Mental Retardation:
A Family Crisis--
The Therapeutic Role
of the Physician

formulated by
the committee on mental retardation

Group for the
Advancement of
Psychiatry

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104 East 25th Street, New York, New York 10010
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MENTAL RETARDATION: A FAMILY CRISIS

Statement of Purpose

The GROUP FOR THE ADVANCEMENT OF PSYCHIATRY has a membership of approximately 185 psychiatrists, organized in the form of a number of working committees which directs their efforts toward the study of various aspects of psychiatry and toward the application of this knowledge to the fields of mental health and human relations.

Collaboration with specialists in other disciplines has been and is one of GAP's working principles. Since the formation of GAP in 1946 its members have worked closely with such other specialists as anthropologists, biologists, economists, statisticians, educators, lawyers, nurses, psychologists, sociologists, social workers, and experts in mass communication, philosophy, and semantics. GAP envisages a continuing program of work according to the following aims:

1. To collect and appraise significant data in the field of psychiatry, mental health, and human relations;
2. To re-evaluate old concepts and to develop and test new ones;
3. To apply the knowledge thus obtained for the promotion of mental health in good human relations.

GAP is an independent group and its reports represent the composite findings and opinions of its members only, guided by its many consultants.

MENTAL RETARDATION: A FAMILY CRISIS—THE THERAPEUTIC ROLE OF THE PHYSICIAN was formulated by the Committee on Mental Retardation. The members of this Committee as well as all other Committees are listed below.

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To the memory of

JOHN FITZGERALD KENNEDY

1917-1963
Mental Retardation: A Family Crisis -- The Therapeutic Role of the Physician

I. INTRODUCTION

The physician today is confronted with more mentally retarded children than was his counterpart a few decades ago. The advances in modern medicine and the availability of new lifesaving techniques have led to the survival of thousands of newborn infants and seriously ill children who would have died even as recently as ten years ago. Adding to the pressure for medical attention for these children has been the upsurge in public, professional and official governmental interest in the complex syndrome of mental retardation. More families now realize the wisdom of seeking medical assistance for their youngsters. The problems they bring to physicians are many and varied. Some are practical problems of diagnosis and medical management, but many others—some obvious, some more subtle—are emotional and psychological. It is with these that we are primarily concerned in this report. It will not deal in any detail with the medical management of the organic problems of retarded children.

The purpose of this report is to discuss the family's emotional reaction to its crisis and the physician's own reactions when confronted with these problems. It will also consider the child and his emotional status. We intend to deal primarily with families of those children whose mental retardation is moderate to profound. Although the report is directed to the family physician, we hope it will also be of value to other interested professional personnel. Since it is not our primary purpose to discuss clinical entities, we have appended to the report a brief summary and discussion of classifications and a suggested reading list.

Mental retardation is a syndrome resulting from a variety of causes, present from birth or early childhood. It is characterized by impaired intellectual functioning and inadequate adaptation to the daily demands of society. The diagnosis is made on the basis of complete medical evaluation, including assessment of intelligence and adaptive behavior. Children, as well as adults, with this syndrome fall into one of several subgroups according to the degree of retardation: profound (eventual mental age under two years); severe (eventual mental age between two and four-and-a-half years); moderate (eventual mental age about four-and-a-half to seven years); mild; border-line. The mildly retarded and borderline children usually do not come to the attention of the practicing physician in infancy or in early childhood, at least not with retardation as the chief complaint. Families with children in the other three categories usually do turn to the physician relatively early in the child's life.

Although the majority (nearly 90 per cent) of the mentally retarded fall into the mild or the borderline group, this report is not concerned with them. Youngsters who fall into these categories are often not recognized as retarded until they attend school. Many of the parents of these children also have limited intellectual functioning, often related to social and cultural deprivation. Accordingly, the disparity between the intelligence of these parents and that of their mildly retarded child may not be great. The parents of these children may have

*This Nomenclature is taken from A Manual on Terminology and Classification in Mental Retardation. Monograph Supplement to the American Journal of Mental Deficiency, 2nd ed., 1961. Available at $2.00 per copy from the American Association on Mental Deficiency, P. O. Box 99, Willimantic, Conn. For epidemiologic information, see BASIC CONSIDERATIONS IN MENTAL RETARDATION: A PRELIMINARY REPORT, GAP Report No. 43, December 1939.
such modest expectations that the retardation often remains unnoticed by the family. Of course, even highly intelligent parents may also fail to recognize mild retardation prior to school age.

