we have no answers is not as disturbing as the lack of interest in the problem—despite the fact that on the surface, at least, a systematic study of the problem may shed important light on the problem of mental illness.

In the past twenty years many studies have appeared describing the autistic and the schizophrenic child. Previously, such kinds of cases went unnoted and were misdiagnosed. Even before there was anything resembling general interest in these cases, Dr. Howard Potter raised the question about the number of children in our institutions for the retarded who would not have been so diagnosed if adequate psychological, psychiatric, and developmental studies had been done. To the best of my knowledge, Dr. Potter's suggestion has never been carried through.

Dr. Yannet has already mentioned the familial or garden variety (or Kallikak type) of mental deficiency—the largest sub-group with which we have to deal. Discussions on the etiology of these cases have foundered on the relative importance of heredity and environment. I am of the personal opinion that heredity is a factor in determining adaptive capacity of an individual. Having said this, I would like to make clear that such a belief does not at all justify attributing present level of functioning to genetic factors. One could point to many conditions in which the genetic factor is known but where the range of effect of that factor is large. Because a child and his parents get low test scores does not permit us to conclude that the child's current level of functioning is a function of a genetic factor. Put in another way, we cannot conclude in such a case that the current level of functioning is the upper limit imposed by the genetic factor regardless of the psychological and cultural factors at work.

In the case of the familial defective we know that he comes from a familial and cultural background which is rather different from that of our middle class school culture. We also know that our psychological tests and psychiatric criteria contain a strong middle class bias. What we do not know is how such differences in background and experience become integrated into a personality configuration and how the conflict between one's own and another cultural pattern is experienced and resolved, if it is at all resolved. In terms of the questions we ask in our attempt to understand an individual's behavior (as indicated at the beginning of this paper), it would be presumptuous to say that we have a good idea of the psychological characteristics of the familial defective.

In connection with the familial defective I cannot refrain from mentioning the work of Thompson at McGill with inbred strains of mice. One group was allowed normal exploratory behavior, while the other group was not allowed normal exploratory behavior for a period after birth. In later tests of learning these two groups differed markedly on various criteria of learning, the group not allowed exploratory behavior being, as one would expect, the poorer group. I mention this study only in order to reiterate a caution against two kinds of assumptions: (a) that test scores are valid measure of a potential determined by genes; (b) that test scores are a valid measure of capacity as distinguished from the observed level of functioning.

If our understanding of the psychological characteristics of the retarded is as superficial as I think it is, it should not cause surprise. When one considers that the fields of psychology, psychiatry, child development and anthropology have paid little attention to the retarded—and what work has been done by workers in this field has been for the most part descriptive and tangential—it is no wonder that our knowledge is meager.

What seems to be overlooked is that the psychological problems in mental retardation are in need of investigation not only because we need a better understanding of such problems but because the answers to these problems may shed much illumination upon the nature of our society as well as the nature of problems which, in my opinion, have far too long been considered apart from those in mental retardation.

# Social Factors — Family and Community

HOWARD R. KELMAN. M.S.W.

Consultant, Community Services, National Association for Retarded Children

IN THE TOTAL EVALUATION of the mentally retarded child we are concerned not only with an assessment of the child's biological equipment, but also with an analysis of his functioning as a human being in a particular social setting. The clinician or clinic team is called upon to make judgments regarding the child's abilities and limitations in this sphere, and to evaluate the complex interaction of those forces, both historic and situational, that condition the present and future course of the child's behavior and functioning in the family unit and the larger community.

But for the most part, concern in this area has been focused around the deleterious or harmful social consequences that the mentally retarded child has upon the family and community. Looked at in this light, earlier programs of care and training were evolved to deal with these negative social effects in an effort to lessen their consequences and to control their spread to society's advantage. In the past, this form of social concern resulted in the isolation or exclusion of the retarded from those social institutions serving the more normal population, and in the containment of the most bothersome of the lot in distant institutions, cut off from the mainstream of community life.

It remained for more recent advances in the biological and social sciences to point out that social failure or incompetency are not *necessary* correlates of mental deficiency *per se*, but may instead, in many instances, be more the consequences of our proscribed social treatment and expectations of these individuals and their families.

We can no longer with scientific reverence speak of the retarded as being inherently delinquent or immoral, or capable of diluting the general intelligence level of our population through an ascribed abundancy of procreative abilities. Nor can we in truth regard them all, as helpless and hopelessly dependent creatures, incapable of positive social adaption, and unable to make useful, though perhaps modest, productive contributions to the community.

What is really required, then, is an understanding of the effects that family and community have had in conditioning the nature and extent of the child's mental handicap and the ways in which these social forces along with other influences have molded his existence as a human being.

In so doing we can expect that an analysis of these factors will contribute to our understanding of the child's behavior and functioning and will enable us to select more adequate and realistic treatment goals.

With reference to these two points, our attention has already been drawn

to the heterogeneity and rich variety of types of conditions encompassed by the term "mental retardation."

As we have seen, mental retardation is a symptom—an end-product, if you will—of a variety of processes with differing causes and sources. The end-product, we further observe, varies also both in kind and intensity, and is for the individual neither static nor fixed, but changes with time and with changed social opportunities, social expectations, and treatment.

As a chronic impairment in that organ which, so to speak, regulates the individual's relationship to his environment, the need to structure and adapt the environment is itself implied and, in a sense, required.

Except for those cases of severe mental defect accompanied by observable sensory defects or visible physical stigma, or those marked by prolonged or delayed maturation, the retarded child becomes known to us largely because of his failure to achieve according to some accepted social norm, (e.g., in the classroom learning situation) or for behavior that is not in conformity with accepted community standards for his peer group, or for failure to adequately handle his personal and vocational affairs as an adult.

But within these given ranges of expectations, as child or as adult, there exists much variation and lack of uniformity in definition with regard to what constitutes incompetency, social failure, or even normalcy. Variations exist depending upon the socio-economic complexity of the community or society; cultural orientation, expectations and traditions; racial, national background and social class factors; and the level of health, educational, vocational, and social opportunities available.

Though there is controversy over the question of the normal distribution of "intelligence" in our population, we know that social, economic, and educational opportunities are *not*, and that the abilities and performances of an individual are to a large extent determined by the access to and the use made of these opportunities by him.

Can we say, too, that our testing devices which often determine administratively, at least, if not operationally, the diagnosis of mental retardation, are free of cultural and social class bias? Is the adult retardate who successfully holds down a job no longer considered to be mentally retarded as against the individual with a comparable "I.Q." who cannot do this? Are we penalizing perhaps the aggressive child, or the child of parents of simpler intelligence by consigning more of these children to institutions than the placid, less difficult child whose behavior makes them more "acceptable," hence, in some way, more valuable?

In a more immediate sense, and on a less theoretical plane do social factors need to be given adequate consideration. It has become apparent in the programmatic areas—those specific to this field as well as to those designed for other disability groups—that failure to take into account the concrete and specific social setting in which the child functions can, and often does, result in a wastage of energy or unsuccessful attempts in designing or implementing more or less elaborate treatment or training programs. Or, on the other hand, it can result in stereotyped proscriptions for the child's care and management that cannot be applied in the reality perceived by the child's family or community.

A child is brought to a clinic by a parent, or referred by a physician or social agency, and does not come of his own volition seeking help. The parent is concerned not only about the child's physical well-being, but is concerned, too, about the personal and social implications of the child's difficulty.

It is often these social aspects and personal implications of the child's condition that motivate parents to seek competent professional judgment as a guide to action, as a solution to a problem they face daily, or as a source of comfort or solace to themselves. Surely their views of the child, their desires concerning his future welfare, their problems in fitting him into the family group, and their readiness and acceptance of the views of the professional, as well as the necessity for marshalling their aid and assistance, ought to determine in part the prognosis and treatment plan.

To be meaningful, clinic proscriptions have to be individualized, concrete in the sense of their applicability, and realistic in starting where all concerned parties find a common meeting ground and agreed-upon goals.

Professional persons as individuals, or as practitioners having membership in a distinct social group, have not been unaffected by the prevailing negative community attitudes toward the retarded and their families.

As important determiners, though, of accepted community attitudes regarding health and welfare problems, the professional person is perhaps under a greater obligation to re-examine his traditional views and patterns of responses when confronted with responsibilities in this area.

The difficult struggle that many parents experience in working through their understanding of their child's handicap, their daily problems in living with him, and their ability to contribute to his well-being, is greatly influenced by the nature of professional counsel which they have secured and the fashion in which the professional person has related himself to this struggle.

Indifference and brusqueness in handling the problem have added to the woes of many parents. As part of or reflective of broader community attitudes, they have compounded the parents' difficulties in living with and in making significant decisions regarding their child's well-being.

To recapitulate thus far: we cannot study, evaluate, or plan a treatment or training program for the care and management of retarded children that makes sense and bears a close relationship to his real life situation without an analysis of, and reference to, those pertinent family and community factors which govern his existence as a social being.

In order to do this, we need first to direct our attention to an analysis of the family constellation and the place of the retarded child in it, as well as his relationship to the larger community. In what follows it will not be possible to do more than indicate certain reference points which, in terms of the individual child, need to be subjected to careful scrutiny, and their relative effects weighed.

The retarded child must be viewed as an integral part of the family group and as having distinct relationships to its members. The child, the parents, and the siblings mutually influence one another's functioning and contribute their respective influence to the dynamics of the family unit's functioning as well.

The family group and its individual members had a history, patterns of relationships and, perhaps, difficulties of one sort or another prior to the birth of

the retarded child. The impact the retarded child had upon the members of the family and their inter-relationships is in turn reflected in their responses to the child. Coexistent with this, each family, on a consciously planned basis or perhaps more haphazardly, attempts to weigh and balance the needs of other family members, and is subject to all the varied daily stresses and strains which affect all of us in these times. In addition to creating new difficulties for the family, the consequences of a retarded child in a family group can sometimes exacerbate latent or uncompletely resolved interpersonal difficulties, or plunge the "marginally stable" family (or family member) down the road to partial or complete disorganization.

While it is true that the impact on families and parents is not inconsiderable and is for many a profound shock, this is not to say that its effects are felt uniformly, nor will all families respond to this situation in a similar fashion. The response to, and reaction of the family members is itself conditioned by several interacting factors:

- 1. First and foremost of these factors relate to the child's type of disability, its severity, and the social implications which may surround it.
- 2. The timing and circumstances under which the parents and family become aware or are made aware of their youngster's condition need also to be evaluated.
- 3. A third group of factors relate to the nature of the family constellation itself. Included in this area would be the socio-economic status of the family; its housing, health, and financial position; the size of the family, educational level, and material resources.
- 4. Closely related to this are such factors which might be subsumed under the category of the family's value system: its religious and social orientation and cultural traditions; in other words, its style of living.
- 5. Also, the personalities of the family members, the nature of their interpersonal relations—and their perceptions of the child are of major significance.

A whole host of questions stem from this source of consideration and need, together, to be subject to systematic and individual study to obtain the required picture of the immediate social environment in which the child functions, and to which a judgment of his performance as well as eventual prognosis need to be related.

6. Finally, the family's reactions are conditioned by larger community attitudes toward their child and toward them as bearers of a retarded child.

These latter forces, not directly visable as such, exert their influences nevertheless largely through the family unit and secondarily in terms of the socially sanctioned ways the child is *valued* by other relatives, neighbors, and social institutions such as schools, courts, and health and social agencies. Intermingled with this are the attitudes and notions of professional persons with whom the family and child have had contact in their search for aid, counsel, and direction.

Although major attention has been focused on the family, and for obvious reasons, what is really required is a thorough analysis of the *whole* of the child's social experiences. In addition to the factors enumerated above, we need to know and to estimate the effects upon the child of his school experiences (or lack of them), his play experiences and friends, and the nature of his larger social contacts. What are the particular demands that living in his particular community makes of him? Is it rural or urban; is the child isolated and abused or does he meet with some amount of social acceptance? And, of course, what provisions by way of training and treatment are provided for him? The answers to these questions help to round out our picture further.

It is still all too true, despite some hopeful beginnings, that the retarded individual is pretty much of a social isolate, treated as an outcast or as a deviant, and is victimized by our current exhaltation of the "body-beautiful" and the quick mind. Having no stable and useful status in our larger society, he is one and the same time cast in the role of the fool, the delinquent, and the madman. He lives on the whole a life marked by frustration and social constriction, and with constant and all too obvious reminders of his failures as a human being.

The retarded person is not as we know without feelings and sensitivities, and an awareness of how society values him. He reacts to these perceptions of the world in kind and mirrors quite accurately the role into which he has been cast. He is then further penalized and castigated by the very same value system and social institutions which have made him what he is.

These factors find their inevitable reflection in the kinds of behavioral problems and social difficulties so often observed, and which, by their very force, need to be evaluated to obtain a more complete understanding of the mentally retarded child as a human being.

Thus, we might say, that successful work with the individual child is often predicated upon the ability of the clinic with the resources at its disposal to effectively deal with these social factors, in concert with other agencies and groups in the community whose interests coincide with the clinic's professional concerns.

In so doing, a clinic will not only be offering practical and immediate assistance to the child and family, but of perhaps even greater importance, it will be helping to restore to the child the dignity and self-respect of which he has been robbed, and thus, his status as a human being.

# I. FACTORS IN THE EVALUATION OF MENTAL RETARDATION

# Epidemiological Aspects

PAUL V. LEMKAU, M.D.

Director, Community Mental Health Services, New York City

Community Mental Health Board

I.

THE INVESTIGATION OF MENTAL DEFICIENCY by epidemiological methods of relatively recent origin. The first study of any scope at all, and still one of largest and most significant was no earlier than 1924, the famous English investigation that offered the first important results on the distribution of mental deficiency in a large population. Earlier studies had been, for the most part very markedly contaminated by hypotheses which rather tended to so bias results of studies that their scientific value from the viewpoint of epidemiology was almost nil.

Thus, the work of Binet, while it was tremendously important in founding the whole field of psychological and educational testing, was so contaminated with the earlier therapeutic enthusiasm of Seguin and Itard that its epidemiological importance is small. Nevertheless, it must be recognized that without the test procedures available, the later epidemiological studies would have been impossible. However aware one is of the falacies of most testing procedures a: particularly of cultural contamination tests that interfere with studies across cultural and linguistic lines, and of the failure of tests to result in a total diagnosis, their fundamental importance in the epidemiology of mental deficiency must be acknowledged.

The earlier studies were usually oriented toward some central etiological concept. Lombroso's theory was constitutional basis; Goddard's in the study of the Kallikaks, on the hereditary character of mental deficiency and the ass. ciation between this characteristic and social incompetence and maladjustment In spite of the gross deficiencies of this study and the others of about the same period, the Nam Family, the Jukes and the rest, these had many of the attributes of sound method, particularly perhaps, the insistence on finding the very maximum number of the cases at whatever cost that infinite care an trouble could uncover.

This type of investigation was eclipsed by the rise of psychodynamic theory For many years the field of mental deficiency failed to arouse much scientific interest psychodynamically probably because of two factors. The first was that it was thought that the mentally deficient patient could not profit by psychotherapy because he lacked the capacity to make the necessary associations, an was therefore unsuitable for the popular kind of treatment. With this there grew up what has always seemed to me to be the rather supercilious attitude in the profession that its time was too valuable to be wasted on this group in which psychodynamically oriented therapy would fail. The concept of hereditary susceptibility as the basic cause of mental illness was attacked on almost

every other psychiatric point but this one; in mental deficiency there was little

The second factor in the psychiatric eclipse of mental deficiency was the development of psychological testing. This fitted the rejection just described because the growing profession of clinical psychology was there to accept the cast-off cases, to salve the consciences of the important dynamic therapist for his neglect of the large group of cases. In this connection I often feel toward the faithful institutional psychiatrists who carried the burden of care and the only scientific interest there was in mental deficiency in this period, like Steve Maryk's lawyer felt about the regular Navy officers who revenged his mother while he lived a comfortable civilian life, as depicted so graphically by Wouk in "The Caine Mutiny."

But the eclipse did not last. There were constantly appearing cases that would not abide by the rule that "once a mental deficient, always a mental deficient." This led to the idea that there were cases in which functional changes interfered with the revelation of capacities. These cases were called by various names, notably "pseudo-feeblemindedness." In some cases, dynamically oriented treatment procedures "cured" such cases, resulting in a distinct rise of test mental age.

A particular factor, teased out by Bender, Goldfarb, Spitz, Bowlby<sup>1</sup> and others, contributed greatly to the return of interest in mental deficiency as a functional state rather than a fixed condition. The net result of this work is a generalization now widely accepted, that unless the young child receives adequate stimulation at appropriate times, certain capacities will not develop and if the stimulation is too long delayed, the capacity may atrophy and disappear, not again to be reclaimed. This concept has received a great deal of support in animal experiments by Scott,<sup>2</sup> Hebb,<sup>3</sup> Thompson and Melzah,<sup>4</sup> and others.

This psychological generalization, which has application in a great variety of dynamic problems, may well be one of the great discoveries of our generation.

II.

Another important group of discoveries has to do with another basic etiological fact, that more mental deficiency is caused by events taking place after conception than had been thought to be the case earlier.<sup>5</sup> Even Kallman,<sup>6</sup> whose prime interest has for many years been the heredity of mental disorders, confesses that perhaps 25% of all cases are of non-heredity origin, and others place the percentage much higher, some as high as 60%. Gregg's<sup>7</sup> discovery of mental deficiency in the children of mothers who suffered from German measles during the pregnancy which resulted in the child, began a series of studies which have implicated infectious mononucleosis similarly and have brought measles, poliomyelitis and other viral infections under suspicion, though these have not been convicted as yet.<sup>8</sup>

Other work to be discussed in detail later, implicates other etiological factors, notably obstetrical complications of several types, nutritional factors, histoplasmosis, the meningitides, and some of the encephalitides. While it must be admitted that the total of cases caused in these ways is not yet demonstrably large, the leads have certainly contributed a tremendous resurgence of scientific

See references on page 27.

lower class children, perhaps because of less controlling supervision, tend show more rapid development.<sup>18, 19</sup>

(C) The social class structure of a society presents many epidemiology problems that are still far from solved. One of these that is now attracti:.. great deal of attention is the "nesting" of diseases of widely divergent  $\nu_2$  in a small group of families of a community. This has been illustrated r. clearly, perhaps by the St. Paul study<sup>20</sup> which showed that social and hcproblems, including mental deficiency, were concentrated in that 6% of I population which absorbed 50% of the social, health and recreational sen:.. available in the community. Similar "nesting" of diseases, including me:. diseases, has been reported by Downes<sup>21</sup> on the basis of sickness surveys. .: by Plummer and Hinkle<sup>22</sup> in surveys of industrial health problems ami a telephone operators, though in the last study mental deficiency does not appc to have been a factor.

Although it remains clear that mental deficiency is distributed more hea\ in the lower socio-economic groups than in the higher, it is also clear that ti defectives are not evenly distributed within the lower socio-economic gro-: but are concentrated, along with other diseases and social defects in particu!\_ groups of persons. More defined studies of local distribution are greatly neec:. and offer a challenge to epidemiologists.

# (D) Distribution by Age

In no study of the prevalence of mental defect has the condition been found evenly distributed over the population by age groups. In the Baltimore sun of 1936, the highest rates were found in the age group 10-14 (43.6/1000), iv. highest at 15-19 (30.2/1000), with sharp drop in prevalence on either side a these figures. Of particular interest are the low rates in persons over 20, whick never exceed 8.3/1000 and are very low in the older age groups. The same general phenomenon was found in the Onondaga County study, in which • highest rates were found in the tested cases in the age group 10-14 (52.9 of the tested sample), (highest rate age 10, - 79.8/1000). In the Woods repoc in England and Wales of  $1929^{23}$  the age specific rate was also found to be highest at 10-14 (26.5/1000).

Such remarkable differentials in age distribution are not accounted for r selective mortality since this is known to be an important factor only in tr-most severe grades of deficiency. Nor is there good evidence that mental defe. improves markedly with age, even though, as already discussed, there is ( dence that the consistency of I.Q. is not as great as was once believed. Tht only defensible explanation for the decrease in prevalence is that definiti<: are changed for the older age groups. Mental defect is diagnosed in peo; over 20 only if they present problems of social maladjustment while in younger persons the yardstick includes school failure as well. One is driven to the conclusion that the educational system has not achieved its aim of "education i life," but is still satisfying its critics who hold for the conservative aim of education for academic life; if this were not so, rates of mental deficiency for childrewould more closely approach those for adults where successful adjustme: prevents the appearance of many cases to be counted. There are many follow-u studies of institutionalized and non-institutionalized children which attest:

the fact that a considerable proportion of those diagnosed as defective in the school years are found to have adjusted quite satisfactorily as adults. <sup>24, 25, 26</sup>

These facts need to be faced clearly in designing our educational system. Certainly they indicate that we are testing against an ideal code for children and against a more realistic one for adults. The facts would appear to indicate that the testing procedures used, including school progress as a test, should be interpreted as dictating an education system which will take more fully into consideration the needs of the adult society at all extremes of capacity, avoiding the prevalent notion that the same educational pattern for all is identical with the concept of equal opportunity for all. Opportunity for all to become productive adults does not mean that all must go through the same process to reach their maximal level of productivity.

# (E) Distribution by Sex

All studies uniformly show mental defect to be more common in males than females. This was once thought to be due to the inconsistently greater birth weight of males which predisposed them to brain damage, but Lilienfeld and Pasamanick have shown that there is no correlation between birth weight and the occurrence of mental deficiency. Furthermore, the Onondaga County study indicates that for more severe grades of deficiency, under 50 I.Q. the sex ratio is 1:1, rising to 2:1 or 3:1 only in the higher grades. These findings are further born out by the fact that the male-female ratios in institutionalized mental deficients are approximately 1:1; these are generally of the more severely retarded group.

It appears that male over-representation among mental deficients must rest on bases other than brain damage. It is suggested that the finding is due primarily to two characteristics of the male that are well recognized; first, his retardation in comparison with the female as regards communication skills <sup>17,28</sup> and second, his greater aggressiveness that tends to lead to lower grades in deportment, reflecting his greater capacity to "make trouble" and thus have his defect discovered in the course of a fundamentally unrelated investigation. These two factors are not themselves uncorrelated, as any remedial reading teacher can testify. If these speculations are justified, it would appear that intelligence tests ought to be standardized for the sexes separately, at least for those years when communication skills are in the process of development. It is a curious clinical fact that in grade and junior high schools it is rare to find a boy leading his class while it is rare not to have males leading or competing closely in high schools and colleges.

(F) In most studies up until the latest, the Onondaga and Delaware studies, mental deficiency has proved to be more common in rural areas than in cities. It is speculated that the equalization of educational opportunity between city and country and the mechanization of farms which has brought the rural and urban cultures closer together, have been influential in causing the differential to disappear at least in such highly developed areas as Wilmington<sup>29</sup> and Onondaga Counties.<sup>15</sup> It may also be that the older studies<sup>23</sup> were done at a time when cities were, as was alleged, attracting the more intelligent from the farms, whereas this does not now occur so frequently in the areas studied. In any case, it appears that an earlier rather secure generalization on the epidemiology of mental deficiency can no longer be so completely defended.

the fact that a considerable proportion of those diagnosed as defective in the school years are found to have adjusted quite satisfactorily as adults. <sup>24, 25, 26</sup>

These facts need to be faced clearly in designing our educational system. Certainly they indicate that we are testing against an ideal code for children and against a more realistic one for adults. The facts would appear to indicate that the testing procedures used, including school progress as a test, should be interpreted as dictating an education system which will take more fully into consideration the needs of the adult society at all extremes of capacity, avoiding the prevalent notion that the same educational pattern for all is identical with the concept of equal opportunity for all. Opportunity for all to become productive adults does not mean that all must go through the same process to reach their maximal level of productivity.

# (E) Distribution by Sex

All studies uniformly show mental defect to be more common in males than females. This was once thought to be due to the inconsistently greater birth weight of males which predisposed them to brain damage, but Lilienfeld and Pasamanick have shown that there is no correlation between birth weight and the occurrence of mental deficiency. Furthermore, the Onondaga County study indicates that for more severe grades of deficiency, under 50 I.Q. the sex ratio is 1:1, rising to 2:1 or 3:1 only in the higher grades. These findings are further born out by the fact that the male-female ratios in institutionalized mental deficients are approximately 1:1; these are generally of the more severely retarded group.

It appears that male over-representation among mental deficients must rest on bases other than brain damage. It is suggested that the finding is due primarily to two characteristics of the male that are well recognized; first, his retardation in comparison with the female as regards communication skills 17,28 and second, his greater aggressiveness that tends to lead to lower grades in deportment, reflecting his greater capacity to "make trouble" and thus have his defect discovered in the course of a fundamentally unrelated investigation. These two factors are not themselves uncorrelated, as any remedial reading teacher can testify. If these speculations are justified, it would appear that intelligence tests ought to be standardized for the sexes separately, at least for those years when communication skills are in the process of development. It is a curious clinical fact that in grade and junior high schools it is rare to find a boy leading his class while it is rare not to have males leading or competing closely in high schools and colleges.

(F) In most studies up until the latest, the Onondaga and Delaware studies, mental deficiency has proved to be more common in rural areas than in cities. It is speculated that the equalization of educational opportunity between city and country and the mechanization of farms which has brought the rural and urban cultures closer together, have been influential in causing the differential to disappear at least in such highly developed areas as Wilmington<sup>29</sup> and Onondaga Counties.<sup>15</sup> It may also be that the older studies<sup>23</sup> were done at a time when cities were, as was alleged, attracting the more intelligent from the farms, whereas this does not now occur so frequently in the areas studied. In any case, it appears that an earlier rather secure generalization on the epidemiology of mental deficiency can no longer be so completely defended.

This issue can be discussed in terms of the "culture-brand" of intelligence :. more likely to be developed by people with urban, university-dominated b;:t grounds than those with more strict nature-study and performance  $\pm i$  standards.

# (G) Institutionalized and Non-Institutionalized Mental Defectives

It is estimated that no more than 5% of all mentally deficient children 3\*t institutionalized. The very clinician is aware that many factors in addition mental defect are responsible for institutionalization, among them grade i deficiency, complicating orthopedic difficulties, associated nervous syste\* anomalies, epilepsy, and the like, in addition to numerous social factors i: issues having to do with delinquent or other misbehavior. We have alreadi seen that, so far as it is known, the institutional population approaches a 1:1  $\leftarrow$  ratio, unlike the pattern in the general population. I have sometimes said: no child is ever institutionalized because of mental defect alone, it is only no cause of mental deficiency plus—. In institutional populations generally, prr-: cal complications and brain damage are much more common than in the no institutionalized defective, though it must be admitted that some of the ding ence undoubtedly lies in more complete diagnosis in the institutional C.N-Mental defect is diagnosed more frequently in younger children when ace. – panied by brain damage or other handicap than when it is uncomplicated.

In summary, it may be said that institutional populations of mental I fectives are made up of severely defective cases, cases in which there are  $a \sim$  plications of nervous system, orthopedic or sensory defect, and particularly the older and less severely defective groups, of cases with severe social displ...ments or behavior disorders.

# (H) Distribution by Other Parameters

It is clear that the demography of mental deficiency is far from complete « worked out, that the available parameters are usually badly contaminated with another. There is a tremendous amount of social-psychological resear:: needed to separate such broad factors as "socio-economic" into reasonably cle,, subfactors, such as: minority group membership, local custom groups, occurtional groups, family make-up groups, etc. There is tremendous need to sharr-such groupings if we are to extract the fullest epidemiological returns from s.. studies.

The cultural contamination of intelligence tests must constantly be brouj before the investigator also. In the Onondaga County study, almost  $60^{\circ}$ . o the children reported as mentally defective had I.Q.'s higher than 75, 2 astounding evidence that the public, even the educated public which made u: the referral group in Onondaga County, refuses to be bound by a test definit: e of deficiency. To satisfy this group the tests would need to be even more gre.r culturally contaminated than they are known to be. On the other hand, :re application of identical tests to the up-state farm boy whose father and mot'... went through the eighth grade and to the child of a sophisticated New Y\* -i professional person, or to a child whose parents speak only Spanish and to < .v whose forebears have spoken cultivated English for generations, is obvious quite unreasonable if the subtests make use of language patterns at all. It m: as has been suggested above, be a matter of the cultural evaluation of x:

differences that leads the same tests to be applied to boys and girls, disregarding known facts of differential development.

Before one can be confident of the demography of mental deficiency and before one can draw sound hypotheses for testing against these findings, much work must be done to refine the parameters of measurement of the social groups tested. Furthermore, more work must be done on the test instrument used to insure that it actually tests what one wants to measure and less of where he comes from and what forces have played upon him during his development. It may well be that our tests now measure too little of real capacity and too much of developmental opportunity.

(I) Observed Compared with Theoretical Numbers of Mental Deficients. Most of the studies of the frequency of occurrence of mental deficiency in total populations are quite unsatisfactory, including those for which I have been partly responsible. The reasons have been already detailed in the previous sections, but can be grouped into two classes, difficulties with samples and diffi-

culties with definition of criteria.

One of the basic assumptions in biology is that traits of all sorts arrange in frequency according to a normal distribution curve, the so-called "bell-shaped" curve which is shown in Chart 1. There is no reason to believe that socioeconomic and other culturally as well as individually determined factors are so distributed, though there is a tendency to make the assumption, frequently without recognizing that it is being made, that man's works—as well as his traits—are normally distributed. While frankly recognizing the difficulties such factors impose, it has seemed worthwhile to approach the problem as though

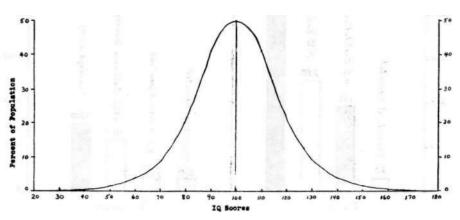
Were this the case, 50% of the population would have I.Q.'s of 100 or above and 50% would fall into the group of 100 or below. By the normal curve, 3.04% of the population would have I.Q.'s of 70 or less and an equal number

mental defect were a purely biological variant, with the multiple social factors

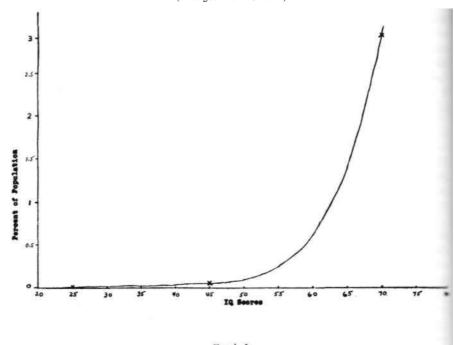
influencing the state of only very minor significance.

Chart I

THE NORMAL CURVE OF INTELLIGENCE QUOTIENTS

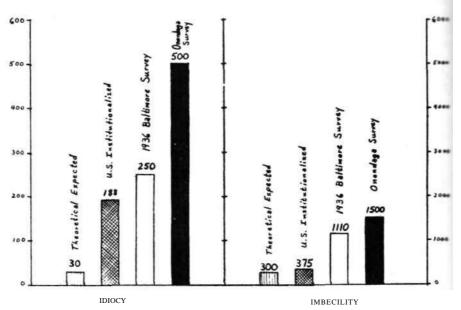


 $\label{lower_continuous} Chart\ II$  Lower portion of the normal curve of intelligence quotients  $(Enlarged\ from\ Chart\ I)$ 



Graph I

Comparison of the Theoretical and Observed Incidence of Idiocy and Imbecility per 1 Million Population



I.Q.'s of 130 or above. The theoretical number of persons having I.Q.'s less than 45 or greater than 155 would be 0.03%, while I.Q.'s of 25 or less or 175 or more would occur 0.003% of the time or three persons in 100,000. These figures are represented on Chart 2.

On the basis of 1,000,000 perfectly distributed population one could expect approximately 30,100 morons, that is, people with I.Q.'s from 70 to 45, nearly 300 imbeciles and about 30 idiots, persons with I.Q.'s below 25. For the U.S., figuring the population 160 millions, this would, roughly, amount to 4,816,000 morons, 48,000 imbeciles and 4,800 idiots.

There are presently about 150,000 mentally defective persons institutionalized for this condition in the U.S. Of these (according to the best estimates available) approximately 20% are idiots, 40%, imbeciles and the rest, 40%, morons. This would mean, 30,000 idiots, 60,000 imbeciles and 60,000 morons. It is clear that the idiots particularly, but also the imbeciles, are much more common in the population than the theoretical normal distribution would indicate. This is shown in Graph 1 which represents the lower end of the distribution curve with these minimal figures for frequency of imbeciles and idiots.