When the physician recognizes mental retardation as a predominant problem early in the youngster's life, he is usually dealing with a child who is more overtly retarded. The parents of such a child find themselves bewildered by many problems. They may initially overwhelm the physician with a series of extremely complex questions, such as: "Is my child really retarded?" "Why did we have a retarded child?" "Whose fault is it?" "What can we do about it?" Only some of the questions can be answered; many others will require further study. Often the family comes to the physician with many questions that they cannot face or openly express.

The physician then finds himself under pressure to help solve the family's problems, both conscious and unconscious. Since they are presented to him in the heightened emotional setting of a major family crisis, he, too, has his own reactions, both conscious and unconscious, to the family, to the child, and to the child's impairment. The physician's ability to understand and manage this complicated set of difficulties may greatly influence the child's fate.

We would stress at this point that there is no single answer or formula for the physician in the management of a mentally retarded child and his family. However, if the problem is approached as a complex and challenging one and early use is made of consultants and specialized diagnostic services, the rewards of successful management will more than outweigh the additional effort that may be required. The psychiatrist's role in the program of evaluation and treatment of the mentally retarded is increasing, and there are some psychiatrists who specialize in this field. The psychiatrist can not only be helpful in establishing the diagnosis and evaluating the family interrelationships, but may also be utilized therapeutically in the long-term management of both child and family.

Although closely interrelated, the problems of the parents and the physician will be considered separately in this report. A brief summary will follow on how best to meet the child's needs.
II.
THE PARENTS

When parents are first confronted with what might seem to be the obvious fact that they have a retarded child, their initial reaction is frequently one of denial. This is one of the psychological mechanisms of defense, all of which are unconscious. Through denial, the obvious is treated as if it does not exist: “This cannot be” or “The doctors are wrong.” At this point many families begin “medical shopping.” They look for a physician who will tell them either that the other doctors were all wrong and the child is really normal or that, even if the youngster is somewhat retarded, he will “grow out of it.”

Example

“No one has told us anything,” complains the harried mother of a moderately retarded five-year-old child after consulting many physicians, all of whom recommended placement. “He’s a sweet boy and just a little slow. Can you help him catch up?” It is quickly apparent that she has already been told the answer to this question, and in a variety of ways. Equally obvious is the extent to which she has not allowed herself to accept the diagnosis or the advice about placement. The diagnosis had been recognized by all the physicians and had only been phrased differently. All of these differences in the attempts of physicians to explain her son’s condition were used by the mother to accuse them of lack of knowledge. She continues to ask what is wrong with her child and what can be done for him, but refuses to hear the answers.

The prospect of separation frightens her and is completely unacceptable.

As these parents go from one disappointment to another, additional reactions begin to appear. Guilt feelings arise as they wonder what they might have done to produce this retardation. Since such feelings are painful, it is not unusual for another mechanism of defense to be utilized—projection of the blame onto someone else. Frequent targets for this blame are the marital partner and his ancestry, the obstetrician, or the pediatrician. Either parent may attribute the problem to the other because of family background or “bad habits.” The mother may feel that her labor was allowed to go too long and, therefore, it’s not really her fault, but the obstetrician’s. She may decide that the pediatrician did not see the infant soon enough after birth and that something preventible must have happened. Once again, the blame is not hers. Sometimes the projection is to an impersonal event or thing: “It is due to that fall I had,” or “I’m sure it’s the result of that attack of flu during my eighth month of pregnancy.” All of these projections are unconsciously developed to diminish painful guilt feelings.

The appearance of at least some transient conscious or unconscious guilt feelings in the parents of retarded children can always be anticipated. They, and they alone, were responsible for the child’s conception, and, if the infant is defective, there is an understandable tendency for them to feel that the fault was theirs. The physician should realize that parents feel guilty and that he himself may often be the target for some of their unrealistic hostility. He may or may not have played a part in the earlier care of the child, but he will be an available and symbolic person against whom the parents can turn their frustration and hostility.

As the child grows older and the burden of his care becomes heavier, another reaction may occur: the wish to be rid of both the child and the problem posed by his mental retardation. It is important to realize that care of the more seriously retarded child does make excessive demands on the parents and that it
is neither unusual nor abnormal for them to wish that the
problem, and even the child, did not exist. Such a thought is
unacceptable to the parent and cannot be allowed conscious
expression even for a fleeting moment. It must be warded off.
Using another common mechanism of defense, reaction forma-
tion, many parents develop an overt attitude that is the op-
posite of the unconscious wish. They overreact or overcom-
penstate in the form of excessive care, protection, and concern, and
in demands for additional attention for the child. They develop
bitter hostility toward anyone who seems unwilling or unable
to meet their excessive demands. Doctors are only one group
toward whom this hostility is directed. The siblings, neighbors,
school authorities, and various community agencies may also
be accused of callous disregard of the child’s needs.

The development of these parental emotional problems in
regard to a retarded younger generally proceeds about as
follows: Initially, the parents begin to realize that their infant
is not developing as rapidly as they feel he should. He does
not seem as alert and aware of his surroundings as other infants
they know. He does not sit up or crawl as soon as he should. As
their concern grows, they reticently ask the pediatrician about
the child’s development in a manner that almost demands re-
assurance. This reassurance is often given, understandably but
unrealistically, by the physician. As the evidence accumulates,
however, the parents begin to apply more pressure on the phy-
sician. The need for a consultation or a complete study at a
medical center becomes more obvious. Here the parents are
told they have a retarded child and are probably given con-
siderable additional advice. Since the initial diagnosis may still
be difficult for them to accept, they begin “medical shopping”;
or, especially if the diagnosis becomes incontrovertible, the
parents may then turn to “therapeutic shopping.”

In the first instance, the parents are looking for a medical
authority who will make a different diagnosis, one more ac-
ceptable to them. Not infrequently, today’s enlightened parents
prefer the idea that their child is autistic, rather than mentally
retarded. They have read or heard that such a diagnosis carries
with it greater therapeutic possibilities than does mental re-
 retardation. “Therapeutic shopping” ensues, after the parents
have accepted the diagnosis of mental retardation, because they
feel that the particular syndrome presented by their youngster
must be amenable to some type of curative treatment.

Finally, the reality of their child’s slow development forces
these parents to begin to accept the problem, and this is the
point at which they often return to their family physician for
advice and counseling.
III.

THE PHYSICIAN

The physician is still dealing with parents who have a multifaceted problem:

1. They may not have fully accepted the diagnosis of mental retardation.
2. They have varying degrees of guilt feelings about their possible role in the causation of the child's condition.
3. They resent the fact that this has happened to them and tend to try to find some outside influence on which they can blame the problem.
4. They hope for a magical solution.
5. They have a wish, usually unconscious, to be rid of this burden.
6. They have come seeking advice.

Each of these factors deserves separate consideration by the physician, who must realize that he himself will have certain reactions to the child, to the child's condition, and to the parents and their emotional problems.

Helping the Family Accept the Diagnosis

A fundamental rule in dealing with the parents of a retarded child is that the physician must meet them at the level at which he finds them. While some parents may be ready to accept the diagnosis, many others are far from doing so and are still denying or projecting. If, when the physician first meets the parents, they are inclined to continue diagnostic shopping, he can help in at least two ways. First he may be able to get them to see what they are doing and to encourage them to stop running. Second, he may be able to guide them toward a recognition of their child's problem through using their own observations, i.e., what they themselves have noticed about the behavior of their child. He may, for instance, be able to ask a mother to compare the child with his siblings at a particular age, or with other children she has known at that age. He may encourage her to give other facts about the child's development and then ask how she feels he measures up to other youngsters. If this material is then re-presented to the parent, it will be more acceptable than if it were originally given by the physician.