The Baltimore 1936 survey, based on approximately 100,000 population of a somewhat underprivileged area, discovered 25 idiots and 111 imbeciles. These observed figures, which are certainly more dependable than the raw national figures and estimates just presented, are also on the bar graph. In the more recent and more thorough survey in Onondaga County, the rates were recorded as .5/1000 for idiots and 1.5/1000 for imbeciles as indicated in the bar graph.

These comparisons make it very clear that even with the least adequate survey method we have, the U.S. compilations on institutions, idiots are far more common than the expected number on the theoretic curve. This is the case with imbeciles as well, although to a lesser degree. It is probably fair to say that this difference lies in the rate of finding cases. Idiots, because of the severity of symptoms are relatively frequently found; imbeciles are more likely to "float" in the population and remain undiscovered.

This upward skew of the lowest part of the curve of distribution of I.Q. in the population has been recognized for a long time as having important significance regarding the inheritance of mental deficiency of severe grade. Oster, 31 in a review of scientific problems in the field in 1955, stated it as follows: "Investigations into the intelligence distribution within a population show, in fact, a skew distribution curve, with preponderance of low degrees of intelligence presumably due to 'pathological aments.' "It is an interesting clinical observation that idiots tend to occur in all socio-economic and cultural groups, not sparing the upper groups as much as do imbeciles and morons, a distribution which could not hold true if the severer states were due to heredity. So far as I know, there are no clear data to support this observation now available.

In summary, it may be said that the most severe cases of mental deficiency occur more frequently than would be expected from the theoretic distribution curve of I.Q. within population. Whatever else this means, it certainly casts grave doubts on the hereditary character of these severe disorders. The findings, furthermore, are indicative of severe under-reporting in all present surveys. It is not unlikely that there is definite over-representation of imbeciles as well, and it is not impossible that there are a considerable number of morons beyond

those to be expected on the basis of the theoretic curve, if we but had the to prove it.

(J) Epidemiological Studies on Etiology Other Than Heredity.

Theoretically, the ordinary action of heredity should produce a nor distribution curve. The skew therefore must be determined on other! hereditary grounds. This line of thinking has opened up new vistas in epider logical research in the last few years, particularly on the association of mendeficiency with obstetrical complications <sup>2/</sup> and prematurity. <sup>32</sup> These research have led me to the firm belief that a considerable proportion of all mccgoing into future research on mental deficiency ought to be devoted to rese^-. in obstetrics, from the nutrition of the pregnant woman to the secrets of 3 biochemistry of hypertension of pregnancy, eclampsia, and other obste:: -complications. There is much to be done about the prevention of mental ciency by obstetricians, just as there was much done in the prevention of p by the syphilologists.

There are other areas that aire only beginning to be envisioned. \ biochemical mysteries of phenylpyruvic oligophrenia are beginning to yield study. When they are solved, this small group of disorders may well c within curative if not preventive possibility. If Benda is correct that Mongo is an endocrinologic disorder, 33 this larger group of mental defectives mas relieved or prevented by replacement of the lacking hormone to the mother the child. It does not seem too fantastic to dream of an increase in intelli commensurate with the increase in length of life this group is showing.

The factor of understimulation has already been discussed earlier. It,  $\bullet$  offers on quite a different basis opportunities for research to find ways x means of avoiding the dangers of loss of capacity through neglect.

# CONCLUSION

In this review, epidemiological aspects of mental deficiency have been sented. The historical background of the field has been reviewed, recording early period of hopefulness about educational methods. This period, ending considerable discouragement, was followed by a healthy growth of diagn •• tools and broader concepts of classifications. More or less excluded from earlier concerns of psychodynamic psychiatry, the field has now begun to a" attention through the epidemiological studies on the effects of isolation. study of the distribution of mental deficiency in populations has shown opportunity as well as capacity determines test intelligence and that her may not be the strait jacket, confining preventive efforts, it was once thou to be. A study of the distribution curve indicates that there must be specs causes for many cases of mental deficiency of severest grade, and studies ind: that these may be found in obstetric complications, metabolic and endoc logical dysfunctions.

Mental deficiency is now a very lively and productive field for re: and treatment; it seems fair to say that the epidemiological studies have a most significant contribution to this happy state of affairs, furnishing the w for the areas of research most likely to result in successful prevention of sc cases.

### REFERENCES

- 1. Data on summarized in, Bovvlby, J.: Maternal Care and Mental Health, World Health Organization, Geneva, 1951.
- Scott, J. P., Fredcrickson, E., and Fuller, J. L.: "Experimental Exploration of the Critical Period Hypothesis," *Personality*, 1: 162-183 (1951).
- 3. Hebb, D. O.: The Significance of Neurophysiology Theory for Psychiatry, paper read at the annual meeting of the Am. Psychiatric Assoc., May 6, 1954, at St. Louis, to be published.
- 4. Thompson, W. R., and Melzah, R.: "Early Environment," Scientific American 194, #1, 38-42, January 1956.
- 5. Lemkau, P. V.: Mental Hygiene in Public Health, McGraw-Hill, 1955, 2nd Edition.
- 6. Kallman, F. D.: Heredity in Health and Medical Disorder, W. W. Norton, N.Y., 1953.
- Gregg, N. McA.: "Congenital Cataract Following German Measles in the Mother," Tr. Ophth. Soc. Australia, 3: 35-46 (1941).
- 8. Amer. Psychiatric Assoc, Report of Public Health Committee to be published.
- 9. Ingalls, T. H.: "Mongolism," Scient. Am. 186: 60-66 (1952).
- Lemkau, P. V.: "The Epidemological Study of Mental Illness and Mental Health," Am. J. of Psych., Vol. III, No. 11, May 1955.
- 11. Kallman, F. D.: Heredity in Health and Mental Disorder, W. W. Norton, N.Y., 1953.
- 12. Burt, Cyril: "Intelligence and Fertility: The Effect on the Differential Birthrate on Inborn Mental Characteristics," *Occasional Papers on Eugenics*, No. 2., The Eugenics Society and Hamish Hamilton Mcchcal Books, London, 1946.
- Knobloch, H., and Pasamanick, B.: "Further Observations on the Behavioral Development of Negro Children," /. of Gen. Psychol, 83: 137-57, 1953.
- 14. Lorimer, F., and Osborn, F.: Dynamics of Population, Macmillan, N.Y., 1934.
- 15. Grucnberg, E. M. et al: Onondaga County, N.Y., Mental Retardation Prevalence Survey (Unpublished).
- 16. Goodman, M. B.: A Prevalence Study in a Metropolitan Area (Unpublished).
- 17. McCarthy, Dorothy A.: The Language Development of the Preschool Child, University of Minnesota Press, Minneapolis, 1930.
- Davis, A., and Havighurst, R. J.: "Social Class and Color Differences in Child Rearing," Am. Sociol. Rev., 11: 698-710 (1946).
- Williams, J., and Scott, R.: "Growth and Development of Negro Infants. IV Motor Development and its Relationship to Child Rearing Practices in Two Groups of Negro Infants," Child Development, 24: 103-21, 1953.
- Buell, Bradley and Associates: Community Planning for Human Services, Columbia Univ. Press, N.Y., 1952.
- 21. Downes, Jean and Simons, Katherine: "Characteristics of Psychoneurotic Patients and Their Families as Revealed in a General Morbidity Study," *Milbank, Quarterly*, January 1954.
- Hinkle, L. E., and Plummer, N.: "Life Stress and Industrial Absenteeism," Indus. Med. and Surg., 21: 8, August 1952.
- 23. Report of the Mental Deficiency Committee, being a Joint Committee of the Board of Education and Board of Control, Parts I, II, III, IV, London, England. H.M. Stationary Office, 1929.
- Campbell, C. M.: "The Subnormal Child—A Study of the Children in a Baltimore School District," Ment. Hyg. 1: 97-147, 1917.
- 25. Fairbank, R.: "The Subnormal Child-Seventeen Years After," Ment. Hyg., 17: 177-208 (1933).
- 26. Words, J.: "Mental Retardation as a Public Health Problem," Am. J. P. H., 45: 632-636, 1955.
- 27. Lilienfeld, A. M., and Pasamanick, B.: "The Association of Maternal and Fetal Factors with the Development of Epilepsy," *J.A.M.A.*, 155: 719-724 (1954).
- 28. Gesell, Arnold: First Five Years of Life, Harper & Bros., N.Y., 1940.
- University of Delaware, Dept. of Psychology: "The Incidence and Nature of Mental Retardation," Progress Reports, December 1952-August 1955 (Unpublished).
- Sloan, Win.: "Some Statistics on Institutional Provisions for the Mentally Handicapped," Am. J. Ment. Def., 59: 380-382, 1955.
- 31. Oster, J.: "Scientific Problems, Progress and Prospects," Am. /. Ment. Def., 59: 3, 425-33.
- 32. Knoblock, H., Rider, R. V., Harper, P. A., and Pasamanick, B.: Neuropsychiatric Sequelae of Prematurity—a Longitudinal Study. Paper given at A.P.H.A. 1955 Annual Meeting.
- 33. Benda, C. E.: Mongolism and Cretinism, Brune & Stratton, N.Y., 1949. 2nd Ed.

# Psychiatric Aspects

ARTHUR M. MEISEL, M.D.

Psychiatrist, The Jewish Hospital of Brooklyn

MENTAL DEFICIENCY SHOULD BE CLEARLY DEFINED in order for it to be cussed intelligently. It must be especially clearly defined if an effort is I made to distinguish it from other disorders to which it bears a resembL

Mental deficiency is that condition which exists when some disord; suiting from anatomical or gross derangement of the central nervous eler lowers the efficiency of the individual significantly below the statistical during childhood.

The conditions from which mental deficiency must be differentiated

- 1. Primary disorders of function
  - A. Autism
  - B. Schizophrenia (childhood)
  - C. Schizophrenia (adolescent)
- 2. Pseudo Retardation
  - A. Neurotic
  - B. Miasmic
- 3. Primary sensory or integrative deficit without general retardation
  - A. Blindness
  - B. Deafness
  - C. Limited Aphasic or Agnosic Disturbances
- 4. Motor Disorders Without Mental Deficiency
  - A. Movement—dyskinesias
  - B. Speech—dysarthrias
- 5. Heller's Syndrome

The diseases which comprise the rather broader groups known as "mr deficiency" are heterogenous. Among this group are:

1.	Familial	6%
2.	Mongolism	19%
3.	Resulting from birth trauma	15%
4.	Due to unknown causes or undiagnosed	18%
5.	Due to developmental cerebral anomaly	10%

68%

When we add to this group

- 6. Other organic diseases
  - a. Epilepsy.....6%

14%

We have a representative total of 82% which accounts for most of the cases examined at a California hospital in a series recently reported by George Tarjan and L. Forbes. Other important causes include endocrine; e.g., thyroid, and metabolic; e.g., phenylpyruvic oligophrenia.

This group contrasts with a group reported by Tredgold<sup>2</sup> closer to the beginning of this century when he considered 72% of his series to be simple-familial as contrasted to the 6% listed in the more modern group.

This comparison illustrates the fact that the present trend is toward more detailed and definite diagnostic work in order that the exact deficit be arrived at and a more logical remedial program organized.

In general, diagnosis is useful in proportion to the help it gives in preventing and treating diseases, and it is because the essential treatments may vary that a correct diagnosis is important.

None of the diseases mentioned with the exception of the specific syndromes such as "Mongolism," tuberous sclerosis, or Tay Sachs disease form such a distinct entity that some one or few diagnostic clues is sufficient to identify it. Therefore detailed, and sometimes prolonged examination is necessary before a diagnosis is arrived at. A period of ward observation or trial period with a group or individual is often very helpful.

The elements of the examination include:

- 1. Family history
- 2. Personal history
- 3. Physical examination
- 4. Laboratory examination
- 5. Psychiatric examination
- 6. Psychological examination

As can be inferred the examination often involves several individuals, and if possible an integrated team approach will be the most efficient method.

A group conference of all participating workers should be held before a final diagnosis is made and a treatment program outlined.

Even if the examination is carefully done, one should not feel disappointed if a final diagnosis must await a longer period of observation.

Most workers in the field of mental retardation must depend for their gratification upon clarification and help rather than cure. The goals must at times be limited, but the help offered even then is often most gratefully received.

In order to limit this presentation to reasonable dimensions, it is best to

See references on page 34.

limit the differential discussion at this point to a differential betweer. diseases regarded as primary disorders of function; namely, infantile. and childhood schizophrenia; and mental deficiency as such. There are c\* in whom the final diagnosis must remain debatable. There are evegrounds for placing the schizophrenic and autistic children into the t organic category—but logically one runs into the difficulty of grada:. i both ends of the scale. That is, if the schizophrenic children and autis:.. dren are regarded as having some anatomical or gross derangement o nervous elements, due to physical or chemical (toxic) causes, then the tion of these from neurotic children becomes necessary and we find ou: in the middle of a very active controversy. However, if we try to draw ::,-of separation at the organic end, we do serve a useful purpose with so less controversy.

Some of the schizophrenic children, and possibly some of the k-children, may be benefited by the type of play therapy or so-called  $\mid$  therapy which usually does not benefit the mentally deficient child, unle» mentally deficient child is near borderline (and then there may be doubt the validity of the diagnosis) and presents a neurotic complaint charact by the usual unconscious compromises.

In the family history of schizophrenic children there will usually be a 10% positive family history of schizophrenia.<sup>3</sup> This corresponds to the centage of positive family history in adult schizophrenics; and unless p is absent nine out of ten times and, although it offers us only nominal it should be considered.

The autistic child, on the other hand, does not usually have a fc\* history of schizophrenia greater than that of the general population; br family frequently shows obsessive traits. The retarded child who falls in: group of specific syndromes or familial deficiencies including hematol\* incompatibilities comprises about 10% of the retarded group and, likr « schizophrenic group, the family history is important in this group if posith:

In the personal history it will be found that the schizophrenic child will not have a higher percentage of birth abnormalities than the gete population. This is also true of the autistic child. The retarded chile frequently have a positive history of some birth or prenatal irregularity or I physical anomaly noted at the time of birth.<sup>5</sup>

Developmentally, schizophrenic children are usually normal or rapid the second to fourth year of life. The symptoms of schizophrenia, however, a appear at any time between birth and the eleventh year and still fall int broad category of childhood schizophrenia. After this time, it is include: the adolescent schizophrenia.

The autistic child usually shows its autism early, and does not for:. close relationships with parents which can characterize both the schizophrrs and the retarded child in infancy. These children prefer to relate to ob»c do not communicate readily, and a substantial percentage do not commun, well during their entire lifetime. Other motor and sensory activities ma\ well performed, and it is this which serves to distinguish them from the tarded child, while their autism separates them from the aphasic or dysan or occasionally from the deaf child.

The mentally retarded child shows great variation in the developmental history, depending, of course, on the severity of the retardation. Often these are irregularities and discrepancies of development. The relation with the parents, that is, the ability to relate to the parents is commensurate with the general level of development. These children usually show appropriate emotional response to parent figures when the physiological development of the central nervous system has reached the point where such figures can be adequately distinguished and recognized. Although the slowness of development may become more recognized after the time of the development of the motor and sensory functions, we do not see the abrupt failure of development and disintegration of behavior which is seen in the schizophrenic child when it has reached the age when nervous system maturation has occurred, and experiential integration, especially social, is due to predominate.

If the physical examination reveals demonstrable evidence of central nervous system pathology, then the child should belong in the group classified as mentally retarded, rather than schizophrenic or autistic. In these children, medical, social, and pedagogic methods of treatment are to be preferred over psychotherapies; and there is evidence of a damaged central nervous system to account for behavioral irregularities despite the apparent neurotic or disorganized quality of the behavior. The usual signs from which damage to the central nervous system may be inferred are:

- 1. The presence of a positive Babinski or confirmatory response after the age of four.
- 2. Unilateral reflex changes.
- 3. Hypotonia seen together with hyperreflexia.
- 4. Absence, especially unilateral, of the superficial skin reflexes.
- 5. Loss of simultaneous perception of two stimuli; if the patient has passed the mental age of six; also, finger agnosias.
- 6. Cerebellar deficits; especially if unilateral—these signs are sometimes evidence of frontal lobe rather than pimary cerebellar damage.
- 7. Unilateral sensory deficits.
- 8. Trophic changes; especially unilateral—including hemihypertrophy.

Other aspects of the physical examination may also permit the diagnosis of mental deficiency to be made. These include the specific stigmata; laboratory examinations including electroencephologram; X-ray, etc., are of varying importance. In one instance at least (phenylpyruvic oligophrenia), a simple test can establish the diagnosis. The electroencephologram has not been of special value because of the variability of the normal sleep record in children and the rather "yes or no" character of the end result. However, it should be done for possible localization.

The observable behavior and reaction patterns of these groups also may help to distinguish among them, and also leads to certain general inferences regarding the functioning of the central nervous system.

The autistic child may show great variability in his level of social functioning ranging from complete lack of communication and total loss of social functioning, to active participation in group activities. The diagnosis of autism

might possibly be questioned in a child who has achieved a very high of social function. Nevertheless even these children show an inapproc literalness; and a real lack of the knowledge of the appropriate em • responses in human relationships. Despite their apparent retardation, the\ i show high level responses in certain mechanical or concrete areas. The\ | times can be found to have abilities which are unexpected. It is the indiv:: oriented, unresponsive, affectless behavior which is most striking and I differs from the other two groups. They do not show the pan-anxiety the other two groups show, but do have an obsessive desire for the main:- - of sameness. This does not usually result in neurotic, and psychotic^. appropriate hyperactive behavioral attitudes of the schizophrenic an mentally retarded child. Some idiots-savant may be autistic individuals.

Besides the now classical whirling, stickiness and waxiness of the \$phrenic child, the most outstanding characteristic is "that every area gration or patterning of the central nervous system" is involved. In ac they often show bizarre or peculiar behavior, including delusions, hallucir..-ideas of reference, cosmic feelings, which are characteristic of schizophrer—all its forms. As the schizophrenic child grows older, and its knowlec.-creases, it uses the same rationalizations as adults and develops cosmic: and interests in the workings of things. Such children often develop intr\* but poorly organized schemes and concepts about astronomical and | sophical subjects. These children can usually be distinguished rather rej from the mentally defective child, although there may be some difficn separating the more highly organized autistic child from the relatively functioning schizophrenic child.

The younger and more severely disturbed schizophrenic child may fur random, wandering, restless, inattentive manner reminiscent of the  $r_{\cdot\cdot}$ : behavior of the more severely disturbed child with a damaged central ner system.

The schizophrenic child is more influenced by apparently internal I and stimuli and their wanderings are less random and more quirkish. O: these children, for example, might rush about a room until he came to a nn and then sit before the mirror crooning gently to himself as he carefulh methodically surveys his features. In the rest of his behavior he may seemed random and wild, touching this, tearing that, discarding some seemed random and wild, touching this, tearing that, discarding some seemed the disproportionate degree of organization and interest together vinability to suddenly control and direct behavior in certain situations, whi; some reason has special importance for the particular child is rather unchild teristic of mental deficiency caused by central nervous system damage as der.: and is characteristic of the schizophrenic process.

Prolonged observation and sensitivity are necessary in order to distinr. the one from the other, but the schizophrenic child does often respond I own needs, despite his withdrawal and seemingly random activity. Givich and others have described reversal of the disorganizing processimprovement in behavior.

The behavior of the mentally retarded child as observed during the p> atric examination may vary from wild, random, functionless, through the .

subtle deficits as we approach the borderline. There is, of course, a continuum as with most medical conditions. There are several aspects of this behavior which are rather typical and which may throw light on the disturbances of behavior in general as they are seen in mentally retarded children.

While the schizophrenic children show plasticity of movement, posturing and such, their movements in general are not ungraceful. The child with mental retardation, on the other hand, usually shows awkwardness of motor activity. These children are clumsy, unsure and non-rhythmic in their movements. Often only a subtle awkwardness of carriage is seen. Probably the dysarthric, slow, or unclear speech often noted belongs to this symptom too.

As the mentally retarded child develops from childhood through adolescence the behavior often changes from random, hyperactive and disinhibited to excessively inhibited. This parallels the normal pattern of growth. Explorative and undisciplined behavior in normal children which requires externally imposed guidance, discipline and standards gives way to adult behavior where the imposition of controls is internal.

Normal behavior, starting with random movements, sounds, and expressions is experientially molded by the resultants of the behavior into organized and goal-directed patterns of activity on a highly abstract and socially integrated level.

In the retarded individual, the ability to selectively inhibit behavior is decreased. Therefore, as the behavior shows increased randomness prior to adolescence, either experience, physiology—or more likely the mutual interaction of both—result in excessive, unselective inhibition after adolescence. While this pattern is not invariable, it is frequently seen. There are, of course, residuals of disinhibition even after the adolescent inhibition has begun.

In addition to these, we frequently note poor rote memory and poor ability to abstract and to form concepts. These latter "organic" signs are common to many conditions of damage to the central nervous system.

All of the above are evidences of the failure or inadequacy of the stimulus-integration-response mechanism which operates in organisms above the spinal level of response.

The subjective results of such a failure is anxiety. When the organism fails to respond smoothly to stimuli in an integrated and meaningful way, the failure either results in, or is perceived as anxiety.

The similarity of this situation to the anxiety in childhood schizophrenia is rather well known. Silvers<sup>10</sup> felt that the anxiety and failure of adequate ego development in schizophrenia is evidence of a retention of certain embryological characteristics in homeostasis, muscle tone, motility, respiratory patterns and states of consciousness. The manifestations of anxiety and lack of definition of ego boundaries with development of secondary neurotic defenses and panneurotic symptomatology result from this.

In the organic child then, the ego fails to crystallize into an adequate structure because of failure of the central nervous system. Very probably it is the total amount of brain damage rather than the exact localization which is important. There are critical brain areas which seem to serve as integrative centers—but, if the damage is early and discreet, the total disability will still be more

diffuse and effect total functioning more generally than the discra syndromes seen in adults.

In the schizophrenic child some as yet unexplained mechanism I a similar picture.

The autistic child, too, has a failure of ego development but th: seems milder, social effect is less and the neurotic symptomology . compulsive.

Since the number and variety of responses to stress is limited, the:. picture seen in all individuals reacting to disorganization is similar.

At this point it seems as if central nervous system function and a are the same thing. This is true. Subjective experience is the end M the nervous integration of the reticular and cortical structures.

Interruption of the integrity of this system interferes with or affe: sciousness, or in psychoanalytic terms—ego.

Because of the weakness of this "ego structure" the retarded ir. slips into a psychotic reaction rather easily under stress, and may rec « equilibrium if the stress is removed or the central nervous system <=: by medical means.

It has been noted that the schizophrenic child does respond to therap\* psychological-symbolic level. He also responds to structuring and pecL. stabilizing influences, but probably in a more general way.

The mentally retarded child, on the other hand, usually requires <• ening of his ego; and this is best accomplished through medical, social<- • ment, and pedagogical methods.

Much more can be said on this broad topic. I have tried to give an without filling in all of the details, and to point out some of the man\ lating areas of work to be found in the field of mental deficiency.

I should also like to emphasize the necessity for a clear diagnostic eva: preferably by a team of workers in order that the best possible the: program may be outlined.

#### REFERENCES

- 1. Tarjan, G., and Forbes, L.: Am. J. Ment. Def., October 1955, Vol. 60, #2, p. 340.
- 2. Bolliere, Tindall, Cox, and Tredgold,: A Textbook, of Mental Deficiency, London, ••
- Kallmann, F. J., and Roth, B.: "Genetic Aspects of Preadolescent Schizophrenia. Psychiat., Vol. 112, #8, February 1956, p. 599.
- 4. Kanner, L.: "Autistic Disturbance of Affective Contact," Nerv. Child., 2: 217, 1943.
- 5. Lilienfeld, A. M., and Pasamanick, B.: "The Association of Maternal and Fetal Fa,- the Development of Mental Deficiency," *Amer. J. Ment. Def.*, January 1956, p. 557.
- 6. Bender, L.: "Childhood Schizophrenia," Psychiat. Quart., Vol. 27, #4, 1953, p. 663.
- Silver, Archie A.: "Management of Children with Schizophrenia," Am. J. Psychotherj-1955
- 8. Gurevich, S.: "Direct Analytic Treatment and Symbolic Fulfillment Reviewed as to App in Childhood Schizophrenia," *Quart. J. Child. Behavior*, 3: 276-288, 1951.
- Geleerd, E.: "Psychoanalysis of a Psychotic Child," Psychoanalytic Study of the C %. 311-332.
- Silvers, Archie A.: "The Preadolescent Exceptional Child," Proceedings of the Woods S\* May 1953, p. 10.

# Pediatric Aspects

MEYER PERLSTEIN, M.D.

Assistant Professor of Pediatrics, Northwestern University Medical School

IN MY PRESENTATION, I shall try to cover the clinical pediatric side of differential diagnosis.

If a child is born with an obvious gross defect of the skull and brain, such as a pin-point head, you can easily see that he's likely to be retarded in his ability. Sometimes these defects are not always present at birth—they may occur a little bit later when the child may develop certain changes in his skin, like a tuberous sclerosis, or develop certain degenerative diseases. When these stigmata do occur, they are quite characteristic; all you have to do is see a few clear-cut cases to learn to make the diagnosis because many of these conditions run in categories and follow clinical symptoms that are very much alike.

If a child has nothing wrong with him except that he's a pure mental defective—that is, nothing *else* is wrong—then the diagnosis lies primarily in the field of the psychologist. He should be able to tell by his testing whether the child is retarded and how much.

Sometimes, however, you run into the problem where the child has some type of physical defect and doesn't develop normally; then the question comes up, "Why?" For instance, he might be born with weak muscles, like in amyotonia congenita, or have a more severe physical condition because of which he may never walk, but he might have normal intelligence. Unless you are aware of this fact, you might say, "Well, because he isn't developing motorily at a normal rate, there must be something wrong with him mentally"; in this, of course, you will be mistaken if you do not fully examine him. When you have examined him and know that he does not have the mucular wherewithal to walk, then you do not depend upon motor abilities like walking, sitting, and standing to give you any clues as to what his mental condition is. You eliminate those items from testing or observation and then come to the conclusion as to his mental ability on the basis of what is left in him. You don't always have to have a bunch of tests in your hands to do it. A pediatrician who has seen a lot of normal children is supposed to have a sort of built-in Gesell scale so that he can readily look at a child and get a pretty good idea of where this child belongs in relationship to mental adequacy.

Sometimes you don't see anything motorily wrong with a child born with missing limbs or poor muscles. Sometimes you don't see anything wrong with a child when you look at him and he still is slow in talking. When that occurs, the pediatrician says to himself, "Could there be something wrong with the sonsory apparatus? Could this child be deaf?" All you have to do to be correct in your diagnosis is to *thin*\ of these factors. If you just think of the possibility,

the chances of missing it are rather remote. If you keep in mind that a defect like deafness will certainly interfere with speech development, do not expect the development of speech to be your criterion of the ability of this child.

This goes, too, for visual defects all the way from total blindness: | defects of various types if, you are aware of the fact that a child whi may walk a little bit later than a child who isn't. There may be some versy as to whether children who are blind walk a little bit later. In m< experience, they do. If they're partially blind, they seem to walk late: they're totally blind.

One of the greatest difficulties in the diagnosis, evaluation, and a of mental ability occurs with those children who have what is called "brain disease"; that is, children who have had damage to the brain be after birth. As a result of such damage, the child may have a mental perhaps convulsive seizures, personality defects, and motor defects. The d question is how much of each ingredient makes up the total picture and :: evaluation and treatment, what phase should gain priority?

Children who are cerebral palsied or have had brain damage at birti have perfectly normal intelligence and still be delayed in their general de \* ment. In such cases, it is necessary to have had a lot of experience with IVII children before you can assay what you're dealing with. For instance, you s know that in a child who cannot move his arms or legs because of br^: volvement, you can't expect to find the usual motor patterns; you can't e^ such a child to grasp in the normal manner or at the normal age. The have to say to yourself, "If I offer this child the ring or something and he take it with his hand, is this a failure of mental ability or not?" Then y< . to use your intuitive clinical senses and say, "Do I think the child tried after it? Did he want it?" As Gesell says, "Did he grasp it with his evecouldn't grasp it with his hands?"

These are the important little points which should be kept in in. evaluation. One of the first questions which should come to mind is, "Is a in the history something which gives a hint of such an injury?" For im. was the mother Rh negative? Was this an extremely difficult delivery it a breach? Did the mother have German measles during her pregn^rt If these ideas are kept in mind and you explore them thoroughly, the:. should be able to recognize the condition in the child.

We talk rather glibly about cerebral palsy, muscular dystrophy and mc deficiency as if they were distinct diseases; they are not really diseases generic terms which include a whole multiplicity of specific syndromes, h example, if I said a man had lung trouble, you wouldn't know whetbe meant he had tuberculosis or asthma or cancer of the lung or any of a nunr of other conditions. In the same way, terms such as cerebral palsy or mo deficiency cover so many different types of things that when we discuss diagnosis, management or treatment of a child with mental deficiency, we • be much more specific. For this reason, it is necessary to be able to recou some of the clinical syndromes.

For instance, if you are aware of the fact that a child who has a form cerebral palsy known as athetosis might also have difficulty in moving his e

thing is that their verbal ability seems well advanced but their abstract reasoning shows marked retardation. It is not correct to es drop of the whole mental level; but rather there are specific asset tions in certain areas.

Some children with organic brain disease also have seizures. > the seizures may overlay other physical and mental factors just the « tional factors may overlay intelligence. Parents of such children desaying, "Sometimes my child seems to be under a cloud and I can't rr at other times the cloud seems to go away and he seems to be perfect and able to do a whole lot of things." These are the children who are it home from school by the teacher who says, "You know, your boy is m can do the work, but he just doesn't want to try or he doesn't wa attention." When that occurs, you always think that you are dealing specific type of perceptual defect in a child with organic brain diseass.

Not all epileptic episodes are associated with real convulsions; be equivalents. It is frequently seen in children with brain damage. perceptual defects are evasive. Sometimes they're there, sometirr.r not there—just like their behavior. The behavior of the post-enceph child with organic brain disease may be hyperactive, almost like that ized by intense organic drive. In the encephalitic, however, the hy is present all the time, as a general rule. On the other hand, in the an ordinary functional disturbance, there are specific "triggers" whid unusual behavior such as temper tantrums. The "trigger" or reason is a child feels thwarted—he doesn't get his piece of candy or he doesn't to the movies so he throws himself into a tantrum. But in some of the a who have the epileptic equivalent of behavior disturbance, there's i i suppression for a period of time and the unusual behavior often is not ir<sup>1</sup> but seems to come on spontaneously and for no apparent reason. Ni quently in such children you will find typical changes in the electroercs gram and frequently a drug therapy may be effective in controlling or - i ing the epileptic seizures. Then you may observe that their IQs appear: ; However, this probably means that you were incorrect the first time yc\*

Many of these children are getting drugs that have side effects wh::\* them dizzy or stuporous. In a few extreme cases, the children receiving i may not want to do anything. I remember one child that hadn't walij four years because of the effects of dilantin. It is an illustration of the rV sometimes the treatment is worse than the disease.

I have attempted, in my presentation, to mention briefly some of th:: that are important in the differential diagnosis. Little things must be sou\*.: As another example, we should be aware that an infant with organ.: disease may be hypotonic, that is, may have very little tone; however, a<:• older he may become a hypertense child and a very tense adult. We abremember that normal motor patterns are found in some retarded c\_Similarly, if a child walks on his toes, this observation has no special mar because a lot of children walk on their toes when they begin to walk. Tr.t question for the pediatrician is, Can he get down on his heels? If he can. i

is nothing wrong with the heel cords but if he cannot, the pediatrician must look for the cause of the defect.

When a normal child begins to grasp, he does so with his fingers outstretched; when you touch the palm, he closes it. After half a dozen trials, he begins to approach the object with his fingers closed. If he has something wrong with him motorily, he will continue to approach every time with his fingers extended even when he's a year or two years old. He will not grasp until you touch the palm with the object because this is a reflex. If you are aware of the fact that this type of slowness in grasp may be a difference in pattern, then you may not interpret it as being due to mental deficiency but due to some motor deficiency.

In closing, I should like to point out that although we physicians like to think of ourselves as scientists, medicine is far from being a science—it is simply a practiced art with some scientific backing.

# Psychological Aspects

HERBERT G. BIRCH, Ph.D.