Once the parents have begun to accept the fact that their child is different, it may be of help to review previous clinical evaluations, and thereby to establish a firmer basis for their acceptance of the diagnosis. The parents may be asked to outline what they have been told by other physicians. What they remember may not be completely accurate, but it still will contain many elements that obviously indicate mental retardation.

As noted earlier, some parents will have accepted the diagnosis and then shifted to therapeutic shopping. They may have heard about a physician somewhere who has an operation, drug, or diet that is “guaranteed” to cure any mentally retarded child. They may know someone who had a friend who had such a child and when this youngster received a series of injections,” he became perfectly normal. Such parents should be encouraged to realize that when important medical advances are made, they are disseminated to the entire medical profession. Similar reactions are seen in the parents of children with leukemia or nephrosis. All are searching for some magical cure and are relatively easy victims of charlatans. Because they desperately want their child to be made well, their ordinary good judgment is distorted. If, however, they can be reassured that the physician is sincerely interested in helping and convinced that his assistance is based on the general knowledge of
the medical profession, they are more likely to be willing to listen.

Another supportive measure that is usually helpful is referral to the local parents' organization for the mentally retarded.* In this group the parents will begin to realize that their problem is not unique and that others have the same feelings. They will also find that others before them have investigated and learned the truth about widely touted but useless "miracle cures." Parents' organizations, such as the National Association for Retarded Children, support and encourage reliance on scientifically proven methods for dealing with the retarded; they are also helpful in countering the tendency toward needless medical shopping.

Parental Guilt Feelings

Once the parents have begun to accept the diagnosis of mental retardation, they begin to verbalize their feelings of guilt. Earlier denial and projection diminish and, as the feeling of personal responsibility increases, there is need for active intervention. The parents should be encouraged to talk about their feelings, and should be helped to understand what is known about the etiology and the therapeutic potentials of their child's condition within the limits of current scientific knowledge.

Example:

Following two miscarriages a mother in her thirties gave birth to a mongoloid child. The mother remained apathetic and anorexic after delivery, and was unable to return to her housework and the daily care of her healthy four-year-old. She could not care for the new baby, and did not want

*Inquiries concerning local groups and reading material of interest to parents should be directed to the National Association for Retarded Children, 380 Park Avenue South, New York, New York 10016. See also the appended "Suggested Reading List for Parents."

...to look at it or touch it. In an interview with her physician ten days postpartum, the mother began to weep and poured out a guilt-ridden, confused tale involving her belief that mongolism is an inherited disorder. She said her grandmother had had a mental illness in later years, a cousin had had a retarded child, and she herself had been promiscuous in her twenties prior to her marriage. There are other situations in which the factors of cause and effect are clearer, but still require elucidation, as in the case of the mother who has had German measles during her first trimester of pregnancy. Certainly the fact that she had the measles is not her fault, and she can be helped to understand why she is not to blame for the sequellae.

It is important for the physician to realize that parental guilt is universal. Since the parents conceived the child they feel responsible for any difficulties he may have, just as they would take pride in having a gifted child. The guilt can be modified by the physician's understanding attitude as well as by the presentation of scientifically validated information to counteract their distorted views. One of the factors that most often intensifies parental guilt is the birth of a mentally retarded infant whose conception was neither planned nor wanted. In general, parents strenuously attempt to adopt an attitude of complete acceptance of the arrival of the unwanted child, but their psychological defenses are overburdened when the youngster proves to be mentally retarded. Their fundamental resentment of the pregnancy and the child's arrival is aggravated by the fact that he is retarded. Such hostile feelings give rise to excessive unrealistic guilt and require even more active counseling by the physician.