Research Associate, Institute for Physical Medicine and Rehabilitanc
New Yor\ University-Bellevue Medical Center

THE PROBLEM OF DIFFERENTIAL PSYCHOLOGICAL DIAGNOSIS in menu! mality has been approached over and over again during the seventy-:: or more of concentrated clinical and scientific interest in the probleir. span of years stretching from Ireland's¹ early effort at typology to K\_» recent suggestion that we divide subnormal individuals into the t categories of absolute, relative and apparent mental deficiency, numerous - of differential diagnosis have been advanced only to be speedily rep.^ - rejected. It is not the intention of this paper to provide yet another ex>-:\_ system of classification. Rather it is felt, that it will be more profitable: approach the problem of differential diagnosis functionally and with t: - nition that it is only through its usefulness in prognosis and treatrr.r:. differential diagnosis has its raison d'etre.

A functional approach demands that we start our inquiry with the recognition that mental subnormality does not in itself constitute a discj\* is in fact merely the composite end-result in disordered or inadequate bx adaptation of any of a variety of underlying processes. Consequently, the nition of mental subnormality never constitutes a diagnosis, but is r^LS phenomenon that must be differentially diagnosed. In the same way tha: rrblood pressure is a physical finding that may reflect physiological dy^: ranging from adrenal tumors to emotional disturbance, mental subr. I constitutes a set of psychological findings that may in different indiv;di reflecting a disordered psychological functioning which takes its oric: sources as different as cerebral agenesis and personality disorganizati-.

It should be noted that thus far the term "mental subnormality" used in place of the more commonly utilized designations of mental. • tion or mental deficiency. This usage has been adopted as a consequer..-cogency of the remarks made by the Joint Expert Committee in the I Health Organization technical report *The Mentally Subnormal Child.'* '. usage, "mental retardation" refers "only to those whose educational a:\_: performance is markedly lower than would be expected from what i< i of their intellectual abilities." They go on to make the following 'observations:

"When terms are needed to describe conditions in which the ma pacities themselves are diminished as a result of pathological causes. a<

See references on page 49.

to environmental causes which may lead to mental retardation, 'mental defect' and 'mental defective' are used. (Those who suffer from mental defect may, of course, also be retarded.) The term 'mental subnormality' is proposed as a general term to describe the mentally retarded on the one hand, and the mentally defective and those whose mental endowment is so poor that they are remarkable for their dullness even if functioning to the best of their abilities on the other." (pp. 6-7)

These considerations provide us at once with the generally descriptive fact of mental subnormality and with the differential categories of retardation (or suboptimal functioning) and of mental deficiency (or biological adaptive inadequacy). Hegge, 4 too, has made this distinction and has tried to delineate the functional consequences of "retardation" and of "deficiency."

Obviously, the first task confronting the psychologist is the determination of the presence and degree of subnormality. In the main this is done by estimating both the adequacy of social functioning of the person and by assessing his performances on some scaled inventory of intellectual tasks. In making either of these assessments it is necessary to leaven all measuring devices with the ferments of experience and of clinical judgment. We must never forget that all measures we obtain are performances, not capacities. Notices of capacity are always inferences drawn from the fusion of the psychologist's observations of the specific performances made by the patient with the accumulated knowledge of the causes which may underlie a given performance pattern. Thus, the I.Q. is a comparative measure in which the performance level of a patient is invidiously compared with the average performance level of his chronological age group and not a measure of "intelligence" or of mental capacity. As Doll has so aptly put it, our measures at first give us a valuable estimate of "performance 'as is'" and not direct information concerning the "reasons underlying such performance"<sup>5</sup>. These considerations lead to two cautions: First, one should not confuse performance with capacity to perform. Second, finding the reason for the disability is not a valid basis for the psychologist to explain away or disregard the FACT of the subnormal or distorted performance. Therefore, while it is invalid to conclude directly that a low I.Q. is a manifestation of "mental deficiency" or biological inadequacy, it is equally invalid to explain away the low I.Q. as a fact which objectively illustrates subnormality of effective functioning. The first task, then, is to determine whether or not a given individual is IN FACT functioning at a subnormal level.

Much concern has been expressed over the fact that in the United States the Mental Age or the Intelligence Quotient have been used too exclusively as the measures of subnormality to the neglect of measures of social adequacy. It is undoubtedly true that intelligence testing alone is insufficient as an adequate sample of a patient's performance and that knowledge of the level of social competence is invaluable in estimating the general quality of present functioning. Further, it is clear, from the evidence, that particularly isolated or culturally deprived social sub-groups are necessarily underestimated when intelligence test performances are used as the sole criterion of competent adaptation. Moreover, in clinical practice it is almost impossible to ignore the question of social competence since it constitutes the primary basis for psychological referral. In a sample of 100 cases chosen at random from the psychological files

- of a hospital child guidance clinic, real or fancied environmental i accounted for more than 95% of the presenting problems. A br: the most prominent of these complaints, any of which may apjx manifestations of mental subnormality, will be helpful in establish.: . ing point of a differential diagnosis. Among the reasons that **are** , requesting a psychological evaluation of the child the follow prominent:
- (1) Slowness in the rate of motor development: Perhaps the most r of developmental changes in young infants and children is the incrtii plexity and definition of motor acts. Both parents and the Gesell Dr--Schedule focus on the sequence of these changes, and parents?•: cerned when the child's rate of motor development exhibits signir... While lags in the elaboration of motor skills are frequently assr>:::r more general subnormality, motor inadequacy is in itself an insufrc for concluding that a given child is intellectually subnormal. Be: • conclusion is arrived at the child must be assessed totally. Medical ermust exclude the presence of specific disorders of motor function:: . motor dysfunction must be viewed by the psychologists within the :• of a broad view of the child's performances. Additional perspective < if an evaluation is made of the patient's comprehension of language. -ness to general environmental aspects, recognition of people and objec to anticipate simple repetitive acts on the part of the examiner. . priateness of emotional expression. Slowness of motor development is. in itself insufficient evidence for mental subnormality.
- (2) Inadequate self-care, self-feeding, toileting. The young chile. during the first and second years of life begins to develop skills ar. in these areas. In the Vineland Social Maturity Scale, Doll has w age-level sequences for eight different features of developing envi: adequacy. Even the young child at less than a year of age anticipate the movements of dressing and undressing. He feeds himself fir-: hands and later with a spoon, and at a later date responds appro: toilet training. Backwardness in these concerns almost inevitably is a of mental subnormality. However, motor disability (as in cerebral j reactive emotional disorders such as those produced by excessive overpor rejection, overdependencies as the product of prolonged illness, n features, and hyperdistractability may contribute to inadequate:'... as, too, can autistic and juvenile schizophrenic developments.
- (3) Problems of expressive language and of language comprektthe most usual mode for the expression of thought, language developrr«
  frequently reflects the degree of mental development. Thus, perform\*
  the vocabulary section of tests of general intellectual functioning correLthan any other sub-test with total test performance. Common-sense:
  clinical experience attests to the relation of language to thought. Conseq
  inadequacy in language function is often a sign of mental subnormals
  five and limited expressive difficulties as well as emotionally produce:
  tions, however, are also not infrequently manifested in language disn
  and must be eliminated as causal factors in the difficulty before the '.xt

lack can be attributed to mental incapacity. The psychologist must also be aware that language and speech are not identical functions. Care must therefore be taken to explore gesture and other modalities of communication before it is concluded that a language rather than a speech or hearing disorder exists. Subtleties, in language dysfunctions such as aphasia, agnosia, apraxia, in speech disorders including dysarthria, and in hearing disturbances ranging from deafness to central auditory misperception, <sup>14</sup> are so complex that they are best explored in close collaboration with a speech and hearing pathologist.

- (4) Peculiarities of attention: To behave appropriately a person must be able to differentiate his environment into figure and background. Inability to keep a given aspect of the surroundings dominant and other features subordinate is reflected in behavior which is unfocused. Two paradoxical features of attentive difficulties which are usually found in close association with one another, distractability and perseveration will be treated in a later section.
- (5) Disturbances of play and of social relations: When normal patterns of play fail to develop, when behavior is directed into futile repetitive activity or when relations to objects and persons are characterized by destructiveness, by persistent aggressive hostility, or by unresponsiveness it is usual to seek for the roots of the difficulties in either emotional disturbances, intellectual inadequacy or both. The existence of one of these causal factors by no means excludes the presence of the other, and evaluation of the patient should include a consideration of both dimensions of functioning. Frequently, mentally deficient children develop reactive behavior disorders to the unmeetable demands of normal social circumstances. It is the rule rather than the exception to find emotional difficulties in close association with mental subnormality. It should be remembered, too, that damage to the cerebrum of a type which produces disturbances in the normal balance of excitation and inhibition can produce behaviors in play situations in which aimless flitting, toy grabbing, hitting, and perseverative unproductive activities are prominent. Play inadequacy and social disintegration are also present in autistic children and in juvenile schizophrenics.
- (6) Problems of judgment: Excessive timidity, lack of normal caution, unselectiveness in eating and swallowing objects, and general failures to make appropriate appraisals of the requirements of a situation are frequently occurring and presenting problems.
- (7) Disturbed affective behavior: Lack of normal emotional control, continual whining and crying, clinging, struggling and screaming at a caress, temper tantrums, negativism, and inappropriateness of emotional responses bring many children to the psychologist's attention. These behaviors may be accompanied by motor disorders, seizure patterns, or by the ineffective acquisition of the skills for daily living. When the latter is the case it is necessary to determine whether the failure to learn has been the product of intellectual inadequacy, the consequence of overriding emotional disorganization, or of both emotional and intellective disturbances acting in concert.
- (8) School failure: Finally, a significantly large group of patients are referred for psychological evaluation because of deficient school performance. Sometimes the school difficulty is limited to the failure to acquire one or an-

Even brief consideration of the complexities which are founii senting problems indicates that adequate psychological evaluation i analysis of both social and intellectual performances in such a w out those factors which are primary to the disordered functioning .: to them the derivative disturbances which contribute to the observed inadequacies. Analysis always involves the use of testing instrumc: with careful clinical observation of the qualities of performance. I both subjective and objective data are utilized. Most helpful, too, in the of psychological functioning is an adequate history of behavior, vvh» include a careful measurement of current over-all social function. Vineland Social Maturity Scale) as well as information on the time of behavioral development.

Much has been written about the special precautions that must b in determining the intellectual status of persons with specific rece: expressive disorders. <sup>15</sup> Various adaptations of standard tests have bet: altered and weighted scoring standards have been offered, and spc: ments have been constructed for use with given expressive and recep orders. <sup>16</sup> It is not possible to go into a detailed consideration of these I tions at this time. However, it should be recognized that no modifk-been completely satisfactory and that experience and clinical judgmc.v the essence in the analysis of intellectual functioning in the patient wh and motor defects.

### SOME PATTERNS OF DYSFUNCTION IN MENTAL SUBNORMALITY

(1) The child with cerebral damage: Since the appearance of the Injured Child" by Strauss and Lehtinen some eight years ago, we h nessed a growing tendency to discuss "the brain-injured child." Whilt can be little doubt that this work does call attention to important: phenomena, a serious question may be raised as to the general validit\ syndrome for all types of cerebrally damaged children or even for an\* cerebrally damaged child.

It should be noted that the "brain-injured child" of Strauss and Ld or the "neurophrenic" child of Doll is not a "child" at all but a stas generalization derived as a composite from a population of children. • cursory glance at the original research reports reveals that the group of d from which the composite picture was derived is by no means homogn On the contrary, every task from critical flicker fusion to concept f<-and thinking clearly exhibits the heterogeneity of functioning in the

brain-damaged group. In many instances the *individual* performances of the brain-damaged children overlap with and are indistinguishable from the behavior shown by members of the normal control group.

In the course of daily activity in a rehabilitation clinic, it soon becomes clear that a unitary typology for brain-damaged children is inadequate and that a less omnibus system of classification is required if adequate diagnostic and therapeutic decisions are to be made. A beginning step toward refining our conceptions is made if we discard the idea that brain damage *as such* is a meaningful designation. The cerebral cortex is not an undifferentiated fluid medium. It is a complex, highly differentiated functional unit with unequal interrelations among its parts. Thus the locus and the extent of damage may operate in important ways to determine the nature of behavioral sequellae. Further, since the functional properties of the cerebral cortex are significantly modified by experience, the time at which damage occurs in the life history of the person figures critically in the determination of consequence. As both Hebb<sup>17</sup> and Goldstein<sup>18</sup> have shown, the severity of effect for equivalent cortical destruction is very different in the very young than in the more experienced organism.

Still another variable to be considered is the nature of the lesion itself. Is the lesion a passive subtractive one or is it active and additive as the consequence of scarring? Is it so situated as to produce diaschisis?<sup>19</sup> Does it have the physiological consequences of facilitating inhibition or does it act as a disinhibitor of cortical activities? Does it disrupt cortico-sub-cortical relations?

Therefore, far from being a single entity, brain damage itself is heterogeneous and must be considered in terms of time, place and variety. If brain damage is so diverse, one may well ask, how can we speak of the brain-damaged child?

Unfortunately in retardation centers, the possibilities for determining the anatomic and physiologic character of cortical lesions are poor. Consequently, we only infrequently have sufficient specific information about the cortical damage against which we may array our behavioral findings. However, such a lack is not sufficient basis for either denying or ignoring the heterogeneity of cerebral damage. On the contrary, the lack of an adequate physiological substratum makes it all the more necessary that we refine our psychological conceptualizations in the analysis of behaviors shown by cerebrally damaged children. The entire history of pathology provides evidence that it is only through such a careful delineation of clinical patterns of behavioral dysfunction that subsequent solutions to our problems can be advanced.

In a general way it is possible, even at this stage of our experience, to distinguish at least three patterns of psychological functioning in children with cerebral damage. For convenience in identification these may be designated as: (1) Subtractive or passive losses; (2) Additive or active losses; and (3) Combined losses.

In many ways children with subtractive losses are often indistinguishable from the "so-called" endogenous mental defective. Temperamentally such children are relatively passive and unresponsive, hypoactive rather than hyperactive. Intellectual functioning is depressed relatively evenly and does not exhibit the wide spread between basal and terminal performance levels or the unevenness in psychological capacities that have become the stereotype of the "brain-

injured child." While perceptual and motor inadequacies may be are subtractive in character and do not exhibit eccentricities such ground reversals, bizaarenesses, or disturbances in movement percer: they are exhibited as lacks or as impoverishments of experience. This exhibit some tendency toward concreteness, but the degree of cor\* appropriate to the general level of adaptive functioning and does r. r any special area of inappropriate dysfunction.

The second pattern to emerge from our observations is marke.i.< from our first. At the risk of being unclear, I have called this: "additive loss" to distinguish it from the "subtractive" dysfunc scribed. In some ways the children who exhibit additive or active loc. the model advanced by Strauss and Lehtinen. Their behavior a: • marked by disturbances of functional equilibration. Most promitive children is a disturbance in the mechanism of inhibition. Ongoir... i are incapable of diminishing the child's responsiveness to stimula: ing upon either the exteroceptors or interoceptors. Under other cir. a the ongoing activity so dominates function that new stimulation I tively to modify behavior. Consequently, one is confronted with ch. show the paradoxical patterns of distractibility and perseveration u. - hyperactivity and a lack of impulse control "organic driveness."

A recent investigation utilizing the conditioned reflex technic J on by one of my students and by myself indicates the importance of 4 lem of peculiarities in inhibition in the comparison of two clinic<sup>^</sup>. mental subnormality. The experiment was one in which the psy;: response to an electrical shock of mild intensity was conditioned to i patory flash of an electric light bulb. Two groups were studied :r sively. The first group consisted of hyperactive children with cerebri i and the second group was composed of Mongoloid children. In the a conditioning it rapidly became apparent that the hyperactive bra:.--a children were being conditioned not merely to the light but to m^-features of the environmental situation. There seemed to be an inab:> part of the child to be responsive selectively to a given aspect of the a ment. The Mongoloid children, however, tended to show clearly c: conditioning to the light itself. Most interesting in the course of tr.j ment is the events which occur when an attempt is made at extinc. a conditioned reflex by the presentation of unreinforced stimulations » light alone. As Pavlov has viewed it, the process of the extinction : ditioned reflex is the process of the development of inhibition. In the hyji cerebrally damaged children extinction is very difficult to establi'i marked by frequent bursts of high level conditioned reflex activity, t. tion of unreinforced light stimulation in these children produces an i restlessness and generally heightened activity level. In the Mongolo: : however, extinction occurs rapidly and inhibition appears to deve. great ease. In the course of our experiments more than 50% of the M children achieved such a depth of inhibition during the extinction • they fell fast asleep. Clearly these results indicate that, whereas, the activity of the hyperactive brain-damaged child is characterized by a in inhibition, that of the Mongoloid child tends to be in the direction of

tion of cerebral activity by the inhibitory process. These differences in neurodynamics present the possibility for the development of a new diagnostic instrument utilizing the conditioned reflex and for a clearer picture of the events which underlie distorted behaviors in mentally subnormal children.

A further feature of behavioral dysfunction that exists prominently in these children involves profound alterations or reorganization in the relations within and among sensory systems. Adequate perception as several hundred Russian researches recently summarized by London, <sup>20</sup> and the current work of Werner and his associates <sup>21</sup> indicate, is dependent upon the adequacy or normality of intersensory relationships. Therefore, in these children with marked aberrations in intersensory function, one finds frequent examples of distortion in perception, reversals in normal perceptual dominances, bizarrenesses in perceptual equivalence, disturbances in body image, distorted laterality, and peculiarities and uniquenesses of action and thought which adequately reflect the perceptual difficulties, but only distortedly reflect external reality. These do not represent perceptual subtractions but accretions and propensities that reflect changed cortical organizations.

Thirdly, children with cerebral lesions that have active reorganizational consequences present peculiarities of adaptive intellectual activity which suggest the functional isolation and even the relative independence of psychological capacities from each other. Performances on intelligence tests, in school, in play, and at home are characterized by marked unevenness of level. On intelligence testing, wide gaps may exist between basal and terminal performances. Verbal conceptualizations may be adequate or even superior, while numerical amount concepts or perceptual generalizations are markedly inadequate. It is most probable that such disturbance of behavior is not the direct consequence of cerebral damage but rather the indirect result of disordered learning based upon deranged perceptual organization. It is entirely possible that a carefully constructed developmental regimen may function to moderate such discrepancies of functional level.

A fourth characteristic that may be noted in some children with cerebral lesions is what may be called an isolation of skills—learnings that normally form integrative functional patterns occur in these children as discreet items of behavior and not as patterned wholes. A child with such difficulties is frequently able to learn to read as a visual-vocal task but is unable to comprehend that which he is able to read. However, on other occasions the child is able to comprehend the materials if they are read to him. Thus, he exhibits no difficulty in comprehension when someone else is doing the reading but is himself unable to comprehend when he is actively engaged in the act of reading. Apparently the activity around the visual-vocal task is so dominant that it makes impossible reception at the level of communication.

These characteristics of inadequate inhibition, abnormal intersensory functioning, unevenness in acquisition, and isolation of functional skills one from the other contribute to peculiarities of generalization and to special problems in learning. When in addition to these difficulties we also find an overlay of emotional disturbance, disordering of body image, and phenomena of sensory extinction we are justified in suggesting that the difficulties of the child stem from actively interfering cerebral damage.

Since Dr. Meisel has so fully dealt with the problem of differential < of the schizophrenic child and of the autistic child it would be r. deal with that problem in this paper. Rather, I would like to turn to question and to consider briefly the adequacies and inadequacies of d ments for differential diagnosis which the psychologist has at his

In the main, clinical psychology over the past 25 years has cxa dominated by tests. Many years ago, Wells, in viewing the rapid gr mental testing movement, expressed the fear that this movement tion to place marked limits on the clinical activity of the psychi. fear was based on the fact that tests are devices in which various fur..to be studied discontinuously. For example, if we take any of the : disposal and examine them in terms of a psychological function su. perception we immediately see that none of the standard tests g tinuous picture of the various levels of organization that occur in ment of the perceptual processes. Rather we are presented at difTert: with episodic perceptual demands which tend to indicate merely not the child has reached this level of perceptual competence and what his general perceptual characteristics are. Such instruments: only to get an extremely rough notion of what some of the probk tered by the child may be and by no means provide us with a pic competencies in the area of mental development. It grows more an. parent that a primary task is the investigation of the natural his; • development or genesis of psychological functions. A beginning in : tion is to be found in the work of Piaget and his students and in th. tions of other European investigators like Wallon, Claparede, and Pc. investigators have begun to examine the ordinary sequence of ps development and to provide us with a picture that fills in and er skeletal outline already available to us. The continuation of such lin-. is an essential precondition for more effective psychological diagnosis problem involved in the instruments that are most frequently use psychologist is their negative orientation. As Haeussermann has p psychological test item usually demands that the child adapt to it. Tr of proof for a function, therefore, rests upon the child. Another apj the problem is one in which the burden of adequacy may be place: test item. Thus a child whose number concepts are being examinee be incapable of dealing with the idea of the number TWO but may ; be able to select two cookies or two blocks, etc. In short, if we are in what the amount concepts of a given child are, rather than wh.: not, it becomes necessary for us to develop a scale of items that rans way from a demand that the individual indicate which of two group\* or smaller up to and including abstract number concepts. This appn i out not with the question of whether the child has number ideas by.r desire to probe the level to which his amount concepts have deveh; and more it becomes important to develop techniques and metho permit of probing the child's capacities rather than testing him. Onh such a positive exploration of capacity is it possible for diagnosis to fullest contribution to prognosis and treatment. It is necessary, ther psychology to take under serious consideration Hughlings Jackson"

concerning the importance of studying the positive as well as the negative symptoms of disease. Through the development of such positive instruments it will become more and more possible for the psychologist to make a full contribution to the task of differential diagnosis in mental subnormality. Mental deficiency, cerebral damage, pseudo-retardation, and emotionally based disorganization all will become easier of definition if our approach to the problem turns in a positive rather than in a negative direction.

#### REFERENCES

- 1. Ireland, W.W.: On Odiocy and Imbecility. London, Churchill, 1877.
- Kanner, Leo.: "The Problem of Mental Deficiency in Children." The Journal of Post-Graduate Medicine. 13: 363-373, 1953.
- 3. "The Mentally Subnormal Child." *Technical report, Joint Expert Committee,* World Health Organization, 1955.
- 4. Hcgge, T. G.: "Psychological Aspects of Mental Retardation." Rehabilitation Service Series #123, Fed. Sec. Agency, 1950.
- Doll, Edgar A.: "Mental Evaluation of Children with Expressive Handicaps." Amer. J. Orthopsychiat. Jan. 1951.
- 6. Sarason, S.: Psychological Problems in Mental Deficiency. New York, Harper Bros., 1949.
- 7. Gesell, Arnold, et al.\ Developmental Diagnosis. Paul Hoeber, Inc., N.Y., 1941.
- 8. Cf. Ref. 5.
- 9. Silver, A. A.: Diagnosis of the Various Syndromes Encountered in the Retarded Pre-adolescent Child. Woods School Conf., May 1953, 10-20.
- 10. Strauss, A. and Lehtincn, L.: Brain Injury in Children. Psychopathology and Education of the Brain-Injured Child. N.Y., Grune & Stratton, 1947.
- 11. Kanner, Leo: Child Psychiatry. 2nd edition. Springfield, 111., C. C. Thomas, 1948.
- 12. Richards, B. W.: "Childhood Schizophrenia and Mental Deficiency." /. of Mental Science, 97: 290-311, 1951.
- 13. Goldstein, K.: Language and Language Disturbance. Grune and Stratton, N.Y., 1948.
- 14. Kastein, S.: Central Auditory Misperception.
- 15. Doll, Edgar A.: "Intelligence and Cerebral Palsy." Cerebral Palsy Review, 15: 6-7, 1954.
- 16. Cf. Ref. 10.
- 17. Hcbb, D. O.: The Organization of Behavior. Wiley, N.Y., 1949.
- 18. Goldstein, K.: "The Brain-Injured Child." Chap. 6, in *Pediatric Problems in Clinical Practice*, 1954.
- 19. v. Monakow, C.: Gehirnpathologie. Alfred Holder, Vienna, 1905.
- 20. London, Ivan: "Intersensory Studies in Perception," Psych. Bull., 1955.
- 21. Werner, H. Studies in Sensory-Tonic Theory.

# Laboratory Data and Their Significance

GEORGE JERVIS, M.D.

Director of Research, Letchworth Village

THIS PRESENTATION IS INTENDED as a brief review of laboratory which are used in diagnostic work with mentally retarded childrer. assumption is that mental retardation is only a symptom and thai diversified etiologic factors may be responsible for it. It is in the some of these factors that laboratory data may be of assistance in arrj correct diagnosis. A second point pertinent to a discussion of latxr\* in the field of mental deficiency is the contribution of laboratory tecrti better understanding of the nature of some forms of mental retards

In reviewing diagnostic laboratory procedures, I shall make i comments based on my experience.

X-ray data—Whenever possible, X-ray of the skull should bx every obscure case of mental retardation. Flat plates are of assistance I visualizing abnormal shape of the head and are indispensable in .; the presence of abnormal intracranic calcifications. Occasionally, •-of tumor may be suspected and further study warranted. Air encr;« is performed routinely in cases of severe mental deficiency in certi:: I doubt the wisdom of this procedure since the information obtain encephalogram is usually scanty and in my experience correlates p clinical or pathologic findings. Moreover, the procedure is painfentirely exempt of risk. However, in selected cases where gross deir's. brain are suspected, air encephalogram may offer significant data. '. cases of clinically unsuspected extensive internal hydrocephalus •. disclosed only by this technique. X-ray of the bones other than t;\_: recommended in cases of mental retardation accompanied by dysos: plete forms of gargoylism, for instance, can be recognized mainly of extensive X-ray study of the entire skeletal system.

Electroencephalogram is a relatively new technique and as it b all new developments in medicine, much hope was raised and e claims made as to its value in mental retardation. In my opinion. :: correctly together with other data, the electroencephalogram is v every mentally retarded child should have the benefit of this harmle>t less procedure. The presence of brain damage may be disclosed in cr mainly by this technique. In cases of epileptic seizures, past or : encephalogram is indispensable. There are many pitfalls in the re;

interpretation of encephalograms in children; much patience, skill and experience is necessary. I would like to recommend strongly the taking of sleep records in retarded children as advocated recently by Gibbs and his group.

Basal metabolism is still performed in many hospitals on retarded children as routine determination of thyroid function. In my experience, the test is somewhat outmoded and at any event the information obtained is often not clear-cut or reliable. Certainly in this respect, cholesterol level in the blood is a more exact index of thyroid function. However, the methods of choice today are the determination of radioactive iodine uptake and of protein bound iodine. These two tests, available only to well-equipped laboratories, are an indispensable tool for the diagnosis of the various types of hypothyroid retarded children. Tests for other endocrine functions are of significance with study of mental retardation but their practical value is still undetermined aside from rare specific instances.

Spinal fluid examination in every case of mental retardation is a routine procedure in many hospitals. However, the information obtained is usually meager. If the mental retardation is due to an acute process (e.g., encephalitis), the process is usually quiescent by the time the examination is performed and consequently the spinal fluid is normal. It is a well-established procedure that in all cases of mental retardation in which congenital syphilis is suspected, a complete spinal fluid examination must be done. In the rare cases of brain tumor, spinal fluid examination is, of course, important. In cases of degenerative forms of mental defect, such as Tay-Sachs or phenylketonuria, abnormal products of metabolism may be found in the spinal fluid, a lipid in the former and phenyl compounds in the latter. However, the diagnosis in these cases is possible without examination of the spinal fluid.

Blood examination—Serological tests are usually limited to the Wassermann reaction or similar tests for detection of syphilis. In our hospital, cases of mental retardation due to congenital syphilis are becoming rarer and rarer, and the Wassermann reaction is used mostly in detecting acquired syphilis in high grade defectives. This, of course, is of no significance in the evaluation of the etiologic factors responsible for the mental retardation.

Other serological tests are performed in special cases: Toxoplasmosis occasionally causes mental retardation and can be easily detected by serological methods available in specialized laboratories; however, the interpretation of the results should be made with caution since normal individuals often show positive reaction. In cases of mental deficiency due to congenital toxoplasmosis the antibody titer is very high in early infancy and tends to decrease later; titers in the mother show a similar decrease.

It would be of great assistance in the diagnosis of post-encephalitic mental retardation if serological tests were available indicating that a certain type of encephalitis had occurred. Unfortunately, viruses or microorganisms which produce encephalitis cause usually systemic disease without involvement of the central nervous system so that the presence of blood antibodies against a particular virus or organism is a sign of a pre-existent infection but not necessarily of encephalitis.

A serological test which has been widely used in the study tardation is the determination of the Rh factor and other blood h is a fascinating new development in our field but, as usually happenew discoveries, many uncritical statements have been made. We i mination of Rh factor whenever possible in both retarded child .. But the mere finding of a Rh positive child of a Rh negative motton nothing more than the need for further investigation aimed at obt.. additional evidence that iso-immunization existed in the mother pregnancy and brain damage of the child had occurred.

Morphological examination of the blood offers little of signifies diagnosis of mental retardation with rare exceptions; for instance. • cell anemia is found in a retarded child, the possibility should bt of brain lesions due to multiple thrombosis of brain vessels; when a;\ is present and somatic anomalies are noted in a retarded child, the Franconi syndrome is justified. Chemical examination of the bio • portance in cases of hypothyroidism where hypercholesterolemia is . in forms of mental retardation accompanied by alteration of metaS instance, in phenylketonuria, very high content of phenylalanine i which is easily detected by simple unidimensional paper chromat .

*Urine examination* is done routinely in every case and is, of coo sary in the medical evaluation of the child. Its diagnostic value a< of mental retardation is however quite limited. Phenylketonuria; nosed in a few seconds by adding a few drops of ferric chloride to urine; a green color develops. This simple test should be perfonr.: case of mental retardation.

Thus far, diagnostic laboratory procedures have been mend may be of assistance in the clinical work with retarded children. laboratory workers contribute much more to the field of mental de::. mere diagnostic tools. I would like to mention in closing the com neuropathology and of biochemistry to a better understanding of the esses underlying mental retardation. If one looks back to the pav mental retardation, it is easy to realize that the pathologic study has played an essential role in the development of our present-da\ The painstaking study in the laboratory of brains from defective-was the basis upon which classification into distinct groups was mac hypotheses were formulated, and clinical correlations attempted.

More recent but certainly not less important is the contribuchemists. In fact, it is not exaggeration to say that in the futur significant contributions to the field of mental retardation are exr biochemistry.

## Medical Treatment

JOSEPH WORTIS, M.D.

Director, Division of Pediatric Psychiatry, The Jewish Hospital of Brooklyn

MENTAL DEFICIENCY, like physical deficiency, may either represent a state of biological handicap limiting the developmental potential of the individual, or else a state of relative incompetence or ineptitude due to lack of opportunity or experience. In actual practice we are likely to encounter various blends of the two factors, and clinical judgment must be used to discriminate between them. A one-legged man is at a disadvantage in a tennis game, but given a good artificial leg and a period of practice, he may outplay a two-legged man like me, because I lack experience, incentive, and have other disabilities. Similarly, a small or defective brain may respond quite well to special tasks; new levels of functioning may be slowly reached and a mild handicap may often be adequately compensated for in adult life. Fortunately most mentally retarded children are mildly retarded and can usually find some place for themselves in the normal adult community. 1,2 More severely retarded children require more help, mainly through the general techniques of rehabilitation. These techniques I shall leave to the other discussants to describe. I shall limit my remarks to a discussion of the more conventional medical skills used in the relief or cure of the biological or physiological deficiencies with which we have to deal.

The biological deficiencies encountered in mental retardation are extraordinarily varied and it is no exaggeration to say that hundreds of different etiologic factors may be involved. What is more, new ones are constantly being discovered. To help impress upon you this great variety of factors, let me list a by no means exhaustive sampling of them, arranged in chronological order in terms of the development of the organism.

First, there are the developmental anomalies affecting brain structure and function that are due to genetic faults. These include such entities as tuberous sclerosis, phenylpyruvic oligophrenia, galactosemia, Tay-Sachs disease, gargoylism, Van Recklinghausen's disease or neurofibromatosis, nevoid idiocy (Sturge-Weber's disease), hepatolenticular degeneration (Wilson's disease), diffuse sclerosis (Schilder's disease), the cerebellar atrophies, muscular dystrophies, as well as several other rarer entities of mainly theoretical interest. To this group of genetic or hereditary diseases we can probably add Mongolism and certain types of epilepsy associated with mental defect. Now, when you consider that many modern geneticists regard genetic factors as enzymatic in nature, distorting the normal chemical balance of the body, you will recognize

See references on page 59.

that the presence of a genetic anomaly by no means eliminates the possibility of medical correction or relief.

At a later stage in the development of the organism, during early embryonic life or later gestation, another great variety of factors may complicate, impede or interrupt brain development. Here again all sorts of noxious agents are involved; crude physical assaults on the embryo or a variety of poisons; either of these noxious agents may result from accident or from attempted abortions. We have been impressed by the relative frequency of attempted abortions in the early histories of the children we see at our clinic. Infections such as German measles, syphilis, or infestation with toxoplasmosis, as well as several other infections, may all affect the fetus; placental infarcts or placental detachment are not uncommon factors; exposure to irradiation, starvation, or more specific nutritional lacks or a variety of intercurrent diseases of the mother, may all be implicated. Many mothers exposed to irradiation at Hiroshima and Nagasaki gave birth to mental defectives.<sup>3,4</sup> Children born in concentration camps also show a higher incidence of mental defect,<sup>5</sup> and in general our low income population tends to show a significantly higher incidence of children liable to cerebral defect. Here, too, the early correction of some of these defects, by anti-luetic treatment\* for example, by correction of endocrine deficiencies in the young child, or the general correction of nutrition, may all help to improve the efficiency of brain function, so that the mere diagnosis of a developmental defect during gestation need not lead to an attitude of despair. A child seen recently at our hospital was born with a severe scaphoid or hatchet-shaped deformity of the skull due to premature closure of the sagittal suture; a corrective operation relieved the deformity and promoted normal brain growth. Other types of skull deformities can also be helped by proper neurosurgical intervention, and certain forms of hydrocephalus respond to surgical procedures. The glial or meningeal scars that form after the destruction of brain tissue not only represent a deficit in brain function but may exert a positively harmful irritative action on the surrounding normal tissue. For that reason the excision of irritative meningeal scars, or the more drastic hemispherectomy<sup>7</sup> of Cairnes (so far only performed on a few cases) may sometimes be considered.

The cerebral injuries due to complications of birth are well known to you: they fall particularly into the two groups of direct mechanical injury to the brain, or anoxic damage, with considerable overlay between the groups. Early recognition of this nature of the defect, prompt relief of the anoxia, surgical intervention to remove blood clots and, above all, recognition of the importance of even mild degrees of anoxia, all provide important medical means of preventing or alleviating brain damage.

In early infancy a variety of new factors may injure brain function: infectious, toxic, or allergic encephalitides or encephalopathies are relatively common—we have seen examples of all of them in our clinic. Whooping-cough, pneumonia, intense anesthesia, or carbon monoxide poisoning, all renew the danger of anoxic damage, while metabolic and nutritional disorders in the post-fetal period may still exert a harmful influence. In fact, all of these problems merge into considerations of general pediatric care requiring the diagnostic and therapeutic skills of the physician. Hearing loss and visual handicaps should be detected and corrected as early as possible. From 25 to 55% of

mental defectives have been found to have significant hearing loss.8 Half of our clinic cases have significant eye complications, strabismus being the most common, and a distressingly large proportion of these retarded (as well as cerebral-palsied) children are found to have some visual loss in later life. not due to refractive errors, and probably due to a partial blindness from disuse. This strabismus may sometimes be due to specific nerve injuries, such as a 6th nerve palsy, but is probably most often due to a simple delay in the development of binocular vision or to damage of the visual cortex. Its early correction is important not only for its own sake, but for cosmetic reasons as well. Unfortunately, some specialists feel that a retarded child does not merit the special measures needed to correct these defects, but it should be impressed upon them that the retarded child has a particularly urgent need to have as many of his defects remedied as possible, precisely because his handicap makes every gain so meaningful. This is also true in the orthopedic area, where motor handicap deprives a child of ordinary opportunities for social and play experience and thus further constricts and hampers the child's development.

A crucial consideration in evaluating all medical treatments for mental deficiency is this: the most common pathological basis of mental deficiency is the lack or loss of brain cells, particularly of the cortex; and brain cells, once destroyed, cannot be regenerated. The absolutely hopeless implications of this fact, however, are relieved by three considerations: (1) that the lost function of the dead cortical cells may within limits, be taken over by intact cells, (2) that short of the cell's death, impairment of its vitality may, within limits, be relieved and (3) preceding the actual death or destruction of the cell, a period of pathophysiological attrition often exists during which the destructive process may be halted or reversed. Aviators at high altitudes, or skin divers far below the surface, will die if their oxygen supply is interrupted, but promptly recover if the respiratory embarrassment is brief. The same is true of individuals buried in an avalanche, exposed to carbon monoxide or cut down from attempted hanging. But if the anoxic embarrassment continues beyond a certain period, cortical malfunction associated with confusion may supervene before recovery. It is in this intervening period of vital but inefficient function, which may extend from a matter of minutes to a matter of years, depending on the noxious agent, that therapeutic intervention is most meaningful. There is a general positive correlation between the promptness of respiration in the newborn and the later functioning of the brain. It is therefore obvious that the obstetrician will have to be especially warned of the importance of prompt resuscitation to prevent the minimal anoxic damage that is so difficult to detect in early life. In later life—if we omit from consideration cases with gross cerebral defect the only types of mental deficiency associated with diminished oxygen uptake are Mongolism, phenylpyruvic oligophrenia, and cretinism. <sup>10</sup> The Beck-McKhann operation was advocated not long ago as a treatment for mental retardation because it purported to increase the amount of blood flowing to the brain. Since on the one hand no lack of blood flow to the brain has ever been demonstrated in mental deficiency, and since on the other hand the operation did not in fact improve the blood flow, it was foredoomed to failure and has been abandoned.

The oxygen uptake of the brain in cretinism can be restored to normal

values with thyroid medication, if begun early enough. This thus represents one of the three or four really specific treatments that we can boast of in this field. But unfortunately cretinism is a relatively rare cause of mental deficiency.

A second specific treatment has been developed for phenylpyruvic oligophrenia. Phenylpyruvic oligophrenia, or phenylketonuria, is a form of relatively severe mental retardation characterized by the inability of the organism to metabolize phenylalanine, an essential amino acid found in all protein foods. Its accumulation in the blood and excretion in the urine in the form of phenylpyruvic acid are pathognomonic. It was Woolf<sup>11</sup> in England who first suggested several years ago that the mental deficiency might well be due to the toxic depression of brain function from the high concentration of phenylalanine in the blood. Himwich had previously discovered that brain oxidation was actually depressed in these cases. Bickel and his associates, 12 using a phenylalanine-free casein hydrolysate diet reported a remarkable transformation in a young phenylketonuric child. Several similar reports have since been published 13-14; the results have not been uniformly good, and bear a direct relation to the age of the child, since irreversible changes appear to take place very early. At any rate, in this relatively infrequent form of mental deficiency, a real medical triumph can be recorded, consisting of systemic analysis and rational correction of a bona fide disease. Galactosemia, a more dangerous but even rarer condition associated with mental deficiency, has also very recently been similarly analyzed and treated. 15 It also is due to a genetic enzyme deficiency and its treatment consists in the preparation of a special galactose-free diet. With some of the modern technological resources available for the pursuit of these studies, I think one can safely predict that new types of enzymatic deficiencies susceptible to diagnosis and treatment will be uncovered in time. The recent discovery that some of these cases remain undiagnosed because they are only partially or occasionally unable to metabolize these substances, increases the importance of this work.16

Incompatible fetal and maternal blood can also lead to serious brain damage. But the early recognition of erythroblastosis fetalis due to Rh incompatability now makes it possible to treat the condition by total transfusion so that brain damage can be averted.

Glutamic acid is the only amino acid that can be oxidized by brain tissue in vitro. It is found in large quantities in the normal brain and it promotes acetylcholine production through its coenzymatic effect on cholineacetylase. When first used experimentally by Price, Waelsch and Putnam in 1943 in the treatment of petit mal epilepsy a general improvement in alertness, energy and mood was noted and it was therefore administered to a group of 8 mental defectives, 7 of whose I.Q.'s promptly rose 5 to 17 points under the drug's influence.<sup>17</sup> But when the experiment was again repeated in a larger group of more severely retarded children, the results were insignificant. For the past 10 years conflicting reports have appeared in the literature, but the current consensus of opinion is that the drug has no specific value.<sup>18,20</sup> In fact, it has been established that glutamic acid administered by mouth cannot penetrate the blood brain barrier to reach the brain, and it is now believed that it acts mainly on peripheral organs to produce a type of adrenaline-like stimulation. I think there is hardly a parent in the Association for the Help of Retarded

Children who has not at some time or another—often at considerable expense—been told to try glutamic acid for his child. Yet when a distinguished pediatrician recently announced to a large Association for the Help of Retarded Children audience that he had found it worthless, his statement was greeted by a spontaneous burst of applause. References to its use in mental deficiency have almost disappeared from the scientific literature, and the last dozen reports were either flatly negative or described minor benefits in stimulating interest and activity in mildly retarded children whose demeanor had been rather apathetic. When the trouble, expense, and annoyance to the child are considered, it will seldom be worth while to recommend it.

Other stimulant drugs, as well as sedatives, can assist in the medical treatment of retardation. Apathy and restlessness are important physiological modalities which may affect intellectual development. In its extreme form, apathy may lead to a vegetating type of indolence or to the peculiar inward type of activity we call autism; restlessness and distractability may range from moderate hypermotility upon stimulation, to constant wild and unmotivated excitement. Pharmacological agents may be effectively used in either case. Though such agents may thus improve intellectual performance or even lead to a raising of the I.Q., the public should not be misled into thinking we have thereby found a medical cure for mental deficiency. Unfortunately several recent premature press reports, especially those involving chlorpromazine and reserpine, have already raised false hopes.

Malnutrition, vitamin deficiencies, or the lack of certain trace elements, can all undoubtedly contribute to the apathy and dullness of the child and sometimes demand attention and correction. But here, too, it should be emphasized that in spite of occasional benefits in particular cases, vitamins have no demonstrable specific value in the treatment of mental retardation and parents' hopes should not be raised by unsubstantiated claims or promises. The fact that animal experiments have shown that Vitamin A deprivation during gestation produces malformed monsters with cerebral defects does not justify the expectation that Vitamin A will cure mental deficiency. The same applies to Vitamin B-l and Vitamin B-12.

What can be said for vitamins is equally true of hormones. There is no doubt that various endocrine disorders may, and sometimes do, affect intellectual function; but aside from these general considerations which should keep us medically alert, there is no known specific relationship between any endocrine deficiency and mental retardation, with the single exception of cretinism, which is relatively rare, and the possible exception of Mongolism, where the relation is obscure. Only cretinism can be specifically helped with thyroid medication. Mongolism may be helped to some modest degree by Benda's formula of whole calf pituitary and thyroid.<sup>21</sup> Thyroid is being widely prescribed, however, for many cases of mental deficiency, where it helps, or seems to help, like glutamic acid or benzedrine, mainly by its stimulant effect. But except in cases where a specific hypothyroid factor can be demonstrated, I think its use should be discouraged.

A variety of metabolic, anatomical and functional abnormalities have been described in Mongolism, for almost all the body systems and organs are implicated in the disorder. The recent finding by a group of workers at our clinic

that Mongoloid children have impaired Vitamin A absorption should not arouse premature hopes. Glucose absorption is also impaired. A number of other metabolic abnormalities, such as large molecule lipo-proteins in the serum, have been described in this condition, which may prove to be related to impaired liver function. Mongoloid children almost all have liver damage, though, interestingly enough, liver damage is encountered in other types of mental deficiency as well. Mongoloid children also have high gamma globulin values, but this is encountered in other mental defectives too. <sup>22 25</sup>

There has lately been some stirring of interest in the New York area in the reputed efficacy of a new treatment of Mongolism developed by a Dr. Paul Niehans of Switzerland. The preparation administered is a cellular extract which can now be imported from abroad. I have made serious efforts to inform myself on the scientific status of this preparation. Unfortunately the bibliographic service of the American Medical Association knew nothing of Dr. Niehans and no scientific publications by him have been recorded in the world's medical periodical literature for the past 10 years. I could, however, find an extremely sketchy, anecdotal and thoroughly unscientific pamphlet of his published in German in 1948 and translated into English in 1952, which claims successful treatment of dozens of medical diseases with his cellular injections—but without mention of Mongolism. A popular article on Dr. Niehans' cellular therapy appeared in a German periodical, the Berliner Illustrierte Zeitschrijt, the German equivalent of our Loo, in March 1954, describing his successes and showing the photographs and X-rays of a 13-year-old Mongoloid girl called "little Gisela," successfully treated between 1951 and 1954. The magazine boasts that it is the first periodical to announce his "sensational success." The same photos of the same girl were also, I found by chance, later reproduced in a scientific medical journal Aerztliche Forschung last year in the course of an article by a Dr. Hellmut Haubold of Munich,<sup>26</sup> in which he claimed more modest successes with a more complex approach in which he used not only Niehans' cells but also vitamins A, B, C, phosphate, calcium, iron and other metallic salts, yoghurt, liver, a variety of endocrine preparations, etc. Here little Gisela was called I.K., while her supposed X-rays became those of a Mongoloid boy H.K. aged 5 years! Of 126 cases, 50% were said to respond "surprisingly well" and another 20% "pretty well."

I do not wish to disparage serious work, but this manner of sensationally publicizing a single anecdotal case through unscientific channels or publicizing data without satisfactory experimental procedures or controls does not seem to warrant the confidence of physicians or parents. The use of cellular extracts as biogenic stimulators—usually associated with the name of Filatov—has attracted serious attention in medical circles throughout the world but so far as I know no serious scientific claim has ever been made by any of the many workers in this field that it can cure Mongolism.

# CONCLUSIONS

Medicine has an important and essential contribution to make to the diagnosis, medical treatment and general management or rehabilitation of the mentally retarded. It has a central role in research and a strategic role in prevention. Because mental deficiency is a symptom and not a disease and because it is due

basically to interference with brain and body function, all the resources of medicine may be implicated in its treatment. Mental retardation is not the dead end product of an immutable state. Since brain cells, once destroyed, cannot be regenerated, there are serious limits to our medical help, but even within these limits much can be done—and fortunately the destroyed brain cells are seldom the only factors we are called upon to treat. And finally, diagnosis, treatment, research, and prevention, are all so intimately bound up with each other that physicians can find rich and rewarding opportunities for fruitful participation in this field.

#### REFERENCES

- The Mentally Subnormal Child, World Health Organization Technical Report Series No. 75, 1954, 46 pp.
- 2. Tizard, J.: Bull. World Health Org., 9: 423, 1953.
- 3. Plummer, G.: Pediatrics, 10: 687, 1952.
- 4. Yamazaki, J. N, Wright, S. W, and Wright, P.M.: Am. J. Dis. Child., 87: 448, 1954.
- 5. Klcbanow, D.: Deutsche med. Wchnschr., 19, 606, 1949.
- 6. Rider, R. V., Taback, M., and Knobloch, H.: Am. J. Public Health, 45: 1022, 1955.
- 7. Cairnes, H.: Lancet, 2: 411, 1951.
- 8. Foale, M., and Paterson, J. W.: Am. J. Ment. De)., 59: 255, 1954.
- 9. Breakey, A. S.: Arch. Ophth., 53: 852, 1955.
- Himwich, H.: Cerebral Metabolism and Mental Disorder, Baltimore, Williams and Wilkins, 1952.
- 11. Woolf, L. I., and Vulliamy, D. G.: Arch. Dis. Childhood, 26: 487, 1951.
- 12. Bickel, H., Gerrard, J., and Hickmans, E. M.: Lancet, 2: 812, 1953.
- 13. Woolf, L. I., Griffiths, R., and Moncrieff, A.: Brit. M. J., 4905: 57, 1955.
- 14. Armstrong, M. D., and Tyler, F. H.: /. Clin. Invest., 34: 565, 1955.
- 15. Kalckar, H. M., Anderson, E. P., and Isselbacher, K. J.: Proc. Nat. Acad. Sciences, 42: 49, 1956.
- 16. Keup, W.: Mschr. Psychiat., 129: 344, 1955.
- 17. Waclsch, H.: "Metabolism of Glutamic Acid and Glutamine." In *Neurochemistry*, by Elliott Page and Quastel, 900 pp., Charles C. Thomas, Springfield, 1955.
- 18. Leedham, J. N.: Medical Officer, 93: 117, 133, 1955.
- 19. Koch, H.: Arch. f. Psychiatr. Nervenk.r., 191: 463, 1954.
- 20. Muller, H. W.: Oeff. Gesundhdienst., 15: 387, 1954.
- 21. Benda, C. E.: Quarterly Rev. Pediatr., 8: 79, 1953.
- 22. Donner, M.: Ann. Med. Exper. Viol. Fenniae, 32: Suppl. 9, 1954.
- 23. Torre, M., Scarzella, R., and Zanalda, A.: Boll. Soc. ital, biol. sper., 31: 54,: 1955.
- Simon, A., Ludwig, C., Gofman, J. W., and Crook, G. H.: Am. /. Psychiat., 111: 139, 1954;
   Ment. Sc, 100: 894, 1954.
- 25. Crome, L.: Some Morbid-Anatomical Aspects of Mental Deficiency, pp. 894-912.
- 26. Haubold, H.: Aerztliche Forschung, 9: 1-211, 1955.

# Physical Medicine

JEROME S. TOBIS, M.D.

Professor and Director, Department of Physical Medicine and Rehab: New York^ Medical College

THE FIELD OF PHYSICAL MEDICINE AND REHABILITATION concerns its: the care of children with neuromuscular and musculoskeletal disorder-fore, the contribution of the field of Physical Medicine and Rehabik:-directed primarily toward the mentally retarded child who has cerebr. or manifestations of other neuromuscular dysfunction.

The philosophy of Physical Medicine and Rehabilitation is base.: concept of total care. It looks upon disease as more than the specific;. For example, a child who has a tuberculous hip joint is suffering frethan the particular tubercle bacillus and the destructive processes to the is suffering from the social psychological effects of invalidism. The an impact upon the family as well. In evaluating disease, the field of Medicine and Rehabilitation as, in truth, all of medicine does and states its attention to the totality of the problem.

The disease in a handicapped child has a social character as biologic one, and it therefore requires more than the specific clinical is traditionally employed in medicine. Thus the optimal care of h children requires the contribution of many medical and other pr disciplines working together as a team. However, the special skills i : discipline must be subordinate to the programmatic considerations in of the child. Thus, in the care of a child any one discipline may have M less than the maximum of service available.

I would like to cite as an example of this concept the case of a palsied child with mental retardation who is participating in a program, but who requires extensive dental care—dental care to the it would completely disrupt his therapeutic program. It may require. a case, that the child have less than the maximum, less than the optim.. care so that the total programmatic considerations of this child will into account and the dental care prescribed scheduled within the: ment plan.

We in Physical Medicine and Rehabilitation feel that in the care children effective teamwork is very important, but sometimes te... occasionally identified with anarchy. Teamwork requires a leader direction. It also requires the mutual respect of the participants i: different disciplines to work together. It is my personal belief that s::: dealing with biological phenomena, i.e., clinical problems, that sue should be under the direction of the physician.

There are two major physiological areas with which the field of Physical Medicine and Rehabilitation is concerned. One is the learning process, and the second, motor activity. Rehabilitation is primarily a learning or relearning process. In children it is a process of learning new functions, and therefore sometimes the term "habilitation" is perhaps more appropriate than "rehabilitation."

The brain determines all motor activity, and it, in turn, is dependent upon the capacity of this brain to receive and organize sensory stimuli from the outside world. Motor function is, from this approach, only the end result of the response to perception and organization of exteroceptive and interoceptive stimuli. Rehabilitation care, therefore, requires a thorough evaluation, especially in the brain-damaged child, of (1) sensory perception, (2) his capacity to organize that which he perceives, and (3) his motor function in relation to this sensory organization.

In our children's program at Bird S. Coler Hospital all children routinely have ophthalmological, hearing and psychological evaluations. These procedures are not done simply to obtain an intelligence quotient, but they enable us to determine what and how the child perceives the world around him.

From this we gather insight into the child's learning capacity, and thus develop techniques by which to work with these children. For example, we have had a child who is considered severely retarded, and who does not respond to verbal stimuli. We observed, however, that if he is placed in a darkened room he follows oral commands readily. By this procedure we have improved one area of his sensory perception (the auditory) by repressing another sensory perception (the visual). Out of these observations we have tried to analyze each sensory activity and have attempted to resynthesize them, where possible, in accordance with the patient's needs. Thus, this may mean at one time reducing the stimuli impinging upon the child, and within this framework the child with brain damage usually requires a well-structured and quiet environment. The more stimuli impinging on his nervous system, generally, the more disorganized the response.

However, in a second child it may mean that in addition we may have to provide other cues, such as the use of sound or color. In a third child it may mean the use of the supportive device, not for weight-bearing purposes or stability, but for proprioceptive stimuli, so that the child may be aware of where his leg is.

The second major area in Physical Medicine and Rehabilitation is motor activity. Motor activity is dependent upon muscle bulk, and this depends upon active exercises which will increase motor power.

Now, with these two factors in mind our field attempts to increase the function of the brain-damaged child. These functions include the following:

- (1) To improve his strength and skillful use of his upper extremities so that he will be able to attain a greater degree of independence. Thus he may learn to feed himself, to dress himself, and to participate in other activities of daily living. Sometimes we provide special self-help devices to facilitate in this activity.
  - (2) We attempt to improve the child's ability to ambulate—to get from

here to there. This entails increasing the child's strength, his balance, and his capacity to move forward.

The third area that Physical Medicine and Rehabilitation participates in is the correction of deformities. This is especially seen in the cerebral palsied child, where there are frequently contractures, shortening of muscles and deformities. This is done by passive stretching and by active exercise.

The fourth area is a responsibility to the parent, so that when the child leaves our institution or the clinic these activities will be carried on in the home setting. And so the parent is informed: first, the reasons why we are doing what we do and, second, the techniques for carrying the program through in the home.

And, finally, we feel that the role of work therapy is important in these children and adolescents. The use of Occupational Therapy may be valuable in this. We have, for example, at Bird S. Coler Hospital a sheltered workshop in which our cerebral palsy adolescents (many of whom show moderate to severe retardation) are participating, in which they are doing meaningful, socially useful work, and for which they receive a modest financial return.

Finally, I would like to discuss some principles of care.

From these remarks one can see that rehabilitation requires the active participation of the patient. No matter how effective a device, gadget, or self-help instrument may be in facilitating function, no device ever will be invented that can replace the active participation of the patient.

Secondly, rehabilitation is symptomatic therapy. Although an understanding of the pathophysiology is essential to evaluate prognosis and contraindications, treatment is directed to the symptoms and not to the disease. Therapy is conducted to gain skills, no matter where the locus of brain pathology or what the etiologic agent, whether it be an Rh factor, a virus encephalitis or a genetic cause.

Thirdly, there is an important difference between the brain-damaged child and the brain-damaged adult. In the disabled adult we attempt to restore an established pattern of social activity; in the child we must guide the development of a pattern of social behavior. This includes his education, his vocation, his experience and emotional maturation. It means, therefore, that we must strive to develop a pattern of behavior that will enable him to become as socially useful a citizen as possible.

In order to obtain this objective there must be constant re-evaluation throughout the child's care, with short-term goals and rediagnosis and arrival at new goals. Only in this way may we apply the principles of growth and development in an integral manner through therapy. Too often we label the diagnosis in a static manner and as a result too often our therapeutic objectives remain static and unchanging. This is the key to the care of all handicapped children and it applies to the mentally retarded as well.

# Psychological Treatment

HAROLD MICHAL-SMITH, Ph.D.

Chief Clinical Psychologist, New Yor\ Medical College

THE ROLE OF THE PSYCHOLOGIST in the team approach in a clinic for the mentally retarded is to contribute to the formulation of the diagnosis, prognosis, and management of the child. Each patient is given a psychologic evaluation as part of his complete work-up. As the result of this evaluation a determination of the extent of the deficiency in the child's intellectual, emotional and social development is made. Concomitant with this, the psychologist further seeks to determine whether factors other than true mental retardation contribute solely or in part to the functioning at a retarded level. Factors which may influence or complicate the diagnosis of mental retardation are organic involvements (cerebral palsy, brain damage, epilepsy), emotional disturbances, language and motor disabilities, cultural and social factors. It is particularly important for the psychologist to determine whether these factors are a cause, effect, or combination in the pathogenesis of the retarded function.

One of the most important functions of the psychologist is to ascertain the child's intellectual abilities and emotional maturity. An examiner should endeavor to draw as many inferences as possible from the test material concerning the quality of "natural endowment," the influence of the educational environment, the effect of schooling and of life experiences, and the effect of special cultural patterns to obtain a baseline against which to evaluate the implications of specific problems concerning the child or special strengths which he may appear to have. The type of personality development, the setbacks and arrests of intellectual development, the impairments of previously achieved levels, and the temporary inefficiencies which prevent an impaired individual from functioning well should be presented in the case of a suspected mentally retarded individual.

In some measure the responses of a child to the test are replicas of his responses to life situations. Attitudes are also suggested. Psychological tests give an opportunity to compare the performance of the child with that of other children of his age and social status. Such a possibility of comparison would seem to be a fundamental value of intelligence and personality tests.

During the time the examiner is giving the test or tests, he has the opportunity of observing the child's behavior. Often this behavior is very suggestive in leading to the discovery of the etiology of the particular problem.

The great variety of standardized tests presently available for measuring many sorts of performance makes it possible for the examiner to gain a well-rounded picture of the child's ability. Primarily, every test measures a certain type of performance of a certain child at a certain time. The performance may

be verbal or manual; it may involve visual, cutaneous, kinesthetic, or auditory sensitivity; it may be influenced by emotional conditions, physical status or other factors. The performance of a child at a given time is no guarantee that a future performance will be exactly the same, or that his success will be of similar degree on another type of test.

While it is difficult to measure the total complex of personality, let alone the process of integration, it is possible to glean a picture of the dynamics of the personality structure. Personality tests are objective psychological devices which have a degree of reliability and validity in measuring various tendencies which are aspects of the total personality.

Following the testing, an evaluation is then made of the intellectual functioning and capacities, academic achievement, personal and social adjustment, and the intricate personality dynamics are integrated into a psychological report which also includes a diagnostic impression and recommendations.

It is from this point that the psychologist takes on his function as an integral member of the team. On the basis of the diagnosis, prognosis, and recommendations, staff conferences including all other disciplines (pediatrics, psychiatry, social service, education, speech, etc.), are held. Each discipline which has had contact with the patient in question, presents his findings. The recommendations of the psychological examination are integrated with the other findings and final disposition is formulated. This might include further psychological study and examination as well as treatment of the patient.

The psychologist thus far has a two-fold role in this setting. His first being in a diagnostic evaluative position and the second in the actual treatment or carrying out of specific recommendations as worked out by the total team. This latter function is actuated in the following manners: counselling with parents, group therapy with parents or child, individual or group art, music, or play therapies, remedial education. Individual counselling with parents is often held to give them an interpretation of the problem, techniques in management, and assistance in a home-training program when indicated.

Group counseling with parents are for those parents whose children are concurrently seen in group therapy sessions by another member of the psychology staff. The program is focused on problems relating to the children involved rather than on specific personality problems of the individual parents themselves. The pattern employed is that of group psychotherapy. The role of the therapist is to highlight aspects which develop insight and to give individual group members such support as they may need in expressing their feelings and relating their experiences before the group. Immediate and long-range goals in the social management of the retarded child are discussed.

When the child indicates marked social immaturity he is referred for group therapy. The aim of this therapy is to promote emotional growth through social interaction. These children are provided with an interpersonal experience that is usually denied them by unequal competition when among average children. As a result of group therapy experience, the retarded child is given encouragement and opportunity to express himself. This develops within him sufficient feelings of security to extend to the outside world.

Art and play therapy is a diagnostic as well as a therapeutic method in which the child may express his emotional feeling tone through the medium

of graphic arts, drama, and play. His environmental situation as he views it may be discerned through his use of the material. This technique is most valuable because it is a natural mode of expression for children and does not require a great deal of verbal interaction. Its effects in terms of release are similar to those realized in adult form of psychotherapy. The child in therapy can express his feelings on a level commensurate with his maturational process. An interpretative analysis of the art, play, and observations are recorded and used for diagnostic purposes.

Music therapy provides patients with an outlet and release for emotional tension and improves breathing habits, breath control, sound and pitch production and results in better phonation. It provides a pleasurable motivation for improving the use of the hands and fingers through the playing of the various instruments and serves as a socializing agent.

A

Educational therapy is planned to give individual and group remedial instruction, perceptual re-training and supportive therapy to those children who are preparing for school placement or who are experiencing marked learning difficulties.

Finally, the psychologist lends his skills to multi-disciplinary research projects as well as research within his own field.

The task of all who deal with the mentally retarded child is made simpler if the child's environment is adjusted to afford him a chance to feel successful and acceptable. In achieving this environment, parents and family members often need professional counsel and guidance. It is through the team approach that the professional can best meet the needs of the mentally retarded. In this field the need for courage and for deeply felt honesty in admitting what the problems really are is of paramount importance. We can serve the child who is mentally retarded only by learning to know him as he is and training him to be what he best can be in the light of today's knowledge and resources. The gaps in our knowledge and our failures will be corrected only in the light of the philosophy of a never-ending search for the prevention of mental retardation. It is only through the combined efforts of many disciplines that we can look forward to refining the diagnosis, habilitation and prevention of mental retardation.

# III. TEAMWORK IN THE TREATMENT OF MENTALLY RETARDED CHILDREN

# Speech Therapy

DORIS T. LEBERFELD, Ed.D.

Instructor, Department of Speech and Dramatics, Hunter College

IT CAN BE SAID WITH REASONABLE ACCURACY that theories of training in language and speech have progressed from the infancy stage to the early childhood stage. Prior to 1950, the opportunity to work with retarded children was extremely limited inasmuch as comparatively few were presented for evaluation. In the five years that we have worked with the children enrolled in the Clinic at Flower Hospital we feel that we have achieved some sophistication and that we have progressed towards some basic operational beliefs.

In an experiment conducted some time ago at the Clinic for Retarded Children, New York Medical College, Flower and Fifth Avenue Hospitals, it was noted that the children who improved in language and speech as a result of therapy also improved correspondingly in measured mental ability. It would be impossible to draw any definite conclusions from this small pilot study but it would appear to be worthwhile to continue research along these lines in order to further the understanding of the relationship between the development of language and speech and mental abilities.

It has been stated frequently that the retarded child does not profit from language and speech training until he has reached a specific mental age. Estimates have varied but a mental age of five years has often been used as a base line. At present, it is the feeling of those of us who have been working in this speech clinic that the mental age and I.Q. cannot be used as the criteria for introducing therapy. We no longer feel that there is a time when the child is "ready" for therapy unless that time be placed approximately at fourteen to twenty-two months of age when the child would have developed speech had he otherwise been functioning normally. By instituting therapy as quickly as the child can be identified and by providing a structured language and speech environment in the home through the training of the parents, we feel that we can  $ma \nmid e$  the child "ready."

The danger in waiting comes from the fact that one may miss the moment when the greatest response might have been forthcoming and future progress becomes increasingly more difficult. In addition, delay in introducing training may result in further functional retardation since the child's ability to communicate and to interpret what is communicated to him is limited.

We have found, for example, that the child who has been exposed to a home training program in speech is much more capable of profiting from professional training. Even though he may not possess any specific skills, he is far more cooperative and responsive as a result of his home experiences.

The concept of language and speech therapy for the retarded child has

changed radically from the point of view of emphasis. It is now recognized that it is in the language area that the child has his greatest difficulty. Language can be defined as the ability to communicate ideas and feelings through the use of word symbols and the ability to understand and respond adaptively to the ideas and feelings of others as conveyed through the use of word symbols while speech may be defined as the utterance of articulate sounds. Language is the higher function of the two and unless language is present, there can be no true speech. Therefore, in working with these children, stress is placed primarily on language functions with training of articulation taking second place. The aim first of all is to provide the child with the ability to communicate and to respond to communication and secondarily to make this communication an artistic expression.

The global approach to retarded children would seem the only realistic one if their complex problems are to be effectively resolved. The ideal setting for the execution of intensive language and speech training is of course in a center which provides all types of services. The speech therapist depends heavily on the guidance of the other disciplines such as pediatrics, neurology, psychology, etc. When a total diagnostic program is in effect, the speech therapist is better able to plan a program which will attack the basic problems the child exhibits. On the other hand, the speech therapist can be an active and important contributing member of the team because he may observe the child more frequently than almost any other member of the group. In a sense, then, it might be said that speech training is not only therapeutic but diagnostic as well.

Research workers in the field of mental retardation have long recognized that communication problems are associated with inadequate mental development but the challenge for creating techniques which will alleviate this condition remains with the Speech Therapist in association with the other members of the team.