Resentment and Projection

The "righteous indignation" of parents of the retarded child can be one of the most difficult problems with which the physician must deal. He should be aware that the anger of the
parents is not personal, but rather that they are using him as a convenient target for the projection of their hostility. It is important that the physician try to help the parents recognize why they are reacting as they are, and equally important that he not counter with his own hostility. The parents should slowly be led to an awareness that their own resentment is derived in part from their guilt feelings and also from their inability to accept the fact that this has really happened to them. In addition, they need help in comprehending why it has occurred. That it has happened is more a problem of recognition than acceptance, but why it happened is merely one aspect of the dilemma that often confronts the practicing physician: why a person falls ill or why this retarded child was born to this particular set of parents. Here the physician must deal with the natural tendency of the parents to assume that because of their role in the creation of the child, they had a part in the production of the youngster’s defect. He must try to help them understand the irrationality of their feeling that the defect could have been avoided if only a number of things had not happened and that, if they had not conceived this child, the whole problem would not exist.

Hope for a Magical Solution

The hope for a magical solution is to be expected, as is the therapeutic shopping that follows. The physician should be careful to avoid brusquely closing the door on all hope the parents may have for the future of their child. The distinction between presenting stark reality and preserving some hope is difficult because realistically the prognosis for the child may be quite poor. If, however, the physician tells the parents too quickly, or too bluntly, what he considers to be the complete hopelessness of their child, he may drive them into looking further for the “magical solution.” Parents need to realize that advances are continually being made, and that whenever a truly effective therapy is developed, all of the medical profession is made aware of it. This will help them to understand

that unfounded claims are only made by irresponsible people, professional or other. Of course, this reassurance will not be accepted readily and the physician can expect frequent calls from parents asking if he has heard about the new cure described in a popular magazine. Patience and understanding on the part of the doctor will help the parents remain under his guidance and avoid pursuing the magical cure.

Wish to Be Rid of the Burden

The parents’ unconscious wish to be rid of the defective child can be a particularly troublesome problem to all concerned. Parents try to repress such feelings, since their recognition of them would bring forth overwhelming guilt. Reaction formation tends to set in and they become overprotective. They may be overly distressed by the child’s minor illnesses and be irritated if the physician does not seem to share their concern about these minor ailments.

Example:

A mother called the doctor because her retarded child had cut his finger. When she brought him to the office the physician found that it was a superficial laceration. He cleaned it and applied a bandage. The mother became highly indignant, claiming that suturing and antibiotics were necessary and that a surgeon should be consulted. When the physician refused, she left, angrily accusing him of being uninterested and unfailing just because her child was retarded.

While giving the child adequate attention the physician should also help the parents recognize some of their own distorted feelings. Under such guidance they may be able to verbalize their basic resentment of the child and the desire to be rid of him. They need to recognize that such feelings are not unusual. As this recognition increases, the parents’ overprotectiveness diminishes.
Advising the Parents

When the parents have given up some of their defenses and are finally ready for advice, the physician has accomplished much. He can then give logical, realistic advice that can be heard by parents without distortion. A common parental question is “Should we have more children?” The field of genetics is too complex to be included in this report. It should be noted, however, that though there are some specific types of mental retardation that are genetically determined, particularly among the moderate and severe forms, in most instances the genetic role is not clearly defined. The parents’ questions should not remain unanswered. At times referral to a geneticist might be desirable.

As the child grows older and as problems change and/or intensify, the physician’s advice and guidance must continue to be available to the parents. Here, too, the physician may find that membership in a parents’ organization will often help reinforce his advice and provide social and emotional support for the parents in their day-to-day care of their retarded child or in reaching crucial decisions concerning his placement, should that be indicated.

IV.

THE PHYSICIAN’S OWN REACTION

We have thus far dealt primarily with the reaction of the parents to their problems with their retarded child. Another important factor, however, is the emotional reaction of the physician himself. Anxious patients or parents expect the physician not only to have the answers to their difficulties but also to do something immediately. These pressures may mobilize the physician’s need to appear omniscient and to prescribe immediately what he hopes will be a specific cure. This reaction, not unlike that of the parents he is trying to help, may come from a desire to be rid of the whole problem. He may then deal with the parents in a peremptory fashion instead of initiating positive action for the long-term medical management of the child and family.