# III. TEAMWORK IN THE TREATMENT OF MENTALLY RETARDED CHILDREN

## Educational Guidance

CHRIS DI PROSPO, M.A.

Assistant Professor of Special Education, City College of New Yor\

"WHY CAN'T MY CHILD BE PROMOTED from a low I.Q. class to a CRMD class?" "What town in Nassau County should I move to for schooling for my severely retarded child?" "When will my child go to high school? Shall I tutor my child in reading and arithmetic? Will my child be able to get a job and hold it when he leaves school? Should I institutionalize my child?"

You have all heard these questions many times. Yet we must give some type of response. Clinics for the retarded will, I am sure, make it easier to discuss such problems.

One of the common misconceptions about mental handicap is that the condition is a homogenous one as far as behavior is concerned. Since it is not, the multidisciplined approach to the subject is a must if we are to help the child and his family.

When the medical, psychological, and social casework is completed the educational worker must review all the findings and come to some decision as to educational prognosis.

Although this may seem obvious to most of us, there is a tendency in some areas to keep from the educator pertinent information relating to the child. This, many times, is predicated on the premise that such information is either confidential or not in the realm of the understanding of the educator. At times, the person who will work with the child daily is denied information that might lead to better educational planning.

Fortunately, in some clinics this is not the case. Not only is the information available but the various disciplines are ready to cooperate with the educator wherever necessary. I believe this is essential for realistic educational planning.

With this in mind, what then is the role of the educator in a clinic using the multidisciplinary approach? Certain information is necessary to fully carry on a program of educational guidance. Guidance without facts is like eating without food.

Among others, the educational worker must have:

- 1. A complete and up-to-date knowledge of the public school facilities for mentally handicapped children. This also necessitates knowing state and local school regulations.
- A close personal working relationship with the school people charged with the administration of the public school facilities.
- 3. A complete up-to-date knowledge of pre- and post-school facilities.
- 4. A close liaison with the public institutions for the mentally retarded.

- 5. A close association with parent organizations and the service programs they conduct.
- 6. A close working arrangement with the teacher-training institutions within the geographic area.
- 7. An alertness to the services of other agencies not directly for the retarded but who offer service which might benefit our children.
- 8. Knowledge of private school facilities for the retarded.

One of the most important aspects of the teamwork approach is the need for keeping the other disciplines aware of new developments in the field. The educator must get to his team information on new state regulations, educational research, organization of extra and different facilities; in short, anything in the field of education that will lead to better planning for the children. I believe that it is essential to devote some time each year to "refresher" sessions at which each discipline presents the above facts.

For example, I am concerned at the present time with the use of tranquillizing drugs. My concern is purely for the educational effects. If a child shows a certain pattern of behavior and we reduce or eliminate it through drugs, will the teacher be able to modify her teaching technics because of it? More importantly, will she be misled by the seemingly new type of reaction? The answers to this and other problems can only be reached by a complete interchange of experiences and ideas.

It is difficult for many of us to discard some of our pet notions. We educators are inclined to put too much stress on I.Q. ratings. I think one reason is that we deal with great numbers of children and we must have some standards to lean on. I do not think it begging the question to state that the educator has a unique role in his relationship to the child as compared with the other disciplines. We must deal with children in groups while most of the other disciplines have an individual relationship with the patient. The child in a cubicle may be a very different individual transferred in a group of ten children in a large building with fire drills, auditorium periods and the demands of many adults for conformity. More important we must realize that the teachers who handle the children are not experts in such areas as psychological therapy, speech development and medical diagnosis.

It seems easier to cram information into a theory than it is to check theory against fact. The extremely important correlative information that comes from other disciplines must be available to all. The pediatrician and dentist also talk to the parent, the social worker may know the entire family constellation. Unless we are extremely careful each tends to ride his own hobby. The educator sometimes has to make crucial decisions. Should he recommend public school placement? Will the child adjust in the only particular special class available to him? This decision will have immediate repercussion, if it fails, on the child, the family, and the clinic. This brings up the fact that a follow-up system must be installed to keep in touch with later developments, and that immediate counseling be provided for cases that show problems of adjustment.

When we realize the enormity of our problem extending from the cradle to the grave, we must see the importance of being unified whether we be physicians, psychologists, social workers or teachers. When we realize that only through the coordination of all disciplines can we achieve a complete program for the retarded, it becomes imperative that no part of us be divided, either within a particular profession or among the various disciplines.

I do not believe that any one discipline has the complete answer to the problem of retardation. There are many aspects of the problem that are unknown and it will only be through cooperative planning that answers will be found. Other groups, perhaps not even thought of at present, will have to be put on the team as we find their knowledge and cooperation essential.

# III. TEAMWORK IN THE TREATMENT OF MENTALLY RETARDED CHILDREN

## Social Work Services

WINBORN E. DAVIS, M.S.W.

Administrative Director, Louisiana Evaluation Center for Exceptional Children

MY REMARKS ON THE SOCIAL WORKER'S ROLE in the teamwork treatment of mentally retarded children are drawn from some five years of personal experience in utilizing the team approach to the evaluation and short-term treatment of all types of exceptional children.

No effort is made here to indicate that these remarks are a summary of the social worker's role generally, nor is any attempt being made to infer that this is the only way to utilize social work services. These observations are presented, rather, as an example of how social workers may function successfully in a teamwork setting.

## ADVANTAGES OF TEAMWORK

In our collaborative approach to work with the mentally retarded we have simply utilized the methods of a group of specialists who have for a number of years demonstrated the efficacy of teamwork. I refer to the psychiatric clinic team, particularly as it functions in the guidance center setting. We have expanded this team to include all the specialists who work with retarded children, while at the same time seeking to preserve its proven values as an approach to evaluation and treatment.

We hold to the concept that concurrent examination of the child and intemewmg of the parents by separate workers have certain therapeutic values. Social workers have demonstrated their ability to give helpful services to parents in guidance centers and other psychiatric settings. They are the logical persons to work with parents while the physician, psychologist, educator, speech therapist and so on are evaluating and treating the mentally retarded child. Also, we feel strongly that parents should have a continuing relationship with one person throughout the period of diagnosis and treatment in order that there may be a minimum of confusion and a better opportunity for therapeutic gains. Although our parents do see other professionals during their contacts at the Center the social worker is the person that they look to for this continuing relationship.

### INTAKE

There is general acceptance of the idea that treatment and diagnosis cannot be separated, and the social worker's role in teamwork treatment begins with the application for service. Traditionally social workers are trained in the intake process; therefore, we have them handle applications and conduct initial interviews with parents before the children are seen. There is an increased tendency in our Center to give more responsibility to the social worker experienced in psychiatric and medical settings in deciding on such intake matters as the parents' readiness to utilize help, their capacity for change and their resources for carrying out recommendations. Whereas, we earlier conducted intake conferences with medical director, chief psychologist and social worker on *each* case we are more inclined now, when our social workers have sufficient experience to assume this responsibility, to have them make the decision on when a case is ready for admission.

Following the intake interview our social workers are called upon to obtain reports of any previous diagnosis, treatment or training that the child has received from other agencies, institutions or private practitioners. Our beginning point with each case is to secure all possible background information of this type in order that we may know what additional work is indicated to complete the evaluation of a mentally retarded child. In this regard, it may be noted that our findings at present indicate medical diagnoses have generally been very complete when the case reaches us. As our program shapes up, it appears that the greatest needs are for further diagnosis in specialized medical areas, an evaluation of intellectual, social and emotional growth and adjustment, a study of educational limitations and potentials, and counselling with the parents.

#### THERAPEUTIC HISTORY-TAKING AND INTERVIEWING

One of the most gratifying services from the standpoint of social workers is that of therapeutic history-taking. For some time now social work has tended to move away from a structured process of securing social, medical, educational and developmental histories. In our Center social workers are much less information-centered in their work with parents and more oriented to therapeutic interviewing. Professional writings in social work bear out the facts that as much specific background information is received from parents through this method as from the more structured interview and that therapeutic gains are much greater.

An integral part of this history-taking and interviewing process is the offering of support to parents so that they may deal with their own feelings and relationships as they are interwoven with the child's problem. Most of them come to us having shopped around extensively from clinic to practitioner to agency in an effort to find some kind of helpful answer to their concerns. Generally, parents have been given very accurate information concerning their child's condition but they still say of their previous contacts with professional people, "They didn't give me any satisfaction one way or another." Upon analysis of this statement we found that most often a great deal of information had been secured from the parents, put into some meaningful form by professional workers and given back to the parents with instructions on what to do about it. The "satisfactions" which parents complained of not getting apparently lay in the opportunity to react to what they were told, to explore their relationships with the child and to increase their understanding of the emotional factors involved.

With the kind of casework help offered in our Center, the parents, often for the first time, explore their own feelings about the problem with which they are confronted. By and large, they are not emotionally sick people, as one might expect to see in "a psychiatric setting; they are the normal people of our society striving to appear\_adequate...ajid-tQL-liv£.,.up-to,culturalexpectations in the face of a "tragedy that has entered their life. Nonetheless, they are often beset with grieFand sorrow that this should happen to them, a hopelessness about what can be done, anxiety and guilt over what they might have done, or what they might not have done—both before and after the child's birth—to cause the deficiency. Feelings of resentment and anger that this should happen to them and to their child are also noted. While the evaluation process is under way with the child, social workers help the parents, depending upon each one's personality functioning and degree of need, to become more aware of these emotional factors and to gain some acceptance of them. -This is considered to be an integral part of the work we do with the mentally retarded.

## INTERPRETATION OF FINDINGS

The social worker also has a function in what we call the final interview, a session or sessions in which the findings are discussed and recommendations are made. Actually, we observe that if the social worker has been able to work effectively with the parents during the evaluation they have gradually come to accept what they had known already about their child's limitations. These last interviews may be conducted by the social worker alone, by the social worker and one or more other professional members of the staff, or by another professional alone, depending upon the nature of the findings and the team's recommendations.

It is as if the social worker has been preparing the parents all along for the recommendations of the educational specialist since our work is oriented to helping children attain the highest level of adjustment possible with their limited abilities. The educator has often observed that until parents have dealt with the above mentioned feelings and come to an acceptance of their child's limitations they will not be able to see the child's potentials as they really are, nor will the parents accept or participate in realistic planning for their child's training or education based upon his individual needs and capacities.

### REFERRAL TO OTHER AGENCIES

Social workers serve a further function in the team approach when utilization of other community resources is indicated. Being particularly trained in community organization they are aware of the services and referral policies of other community facilities and can often expedite inter-agency cooperation. Generally, they are trained to abstract records and to compile reports in the event of referral to other agencies. Additionally, their continuing relationship with parents may enable them to help mother and father work through any resistances they have to being referred or to using some other facility. This kind of help may be the vehicle by which parents are able to follow through on recommendations made by the staff.

#### SOCIAL WORKERS AND RESEARCH

Social workers may be able to collaborate in research on treatment or other aspects of mental retardation but the dirth of research-minded social workers is often a concern of the profession. Researchers from the psychological field are often loathe to share their research findings with a social worker for the latter will not likely enjoy it as a scientific success but immediately raise the question of how these findings apply to the people with whom he is working. Although some social workers are excellent researchers most of them appear to prefer collaborating with other specialists who assume major responsibility for research with the mentally retarded.

## WORKING AS A TEAM

Whatever the peed, or the extent of specific duties assigned to each discipline it is our opinion that the highest value will be found in a face to face collaborative approach in which each professional brings to bear on a mentally retarded child's problem the understanding and skills of his particular discipline. The quality of performance will increase not only as each professional becomes more competent in his own discipline, but also as he gains understanding and acceptance of what other professions have to contribute. This will naturally increase his skills of functioning as a team member and may result in less and less need to over-define and protect his own area of operation. If it is to be a true teamwork approach no one profession can consider that its services are universally more essential than another, nor can it consider that other disciplines are ancillary to its own. Maximum value in this approach can be attained only when each profession is able to lay aside the prerogative gathered unto it by its own members, or ascribed to it by the culture, and focus its attention and energies along with the other professions on services to children. Out of a much improved method of working together will come increased happiness for handicapped children and their families, and there certainly will be enough room for each discipline to share in the successes.

## III. TEAMWORK IN THE TREATMENT OF MENTALLY RETARDED CHILDREN

## The Role of the Parent

# J. CLIFFORD MACDONALD President, National Association for Retarded Children

As THE PARENTS' SPOKESMAN, I find it a pleasant but somewhat shocking surprise to be speaking of the parents' role on the clinic team. There are two reasons for such an attitude.

In the first place, parents of retarded children have had the repeated experience of being referred from one specialist to another, having no one professional worker to whom they could go to find the answer to heartbreaking questions. Parents have been expected to piece together a difficult jig-saw puzzle of causes and treatment of retardation and desirable practices in rearing a retarded child. Oftentimes, the various specialists even seemed to contradict each other in diagnosis and simple recommendations.

In the second place, past practices have forced parents to accept a passive role because the specialists told them what to do in one, or at most, two overly brief sessions. Parents were lucky if they really felt confident to assume their duties in caring for their retarded children as a result of such disjointed handling.

Today, you ask me to present the parents' viewpoint on their proper role on the clinic team. I say happily that modern practice may assign parents their proper place at last. Please remember that the parents spend incomparably more time with the child than does any other member of the team. The real architects of the child's past, present and future are the parents. Whether the team is a success or failure in giving its skills and time to the child depends upon the parents' understanding and attitudes. The team's effectiveness can be translated into meaning for the child only through the medium of the parents.

Would it be incorrect to say, then, that the most important member of the team is the parent couple whose child is being evaluated and treated? The main ingredient of a successful follow-up plan is not medicine, surgery, pills, injections or even education or training. At the present stage of knowledge, these measures are supplementary when needed, but basically essential is the parents' method of handling the child.

As I see it, competent diagnosis depends to a considerable degree upon information brought to the team by the parents. How did the child develop in sitting, crawling, walking and talking and at what rate? We now are even asked, in a friendly way, to tell how we compare the child's mental, physical and social achievements to other children in the family and/or neighborhood.

To do this, we must arrive at the difficult decision that our child is "slow," "defective," "not like other children" and perhaps use the words "mentally retarded" before other members of the team do it so easily in our presence.

It is an emotional and intellectual struggle for us to lay aside the wavering

hope that the child is really normal and would lose the symptoms of retardation if only some professional treatment could be applied. We ask that your other team members give us the feeling that you are interested, not only in "cold" information but in giving us the chance in a friendly conversational setting, to bring our cloudiest and darkest ideas to the forefront. We must be prepared for the difficult assignment that awaits us. We must be ready to see things as clearly as possible, and to summon energy to carry our large share of the work ahead

After we have given you our information, you have the responsibility of sharing with us, as plainly as possible, your knowledge about causes, treatment and possible future plans for child and family. In the face of prevalent social attitudes of shame, ridicule and hopelessness for the retarded, we are understandably sensitive to the emotional color with which your information is conveyed.

Will you dwell excessively or exclusively on what the child cannot do? Or will you give us a clear and fairly full picture of the things which the child can learn to do now and in the near and distant future? Was it our fault that the child was born or became retarded? What made him that way? Will any of the newer wonder drugs restore his mind to normalcy?

It has been said that many parents really do not want to face the "truth." This may be an oversimplified rationalization for professional shortcomings. If we are members of the team, please remember that we need time to learn our role, and it is imperative that you show all the skill and patience of real teachers and counselors in helping us to understand the diagnosis and suggestions for rearing our child.

Now that we know the nature, degree and growth possibilities for our child, our professional co-members may erroneously believe that we have arrived at the "truth." You must appreciate that the "truth" may call for a rearrangement of personal values—of long-standing relationships between people. There are no stock solutions. We have many decisions to make—some of which are difficult to carry out. Perhaps our other normal children need to be told, or the grandmother and grandfather. For some, there is the question as to whether the child will be helped more at home or in an institution.

Perhaps day classes would be beneficial and they may be non-existent. Should we try to set up such classes with other parents whom we may not yet know so that we can keep the child at home? Are there special classes for adolescents, sheltered workshops, social opportunities and recreation? If not, what can we do to help the child develop the abilities which the team says he potentially possesses?

As you may readily see, the team now turns to us, the parents, and there are infinitely more questions for us to decide than ever confronted the team.

We have to carry out a prescription—how? It doesn't suffice to warn us against expecting too much on the one hand, or "over-protecting" on the other, unless you can help us interpret these remarks as they apply to our child in our home.

Recently a well-known educator who heads one of the more outstanding programs for the preparation of teachers of the retarded noted that his graduates had passed courses in which the principles of educational psychology had been carefully and soundly expounded, but that when observed several years later in their classrooms they were not actually putting them into effect. The professor felt that the university had failed by being afraid to give these teachers sufficient concrete examples of what is meant by "adapting the curriculum to the child's needs," "providing more concretistic learnings, etc.

If teachers can fail, certainly the bewildered mother shouldn't be expected to know that "helping Johnny become more independent" means giving Johnny enough time in the morning to get his own coat on before school and then being gentle but firm in expecting him to do it.

So I urge you to be practical in your advice, take time to be specific; also please be realistic. I know one mother of four, one of whom was speech handicapped though not retarded, who counted up the number of hours a day which she would have spent in the various activities prescribed for her different youngsters in the way of corrective exercises, chauffeuring to therapeutic sessions and what not, and concluded that if she did all faithfully there would be no time to prepare meals in the household.

And please be realistic, too, about the facilities which are accessible to us, in terms of costs, transportation, waiting lists or other pertinent factors.

Suppose that the parents are fairly successful in meeting the huge array of problems which arise after the team makes its diagnosis and prognosis. There remains the problem of adjusting to the changing and dynamic conditions of everyday life. And you must understand that the changes in the **child are only** one of the many other variables that make each individual and each family so unique.

Sometimes we encounter professional persons who erroneously interpret our current uncertainties about what we do for our child as a sign that we did not accept the basic "truth" some time ago. The parents need to go back to the team to discuss the problems confronting the child as he passes through infancy to childhood, from childhood to adolescence and from adolescence to adulthood. It is not easy to translate the understandings of yesterday to the new realities of today, including the discouraging picture of inadequate or non-existent community facilities for the retarded.

And lastly, do you not share with us—again as members of a team—the responsibility for rectifying these deficiencies, for arousing the community to provide for the retarded child, education, recreation, medical services, and protection—all those things which the community provides to supplement and round out the primary role of the home and family for the normal child?

Diagnosis is largely empty if no treatment results; "treatment" for the retarded child will have very limited meaning if it is confined to those services which we as individual members of this clinical team can provide.

We need society on our team, too.

## IV. FAMILY AND ENVIRONMENTAL FACTORS IN TREATMENT

## Parent Counseling

LEO KANNER, M.D.

Director, Children's Psychiatric Service, Johns Hop\ins Hospital

AT THIS STAGE OF THE DEVELOPMENT of professional interest in mental retardation, it may be taken for granted that adequate help to the patients' families is readily accepted as a major obligation. No examination and no plan of treatment can be regarded as complete without a meaningful explanation to the parents and a consideration of their curiosities and emotional involvements.

Parents are no longer dealt with merely as passive recipients of authoritatively presented wisdom but as deeply concerned persons who can, and should be, prepared for the task of becoming understanding and active participants. Parent counseling has rightly become an indispensable part of the overall clinical procedure.

No one has offered more valid and more practically usable material for the contents and logical steps of such counseling than have the parents themselves. There are worthwhile compilations of questions asked by them, indicating specific areas of puzzlement, needs for clarification, etiological quandaries, unrealistic expectations, attitudes of ambivalence, disillusionment, and guilt, over and above the desire for an unequivocal, easily comprehended appraisal of the child's condition in terms of domestic, scholastic, and communal relationships.

These questions vary, of course, depending on the degree of the retardation, the general family constellation, economic circumstances, ideas about social prestige and, last but not least, the inquirers' own personalities. Many, if not most, of the questions are asked not solely for the sake of obtaining factual information but with recognizable overtones of anxiety, more or less veiled requests for reassurance or expiation, sometimes—at least initially—an air of belligerent defensiveness.

A further significant issue is introduced by the fact that, by the time we get to see the parents, they bring with them not only perplexities which have arisen within themselves but also manifold reactions to earlier pronouncements coming from external sources which have exerted a powerful influence on their self-esteem and on their handling of the retarded child.

These sources often represent a network of criticism, injunctions, misconceptions, false hopes or equally false dire predictions pelted upon the parents by well-intentioned but poorly informed relatives, magazine articles, and even physicians.

We are all too familiar with the instances of fathers and grandparents who, closing their eyes to the unwelcome reality, keep blaming the mother for the difficulties presented by the child; she is accused for doing too much for him

or not enough, of being responsible for his developmental shortcomings through pampering or through neglect.

We are confronted more frequently than we should like to be with parents whose medical adviser has thought it expedient to tell them that their child will "outgrow" his lag and "catch up" with his coevals or, at the other extreme, that the child, being hopeless, should be "put away" in an institution, which is presented to them as something like a premature coffin. We hold in recent memory the cries of "Hosanna!" emitted in a widely distributed popular periodical with regard to the brightening effects of glutamic acid, the Bernadine Schmidt claims, and the transvascularization technique.

All of these matters form the gist of parental questions, which are asked regularly with a great deal of feeling and to which the inquirers hope to get straightforward and sympathetic answers, without evasion and without hedging. For the purposes of an organized discussion, these curiosities can be divided into five separate, though interdependent and overlapping, groups centered around the features of diagnosis, genesis, prognosis, the child's place in the family structure, and therapeutic management.

1. It goes without saying that any *diagnostic* formulation offered to the family must be based on the clear knowledge of the patient's status, derived from a thorough physical, psychological, and social investigation. But it is also evident that the form of disclosure must be adapted to the type of the parents' orientation toward the child, themselves, and their environment.

There are those who seek professional confirmation of their own observations which have resulted in a mature acknowledgment of actuality accepted not with glee, to be sure, but with a determination to make life as comfortable for all concerned as is possible under the circumstances.

There are others who, though not unaware of the child's handicap, go about in search of some culprit that keeps their offspring from utilizing his supposedly normal capacities; they look for someone to discover a malfunctioning organ, condemn an allegedly inexperienced school teacher, or recommend harsh discipline for the child who "stubbornly" refuses to live up to their expectations.

There are, thirdly, those who, unable to face an unpleasant reality, resort to its uncompromising denial. Things can be further complicated if the two parents and other influential members of the family group differ in their emotional orientation.

Obviously, it is relatively easy to guide a maturely accepting parent, more difficult to counsel one bent on finding disguises, and imperative to exercise much skill to lift the ostriches' heads out of the sand.

In all instances, much tact is required. Even the most unaccepting parent is not a villain. The different types of attitudes are deeply anchored in the emotional backgrounds of the individual parents.

We cannot nowadays dismiss the topic of diagnostic counseling without reference to a trend which, growing in the course of the past decade, has had rather disturbing repercussions. It stems from the recognition that severe emotional disturbance can result in poor intellectual functioning on the part of children who have come into the world with average or better than average

endowment. This is especially true of early childhood schizophrenia and infantile autism.

The increasing knowledge of these conditions marks a major progress in the realm of modern psychiatry. But in consequence of this, quite a few professional people have become reluctant to acknowledge the fact of innate mental retardation as such. Parents are told much too hastily that their imbecile or idiotic children, far from being inherently defective, suffer from the results of an "emotional block" which should be removed by intensive psychotherapy of the child and both parents.

This not only calls for back-breaking financial expenditure but has convinced many parents that it was their emotional status and resulting practices which brought about the child's failure to develop. Far too many patients are taken to our clinic by pauperized, guilt-laden parents after months or years of this sort of treatment.

In view of such experiences, which are less sporadic than one should like to believe, it cannot be emphasized strongly enough that there are adequate differential diagnostic criteria, the disregard of which verges on malpractice.

2. Once the issue of diagnosis has been settled, parental solicitude converges on the problem of *etiology*. These are some typical questions:

What is the cause of our child's retardation?

What about heredity?

Is it safe to have another child?

Is there any danger that our normal children's offspring might be similarly affected?

Have we personally contributed to our child's condition?

Why did this have to happen to us?

It is as yet not possible to answer all these questions unequivocally. Science has not advanced sufficiently to make omniscient persons of the consulted advisers. Aside from the fact that causes of retardation are not always the same in all instances and that there may be multiple contributing factors in the same instance, the search for an ultimate cause runs against the barrier of our incomplete knowledge. We can, in individual cases, refer with assurance to the effects of the mother's German measles in the first trimester of pregnancy or to the vagaries of Rh incompatibility. But in the vast majority, there is no recourse to a specific pathogen.

I have never encountered a parent who respected me less because, in answer to the question about the cause of his or her child's retardation, I made no secret of my inability to supply a definite answer. As I have pointed out elsewhere, intelligent parents usually realize fully that would-be erudite terms, such as congenital or constitutional, beg rather than answer their question.

What most of them hope to hear is indeed not so much a piece of etiological wisdom in terms of Greek or Latin origin as an authoritative and sympathetic endorsement of themselves, of their human and parental competence, of their right not to blame themselves for what has happened. They certainly can get the satisfaction of learning from an expert in the field that they as well as the patient can be acquitted of any responsibility for the developmental lag.

Even this attempt at needed exoneration calls for an overhauling of the parents' reasons for their belief that their own interference is the primary cause of the trouble. Such a belief may have complex and conflicting ramifications. It may conceal the hope that, if the condition is one made by man, it can also be unmade by man and is therefore reversible.

At the same time, however, there is the more easily ascertainable tormenting hunt for deeds and omissions which might have stunted the child's progress. This addition of self-insult to injury may have been reinforced by unfriendly in-laws and neighbors and, even more harrowingly, by looking upon the child's retardation as a punishment for premarital missteps.

At that, we are on safer ground in our counseling functions when we try to relieve parental guilt feelings than when we are faced with the issue of heredity. The parents' interest, when they express their curiosity, is more than academic. By the time they come to us, they have more than likely ransacked their family closets and may, or may not, have found a skeleton there. In either case, we cannot be very accommodating in so far as an outright verdict is concerned.

Available statistics are contradictory because some have been compiled in institutions, others extramurally, still others from combined institutional and non-institutional populations. Furthermore, no distinction has been made in most numerical depositions between absolute, relative, and apparent retardation, so that heterogenous elements were thrown together as if they had a scientifically justified common denominator.

The counselor is helped by the fact that parents who themselves are unintelligent are not usually bothered about this issue. Intelligent parents can be reminded that, had they, coming of sound ancestry and being healthy in body and mind, consulted an expert in genetics, he could not possibly have predicted the birth of a retarded child and would have seen no cause for dissuading them from procreating. Their child's retardation must be put down as "an accident of Nature."

If these same parents have one or more well-endowed children, it is pleasant to be able to point out to them that they have the demonstrated capacity for producing normal offspring.

But most inquiries about heredity are less oriented toward the past than toward the future. What about the fate of subsequent conceptions? What is to be expected of the offspring of the patient's normal brothers and sisters?

The problem is especially vivid in the minds of couples whose first and only child is retarded. They would wish fervently to enjoy the experience of bringing up a well-functioning child and yet dread a repetition of the mishap. The assurance that lightning usually does not strike twice in the same place rarely has the effect of alleviating the fear.

Can we as parents' counselors guarantee fair weather ahead? Mongolism, phenylpyruvic acid oligophrenia, Tay-Sachs' disease and quite a number of so-called heredo-degenerative disorders have been known to occur in more than one member of the family. I saw recently two healthy college-graduate people whose first child died of brain tumor at four years, the second, hydrocephalic, was stillborn, the third and fifth pregnancies terminated in miscarriage, and the

fourth child, the only survival, has an I.Q. of 65. In this instance, one would certainly be positive in discouraging further procreation.

On the whole, however, it seems wise to point out to parents whose first child is retarded that, as their experience has shown, every pregnancy entails a risk and that no one can predict the outcome with absolute certainty.

It is well to remember that the parents' inquiry is more than a simple quest for information. Behind it is sometimes a scheme, not altogether conscious, to be sure, to throw the whole burden of responsibility on the adviser. If they are told to go ahead and the second child also turns out to be retarded, they are clear of any blame. They can point an accusing finger at the adviser who has told them what they wanted to hear.

The initiative should always be left with the parents. If they do commit themselves in favor of having another child, they should be advised to do so only after they have been able to free themselves of the anticipation of disaster. Constant dread before and after the arrival of the new baby is apt to create an attitude not conducive to a wholesome relationship even with the healthiest and sturdiest child.

3. Parents who watch their child fall behind reasonable expectations cannot help but wonder about his future. They look for *prognostic* guidance from their professional mentor. They ask: "What will our child be like when he (or she) grows up? Will he *ever* talk? Can we expect graduation from high school? From grammar school? Will our child ever be mature enough to marry? Do you think that our child should be sterilized and, if so, at what age?"

As everywhere in medicine, any prognostic evaluation depends, of course, on a correct diagnosis. There are situations, especially when we are confronted with patients in the first two or three years of life, which call for caution in arriving at a definite conclusion. Matters of responsiveness, negativism, reactions to separation from the mother or, in her presence, clinging to her may blur the psychometric results even at the hands of a skillful examiner.

It is then best to keep one's own judgment in abeyance and suggest repeated studies in stated intervals until a clear picture emerges. When we ourselves have obtained a sufficiently adequate estimate of the child's present and future potentialities, we are under obligation to transmit our information to the parents frankly and kindly.

I have known pediatricians who, out of a mistaken notion of charity, withheld their knowledge from the parents with the underlying attitude: "These are nice people and I hate to shock them; let them find out for themselves in the due course of time and then it will be easier to advise them."

Deception, no matter from what motive, is deplorable. We have no right to lull parents into a false sense of security. They expect the truth from us. Frankness, to be effective, does not have to deteriorate into brutal and argumentative frankness.

If parents are too distressed about the future outlook, they can be helped to learn to take the child in installments. They can see progress if a child, however retarded, can do more at the age of five years than he had done at four. This makes them look forward to the time when, at six years, he will be capable of doing more than he does now at five.

4. The retarded child's place in the family structure represents another

important area of parent counseling. Parents ask: "How are we to explain him to our normal children? How is his presence in the home likely to affect them? How can we give him the needed extra attention without making them feel that they are neglected?"

In addition, there are many quandaries which are not formulated as clearly conceived questions but can be inferred from the parents' general attitudes which ring through the tenor of their part of the interview as genuine fondness, sacrificial overproduction, resigned fatalism, perfectionistic impatience, or outright hostility.

Besides, in considering the family structure, more than the parents and children are involved. The parents' relationship with their own parents and siblings and the groups of in-laws is often tied up inextricably and sometimes confusingly with the role assigned to the retarded child in the total kinship circle.

The degree of his retardation, his placidity or restlessness, sedateness or destructiveness tend further to mitigate or aggravate already existing attitudes. It must also be remembered that aggressiveness and irritability are not necessarily the attributes of retardation but, more often than not, are the child's response to pressures put upon him from without by demands exceeding his ability and from within by self-contrast with his normal siblings.

Jealousies on his part may arise on this basis, especially if he is made aware of his imperfections through teasing and name-calling, and jealousies on the part of the siblings may be based on their resentment of any protectively or pityingly preferential treatment given the retarded child.

There are many parents who heap all their attention on their handicapped offspring because they feel, or like to make themselves believe, that their normal children are well enough to "shift for themselves."

I know a chemist and his wife who wrapped themselves completely around their imbecile son and so utterly obliterated their contact with the healthy daughter that she developed a hatred of her parents and her brother, left them as soon as she was old enough to do so, and has no communication whatever with them.

Early parent counseling might have precluded this anomalous situation.

5. All of these considerations are an indispensable prelude to the kind of *therapeutic planning* which could be worked out with the family as informed and understanding collaborators.

Much has been made of the issue of parental cooperation, with the ready bestowal of laudatory epithets on those who obediently nod consent and the disapproval of those whose emotional involvement makes it difficult for them to bow to *ex cathedra* recommendations of residential school placement, special classes, or anything else.

Cooperation is not submission to the mentor's precepts. The term, "parent counseling," would be a misnomer if it were understood as a one-sided exercise in dispensing a take-it-or-leave-it set of rules.

Good counseling knows how to listen, how to sense parental attitudes so that, if this be required, they can be modified for their own benefit and that of the child and the rest of the family group. Any arrangement, whether it be of a medical, psychological, sociological, or educational character, will have its maximal effect only if considered in the light of this overall setting.

## Home Training

VINCENTZ CIANCI, M.A.

Supervisor Special Education, New Jersey Department of Education

EDUCATIONAL CONCEPTS OF THE MENTALLY LIMITED CHILD have undergone a radical change in recent years. Though educators have long accepted the theory that the education of the total child begins at birth, in the home situation, it is only lately that they have applied this principle to the mentally retarded child and his parents. Since these children are infrequently able to participate in the local school program, some alternative clearly had to be devised.

The first two States to come to grips with the problem of providing a suitable developmental program for the severely retarded were Massachusetts and New Jersey. The programs were similar in many ways. Both were free state services, organized to help parents gain insight into their long range problems, postpone institutionalization of the children and to assist the children in their adjustment to the demands of family and community life.

The only striking difference between the programs was in the orientation of the personnel who implemented them. Massachusetts recruited social workers who had necessarily to adapt themselves to educational concepts in their work with the individual children. New Jersey employed teachers who found themselves acquiring the social service point of view in their dealings with parents and community.

Both these programs, it is interesting to note, were initiated by state agencies that had as their primary responsibility the care and training of retarded individuals in a residential setting.

Home training in New Jersey was instituted in September, 1943. Like other states, New Jersey had a lengthy waiting list of children whose parents sought to admit them to state residential schools for permanent care. Under the then existing laws, children became eligible for admission at the age of five; the ordinary waiting period was from five to ten years. Since some of the institutions were considered purely custodial in function, preference had necessarily to be given to those children whose continued presence in the home constituted a clear and present danger to themselves or those around them. It must also be remembered that custodial institutions ordinarily give life-time care, and that vacancies are created only by death, with a remarkably limited turnover resulting.

The Department of Institutions and Agencies felt a grave responsibility to those children who were awaiting admission to one of the State Schools, and sought to close the gap by initiating an experimental program called Home Training. Its goal would be to find an alternative to the existing deficiencies in community resources for the mentally handicapped.

range ren Parents in 1943 were as deeply concerned about their situation as are the parents of 1956. They realized that the optimum training years were passing without any benefit to their children, because of lack of adequate facilities. Some thought that this could be remedied by extending the special class facilities in the public school program to include those children at home. However, more than a decade passed before legislation to extend public school facilities to many handicapped children was enacted.

It was apparent that the negative attitude of society toward the mentally limited, and the stigma of this handicap which extended to parents and siblings, had exerted a profound effect on the social attitudes of families in which there was a retarded child. This community rejection produced parental doubts and fears, which were aggravated by the parents' own preconceived and often unfounded opinions. This confusion twice compounded left the parents in a state of hopeless frustration. It is also clear that parents in a state of continuous, almost unbearable tension cannot reasonably be expected to follow a formal, systematic program of learning with their children until they have had help in adjusting to their problems and can acquire an insight into the nature of the child's learning program.

The first step in the Home Training program was to formulate the norms by which a child would be judged capable of benefitting by the training. The first factor was necessarily the mother's readiness for such a program, and her receptiveness to the philosophy underlying it. Second, the child's own ability to profit by instruction was considered in the light of medical and psychological findings on his condition.

The director of classification and education referred fifty-four children to the Home Training Department by 1946, of whom nine were excluded from the initial training list. They were considered beyond the scope of the Home Training program because of various factors; either the mothers were so exhausted physically and mentally that they could not cooperate effectively; other members of the family discouraged the mother from taking advantage of the program; or the child was the product of prolonged adverse training.

All the children nominated were visited for screening.

It was useless to try to acquaint mothers, who were desperate and at the end of their endurance, with the virtues of the Home Training program. The only way they could be helped was by facilitating institutionalization, and this was done in those cases.

After observation, it was found that all the children on the Home Training list fell into two groups. In one group were the very young children and the very severely retarded children, many of whom were multiple-handicapped. It must be realized that any progress with these children is abnormally slow; moving with almost glacial speed. Their parents need help and encouragement during the long months in which there is no apparent gain in skills. For these children, emphasis was placed on habit formation, emotional control, self-help habits, language development and play activities. It was found that many of their parents were unacquainted with basic facts of child growth and development and the important roles which time and maturation play in these patterns. Many of them had reared normal children successfully but were at a complete loss in approaching the training of a retarded child.

In the other group were the children whose maturation was such that they could absorb the training the teacher was prepared to give.

It was found that many parents had been firmly discouraged from making any attempts at training, because the professionals they had consulted felt that any such efforts would be futile, in view of the child's limited mental capacity. Other parents had been equally misinformed by professionals who had assured them that the children would eventually outgrow the difficulty!

Parents who have been grossly misguided need special help in regaining their perspective. A positive approach to this problem can be successful if the teacher shows the parent how training of the mentally retarded correlates with training of the normal child. Parents were encouraged to make a new inventory of their children's needs, and challenged to meet these needs, as it fell within their capacity. They were given basic information to assist them to evaluate their children's development, and direction in the courses of action which should be taken.

Parents soon found that the needs of these special children did not differ essentially from those of normal children, and that they responded to love and security. Some gave up fruitless yearning for community facilities, and set about helping themselves and their children.

Parents differ in personality and emotional strength, and there is no way of knowing how long it will take an individual to adjust to the demands of a special situation or how long it will take to resolve the conflict. Some require many years to reach a constructive acceptance of the facts as they exist.

Fruitless shopping for non-existent cures is not confined to the parents of the mentally retarded. It seems to be common to the parents of all types of handicapped children. Aside from its essential uselessness, this frantic search is costly and can have devastating mental and physical effects. It causes untold suffering and can lead to total neglect of the needs of other members of the family unit. In many cases, the Home Training service helped these parents to make a more effective approach to the problem of diagnosis. They were helped to see the importance of securing a sound evaluation of the child, but this would be of small value unless the parents accepted the findings and made use of the knowledge in a positive way.

Since the New Jersey Home Training Service was carried on in an area where competent psychological services were readily available, this phase of diagnosis was not a problem. It was found that more effective measures for counseling and planning could be undertaken in those instances where the teacher could confer with the psychologist. The psychologist and teacher worked as a clinical team, and each reinforced the position of the other in bringing the truth to the parents.

Professionals in the field of counseling, diagnosing or teaching the handicapped must remember that if they want the parents to be realistic about their problem, they must be realistic themselves. And, above all, they must present to the parents a unity of viewpoint.

Countless parents have been whipped into a state of perpetual turmoil by some adviser who insisted that they find a special class for their child. And the professional adviser, confident that he had made a sound recommendation, left the fruitless search for a non-existent facility to the parents.

The obvious place for such parents to begin their search was in the local public school system, for which their children could not possibly qualify. As a result, many superintendents and school boards became the targets of violent criticism for a situation of which they were unaware, and with which they were not equipped to cope.

For the children of greater potential, the Home Training service was of real value. The teacher, because of her primarily educational background, was able to interpret to the family the function of the public school and its limited services, and to turn their interests to the field of special education, and, also, from profitless anxiety to their present accomplishments.

These more capable children were the second group into which the referrals to the Home Training service fell. They were visited more frequently and the teacher worked directly with the child. The lesson plans and their materials were prepared by the teacher. Parents were encouraged but not required to be present during the actual lesson. As some parents were able to continue the lesson plan between visits, directions and materials were provided by the teacher for this supplementary activity. Those not emotionally equipped to deal with a teaching situation were given materials with which the child could occupy himself between lessons.

The material included in these lessons were paper, crayons, paste, scissors, paints and manipulative toys and pictures. The teacher always began the teaching situation with some activity within the child's range of accomplishment, so that there would be an immediate success experience. This had the twofold effect of encouraging both child and parent, as these parents are sorely in need of a feeling of pride in their children's accomplishments.

The parents of these children need a great deal of guidance. They should be informed about the development process so that they will understand why the child cannot color within lines, cannot cut around a circle or lace his shoes. They needed to know the importance of eye-hand coordination, so important to the child's development. They had to be taught that everything the child learned had to be shown to him patiently, for he lacked both creative and mental ability to pick up simple routines by himself. They had to be shown the end of these slow, patient lessons, and it is not readily seen.

Care had to be taken lest the home lessons become an artificial and meaningless activity. The teacher must know why she has undertaken a certain activity, what its goal is, and be able to explain it to the mother, with its practical application. Parents need to be shown that every situation is potentially a learning situation, and that a child is actually learning when he is permitted to put the silverware away, run small errands, or taught to ride a tricycle. Most parents are preoccupied with the academic aspects of learning and tend to discount the situation which does not foster academic learning. They must be taught that the little things a child learns around the house will assist in his total adjustment to his home situation. Parents were asked to decide whether it would be more profitable for a child to learn, after laborious months of teaching, how to make one or two letters of the alphabet, with no comprehension of the concept of written communication, or whether it would be more profitable for him to learn the elementary self-help habits which would make him a more pleasant person to live with. Most parents will readjust their values in

the light of reality and focus their attention on the child's genuine needs.

Parents who can be led to help their children positively will grow in wisdom and understanding, and find the ultimate care of the child in the home no hardship.

A recent check on the children who comprised the Home Training list in 1946 disclosed that over half of them were still at home, well adjusted, presenting no problem, and accepted by the family and community.

In 1946, the Home Training teacher had 24 children, sixteen boys and eight girls, on the active training list. Their chronological ages ranged from four to eighteen, and their mental ages from one to five years. In 1946, seventeen of the twenty-four parents wanted to have their children institutionalized without delay; five wanted their children to remain at home, and two were undecided. After the Home Training program had been in progress for a few years, eleven of the seventeen parents who had originally wanted to have their children institutionalized, now wanted to keep them at home; five who had wanted to keep their children at home still felt the same, as did the two who were undecided. Only six of the original twenty-four still wanted institutionalization.

In January, 1956, fourteen of the original twenty-four were still at home. Two had moved, and could not be located, so only twelve were visited—four girls and eight boys. Two of the twelve were actually employed; one ran a dishwashing machine in a country club where his father was caddy master, and the other was a helper on a pick-up truck. Another boy helped a park attendant in the summer, but received no salary. All the others spend all their time in their own homes. None of them ever had any training except that given in the Home Training Service, and none of the parents had had further contact with clinics or other agencies since the Home Training terminated.

All these young people participate in the family activities. Where older brothers or sisters had left the home or married, these children were a great comfort to the parents.

It was evident that all the parents had made a profound readjustment of viewpoint and values since the first visit from the teacher. They all accepted the fact that their children had missed the opportunity of going to school, since they are all over age to be included in the recent legislation benefitting the handicapped. Ten of the twelve parents had completed papers for commitment to an institution, and the other two had alternative plans. In two cases, the fathers had died, but the boys were able to stay at home with the mothers. All of the children remembered the teacher, and recalled some of the pleasant things they had done together.

All but one of these families live in the same neighborhood as they did ten years ago, and the mothers report that they are now treated with kindness and consideration in the community. All of the mothers pointed to their children's accomplishments with pride, and many of the children could tell the teacher about themselves. These children had truly emerged as individuals worthy of all the time and effort which had gone into their training.

To be effective, the Home Training program must be continuous. It should be a State service, and available to all parents when they need it. It should have a twofold purpose—educating the children and counseling the parents. Since there is no magic formula, the program must be realistic and based on the

child's and the family's requirements. It must be flexible and make allowances for the family's as well as the child's limitations. It must help parents gain a better understanding of child development, their own strengths and the insight to enable them to live successfully with these tragically handicapped children.

The home teacher should be fully aware of community resources for the handicapped so that she can serve as an effective member of a clinic or school team in the evaluation of a child and the interpretation of the evaluation to the parents. Because of her visits to the home, she can assist in the total evaluation by contributing her knowledge of personal problems. She can help eliminate the useless, heartbreaking search of parents for a cure which does not exist, and can help them adjust to their situation realistically.

The home teacher can serve as an effective liaison between parents and the state institution for those whose children must be institutionalized. She can help those children who can participate in local public school classes, which are developing all over the country.

## IV. FAMILY AND ENVIRONMENTAL FACTORS IN TREATMENT

## Involving Community Resources

ALFRED H. KATZ, D.S.W.

Executive Director, The Hemophilia Foundation, New Yor\

In the course of the last two decades, the dimensions and implications of the problems of mental retardation have begun to be clearly understood. From behind a veil of mystical, superstitious or judgmental thinking, the problems of mental retardation have now come to be viewed as essentially similar to those of any other major chronic illness or disabling condition. That is to say, they are viewed from a public health viewpoint. Great advances have been made in recent years in medical understanding and differential diagnosis of different groups of the retarded and in the development of methods of rehabilitation, education and socialization.

From the deliberations of this institute and your own experience, you are all well aware that only a small minority of the retarded are placed in institutions under governmental and private auspices. The great majority of retarded children should and do remain in the community and at home. Their parents and the children themselves need help drawn from all the specialties in the extensive armory of modern rehabilitative and health and welfare services.

Despite the striking advances in knowledge and technique that have occurred over the past two decades, however, it seems clear that a very large gap exists between what is known about how to help retarded children and their parents, and the help they are actually receiving. This paper will seek to examine briefly some of the factors that have stood in the way of obtaining maximum assistance for the retarded, and will discuss some suggestions for "involving community resources" more fully in their behalf.

From experiences in various services for the retarded, such as clinics and special classes, as well as from the data gathered in various research studies, it is apparent that one widespread experience has been common to the parents of retarded children. This is the experience of finding little initial understanding and receiving little assistance from those very professional sources from whom help might have been most fully expected—physicians, teachers, social workers and social agencies. If in this paper I dwell largely on the latter, it is because I know social agencies and their personnel better than other professional groups, and can therefore speak more confidently about them.

In seeking to improve the current situation, it is important to attempt to understand the factors that have brought about this widespread consciousness on the part of parents of the retarded of being rejected, misunderstood, or illadvised by community professionals, by those in social agencies in particular.

One might use conventional sociological concepts and say that a gigantic "cultural lag" still characterizes the social agencies and their personnel with reference to the problem of retardation, but such a phrase is merely descriptive and does not probe into the reasons for the existence of this problem. It seems to me that four factors may be singled out in this connection from among a considerable complex of others.

First, there is unfortunately no reason to believe that members of the professional community do not share, in a greater or lesser degree, some of the vague popular superstition, moral condemnation and revulsion that has been traditionally associated with the retarded. The veneer of professional sophistication and objectivity may not be very deep.

Secondly, for reasons too complex to explore, there seems to have occurred a very specific disavowal on the part of community agencies concerned with child care and child guidance, as well as with family casework, of the intent to serve the large group of the mentally retarded. Various rationalizations for this have been developed and some have been elevated to an actual philosophy of the denial of service. In effect, the upshot of this position is that the retarded do not have the possibilities of making a "normal" adjustment, and that agency services which are limited in volume, must be confined to those who may be maladjusted but for whom the prognosis is more favorable. Whether or not such a point of view squares with traditional social work tenets of service to those in need will be discussed at a later point in this paper.

Another factor of great importance in the lack of acceptance of responsibility in this field of work lies in the character and patterns of American communal health and welfare organizations. Arising especially from the history of this country and of its social institutions, there has been a greater development of voluntarism in social welfare programs in the United States than anywhere else in the world. The limitations of the American system of voluntarism are that within it coordinating and comprehensive planning are essentially chance processes. There is in effect a kind of free enterprise in social agency relationships. Planning and coordination may come about through voluntary participation by separate agencies, each of which is under the direct guidance of groups that may have special interests. There is no strong pressure, however, upon agencies to participate in coordinating and planning, except the pressures of professional and public opinion. Under these circumstances, autonomous agencies may, at the will of their boards of trustees, choose to serve or to exclude from service any groups in the community. And although presumably representative in character, studies of the social stratification of the boards of directors of these agencies indicate that they are narrowly confined to certain sections of the community and not representative at all of "consumer" interests. Within such a context, it is therefore not to be wondered at, that, what seems to have been an almost systematic pattern of limitation of services to the retarded, has occurred in volunary social agencies in many communities.

The fourth factor that should be singled out is that the development of services for the retarded has been brought about very largely in recent years through the activities of parent groups. The accomplishments and the programs of parent-organized groups, in this field are such that I need not expand on them. It is important, however, to note that unquestionably one of the problems

of professional workers in relation to the mentally retarded is an unfamiliarity with patterns of working with parent-organized and other "self-help" groups. Along with the development of specialized knowledge and skill, which in itself is of course desirable—a skepticism seems to have grown up among many professionals around the potential of lay groups to afford or to develop any adequate service on the self-help pattern. Under the specific conditions of health and welfare organizations in the United States there has been comparatively little development of the self-help form. The usual pattern of volunteer help is one in which volunteer workers are closely supervised and their functions are limited by professional workers. In the case of the parent groups, however, the parents have contributed greatly to focusing attention on the problems, have helped to educate professionals, and helped to formulate service programs. They retain a voice in the management and policymaking functions of the agencies, and it is these differences which seem to make the groups difficult for some professionals to accept, because they are not akin to the type of Board or managing group in the more conventionally-organized social agencies. As an example of the attitudes that influential professional workers may hold about the activities of parent groups, I quote from a communication directed to me by the head of a Council of Social Agencies in a northern city of some quarter million population.

"The leaders of each of these organizations are very aggressive people with a terrific amount of drive and consecration to the cause. They embody all the emotional charge and the zeal of their respective groups. . . . They are not easily turned aside, and are not to be stopped by anything or anyone. They are born promoters, go-getters and super-salesmen. . . . None of these groups is content to stand still and each wants to forge ahead toward a continually larger and more elaborate program operation.

"As a Community Chest and Council of Social Agencies . . . our policy has been one of trying to exert as much containment and repression as possible on the one hand, and on the other, trying to exert as much effort toward coordination with related agencies as we can. Through it all, we know it is trying to ride a wild steer, and that we are up against an almost invincible force."

Yet, despite such characterizations and such misunderstanding, some positive approaches have been worked out and some positive accomplishments have been registered in the mutual cooperation of parent groups and social agencies. It seems to me that such accomplishments have occurred especially in two kinds of situations; the first, where through some instrumentality, clinics for the retarded have been established and have been able to take upon themselves the function of interpretation, referral and professional education to community agencies on a case by case basis. Those who have worked in such clinics report that increased understanding and service to the retarded by community agencies of all sorts, has been won through the patient interpretation and discussion of the needs of a particular child and particular family, or of a group of children and their families.

The second type of situation in which there have been relatively favorable experiences has been those in which a coordinating body, such as a Council of Social Agencies, has been stimulated to take an early and vigorous initiative

in emphasizing and planning for the needs of the retarded. In such a community as Cincinnati, for instance, at the urging of various parent groups in the community, the social agencies and parent groups have been brought together through the Child Welfare Committee of the local Council of Social Agencies to consider and plan for the varied needs of the retarded in areas other than education. In Chicago and other Illinois communities, the Illinois State Commission on Handicapped Children, an official body which has consultative and advisory status, has been able to work closely with parent groups in bringing about a situation of considerably greater understanding and receptivity on the part of local service agencies. Although no comprehensive study of the situation has been made, and from your own experience you can probably fill in a much more complete picture than I am able to give, it does seem evident that where they exist and can be awakened to the problems, such coordinating mechanisms have been and could be utilized to good advantage despite the limiting factors to which I have referred. In such an effort, existing realities should be recognized, and the need for getting the support of powerful individuals acknowledged.

It seems particularly important that those who work in this field be not discouraged by early rebuffs, indifference or passive misunderstanding on the part of agencies or individual professionals, and do not in consequence tend to withdraw into a shell of isolation or hostility, as has happened in some communitites.

The reasons for continuing efforts in the direction of attempting more fully to involve community agencies in the problems of the retarded seem to me to be several fold. In the first place, an excellent body of experience and knowledge, service and resources has been developed in the voluntary social agencies. The knowledge of human behavior and the reactions of family members to one another, knowledge of how to secure more adequate environmental resources and aids from governmental and private sources, and thus helping ease the sometimes intolerable economic and other pressures on families of the retarded; the sensitive dealing with a host of emotional implications around questions of placement or institutionalization—although this has frequently not found expression in work with families of the retarded—the development of differential approaches to recreation needs through the application of group work techniques, the development of the social service aspects of the modern over-all rehabilitation clinic or center; all these have become or should be available to workers in the field of retardation, and should be found within the social agency competence of most larger communities. Professional services in these fields may never have been extended to the retarded, but there is nothing within the philosophy of social work that can justify their exclusion. In fact, the whole historical and philosophical basis of social work points in the direction of a broad inclusiveness—to help all those in need of such assistance in living more fully and developing their capacities to the utmost.

In further illustration, one of the most important psychological problems reported from clinics for the retarded has been the feelings of outrage and frustration engendered in parents by professionals who have counseled them to place or institutionalize their children without true realization of what is involved in the parents' feelings. In its work in child placement, especially

foster care, over past decades, social work has built up an excellent body of knowledge of the problems parents face in working through their comparable feelings around placement, and of techniques in dealing with these problems. There seems to be no reason why this considerable understanding and skill could not and should not be brought to bear in those situations where the institutionalization of a retarded child seems to be truly necessary and desirable. Some good differential thinking around such other measures as temporary shelters, foster homes, "halfway houses" also exists in this field and can and should be utilized in behalf of the retarded. What is required is a process of mutual stimulation and education between those who serve the retarded and the traditional child placement field of social work—the exchange of techniques, information and problems that would do much to assist both groups.

Similarly, in the field of family casework where the voluntary agencies have been developing considerable skill in understanding and in counseling with parents for whom their social situation has created difficult problems. In the City of New York, the numbers of parents of the retarded who are being served by voluntary family casework agencies is now very small. Yet those who have succeeded in being taken on by such agencies have found that they received helpful services. In order to increase the readiness of family agencies to take on more families of the retarded for help in working through their feelings and making appropriate plans and environmental adjustments, a greater educational effort is undoubtedly needed.

It seems to me that action in several areas may be simultaneously required to bring this effort about. In the first place, the schools of social work need to give much fuller recognition than they have until now on problems of retardation as they do to problems of chronic illness and rehabilitation generally. In their casework classes, in their classes dealing with medical and public health problems, in their classes dealing with the organization of community services, a great deal could be introduced which would help to illustrate how widespread, how important, and how typically and squarely within the purview of social work are the problems of retardation. Parenthetically, this approach can and should be extended by the NARC to national agencies in this field—C.C.C., Child Welfare League, F.S.A.A. and others.

The second approach which is more immediately practical in similar situations is, as I have stated, working through a Council of Social Agencies or any other coordinating mechanism that may exist.

One advantage of voluntary agencies is that they can be involved in the kind of legislative and social action which many parent groups have found particularly important and as desirable means of achieving their ends. For those who may not be aware of it, it is worth pointing out that such broad legislative and social action has been a characteristic form of activity of private social agencies in the past, and helped to bring about many of the important social changes in the fields of child labor, housing and public health, social security legislation and so on, although this emphasis has been largely lost sight of in recent years.

Related to this emphasis is the point that those who work in the field of retardation can and should utilize whatever means can be found for strengthening themselves by making common cause with groups and organizations with which they have problems in common. It is unfortunately true that the system of voluntarism also leads to competition for public support on the part of many independent groups; it leads to rivalries and mistrust. It is essential, however, that those who can benefit from a common approach work together. Some insight into what has been achieved from such cooperative work may be found from communities other than New York. For instance, in Newark the establishment of a sheltered workshop serving the needs of both cerebral palsied and mentally retarded was brought about through both groups getting together in an approach to the local Council of Social Agencies. A good deal has been accomplished through joint work on legislation in Illinois, Ohio and other states. Many common problems and needs are found—e.g., schooling, transportation, recreation, group guidance—to name but a few.

The final advantage of working with community agencies that I wish to mention is in the organizational area. Chests and Councils of Social Agencies do have a body of helpful experience on organizational questions; on how to secure support; and particularly on fund-raising, on fact-finding techniques and financing questions—practical issues which clinics, parent groups and others working in this field are facing. It is true that some limitations result from this also, but there seems to be no sounder present way of receiving support and help with program needs. Once such a relationship is established, once the specialized services become part of the so-called "family" of agencies—emphasis and interpretations of the needs to extend services to the retarded become facilitated. In this instance, too, it seems to me necessary that the effort should be both national and local in character.

I stated earlier that a clinic is initially able to demonstrate need and to educate agencies in its community on a case by case basis. It seems to me, therefore, that the responsibilities of a clinic might well be broadened to join efforts on a systematic basis with those who are pressing for inclusion of the needs of the retarded in a community-wide planning program. It seems obvious that the existence of a clinic may serve to bring to the attention of the planning groups the need for either the creation of special services or the inclusion of the retarded in existing services. I am thinking of such fields as the inclusion of retarded youngsters in community centers, day camps, scouting groups, summer camps, day nurseries and other such facilities. The process of such inclusion never takes place automatically. The agencies which give such services are traditionally burdened and chronically under-staffed and under-financed. Only after the process of highlighting of these needs, calling them, perhaps repeatedly, to the attention of those who can meet them, and enlisting the aid of influential persons in the community does action ensue. I am suggesting, therefore, that the demonstration of need by clinics can be used as a lever to bring about the participation of agencies in a comprehensive attempt to meet the needs of all those in a community, including the retarded.

Those of you who have more acquaintance than I with the practical issues may well react that much of the answer should be found in the assumption of large-scale federal, state and local governmental responsibility in the creation and maintenance of these needed services. This may very well be the case. I wish, however, to point out that there is no conflict between long run and short term or intermediate goals, represented by the kind of approach that I

have been outlining. I believe that there is a considerable reserve of untapped social agency professional interest, sympathy and skill which can be tapped on behalf of the retarded. The professional community will respond to appeals in this area if they are approached on the basis of seeking their assistance, and on the basis of a wish to work cooperatively. The isolation that has characterized many families of mentally retarded children, and the isolation that may have characterized parent groups in their early days, is slowly disappearing. Integration, in the fullest sense of the term, in this field also is desirable and necessary, and historically inevitable.

## V. CLINICS IN A TOTAL COMMUNITY PROGRAM FOR THE RETARDED

SALVATORE G. DIMICHAEL, Ph.D. Executive Director, National Association for Retarded Children

THE PURPOSE OF MY PAPER is to attempt to describe an overall pattern of clinical services in a total community program for mentally retarded children and adults. There is no clear-cut pattern established as yet in practice. The attempt to provide clinical services has been piecemeal and unsystematic. Where clinics for the retarded have been set up, it usually has been the product of a pressing single-sided need plus the presence of a willing or half-willing sponsor. In a limited context of services, only leaders of residential institutions and of educational systems have devoted some consistent attention to clinics for their clients.

If we are to set up an integrated group of clinical services for retarded children and adults, and for their families, the most strategic place to plan such a program would be at the state level. The plan would have to incorporate the contributions of public and private resources as well as federal, state and local governments. However, the governmental machinery for attacking the problem of establishing a network of coordinated clinics varies considerably between states. The initiative may have to come from a bureau or department of health or mental health or institutions and agencies or public welfare, education, special education, vocational rehabilitation or of a special agency such as the Institute of Juvenile Research in Illinois. To complicate the picture even more. we must observe that the establishment of clinics may be the prime responsibility of a state department as in North Carolina, or of the county as in Minnesota, or of the local community as in New York. There may be interlocking agreements of different types between all these governmental units in any one state. It is obvious, in light of the above facts, that an attempt to plan a pattern of integrated clinics for children and adults would be a fairly new exploration, discovery and experience from one state to another. The development of a pattern of clinics is obviously a complex undertaking within every geographical area.

If we are to make a serious attempt to meet the problems of the mentally retarded, we must keep in mind the whole gamut of services which are essential to habilitate or rehabilitate the retarded. The clinical facilities must be geared to take their place in cooperation with all the other services. Included among the services are:

- 1. initial diagnosis and treatment of the retarded child, and counseling for the family;
- 2. home training to help parents in rearing the child;
- 3. nursery class experiences for the moderately retarded child, with normal children whenever possible, or special nursery class experiences and day-care centers for the more severely retarded;
- 4. special education for the "educable";

- 5. special education for the "trainable";
- 6. personal adjustment and occupational training, as well as terminal employment in sheltered workshops;
- special recreational and social opportunities where the retarded cannot be integrated in such activities with normal children and adults;
- 8. vocational guidance, training and selective placement in regular employment;
- 9. residential training and care whenever necessary; and,
- 10. occasional supportive counseling whenever stresses of living become excessive for the retarded living in the community.

If one seeks to meet and solve in an orderly manner the gamut of problems presented by the retarded, clinical facilities must be regarded as a basic foundation for a sound comprehensive program. Although this conviction seems selfapparent, the fact is that our more vigorous efforts of the last five years in the whole area of mental retardation have highlighted education, institutions and vocational rehabilitation. Clinical services have not been accorded a proper emphasis. Without speculating on the reasons for a comparative lack of attention to clinics, we must affirm our conviction that a thorough clinical evaluation of the individual, with family counseling, must form the basis for a plan of action to meet the person's needs. A clinical assessment must be made as early as possible, and appropriate treatment begun. In this way, we may correct any form of remediable defect in the earliest treatable stages and refer the child and his family to appropriate service facilities so that habilitation is enhanced. Furthermore, as re-evaluations are required, the individual may be seen again by the original clinic team or by other clinic teams in other settings, during the later years of childhood, adolescence and adulthood.

## CLINICAL FACILITIES FOR INFANTS AND PRE-SCHOOL CHILDREN

From an ideal viewpoint the vast majority of the mentally retarded should be diagnosed and treated at the latest by the fourth or fifth year of life; if the higher-grade are not designated as mentally retarded, at least they should be identified as developmentally slow and most probably limited in terms of future mental growth. We hardly expect to see in the immediate future such an ideal state of affairs; very many children, particularly the "educable" retarded, will be diagnosed and given special help only after they have been admitted to regular school. However, an all-out attack on mental retardation must be preceded or accompanied by earliest possible diagnosis and planning, that is, in the pre-school years.

Such a concept demands effective screening of children suspected to be retarded. For such an approach, the pediatrician is one of the key figures. We would hope that training of pediatricians would include special attention to mental retardation not only in the medical courses but also in the practical training experiences provided for them. An excellent potential for such training is to have a specialized clinic for the retarded in every medical training center where pediatric trainees as well as other medical students could observe and learn at first hand. Another value of locating a clinic in a medical training

center is that other medical practitioners, particularly the general physician, may learn about mental retardation and use the facility whenever they encounter a suspected case in their practice. Another advantage is that parents are more easily disposed to bring their children to an out-patient clinic attached to a hospital with less feeling of stigma and shame.

Another important potential resource for the mentally retarded is the community child guidance clinic not physically located in the hospital. Such clinics seem to lend themselves to a study of the developmental aspects of growth and parent guidance, perhaps more so than a hospital clinic which might tend to emphasize physical examinations and the use of drugs. Actually, a well-conducted clinic for children should consider the whole child and his total family and environment, whether it is physically set up in a hospital or apart from it. However, the professional sponsors and physical setting of a clinic have a real influence upon the approach to diagnosis and treatment. I often have heard from parents and professional people that many child guidance or mental hygiene clinics summarily dismiss retarded children and their parents. The reasons given are that nothing can be done for them (an error of ignorance) or that other children with normal or higher intelligence should be given attention in view of limited resources (an error of bias).

Another potential resource of community services is the clinic connected with institutions for the retarded. In most instances, the demands of institutionalized children and adults have been so great that the clinic staff has been unable to operate as an out-patient community facility, even if it wished to do so. Such clinics have been affected by four main influences in trying to extend services to children in the community. One important problem has been the pressure of the long waiting list of possible candidates for the institutions. This has given rise to pre-admission clinics that emphasize diagnostic evaluation and some social services, particularly in instances where there is an emergency or near emergency situation for institutionalizing the child, or referral to other community facilities as a permanent or temporary measure. A certain amount of pressure for community clinic services has arisen from the institutional authorities who have seen the need for extending their assistance to children in the community. A third influence is our awareness of the parents' aversion to bringing their children to the institution, believing it can only mean institutionalization rather than objective evaluation and guidance. And fourth, progressive leaders among the administrative and professional workers have sought to make the institution an integral part of the regular community, and not an isolated outpost of civilization.

The home counselor or home teacher is not to be found in most communities. Some clinic teams believe such a specialized person is not necessary, provided a complete evaluation is made and plan of treatment conveyed to and accepted by the parent. In most community clinics for retarded children, the social worker is regarded as the main liaison with the family in the home. On the other hand, some professional workers maintain that a home-counselor adds a real and needed service by helping parents in the real setting of the child's home. In any event, it is apparent that the efforts to help the parents in applying the general recommendations on the proper rearing and guidance of the child should be based upon the team's findings. Some people argue that the home

teacher should be on the clinic staff. Only time will tell if the home counselor's functions will become widely accepted.