Particularly if he senses the parents’ denial and hostility, he may utilize this as an excuse for dismissing them. In its extreme, this may take the form of “This is your problem, not mine.” Another variation is “This is not a medical problem, but really a family problem, or a social, or governmental, or religious problem.” All of these are efforts by the physician to avoid facing his own limitations. They also stem in part from his understandable lack of experience with the associated professions and agencies involved in retardation and from the inadequacy of his own training in the subject. He may feel that it would have been better had the child succumbed to an infantile illness. The physician, like the parents, should recognize that these are not unusual reactions and need not be denied. He too must explore his feelings toward the family as well as
the child. He should avoid being drawn into the parents’ re-
action formation because of his own similarly denied feelings.
The physician needs to look at his own emotional attitudes
toward the retarded child and the family so that he may then be
in a position to deal with the problems more realistically.

A physician may tend to identify with the parents and ask
himself what he would do if this happened to him. He may
conclude prematurely that it is an intolerable burden for the
family. While it is important for the physician to identify to
some extent with the family and its problems, it is equally im-
portant that he not allow unrealistic attitudes of his own to
influence the therapeutic management.

Example:

A young couple with an eight-year-old daughter have a five-
year-old son who is moderately retarded. He is lagging in
development, unable to start kindergarten, and obviously
slow. The other child is resentful and upset because she feels
her parents neglect her and are overly attentive toward the
boy. They, in turn, are irritated by their daughter’s attitude.
The physician decides that the simple solution is to quickly
remove this problem-producing child to an institution. This,
however, would be to abandon his responsibility to the
family as a whole. Placement of the child might eventually
prove to be preferable, but only after the entire situation
has been thoroughly explored. Furthermore, precipitous
placement of a child to “cure” family tension may boomerang
and intensify the difficulties it was designed to alleviate.

It is obviously not possible within the limitations of this
report to delineate the specific steps the physician can take
in dealing with these families. It is very important that a pos-
tive approach be taken, because even very severely retarded
children can make some progress. Parents need to feel that they
have helped achieve this growth. The more the physician knows
about retardation and available resources, the better he can
help plan a life-long program.

V.

WHAT IS BEST FOR THE CHILD

To insure adequate personality growth every infant and
young child needs a warm and loving relationship with the
mother. This is true whether the youngster is of normal intelli-
gence or mentally retarded. This early mother-child relation-
ship will be beneficial only if it is mature and devoid of re-
jection, overprotection, or other emotional distortions. There
are situations, however, in which the child’s mental defect is
so severe as to generate emotional difficulties even in the most
understanding mother.

Following is a brief summary of the three types of mentally
retarded children that we have been discussing.

Moderate: These are youngsters whose eventual mental age
will be about four-and-a-half to seven years. They may or
may not require hospitalization at some period during child-
hood. If so, the child is hospitalized because the develop-
ment of emotional problems makes their management diffi-
cult, or because of the presence of a severe physical
handicap. Many of those who are hospitalized will eventu-
ally be able to leave the institution, some to go to foster
homes, others to return to their own homes. If such a child
is returned to his own home, it should be with a realistic
understanding of all the factors involved and not out of a
parental desire to expiate their guilt. The total family sit-
uation, including siblings, must be taken into account in the
evaluation of such a move. The possibility of sexual acting
out of a pubescent retarded child needs careful evaluation.
As a general rule, such acting out is probably in direct proportion to the degree of the child’s emotional difficulty, rather than intellectual capacity.

Severe: These are youngsters whose eventual mental age will be somewhere between two years and four-and-a-half years. Physical handicaps are more prominent in these children, and the need for protective care early in their lives is more frequent than in the moderate group. They can usually be trained for simple tasks. Comfortable, warm acceptance of these youngsters by parents is very difficult, and separation is often preferable to a distorted emotional parent-child relationship.

Profound: These are youngsters whose eventual mental ages will fall under two years. The majority of these children cannot be accepted comfortably even by normal, mature parents. They remain completely dependent and require 24-hour-a-day care merely to survive. Protective nursing care is the rule rather than the exception with children in this group. Modern residential care is making progress in dealing with their problems.