In a few places over the country, nursery or pre-school classes and day-care centers for the retarded are available. If a clinic team is organized in such a facility it should be closely coordinated with general and specialized clinics in the area. All previous data on the child should be obtained from health facilities previously used and an evaluation made in terms of the child's suitability for the nursery class and other services available. Where the sponsors of the nursery classes do not have the benefit of a clinic team of their own, the acceptance of any child should depend upon the referral to, and recommendations of, an available clinic in the community.

Recently there has been some increase of interest in genetic counseling clinics. There are highly specialized facilities intended to help parents vexed by doubts about the possibility of reproducing other children with abnormal conditions or about the possible genetic factors in the already produced offspring. Such clinics are very few in number, probably no more than 15 over the country, but their work and publications are proving to be useful to parent-counselors in general or specialized facilities.

## CLINICAL FACILITIES FOR CHILDREN OF SCHOOL AGE

The largest percentage of retarded children are the moderately retarded or "educable" and most of these are identified after admittance to regular classes. It is regrettable that pre-admission procedures to schools are routine and usually limited only to factors of chronological age and general health. In view of these prevailing conditions, and even if pre-admission procedures were vastly improved, it seems necessary to sensitize teachers of early elementary school classes to mental retardation. Young retarded children should be spared the experience of early failure by being unwittingly forced to compete with normal or bright children in learning the lessons of reading, writing and socializing. Problems are created which quickly become acute; sometimes a chronic pattern of ineffective adaptation is begun that becomes difficult for parents and child to undo. When parents see their child admitted to and allowed to remain in the regular classes, they have high expectations of normal achievement. Without a pre-knowledge or forewarning of the reasons for educational difficulties, the parents may hardly be blamed by the teachers or principals for trying to remedy the created difficulties by having the child work harder, or by asking that the educational methods be improved.

The proper placement of children in school brings out the school psychologist in a pivotal professional role. I would estimate that in about 25 to 30 States the law or regulations of the departments of education require psychological evaluations as the ultimate basis for admitting children to special classes for the "educable," or the "trainable." The psychologist also may be assigned the role of interpretation to and counseling of parents. When a change of school plans for the child seems desirable, the psychologist must re-evaluate, and make appropriate recommendations. Similarly, special problems in learning, and personal and social adjustment are referred to the psychologist. Unfortunately, in many school situations the concept and practice of interdisciplinary teamwork is lacking or carried out with varying degrees of effectiveness. There are

two reasons for such widespread practice: first, the pressure of an excessive load confronting the psychologist; secondly, many school psychologists have not been trained in interdisciplinary teamwork. We might observe that the school psychologist often fails to include the physician, nurse, educator and counselor or home visitor, just as in the preschool years too many physicians fail to utilize the necessary services of the other team members. In most school situations, the initiative of the psychologist is the all-important factor in obtaining reports from physicians, nurses, educators, and counselors, and the psychologist's skill in interpreting these reports is the closest approach (or perhaps near substitute) for interdisciplinary teamwork. The blame for such a less-than-desirable situation should not be placed solely upon the psychologist but also upon the other potential team members. If we may speak of blame, we should ascribe a part of it upon ourselves and society in general for failure to finance the schools adequately, and upon the present critical shortage of trained professional workers.

Psychologists are available for services from several possible sources. In some parts of the country, the state hires them and they work on an itinerant basis; in other places, the county or city engages them for the schools. The psychologist may identify the retarded among children referred to him for other reasons, such as behavior disorders, lack of progress in school, physical handicaps, and in certain situations for placement in foster homes for adoption.

## CLINICAL FACILITIES FOR ADOLESCENTS AND ADULTS

When the retarded individual is near or at working age the need for reevaluation again becomes prominent. The majority of educable children may be helped to find suitable placement through the school, family, or the state employment service without an overall clinical evaluation. A sufficient source of evidence on which to encourage suitable placement is regarded to be the child's performances in school, with the assumed or obtained confirmation of his good health by the family physician. Sometimes the public or private employment services, or potential employers, use group psychological tests as an aid in the job counseling and placement process. Such measures seem sufficient for the non-problem retarded adult in the high-grade classification.

For the retarded who are difficult to place suitably in employment, referral should be made to the state-federal vocational rehabilitation agency. Experience in the rehabilitation agency has pointed up the need for specialized evaluation, including a thorough medical and psychological evaluation, and social assessment. The referral of potential clients from the schools has shown that the cumulative records in the educational files is not entirely sufficient. The cumulative records are oriented to educational and not to vocational problems. In other words, the schools show a disposition to think of the adolescent and young adult almost entirely from an educational viewpoint; they have not counseled him adequately about his vocational plans.

The rehabilitation counselor must seek out a psychologist who understands the retarded as adolescents and young adults, is skilled in methods of vocational assessment, and knows the occupational world. Many school psychologists need extended training to become proficient in the area of vocational guidance. Similarly, other team workers find themselves at a loss, with the result that

the counselor either makes up for their inadequacies by his specialized knowledge or finds himself unable to cope with the problems.

A service resource to be found in some geographical areas is a Personal-Adjustment and Vocational Training Center and Workshop. These facilities may have evaluation teams that could admirably help the rehabilitation counselor. A work-tryout period may be included in the service of the training center and workshop; if so, the work-tryout period may help to resolve doubts concerning a person's employability potential.

Sometimes, the specialized clinical facility in the community which handles young children is also prepared to evaluate adolescents and adults for admission to the sheltered workshops. In these situations, the supervisor or counselor of the training center and workshop should be a member of the clinic interdisciplinary team and help the latter to adapt the evaluations to vocational rehabilitation.

#### SPECIAL CONSIDERATIONS

An overview of clinic facilities in a total community program for the retarded demands attention to special considerations which we have not yet mentioned. First, we may make several observations on the matter of specialized and general clinics. Some people proceed on the false assumption that one must argue for one against the other. Both are necessary and complementary. Under present conditions in which the mentally retarded find themselves so short of all kinds of services, and in view of the fairly wholesale ignorance of many professional workers on dealing with the retarded, the establishment of many more specialized clinics appears to be necessary. Parents must have an identifiable facility of reputation and quality if they are to minimize their understandable need to shop from place to place in search of competent diagnosis, treatment, and plan of management. Professional workers must also have a place of referral for the more severely retarded, or a source where perplexing problems of any suspected or known retarded individual may be finally resolved in the best light of present knowledge. Such specialized clinics may be demonstration and learning centers for trainees or practitioners of various professions, including medicine, psychology, social work, nursing, education, and rehabilitation.

Experience in other countries, such as England, Canada, and Scotland, corroborates the conviction of specialists in mental retardation in this country on the need for more specialized clinics. For example, Gibson's recent article states: "Our clinics for the mentally handicapped have now been set up in six centers, and some indication of their usefulness as a parallel service to the child guidance and general psychiatric clinics might perhaps be seen in the recent decision of the Scottish Association of Mental Health to urge the adoption of the system in other hospital regions." In such specialized clinics, we should find speech therapists and dentists in addition to the basic team because speech and dental problems are frequent among retarded children and sometimes require special orientation and a desire to work with this handicapped group. Perhaps we may add that an opthalmologist and audiologist should be sought with the patience and interest to help the occasional child that needs special handling.

The general clinics must broaden their services to retarded children. In fact, specialized clinics will have to rely upon all facilities because the retarded have health, education and welfare problems similar to all people. The need for preventive and corrective measures is ever present, and can be carried out effectively for the moderately retarded by general clinics. For the more severely retarded, the general clinic may continue to provide general health and guidance services in keeping with the recommendations of the specialist team.

General professional practices have an important role in the total picture of services to the retarded. The general medical practitioner or family physician is potentially a key person in the majority of the retarded because they administer to the health needs of more children than any specialized group. Probably the general physician is our best potential first line of defense in screening, and helping parents to guide children in the middle and high-grade retarded groups. The general physician must be made aware of the significance of consistently slow development in the child, should be ready to counsel with parents of children suspected to be retarded, and to mobilize a professional team to clinch the diagnosis and advise on a total plan of treatment. The public health nurse is in a strategic position to screen children suspected to be retarded, and to follow through with such children and their parents. The general social worker, psychologist, and regular classroom teacher should be prepared to screen and sometimes identify such children, and to render professional assistance in follow-through with other professional workers.

## RURAL CLINICAL SERVICES

The application of clinical services for the retarded in rural areas of the country merits a special paper, if not a conference, for a proper treatment of the subject. We know that health, education and welfare services are critically inadequate for rural people. The cultural environment of such areas is distinguished by an open knowledge of one family by others, a condition which sometimes makes it more than ordinarily difficult for parents to accept special services that place a label of "mental retardation" upon the recipient. Besides, the higher levels of retardation have to be assessed in terms of immediate cultural surroundings so that the very diagnosis of the condition may be effected.

Our attempts to establish clinical services in rural areas are acknowledged to be woefully inadequate. Traveling clinics seemed to hold promise a decade or two ago, but their potential values have not been realized because of shortages in personnel, the rapid turnover of team members, and the deeper realization that diagnosis without consistent follow-through in treatment is most unsatisfactory. Itinerant psychologists have been hired in some states and counties who, with fortitude, have brought some help to retarded in rural areas but the overall conditions in which they work leaves so much to be desired—not with blame, but, rather, credit to the psychologist in such situations. In some localities, volunteer teams have been tried and appear to be initially successful in the first flush of enthusiasm, but not in the long run. Rural professional workers also have few opportunities for sustained in-service training. This condition is fatal as far as the mentally retarded are concerned because the professional workers received little if any constructive training in retardation during their graduate school courses.

It seems that clinical services in rural areas have been most valuable to the retarded when a professional person who is well versed in the subject has been available. Such a person can bolster the faltering steps of the other professional workers in the area without some knowledge of mental retardation. Just as we have spoken about the need for specialized clinics for the retarded in urban areas, the specialized worker in mental retardation appears to be the most solid source of service and training in the rural sections. Sometimes the specialist is a social worker, less frequently a physician, or a special teacher, and more often a psychologist—at any rate it has so impressed me.

## INTEGRATION OF FACILITIES

It has become almost a by-word of modern thinking in professional services to emphasize cooperation and voluntary integration. Although the concepts may sometimes appear to be overworked by the frequenter of institutes and meetings, they represent virtues to be attained in the dismally small repertoire of services for the retarded. For too long, facilities for the retarded have operated almost in isolation. Institutions have been regarded as "separate and self-sufficient communities, schools have left out the trainable until recently, the educable have been permitted to drop out of school and out of sight, sheltered workshops and training centers have been very few and feel the schools have not properly prepared children for adult roles. Vocational rehabilitation has picked up too many retarded clients years after they left school, and community clinics have recommended institutionalization and oftentimes left it up to the resourcefulness of the parents to find a suitable residential center. The story of parents shopping from one specialist to another has been too frequent to need even the repetition of a mention. These occurrences are not from an immediate historical past but typical this very day. It becomes imperative, then, for those of us engaged in helping the retarded to make cooperation and voluntary integration of professional efforts and services a daily symbol of progress.

The voluntary coordination of retardation clinics with other types of clinics, as well as with all service facilities has to be pursued relentlessly. We should expect the specialized clinic to share its information with the family physician, the teachers, school psychologist, nurse and counselor. We shall expect the school to obtain the fullest possible information from resources previously used by the retarded child and his parents. We must stop the wasteful practice of repeating medical, social, and psychological examinations when the child goes to a new facility.

We must look for every possible way to multiply the practice of interservice cooperation. Let us present a few examples. Recently we read that an institution in the mid-west started the practice of having one of its social workers become a frequent participant in the team conferences of a community clinic. This has facilitated shifts of clients between the institution and the community. In another place we observed a formal arrangement whereby the reports and recommendations of a community clinic were accepted by the public schools without a reexamination and reevaluation of the children. We have heard of increasing instances in which medical schools send internes to institutions as a regular phase of practical training. In other places, school counselors for the retarded meet regularly with rehabilitation counselors to make as

smooth a transition as possible of the client from the school to the rehabilitation agency. We have seen placement officers in the state employment service pool their knowledge of available jobs with the counselors of the school, and the sheltered workshop. Probation officers or social workers for certain courts have called upon clinical workers to help in court proceedings involving mentally retarded defendants. Undoubtedly, each facility will have to evaluate the retarded in terms of its special setting, but these evaluations should be built upon existing knowledge of the individual in the files of previously used facilities, and the understanding of its staff.

Our final word may be reserved for the provision of professional training as a regular feature of each clinic for the retarded—in each setting that it may be found. Too few people have the necessary knowledge and skills to help the retarded, many more must be trained. In spite of the great pressures for service, each clinical facility must set aside a regular amount of time to train other workers for the retarded. The training of more professional workers, both specialists and general practitioners, is the best way to multiply our presently limited hands and skills. Any clinic that is featuring the training of additional professional personnel is giving the fullest possible measure of service to all the mentally retarded.

#### BIBLIOGRAPHY

- 1. Bower, E. M.: "California's Program for the Mentally Retarded," Amer. /. Merit. Defic, 1951, 55: 502-514
- The School Psychologist, California State Department of Education, Sacramento, California, 1955, 130 pp.
- 3. Delp, H. A. (ed.): "School Diagnosis of the Mentally Retarded: Symposium," *Training School Bulletin*, 1956, 52: 217-236.
- DiMichael, S. G. (ed.): "Vocational Rehabilitation of the Mentally Retarded," Amer. /. Ment. Defic, 1952, 57: 175-337.
- 5. Gibson, R.: "The Clinic for the Mentally Handicapped," Amer. J. Ment. Defic, 1952, 56: 544-546.
- Jensen, R. A.: "The Clinical Management of the Mentally Retarded Child and the Parents," *Amer. J. Psychiatry*, 1950, 106: 830-833.
- 7. Kloepfer, H. W.: "Heredity Counseling: Starting a Heredity Clinic," Eng. Quart., December 1955, 2: 234-238.
- 8. Stevenson, G. S.: "A Community Program for the Mentally Retarded," Amer. J. Ment. Defic, 1952, 56: 719-726.
- 9. Tarjan, G., and Forbes, L. M., "A Preadmission and Diagnostic Service for the Mentally Deficient," Amer. /. Ment. Defic, 1955, 60: 335-39.
- 10. Vaughan, W. T., and Farrell, M. J.: "Community Program for Mentally Retarded School Children in Massachusetts," N. England J. Med., 1955, 252: 1007-1010.
- Words, J.: "Towards the Establishment of Special Clinics for Retarded Children," Amer. J. Ment. Defic, 1954, 58: 472-480.

# V. CLINICS IN A TOTAL COMMUNITY PROGRAM FOR THE RETARDED

## Discussant:

ARTHUR LESSER, M.D.

Director, Division of Health Services, Children's Bureau

DR. DIMICHAEL HAS BROUGHT out so many interesting points in his presentation that he provides a wealth of material for discussion. I am particularly interested in his comments about the clinic as a part of a state-wide program for mentally retarded children and the relationship of the clinic to other community resources. This is of special interest to the Children's Bureau because we are at the present time engaged in examining how public agencies, particularly State health and welfare departments can extend their present services to include programs for mentally retarded children. I think that as a background for this discussion it might be helpful at this point if I refer briefly to the grant-in-aid function of the Children's Bureau:

Under the provisions of Title V, parts 1, 2 and 3 of the Social Security Act, the Children's Bureau administers grants for maternal and child health, crippled children's and child welfare services. These grants are made to State health departments, State crippled children's agencies and State welfare departments. Under the maternal and child health program State health departments provide services largely preventive in nature, such as are available through well-baby clinics, maternity clinics, immunizations, school health services, public health nursing services, and programs for prematurely born infants.

Although mentally retarded children are seen from time to time in well baby clinics, no special provision is made for them, nor is a specialized staff available in these well-baby clinics. However, these clinics do serve the function of helping parents to understand the growth and development of children, particularly normal children and the importance of keeping their children under health supervision.

The crippled children's program is a medical care program for the location, diagnosis and medical, surgical and hospital care of children who are crippled or who have conditions which may lead to crippling. A little more than half of the 270,000 children who received physicians' services through the program last year were orthopedically handicapped. The rest are children with cerebral palsy, rheumatic heart disease, congenital heart disease, hearing impairment, epilepsy, eye conditions needing surgery and the like. Mentally retarded children who have a physical handicap are frequently seen in these clinics, but usually are not provided treatment. Most of the crippled children's agencies at the present time do not see the importance of providing mentally retarded children with such treatment as can help correct or improve their physical handicaps.

For all practical purposes then, mentally retarded children have been included to a very limited degree, if at all, in these grant-in-aid programs.

Largely because of the activities of local parents' groups and the National Association for Retarded Children and the interest shown by many parents who have written to us, the Children's Bureau two years ago undertook to make a study of how the programs for which we have responsibility may be extended to include mentally retarded children. Last year the Department of Health, Education, and Welfare established a Departmental Committee on Mental Retardation, the function of which was to develop a proposed program for the Department. The Congress has become greatly interested in this problem is exemplified in particular by the interest shown by Mr. John Fogarty of Rhode Island who is Chairman of the House Subcommittee on Appropriations.

The Children's Bureau grant for maternal and child health for 1957 was increased by the House of Representatives last month from almost \$12,000,000 to \$16,000,000. In so doing the Committee on Appropriations expressed the intention that half of the increase be used for programs for mentally retarded children. Our appropriation for 1957 is now under consideration by the Senate.

We have then an expression of considerable interest on the part of at least one House of the Congress, the Department of Health, Education, and Welfare and the Children's Bureau in utilizing the resources of public agencies to develop programs for mentally retarded children.

During the past year with the limited funds available, we have made special project grants to health departments in California, Washington, and the District of Columbia to develop demonstration programs for mentally retarded children. We have also seen many expressions of interest on the part of medical schools in setting up special clinics for these children. In these special programs the evaluation or diagnostic clinic is given much emphasis as a focal point for the services being provided.

We find that one of the problems that is already apparent is that much less attention has been given to the question of how to help the parents with the care and training of the child after the diagnosis has been made. This is in part due to the fact that the pediatricians in these clinics function as clinicians and diagnosticians primarily and work in a way in which they are accustomed to work in pediatric clinics. The problem for the parent, however, really only begins after the diagnosis is established. For him the question is: After the diagnosis—what? It seems to me important to stress that the clinic cannot exist wholly as if it were the total program in itself, but needs to be considered as one resource in a program in which it would be related to other available resources in the surrounding area, such as health and welfare departments, education departments, departments of mental hygiene, councils of social agencies, recreation departments and similar organizations and institutions for the retarded. In the Children's Bureau we are particularly interested in seeing the development of programs which would help those parents who can keep their children at home at least during childhood. We find all too often physicians advise parents to place their children in institutions immediately without consideration for the overcrowded conditions and the long waiting lists which already exist and also without adequate consideration for the wishes and feelings of the parents. Many of them would like to take care of their children at home and many more of them would be able to if they could get the help which they need through a community program. For this reason we are encouraging

the development of programs which would include in addition to diagnostic services, social casework, foster home placement, arranging for placement in nursery schools and day care centers, helping parents in child training, parent counseling, group work with parents, arranging for admission to institutions, and evaluation studies of demonstration programs. The State health departments, by virtue of their organization for services, and their relation to county health units, are in a position to assist parents in the care of their children at home, to provide through local physicians, local well-baby clinics and county public health nurses the follow-up services and health supervision of these children. This does necessitate, however, a close working relationship and understanding of objectives on the part of the staff in the State health department, the diagnostic center, which may be part of the State health department, or located in a hospital or medical school setting, and the various local health units. It means also intensive work in community organization to develop needed resources. It seems to me that by bringing to the problem of the mentally retarded child the experience in programs which have been acquired in organized health services, we will be in a much better position to help parents to care for mentally retarded children in their own homes.

While this program provides a new concept for most health departments, it is one in which we are seeing a rapidly increasing interest. Much of this interest has been created by the parents' group themselves and by individual parents who in a short space of time have organized themselves so effectively. While special clinics and special services of various kinds for the retarded are necessary at this time, we should keep in mind that the ultimate objective of the parents is to have their children participate as much as possible in the regular community programs that exist for all children.

# V. CLINICS IN A TOTAL COMMUNITY PROGRAM FOR THE RETARDED

## Discussant:

MAURICE KOTT, Ph.D.

Chief, Bureau of Mental Deficiency, New Jersey Department of
Institutions and Agencies

THIS PRESENTATION IS INTENDED to address itself to the relationship of clinic services for mentally retarded persons and state government programs. It is therefore required to define to some extent an adequate state program. Since, what I conceive of as an adequate state government program will be outlined with some dispatch, I feel impelled to introduce a word of caution. This subject really requires fuller treatment than possible here.

A state program to deal with the problem of mental deficiency has three aspects. The first aspect is to determine the number of mentally deficient persons who require a kind of service different from that provided the average citizen of the State. The second is to provide special services for the mentally retarded person. And the third is to determine what can be done to reduce the extent of the problem in the future.

- (1) The question of how many mentally deficient persons there are who require "special handling" involves an aspect of enumeration or registration that obviously depends upon facilities for making accurate diagnoses. This is a process of counting noses either as the mental deficient comes to the attention of clinical facilities, or counting noses in an epidemiological study. And the success of any epidemiological study depends to a great extent upon cases having been recognized and classified by competent clinical authorities.
- (2) The second aspect of a state program—the provision of special services for the mentally retarded—may be considered in a general and a particular sense. In general, the services should provide for training to the maximum limits of the ability of the retarded individual, should provide assistance with social adjustment, and assistance in the reduction of tensions almost always observed in situations where exceptional individuals are required to adjust to "average" social circumstances. In particular, the program should include public school education for the handicapped child who is capable of adjusting to and profiting from a classroom experience. It should involve home instruction for individuals, not capable of much growth. It should involve sheltered workshops to provide the handicapped individual with training experiences in production, and an opportunity to learn to interact with other members of a group. It should involve counseling and guidance of the handicapped individual and his family so that there is understanding and acceptance of the handicap, objective planning to establish goals which might be attained, and reduction of anxieties, guilt, and hostilities so frequently observed in this condition.

The program should include supervision of the employment of the handi-

capped individual, perhaps to the extent of making certain that his job placement is one which is within his abilities, and where the employer understands the essential character of the handicapped employee and makes reasonable adjustments to it. The program should involve institutional care and I must indicate that I consider this is a community program because in the absence of direct ties between the community and the institution, no institutional program can develop to much more than detention of an exceptional individual. Finally, the program should involve post-institutional supervision with its aspects of counseling, guidance, and support in employment situations. This is not only necessary for individuals released from institutions, but as well for those who have never been institutionalized.

These aspects of a state program for mentally deficient persons depend upon the development of clinical facilities which meet the essential need for diagnosis, for family guidance, treatment, or appropriate referral and for help in the placement of mentally deficient. Diagnostic facilities are required to determine whether the child can fit into a public school program and if he fits whether he is "educable" or "trainable." Successful operation of a sheltered workshop depends upon the referral of individuals who *can* engage in the operations typical of the sheltered workshop and can adjust to the group situation. Successful employment counseling and placement depends upon fairly precise recognition of the achievements of the individual who is to be employed. And if institutional care is to be meaningful at all, diagnostic facilities must be available to indicate to administrators which children are being committed for training purposes and which children's needs are essentially protection and care.

Although these last remarks point to the diagnostic tasks that clinics are required to provide in a total program for the retarded, clinic functions should not be so restricted. Counseling and treatment services are part of clinic functioning. Further, there is the need for close communication between clinics and institutional or residential centers. Equally facile communication with sheltered workshops and the public schools is necessary. If clinics are to evaluate **their** work as well as their objectives, they should be prepared to receive reports on what happened to children referred to other parts of the total program.

(3) The third aspect of state program mentioned above was research. Research should be a fundamental aspect of all services, be they residential or community oriented.

The principal of continuous study, or research, is essential if the cause or the methods for preventing mental deficiency is to be disclosed and is a basic requirement of an adequate state program. Research is essential for the development of effective methods in training and a necessary prerequisite to developing adequate public knowledge, understanding and in the acceptance of mental handicaps.

The extent of a clinic's role in a research program may be determined by the size of its service load but should never be reduced to no participation.

Departments of State government involved in programs for the retarded have an obligation towards clinics as an integral part of the program. They must make sure that a just, proportionate part of existing budgets are available for meeting the needs for diagnostic, treatment and research services for the retarded. This responsibility, however, does not begin and end with the estab-

lishment of additional clinics or the enlargement of existing clinics. State departments must share the responsibility for realistic policies of clinic operation and for assuring that there is adequate personnel and staffs available to undertake broad communication tasks that are prime requisites of appropriate programs.

In addition to supporting demands for adequate budgets, state departments have other responsibilities with respect to clinics. Support for programs of adequate professional training and public understanding is but one of these. For instance, a State Department of Education might include some instruction on the nature and problem of mental deficiency in an advised curriculum for high school students. State Departments of Education might also make certain that all students engaged in teacher training have fundamental information with respect to the nature and problems of mental deficiency. Early identification of a mentally retarded child by the classroom teacher can be the first step toward professional diagnosis and corresponding development of a program to capture as much of the child's potential as is possible.

Stimulation and training should extend to other specialists as well as teachers. Stipends, scholarships, and fellowships should be offered to students who are planning to become social workers, nurses, occupational therapists, psychiatric technicians, and to other professional workers who might lack complete training. In this respect, the New York State Mental Health Commission, with its granting of scholarships for graduate study in psychiatric social work is probably worthy of signal mention. New Jersey, as well as other States, now offers internship and provides in-service training for psychologists. Extension of internships, to what is conceived of in medicine as residency, would permit psychologists in training detailed experience with specific clinical types, and enable them to approach the first clinical task with a greater amount of practical experience.

Of particular importance to an adequate program in an area which has the scope of the problem of mental deficiency, is "citizen understanding" and "citizen willingness" to meet the cost of such a program. Departments of state government must join with professionals at the clinic levels to disseminate information about the problem in general and about programs which have proven somewhat successful. Agencies must provide strong informational services if citizen understanding is to be obtained. Clinics, for instance, must be available for visits of representatives of the media of public information and participate in the organization of public institutes on professional problems.

We come now to the question of the nature and the kind of clinics we want to evaluate and treat the mentally retarded child.

In 1954, a New Jersey Commission to Study the Problems and Needs of Mentally Deficient Persons addressed itself to this question. Among other things, it was apparent to this Commission that mental deficiency as a clinical problem, suffered in competition with other more insistent and less permanent mental health problems. It was pointed out by the Commission, and it is probably apparent to everyone, that because of the psychiatric orientation of many mental health clinics "there is a tendency to pass over the seemingly deadend problems of the mentally deficient" and concentrate on the difficulties of

the neurotic and disorganized personnel who can be treated and sometimes "dramatically solved."

Despite this recognition, this Commission went on to recommend:

- 1. Expansion of existing mental health clinics to serve persons who are mentally handicapped.
- 2. The development of special clinics for the mentally deficient established with Federal, State, and private funds.

This seems a wise and appropriate recommendation. Further, it might be stressed that State responsibility of the demands for increased services should not be limited to action through State facilities. Out of distinct recognition for the taking up of the slack in mental hygiene clinics, the Department of Institutions and Agencies, as the mental health authority of the State of New Jersey, found it appropriate to underwrite a portion of the expenses of the Clinic for Retarded Children operated by the Essex Unit of the New Jersey Association for Retarded Children. I use the word appropriate advisedly—for no matter where, no matter under what auspices, and in no matter what kind of clinic the diagnostic, treatment, community education and research function are undertaken, the total state program is furthered.

## VI. CASE PRESENTATIONS

# Summary of Discussions

Two selected cases of children with mental retardation were presented and discussed by the staff of the Clinic for Retarded Children, Flower and Fifth Avenue Hospitals.

There was lively discussion and trainee participation, centering around clarification of the diagnosis, treatment plans, and eventual prognosis.

The presentations also highlighted team-work functioning in a clinic by the various disciplines involved, as well as the use of available community facilities.

# VII. ADMINISTRATIVE AND ORGANIZATIONAL PROBLEMS IN CLINICS

# Summary of Discussions

Limitations of space have made it impossible to reproduce the entire discussion which ensued.

Therefore, the following portions have been edited in order to bring out some of the highlights and main points that were made during the discussion which have important implications in the area of the organization and administration of clinics for the retarded.

#### DR. MCNEILL:

The need and demand for clinics to serve the mentally retarded has been amply demonstrated. Once such a clinic is envisaged and organizers are gathering together to push the project, the principle of the shared budget ought to be kept in mind. It is a wholesome thing for a clinic to have its sources of money from a diversity of places. This means that a lot of different people in the community have a stake in the clinic and are therefore willing to contribute a lot of other things and services besides money to the clinic. In this connection, we come to the question of voluntary money versus government money. Voluntary money, we know, is often hard to get. But we also know the value of a categorical appeal—you can get money more readily for a specific group of handicapped children than you can for just children.

Mental retardation clinics at this point are in experimental form. They are somewhat different from one another and voluntary money must be sought to support projects that are still in an experimental stage. When standard operating procedures have been arrived at, then the major source of support for services of proven need should be the several levels of government. Certain government money, notably federal money, has been assisting in the role of providing demontration projects and experimental projects, but once a service has proved itself to be a community necessity, then it seems to me that the time has come for it to be supported by public tax funds; state and especially local.

Also, it seems to me budgets have to be sufficient to provide adequate salaries for staff. We know that the problem of the mentally retarded is a tragic one, and working with them is often taken to presuppose a kind of identification with people who are suffering and in great need, and we may feel that the staff should themselves be self-sacrificing people. This is fine, except that you can't run a program with underpaid heroes and recruit enough in number. A broad program must be based upon adequate recompense for the staff.

### DR. DIMICHAEL:

The manual<sup>1</sup> that was prepared as the basis of our discussion is well conceived but it is set up in a limited context of a basic clinic in a hospital. We have

"Recommendations for Clinics for Children with Mental Retardation," New York Medical College Dept. of Pediatrics (preliminary draft—mimeo).

to give attention to other types of clinics, for example, the evaluation conducted in an education setting is also a form of clinic, and similarly the evaluations made in rehabilitation centers are another form of clinic. We may discuss the administration of clinics, not only in terms of the context in "basic" hospital clinics, but also other forms of clinics.

#### DR. SLOBODY:

These are good points of departure. We might start to focus on setups which might apply to either urban or rural settings. Dr. Bartram, you have a cerebral palsy clinic in Philadelphia. Could you tell us something about it?

#### DR. BARTRAM:

We call our department at St. Christopher's Hospital that of handicapped children. We believe that there is a great deal in common to the clinic approach of the child whether he is cerebral palsied, blind, deaf, mentally retarded, or emotionally disturbed. Many services that we render to all of them have the same approach, personnel, and space. From a community planning point of view it makes lots of sense to deal with these groups together. Although we have our foundation campaigns, and varying spheres of interest and concern about different types of handicapped children, we make use of the factors that they have in common, that are treatable, and that are approachable by the same team in our clinic.

I would like to make the point, too, that when you are setting up the new clinic, it is pretty important to define what that clinic is supposed to do and what you expect of it. I am sure a clinic is not a failure because it has a waiting list of 1,200 children. If its purpose were to provide adequate service to all the children whose parents thought they had a need for it, it certainly would be a failure.

It is important for the people who are running the clinic and for the community, to know what is expected of that clinic: Is it geared only to diagnosis, to establish that the child is retarded, or is it a service clinic in which you are going to do something for the child; or is it a clinic in which the parents are to get some help, or is it concerned with school problems? Is it to be concerned with some of the problems that pediatricians know less about, rehabilitation, vocational guidance, job placement or a sheltered workshop? I hear some people say: "Set up a clinic and solve your problem." If so, maybe we are reaching for something and are not quite sure what it is and we are going to be frustrated when we get it. We must be realistic about what we want to do and can set up.

The point has been made, too, that many of these services should be set up on a state-wide basis. From a public health planning point of view, I think that makes good sense since there are many kinds of problems that need diagnosis.

I think a good bit can be said for centralization of some services and decentralization of others.

# # # # # #

Just for the purposes of offering a viewpoint—still on the subject of organization of clinics—suppose I were to suggest that there should be overall state planning for clinics. In urban areas there should be clinics primarily for children of pre-school age, for evaluation and for proposed treatment, located in teaching hospitals which are recognized in the community as having approved residencies for professional training. When the children are of school age perhaps the clinic center should be in the school system.

\* "Tr Tr w Tr

#### MR. WEINGOLD:

There has been mention of establishing general clinics for all handicaps rather than specialized clinics for the mentally retarded. This viewpoint seems to have come to the forefront only since there has been so much pressure for clinics for the mentally retarded. Specialized clinics may not be feasible in a rural or semi-rural area, but certainly are needed in urban areas.