The normal infant begins life completely dependent upon his mother. For at least a year he relies heavily upon her to meet his emotional and physical needs. It is only when he begins to walk and talk that his parents and society impose steadily increasing requirements for conformity. His dependency slowly begins to diminish as his capacity for independent activity increases. Progress depends upon the parents’ ability to meet the child’s dependency needs and subsequently to impose conformity requirements in gradually increasing amounts as the child matures. They must also foster the child’s growing independence. This sequence is equally true for the mentally retarded youngster, but is delayed and incomplete because he remains dependent longer and his ability to meet parental and social requirements begins later and proceeds more slowly. In general, the parents can overreact in either one of two directions. They can continue to infantilize the child beyond the optimum time, or they may begin to require more from him than he is capable of giving. The parents of a mentally retarded child, especially if they have other youngsters who are normal, may have great difficulty in adjusting to the dependency and adaptive patterns of this youngster.

The more parental emotional distortion there is in the care of the child, the more uneven and slow will be his progress. If parents cannot adequately meet the child’s emotional needs, either because they themselves are too disturbed or because the child is too handicapped, it may be useful to consider temporary foster care or hospitalization. Foster home care, while preferable from the standpoint of providing a family structure, may be less acceptable to the retarded child’s parents. The mother may feel that such a suggestion implies maternal inadequacy. She may be able to accept hospitalization, even though this would really be less desirable (from the child’s standpoint) than foster home care. In either case, the act of placement may be felt as failure by the mother even when she accepts the validity of the decision.

Example:

After a careful diagnostic workup, a family was gradually convinced that institutional hospital placement would be the best solution for the care of their one-year-old defective child. After the child had been placed, the mother, bereft of the child and relieved of her duties, felt a major sense of loss. She became mournful and withdrawn. Such a depression is not uncommon. This clinical symptom serves to illustrate the usefulness of psychiatric consultation in the course of the physician’s relation with parents.

The overprotective family often hampers the child’s attainment of his potential. In the somatic sphere, for example, the child may not have been exposed to the usual childhood diseases, only to contract several of them one after the other.
WHAT IS BEST FOR THE CHILD

when he is finally allowed to mingle with other persons. The child may not have learned to walk as early as he could have because his parents were unrealistically fearful. In the emotional sphere overprotection may lead to prolonged infantile dependency far beyond the point when the child was ready to take the next step toward greater self-reliance.

In summary, then, the question “What is best for the child?” can be answered as follows:

1. The mentally retarded child needs adequate physical and emotional care. If his mental defect and/or physical handicap are quite severe, hospital care may be required.
2. The emotional needs of a mentally retarded child are in essence the same as those of a normal child, but with a somewhat different timetable. These can often be met in the child’s own home. If, however, the retardation is quite severe, it may preclude a warm, comfortable mother-child relationship and thus may make it necessary to place the child in a foster home or a hospital.
3. Distorted parental emotional attitudes will stunt the emotional growth of the mentally retarded child and impair his potential for maturation. Such distortions are usually in the form of overprotection or a rejecting type of harsh overexpectation.
4. The mentally retarded child does not exist in a vacuum, and the whole family must be taken into account when a treatment plan is formulated. Siblings often suffer because of their parents’ unrealistic attitude toward the retarded child.
5. The family itself does not exist in a vacuum, and community attitudes and facilities must be kept in mind in planning for the retarded child. Continuing medical care, special education, day care facilities, family case work, and other community services are indispensable factors that should be familiar to every physician.

APPENDIX 1.

CLINICAL ENTITIES

Although there are almost always multiple factors in the etiology of mental retardation, there are several practical reasons for delineating the various individual clinical entities that follow. First and foremost is the importance of determining specific etiologies because of their implications for treatment. Classification may also help in guiding general management, if no specific treatment is known. Finally, establishing a diagnosis will be helpful in estimating the prognosis.