Some of the first child guidance centers in this country were for the mentally retarded. They changed their focus as emotional disturbance became more fashionable. This is similarly true in specialized education; for example, the Montessori Method was originally developed for mentally retarded children and then was applied to the normal pre-school child. If we do not have a specialized clinic for the mentally retarded, it is my fear, based on experience, that at the first budget stringency the allocation for the mentally retarded will be cut.

What guarantees do we who speak for the mentally retarded have that this will not happen again. I think it is important that when we think of clinics for the retarded and when we are confronted by pressures for general services to the handicapped, that we remember the past history of this field.

I also would like to address myself to the question of adequate personnel and the feeling in some quarters that a clinic should not be started unless and until we do have adequate personnel and budget. I can speak from personal experience in terms of getting money and selling a program to the public and to other agencies. Funds are attracted by projects. Funds are rarely attracted solely by talk or good will, at least not in the same quantity. If you can demonstrate even on a rather meager basis what you have in mind and what you aim to do, and explain that this is on a very insufficient and meager basis, you will attract the funds and the support that you need. This is especially true in the rural areas, where you can't get the personnel. Now, what do you do—do you have no service, or do you say, "We'll have it Saturday morning with whatever pediatricians are willing to pitch in and learn as they go along." Certainly the children and the parents will be getting something that they didn't have before. I think Dr. Slobody is familiar with this because his staff went up to a rural area and helped set up a part-time clinic.

## DR. DUHL:

I recognize that there is a need for specialized clinics. At the present time I am completely in favor of them. However, my experience shows that there is great competition for personnel in clinics. In California recently five clinics for

different handicapped groups were competing not only for the same personnel and the support of the schools and the health department, but also for the same building that happened to be available, though all could have been done together instead of separately.

Dr. Bartram's point that many phases of work regarding the needs of parents and children are similar in all these clinics, speaks for some form of combined services. And the most important common feature in the needs of the family and of the child are the socio-psychological phenomena that accompany retardation and all handicaps.

The second point is the problem of whether you should set up a clinic even though the personnel are inadequate. Some of these clinics have been set up, and have remained inadequate. There is another method of setting up rural clinics without having inadequate clinics to start with and that is to operate on a regional basis. We have used regional compacts between states. Where they do not have enough trained personnel, the states have developed compacts in which they share in the training of personnel and in setting up programs. When you start talking about a rural clinic, you should first start thinking about a county, or even a wider regional plan for a comprehensive clinic that is adequate for the start. The problem of trained personnel still remains. They probably will have to be trained in a central medical school clinic and gradually sent out to non-urban areas.

#### DR. DIMICHAEL:

It seems to me at the present time that specialized clinics are absolutely necessary. Dr. Duhl has made the major point, namely, that so few people are trained in this field, and what we need is a basic core of well-trained professional people of various disciplines who will serve as catalysts to the rest of the field. Unless there is a central focus for the retarded, I don't think we are going to get the "catalytic" professional people that we otherwise need.

Although it may be desirable, as Drs. Bartram and Duhl have pointed out, to combine services, there is still a question of the attitudes of professional people in those clinics. If a psychiatrist, a psychologist, or a social worker in a clinic just doesn't have interest in the retarded, you can't force their interest. There must be fostered among the parents and friends of the retarded, as well as the community at large, a public sentiment that brings about an understanding of the need. In creating this public sentiment, you would find a strong lever of support in the groups attached to NARC. There may be difficulty in trying to help these groups to refine and to delimit their ideas. I can't help but point out the obligation of professional people to help the community people to constructively think through their desire to set up an evaluation center for the retarded. I would certainly agree that all other things considered our effort would be better placed at a state level so that we can get the state people together with the local people to join forces with the state associations for retarded children.

As far as rural areas are concerned, there is obviously a need for combining services. I personally don't think that the traveling clinics have proven successful in meeting the need. A permanently established clinic has many more advantages. In one of the semi-rural sections of North Carolina there is much concern at present about setting up a clinic. They obviously believe it would be a waste

of time to have that clinic too specialized. As long as you find that kind of public sentiment you will have the combining of forces to the advantage of all handicapped people.

However, looking at it from the point of view of the retarded, I can't help but feel that unless there is strong public sentiment to help the retarded together with informed professional persons to help in planning a facility the retarded probably would be left out of the picture again.

#### DR. WORTIS:

I'd like to take the liberty of going a little far afield and view from a distance the function of a retardation clinic in a broader program of help to retarded children because it has been our experience in developing our clinic that we have moved about quite a bit in picturing our function and our role during the past few years. A retardation clinic in any center is almost certain to be a wholesome influence, because some work will be done and a great deal of interest will be created. The mere presence of skilled and seriously interested people is bound to have a useful effect. But soon after we got started, a foreign student here to study social work did his thesis on the question of the meaning of the clinics to parents, and he called at the homes of parents who had been to the clinic, and evaluated their reactions.

An interesting thing which emerged from the study was that the average parent had quite an unrealistic conception of what the clinic could do. They were attracted to us in wholesale numbers because they thought a hospital clinic could cure their retarded children. I think that around the vivid interest of parent's groups in setting up clinics is often a certain element of unreality about what the function of such a clinic could be.

When we got down to cases and worked with the children in a way that we thought would be helpful, we found that many of the functions that we were called upon to assume became quasi-educational, and the problem of accumulated numbers of long-term programs, of types of personnel, began to raise doubts in our minds as to the appropriateness of placing such long-term rehabilitation tasks in a hospital setting. For that reason I think it would be reasonable, if one were to move into a virgin territory where there were numbers of retarded children uncared for, to place primary emphasis upon the development of educational facilities for those children. Education facilities mean several different things. It means attention to the mildly retarded child in a normal class setting; it means the development of special classes for the school population who justify it; for dealing with the more severely retarded; and perhaps the development of special settings, special institutions (not necessarily custodial institutions) for the doubly handicapped, the blind and deaf, or cerebral palsied who are also

A second thing that I would give high priority to in developing a community plan for retarded children is the problem of vocational placement. In fact, that is more important than seems to be true at first. Unless you have realizable goals for the young adults who are retarded, your educational program falters and bogs down when you lose this incentive. As soon as you have

in a community the adequate facilities for vocational placement, sheltered workshops, special protective legislation, and things of that sort, then you have realizable goals to aim for and the whole educational process is inspired and sparked into action.

It is in the relationship to these two high priority requirements that I can picture the development of special retardation clinics in their most natural setting. And it seems to me such retardation clinics should preferably, though not necessarily, be placed in hospital settings, because much of the diagnostic work, some of the treatment, and much of the rehabilitation is bound to have a medical character and would profit from medical interest and medical supervision.

Perhaps, ideally, such a retardation clinic in a hospital setting would have close ties with a rehabilitation center, where the more severely handicapped could be dealt with over long periods of time by special teachers, with facilities for physical therapy, occupational therapy, speech therapy, and other long-term help that much children need.

In our clinic we have, at long last, developed a very good liaison with the school system so that a representative of the school system is a part of our clinic staff. We can now discuss problems of school placement and special education and that seems to me to be a very desirable and natural development. Such clinics should become centers for research and for the training of medical students and of other personnel. But so far as the long-range treatment is concerned, I cannot picture such clinics in a hospital setting doing more than initiating the rehabilitation process, or picking demonstration groups to show what can be done in the way of rehabilitation, or referring cases to cooperating agencies where rehabilitation work can be done; and of course working with the parents to see that the home situation and home training is improved. So that, when we speak of clinics for the rehabilitation of retarded children, we may, I think, be biting off more than we can chew, although, as an initial program, rehabilitation can be centered in such hospital settings. For the long view we have to picture a complex of community services in which the retardation clinic will be a part, perhaps a central part, but still just a part.

#### FROM THE FLOOR:

I think Dr. Wortis has brought out a very important point as to whether or not these diagnostic plants for mentally retarded children where the major part of the treatment is education belong in hospitals. We have set up an institute for mentally retarded children which is not affiliated with any hospital or medical school. We have centered our institute around our educational work and around our social services. These children who are of the school age group, who attend school on a part-time basis, and those that are too young for school—children under five, whom we counsel medically—are under the guidance of social service. It is questionable whether it is the function of a hospital to set up this kind of an institute for retarded children. The medical diagnosis, of course, and whatever medical care is involved certainly should be carried out under medical auspices, but that would be on a short-term procedure and with occasional follow-ups.

I think parents would rather send them to a school setting than to a hospital setting. As Dr. Wortis has indicated, I don't think the hospital has either the

physical space or the facilities to carry on these long-range procedures and I question whether it might not be wise to set up these services for mentally retarded children apart from hospitals, or hospital clinics, and perhaps have an affiliation with the hospital where they can be referred for diagnostic procedures, and for other medical procedures as are not usually done except in a hospital.

#### DR. DUHL:

One thought that came to my mind as you were talking is that in seeing many of the clinics around the country, I have found that most of the medical clinics have concerned themselves with the more severely retarded, and they do not have either the time or the energy, or somtimes interest, to concern themselves with the larger bulk of the problem which is probably around 85% of all the retarded—the ones that are not organically involved. And these are the ones, I think, that reach the clinics centered around educational institutions, but which will never come into hospital clinics.

#### MR. WEINGOLD:

It seems to me that one of the main functions of this very institute has been to provide for the exchange of experience and to show that there are many ways of planning a clinic. Conditions are not the same in each community, and I think Dr. Words' point about the evolution that took place in his clinic has been most constructive.

Considering the figures quoted to us by Dr. Hoch yesterday—Amsterdam, Holland, a city of 900,000 with thirty institutionalized youngsters, and New York State, for example, with thousands of institutionalized youngsters, certainly shows that there is a vast diversity of ways of handling this problem.

#### DR. DIMICHAEL:

I think that planning of clinics is needed on all levels—the local communities, the region, or the state. People in rural areas will have to decide how they want to develop clinical facilities, in cooperation with representatives of a region or a state.

## DR. DUHL:

I would just like to report on Dr. Masland's experience. He is working on a special research project for NARC and told me the other day that as he traveled around the country and talked to parent groups he had been amazed at how unaware they were of the number of people who were available locally who could be of help to them, not only in terms of training programs and the like. The big problem is just getting these people interested in working for the retarded. He said he found place after place where people have been able to do this, and other places where they haven't done it at all because they haven't gone around and looked for the available people.

i3th Sk sJic slic Sk dle

#### FROM THE FLOOR:

I haven't heard much about clinics in institutions. I believe Dr. Duhl said he hadn't found the standards in those clinics very good.

#### DR. DUHL:

I have traveled around and found many of them to be very inadequate, mainly because they don't have enough staff to meet the need of the total area that they serve. On the other hand, there are some that are doing an excellent job, such as the Pacific State Hospital in California, which is running not only an admission clinic, but also a mental health clinic for all mental health problems. The most constructive factor is that the institution is tied in with a university, a medical school, and other centers where they have been able to attract personnel.

#### FROM THE FLOOR:

This is exactly the point that I wanted to bring out—that by attracting competent personnel to your state institutions I believe that you can do several things, such as changing the programs of the institutions—their treatment and training—and raise the standards of service as well as having your already specialized people within the institution to offer service to your community.

#### DR. DUHL:

A real practical problem in such situations is that most of the institutions around the country are pretty far from urban centers, and they have been divorced in research and training from any kind of university setting. This is why some of us believe that the best place to develop clinics is from a central place in a state or in a large urban center, because then you can bring in other disciplines besides those you have in an institution. The institution usually doesn't have enough personnel to cover all the needs for its own residents.

#### MR. WEINGOLD:

I don't think that the location of clinics can be imposed on parents. They must be consulted in some way as to the location of the clinics and the acceptability of the clinic in that location. That raises some very interesting questions:

- 1. Would they accept a clinic in an institution where their child is not institutionalized?
- 2. Would they accept a clinic in a mental hygiene setting whose focus heretofore has been examination for placement in an institution?

How far will parents and children have to travel to state institutions, clinics, or regional clinics?

Before we approached Dr. Wortis of Brooklyn Jewish Hospital for a clinic, we polled the parents and found that a clinic at a hospital, which heretofore had been used for examination for placement in a state institution only (and still is) was unacceptable. Parents would go there with great misgivings if they would go there at all.

#### FROM THE FLOOR:

I'm interested mainly in getting young professional people interested in the area of mental retardation and we found out in our community that work in categorical clinics doesn't attract young people who are just going into the field. We have more trainees in the general team clinic than we ever interested in a categorical clinic.

# # # # \*

#### DR. SLOBODY:

Perhaps we can reformulate a little and then move on to some of the administrative questions that were brought up in the past few days. There seems to be an expressed preference for regional planning, and for a division of clinics into:

- 1. Pre-school age clinics;
- 2. Education-oriented; and
- 3. Pre-vocation oriented clinics.

The pre-school clinics, perhaps, should be in centers which may be connected with a medical school, and they should be attractive to where the parents would like to go. Such a clinic would be highly focussed toward evaluation, parental guidance, and preparing for school. Diagnosis has to be made before you can refer the child and counsel parents properly. Perhaps the preschool clinics should be centered in medical schools, teaching hospitals, or institutional set-ups with staffs of high caliber.

Once education is started, the clinic might be centered in the educational facility. We haven't spoken about the older age group, but I think that when the retarded are near or at vocational ages perhaps it should be centered in a vocational training set-up. We also realize that there are serious personnel and support problems involved.

There were certain administrative problems brought up in the past few days and I would like to raise the first one for your consideration:

Let's take a clinic for the pre-school age group, and start off in an urban area where we do have good facilities. The question that was asked was, who should head up this particular clinic?

### DR. WORTIS:

I would say that, probably in most localities the question of how soon the clinic can be started claims a higher priority than the question of what category of professional personnel should head it up. Ideally, such a clinic should be hospital centered, and headed by a competent and interested physician. It doesn't seem to me to be of too basic importance whether the physician happens to be a well-trained, highly qualified, and very interested pediatrician, psychiatrist, or neurologist, or even an orthopedic surgeon who happens, through interest in rehabilitation and cerebral palsy to relate in an interested way to the problems of chronic brain defects and mental retardation. I do think the evaluation, the complex differential diagnosis, which means more than pinning a label on a child, and the direction and supervision of the rehabilitation process

all calls for medical skill, and I think something gets lost when the coordinating, responsible person doesn't command these medical skills. It is no substitute to have medical people available as consultants without assigning them a real responsibility. So I would say hospital centered and medically directed by way of preference, but if, for local reasons where you have a good social worker or a very good psychologist who is alert to all of the implications of the program and is willing to take over, why by all means, get started and then perhaps the other medical people can be drawn in, in a more responsible way at a later stage.

#### DR. DIMICHAEL:

It seems to me that the basic question has two aspects: who should head up this clinic; and should you have good medical skills available? There is no question about the fact that good medical skills should be available and given as needed. However, as to the question of heading it up from an administrative point of view, my observations would lead me to believe that, if a physician is not interested in administration, a psychologist, or social worker would be quite adequate as an administrator for the clinical set-up.

#### DR. BARTRAM:

I would like to emphasize the fact that whoever does the job and whoever the people are that are in the clinic or in the group concerned, adequate time must be given to do the job. The medical profession has been criticized by parents, and rightly so, for their ineffective work with mentally retarded children. If we set up a clinic and expect it to cover the volume of work, you have to give the man time to work. You can't see a hundred people in a five-hour day, as some of the state orthopedic clinics that we are familiar with do, and expect to give even minimally adequate service. Therefore I would like to stress quality and not quantity on the initial start.

#### DR. MCNEILL

I would just like to make one point: We've mentioned that whoever heads up the clinic should be an administrator. One of the things that I have noticed in any type of clinic is that the administrator has to be a person who not only could administer a program in a clinic, but he also must do a good liaison job with the community. He should have skills in financial matters; getting money, budgeting, and things like that. There are two other areas of important skills; that is, in being able to establish a training program, whether it be in-service, or for people in other agencies in the community. He also should have proper concepts of research, whether it be basic or operational research because the clinic should have an on-going program of self-evaluation. Further, we have to recognize that administrative talents are not built into the training program of either physicians or psychologists or social workers or educators, or the other people that we find concerned with the mentally retarded.

## FROM THE FLOOR:

I think Dr. McNeill has spoken of an ideal situation, but I would like to raise one point, and that is: not all medical people will accept a non-medical person as the top man—administrator—in a clinic.

#### DR. SLOBODY:

That is a good point. I would like to support Dr. Wortis' position that perhaps a medical person—pediatrician, psychiatrist, or, occasionally, a physiatrist—is the ideal person to administer a clinic. I would modify that in one way. When the medical person is not able to carry the whole burden, there may be an able social worker or a psychologist who will be able to take over most of the load of administration. But you still should have the medical person at the head. This is important from another point of view. In order to attract personnel, your top person practically always has to be a physician and, beyond that, of enough stature and able to stimulate the clinic team. Mental retardation is still a field which has great difficulty in attracting able people, so that if you have a well-qualified physician heading up a clinic, other medical people such as pediatricians and physiatrists and neurologists are more willing to come into it. I would advocate that the clinic administrator be a medical person, but that he try to have a social worker or a psychologist with him who will do most of the actual administrative work.

#### DR. BARTRAM:

I would like to underscore what Dr. Slobody said. For one thing, a person who is a good doctor becomes a good doctor because he likes doctoring and doesn't like administration. I think most communities will find it expedient to have two important titles connected with the clinic. The title of director, which lends the tone and the responsibility for policy and for medical management to a medical person, and perhaps the title of administrator or coordinator to a person who can do a lot of the detailed administrative work which doesn't require the medical skills of a physician.

#### MR. WEINGOLD:

It is certainly true that to attract money you need people with stature. Financial support is easier to get if a medical person is heading up your clinic in one way or another. This applies not only for money and services, but more especially for research money and for setting up training programs.

## FROM THE FLOOR:

In our case, we found it best to have a medical director as well as a coordinator who was a psychiatric social worker, and in addition an executive director who was responsible for doing the public relations, fund raising, and other things like that.

## FROM THE FLOOR:

I would just like to say that one of the problems we had was that ours was an "inter-department hospital authority." In other words, we had three directors and the task of coordinating three different disciplines in a hospital is a very tough job. . . . There should be one director, and I think it should be a pediatrician.

# # # # #

#### FROM THE FLOOR:

One of the problems which has come up in our activity is the relation of the pediatrician to the community. There is a feeling that because we have a pediatrician on our staff we will be taking patients away from private practice. I would like to get some comments about how this can be handled.

#### DR. SLOBODY:

That is a very important problem, but not here in New York, neither with pediatricians or general physicians. By the way, let us remember that in this country about 70% of all children are taken care of by general practitioners and not pediatricians. In our overall look at the subject of mental retardation, we have to start way back—to training for medical students, interns, and pediatricians. As I said, we do not have trouble with pediatricians because we have adopted a policy of cooperating with private practitioners.

Pediatricians or general practitioners will use us in one of two ways: (1) to get an evaluation which, for one thing, is cheaper and better than sending the patient around to various physicians, or (2) the general practitioner and pediatrician will willingly have us take charge of the family with retarded children. I would like to add, parenthetically, that I don't think any clinic should be pediatrically-oriented, or psychiatrically-oriented, but rather "total child-oriented."

#### FROM THE FLOOR:

NOW, one of the problems that we are just running into is with people who want to refer their children for the psychological evaluation only, or for the social services workup.

#### DR. BARTRAM:

I don't think it should be a problem. It hasn't been with us. Until we've been at this long enough to have oriented medical students, interns, residents, pediatricians, and general practitioners so that they feel comfortable working with mentally handicapped children, they will be happy to turn them over to clinics. Our problem has been to keep physicians in the picture and to have the family doctor retain the family as his clients and we act as the consultant. We also give partial service, such as a psychological evaluation, or other specific service. We have found it practical.

#### FROM THE FLOOR:

I find it very helpful to have the referring physician, if he calls, to know what the program is, and the nature of our study. In many cases, we send a report to the referring physician, pointing out what we do in the team-work process, how we come to make our recommendation. Then if he wants to handle these recommendations, we will be glad to have him follow-up. When the parent calls himself or herself you generally do not run into that problem.

# # # # #

#### DR. MCNEILL:

I would like to go back to a previous point. We seemed to say that the general clinic was something to be avoided. I would like to know if that is the general feeling of the group. It seems to me that many of the troubles that have come up in our discussion are due to a desire to set up a separate clinic for the retarded.

#### DR. WORTIS:

I think you raise a good question. There are strategic as well as technical reasons for isolating a retardation clinic in a hospital setting at the present time. I don't think either the strategic or the technical consideration is going to operate forever. I would like to look forward to the time, ten or twenty years from now, when a retarded child can walk into a social agency or a child guidance clinic or a pediatric out-patient facility and be given an even better workup than he is likely to get nowadays in a specialized retardation clinic. For the present, however, precisely because the retarded child has been neglected so long and because there is a lot of public interest in the problem, and because people have been so unprepared for this new work, it is good to concentrate one's efforts and engender enthusiasm in a specialized clinic. Even if one were to start retardation work in a general clinic, the natural tendency would be for those with a special interest in the field to form a grouping, confer together, and to concentrate their efforts on the field.

#### FROM THE FLOOR:

I don't know exactly what is meant by an isolated clinic?

#### DR. WORTIS:

I happen to work in a division of pediatric psychiatry where we have several team groupings. One group specializes in speech work—a speech clinic; another group is interested in psycho-somatic work, another group works largely with ward cases and consultation cases, another is dealing with general child guidance problems, while one group is interested in retardation.

## MR. WEINGOLD:

It seems to me that there is a need to get a group of people with interest and knowledge in this field together in a group. At the present time there are so few who know the business that we need specialized clinics for two reasons; a place where you can get the services, and secondly, a focal point where training may be provided.

#### DR. BARTRAM:

There is much to be said on both sides. I think it is important to say that you have a clinic for mentally retarded children, for very practical reasons: it gives the parents' groups who are concerned an interest and a feeling it belongs to them, and it gives them security because something is being done for their

children. You can't identify with a generality; you have to identify with a particular.

From another practical point of view it is important for financial support. At our hospital we have a number of programs for handicapped children and we get money from several different departments of the commonwealth; for a hearing program; from cerebral palsy, etc., and if we get specific assistance for mental retardation, it will have to come from the Department of Welfare. You have to refer to services for specific groups to obtain help for the clinic program.

#### DR. DTJHL:

If all these clinics are grouped together administratively, it is much easier to attract professional people from different disciplines. For example, if you train psychologists, a broad and basic course is required. Then you may specialize in retardation. This speaks for a general basic training first. This is why I would be interested in having all these professional groups together, if possible, in order to think of the programs which are quite similar all the way across the board. Eventually, we may not even have to have specialized clinics for retardation. Maybe the ideal thing in the long run is a family clinic where we are interested in help for the total family; whether the child is retarded, whether he has emotional problems; where mental health is part of it, but where the total health of the child—of the family—is the thing we are really interested in.

#### MR. WEINGOLD:

We have to be careful lest our emphasis on generalized services for all handicapped will again leave out the retarded. It sounds good to say that it will be easier to attract people, to provide better training, at less cost. But let us not forget that our focus is mental retardation. We want to be sure that the mentally retarded are going to get the best clinic services. Do we want to train psychologists as psychologists or are we interested in training psychologists who have a knowledge of mental retardation? Do we want to train social workers in the field of social work which they can get in school, or do we want them specialized in the family problems of mental retardation? In other words, are we going to attract people into the field of mental retardation by a general clinic, or are we going to attract people interested in retardation by a retardation clinic. I am not so sure that it will be even good in the future, as Dr. Wortis said, to have a general clinic. I won't even go that far.

The specialized clinic need not be an isolated clinic. Maybe it sometimes becomes isolated because the other clinics in the hospital aren't indoctrinated as to its functions. But I think at this moment, unless we have a specialized clinic in mental retardation, we are not going to get the development that we want and need in this field; and we will not attract either the money and, likewise, the people that are necessary to carry on this work in clinics and in all the other necessary programs.

### FROM THE FLOOR:

It seems to me that many of us are interested in a great many things besides mentally retarded children, and if not, we should be. I am thinking that

perhaps the retarded child can be helped better by a psychologist, psychiatrist, or pediatrician who has a much broader range of interests than in this specialized work. If you get too specialized it is a little bit of a disadvantage.

#### FROM THE FLOOR:

I can very easily see that the trained professional person in a specialized clinic might be well able te provide greater advances research-wise and service-wise, but before a doctor, let's say, can become a cardiologist, he has to know the whole body. I think it is the same with training other people. You have to know the whole field before you can specialize.

#### DR. DIMICHAEL:

Looking back at my own experience working with the various handicapped groups, I found that there is a certain specialized knowledge and skills with each handicapped group that the professional person must have. And what is this specialized know-how? To some extent it is special professional knowledge, but more than that, it is the acquisition of skills in dealing with these people once they are referred to you. The professional person needs general knowledge and skills and an additional specialized experience. Probably a general clinic with a specialized team for the retarded is a desirable service and training center.

# # # #

#### DR. SLOBODY:

We realize fully that we haven't covered all the problems in administration and organization of clinics, however, we have hit a few highlights. We brought out the fact that organizational planning would be best on a regional or state basis. We brought out the needs for clinics in particular settings—pre-school settings which might be associated with a hospital; education setting which might be located within the school; vocational setting which might be associated with some such vocational setting. We spoke about some problems in actual administration. We have referred to the hard road that mental retardation has had up to now; we feel justified in trying to focus in this particular area so that these children and their parents will receive more than they have gotten and certainly what they deserve.

We are most grateful to the United States Public Health Service for providing the grant to conduct this institute. We need money and personnel and facilities and space, and perhaps these are so interrelated that they cannot be separated. We do hope that this institute will only be the very first of many that will be carried on. We hope further that there will be personnel training centers, such as our new program at the New York Medical College, started in various parts of the city, state, and the country to give us all the personnel we need.

#### DR. DIMICHAEL:

May I speak now for the National Association for Retarded Children. I am sure that all of the parents and friends within that organization are deeply encouraged by the response to this institute. I hope, too, that you have been

infused with some enthusiasm to improve clinical services for the mentally retarded. May I urge you to take your enthusiasm back to your locality.

Please think of ways of multiplying your knowledge about the mentally retarded. You may feel that your recent acquisition of knowledge is modest, but it can serve to interest other professional people in the problem and to sharpen your own thinking.

Perhaps you can fan interest in clinical services for the retarded by inviting professional persons in your community to participate in service and training programs. Their interest and desire to help must be stimulated, and they should be encouraged to find out the challenges and satisfactions which come through serving the mentally retarded. Please let us hear from you about your successes and problems in training other personnel and in establishing or extending clinical services.

#### DR. SLOBODY:

One last note; both Dr. DiMichael and I wish to thank Howard R. Kelman for his indispensable work in planning and in carrying out arrangements for this institute, and the other staff members of the National Association for Retarded Children and the New York Medical College, who contributed to the success of this institute.

# Conference Program

## WEDNESDAY, MARCH 14

#### Welcome

Ralph Snyder, M.D., Dean, New Yor\ Medical College

#### Orientation to Institute

Lawrence Slobody, M.D., Professor and Director of Pediatrics, New Yor\ Medical College

## Tours of Clinical and Training Facilities for the Mentally Retarded Child

CHAIRMAN: Joseph T. Weingold, Executive Director, Association for the Help of Retarded Children

· Clinic for Retarded Children, Flower and Fifth Avenue Hospitals

TOUR LEADER: Margaret Joan Giannini, M.D., Administrative Director, Clinic for Retarded Children, Flower and Fifth Avenue Hospitals

or

 Morris J. Solomon Clinic for the Rehabilitation of Retarded Children, The Jewish Hospital of Brooklyn, New York

TOUR) LEADER: Edmund V. Gordon, M.A., Coordinator, Morris J. Solomon Clinic for the Rehabilitation of Retarded Children, Brooklyn Jewish Hospital

#### Afternoon

· A.H.R.C. Training Center and Workshop, New York City

TOUR LEADER: Nathan Slater, M.A., Director, Training Center and Sheltered Workshop, Association for the Help of Retarded Children

## THURSDAY, MARCH 15

## Morning

### Factors in the Evaluation of Mental Retardation

CHAIRMAN: Paul V. Lemkau, M.D., Director, Community Mental Health Services, New Yor\ City Community Mental Health Board

- A. Etiology and Pathology of Mental Retardation: Herman Yannet, M.D., Medical Director, South bury Training School
- B. Psychological Characteristics: Seymour B. Sarason, Ph.D., *Professor*, Department of Psychology, Yale University
- C. Social Factors—Family and Community: Howard R. Kelman, M.S.W., Consultant, Community Services, National Association for Retarded Children
- D. Epidemiological Aspects: .Paul V. Lemkau, M.D.

#### Afternoon

#### Problems in the Differential Diagnosis of Mental Retardation

CHAIRMAN: Herman Yannet, M.D.

A. Psychiatric Aspects: Arthur M. Meisel, M.D., Psychiatrist, The Jewish Hospital of Brooklyn

- B. Pediatric Aspects: Meyer Perlstein, M.D., Assistant Professor of Pediatrics, Northwestern University Medical School
- C. Psychological Aspects: Herbert G. Birch, Ph.D., Research Associate,
  Institute for Physical Medicine and Rehabilitation, New Yor\
  University-Bellevue Medical Center
- D. Laboratory Data and Their Significance: George Jervis, M.D., *Director of Research, Letchworth Village*

Evening

Social

#### FRIDAY MARCH 16

#### Morning

#### Teamwork in the Treatment of Mentally Retarded Children

CHAIRMAN: Lawrence Slobody, M.D.

- A. Medical Treatment: Joseph Words, M.D., Director, Division of Pediatric Psychiatry, The Jewish Hospital of Brooklyn
- B. Physical Medicine: Jerome S. Tobis, M.D., *Professor and Director, Department of Physical Medicine and Rehabilitation, New Yor\ Medical College*
- C. Psychological Treatment: Harold Michal-Smith, Ph.D., Chief Clinical Psychologist, New Yor\ Medical College
- D. Speech Therapy: Doris T. Leberfeld, Ed.D., Instructor, Department of Speech and Dramatics, Hunter College
- E. Educational Guidance: Chris Di Prospo, M.A., Assistant Professor of Special Education, City College of New Yorf
- F. Social Work Services: Winborn E. Davis, M.S.W., Administrative Director, Louisiana Evaluation Center for Exceptional Children
- G. The Role of the Parent: J. Clifford MacDonald, President, National

  Association for Retarded Children

#### Afternoon

#### Family and Environmental Factors in Treatment

- CHAIRMAN: Paul H. Hoch, M.D., Commissioner, New Yor\ State Department of Mental Hygiene
  - A. Parent Counseling: Leo Kanner, M.D., Director, Children's Psychiatric Service, Johns Hopkins Hospital
  - B. Home Training: Vincentz Cianci, M.A., Supervisor Special Education, New Jersey Department of Education
  - C. Involving Community Resources: Alfred H. Katz, D.S.W., Executive Director, The Hemophilia Foundation, New Yor\

## Evening

## Clinics in a Total Community Program for the Retarded:

- Salvatore G. DiMichael, Ph.D., Executive Director, National Association for Retarded Children
- CHAIRMAN: Philip E. Ryan, *Executive Director, National Health Council* DISCUSSANTS:
  - Arthur Lesser, M.D., Director, Division of Health Services, Children's Bureau

## SATURDAY, MARCH 17

## Morning

#### Case Presentations

Two or three selected cases will be studied by trainees for complete evaluation and suggested plans for management.

CHAIRMAN: Margaret Joan Giannini, M.D.

Morrison Levbarg, M.D., Pediatrician, Clinic for Retarded Children, Flower and Fifth Avenue Hospitals

Cyrille Halkin, M.D., Pediatrician, Clinic for Retarded Children, Flower and Fifth Avenue Hospitals

Elkan E. Snyder, M.A., Assistant Director, Bureau for Children with Retarded Mental Development, New Yor\ City Board of Education

Jerry Adelson, D.D.S., Chief Dental Consultant, Clinic for Retarded Children, Flower and Fifth Avenue Hospitals

Stella Chess, M.D., Assistant Clinical Professor of Psychiatry, New Yor\ Medical College

Howard R. Kelman, M.S.W.

#### Afternoon

Administrative and Organizational Problems in Clinics

CHAIRMAN: Lawrence Slobody, M.D.

Leonard J. Duhl, M.D., Psychiatrist, Professional Services Branch, National Institute of Mental Health

Harry V. McNeill, Ph.D., Consultant in Clinical Psychology, United States Public Health Service

Salvatore G. DiMichael, Ph.D.

Joseph Wortis, M.D.

John B. Bartram, M.D., Assistant Professor of Pediatrics, Temple University Medical School-St. Christopher's Hospital for Children