The Manual on Terminology and Classification in Mental Retardation*, which gives in some detail a classification of mental retardation, is recommended to anyone interested in further study. It also contains the following Simplified Medical Classification:

Simplified Medical Classification

I
MENTAL RETARDATION ASSOCIATED WITH DISEASES AND CONDITIONS DUE TO INFECTION
Encephalopathy, congenital, associated with premalignal infection
Encephalopathy due to postnatal cerebral infection

II
MENTAL RETARDATION ASSOCIATED WITH DISEASES AND CONDITIONS DUE TO INTOXICATION
Encephalopathy, congenital, associated with toxemia of pregnancy
Encephalopathy, congenital, associated with other maternal intoxications

*A Manual on Terminology and Classification in Mental Retardation. Monograph Supplement to the American Journal of Mental Deficiency, 2nd ed., 1961. Available at $2.00 per copy from The American Association on Mental Deficiency, P. O. Box 96, Willimantic, Conn.
CLINICAL ENTITIES

Bilirubin encephalopathy (Kernicterus)
Post-immunization encephalopathy
Encephalopathy, other, due to intoxication

III
MENTAL RETARDATION ASSOCIATED WITH DISEASES AND CONDITIONS DUE TO TRAUMA OR PHYSICAL AGENT

Encephalopathy due to prenatal injury
Encephalopathy due to mechanical injury at birth
Encephalopathy due to anoxia at birth
Encephalopathy due to postnatal injury

IV
MENTAL RETARDATION ASSOCIATED WITH DISEASES AND CONDITIONS DUE TO DISORDER OF METABOLISM, GROWTH, OR NUTRITION

Cerebral lipidosis, infantile (Tay-Sachs's disease)
Encephalopathy associated with other disorders of lipid metabolism
Phenylketonuria
Encephalopathy associated with other disorders of protein metabolism
Galactosemia
Encephalopathy associated with other disorders of carbohydrate metabolism
Arachnodactyly
Hypothyroidism
Gargoysism (Lipochondrodystrophy)
Encephalopathy, other, due to metabolic, growth, or nutritional disorder

V
MENTAL RETARDATION ASSOCIATED WITH DISEASES AND CONDITIONS DUE TO NEW GROWTHS

Neurofibromatosis (von Recklinghausen's disease)
Trigeminal cerebral angiomatosis (Sturge-Weber-Dimitri's disease)
Tuberous sclerosis
Intracranial neoplasm, other

VI
MENTAL RETARDATION ASSOCIATED WITH DISEASES AND CONDITIONS DUE TO (UNKNOWN) PREGNATAL INFLUENCE

Cerebral defect, congenital
Cerebral defect, congenital, associated with primary cranial anomaly
Laurence-Moon-Biedl syndrome
Mongolism
Other, due to unknown prenatal influence

VII
MENTAL RETARDATION ASSOCIATED WITH DISEASES AND CONDITIONS DUE TO UNKNOWN OR UNCERTAIN CAUSE WITH THE STRUCTURAL REACTIONS MANIFEST

Encephalopathy associated with diffuse sclerosis of brain
Encephalopathy associated with cerebellar degeneration
Encephalopathy, other, due to unknown or uncertain cause with the structural reactions manifest

VIII
MENTAL RETARDATION DUE TO UNCERTAIN (OR PRESUMED PSYCHOLOGIC) CAUSES WITH THE FUNCTIONAL REACTION ALONE MANIFEST

Cultural-familial mental retardation
Psychogenic mental retardation associated with environmental deprivation (specify nature of deprivation)
Psychogenic mental retardation associated with emotional disturbance (specify)
Mental retardation associated with psychotic (or major personality) disorder (specify as e.g., autism)
Mental retardation, other, due to uncertain cause with the functional reaction alone manifest.

Simplified Supplementary Term Listing
(Appropriate supplementary terms should be added to the basic classification. In no case should a supplementary term be used in lieu of a primary diagnosis.)

With Genetic Component
CLINICAL ENTITIES

With Secondary Cranial Anomaly
With Impairment of Special Senses
With Convulsive Disorder
With Psychiatric Impairment
With Motor Dysfunction

These eight categories fall into three large groups: biological, environmental, and intermediate. The biological group includes conditions with known organic etiological factors, as well as conditions with organic manifestations, the specific etiology of which is unknown.

Of the known organic factors, infections that may lead to mental retardation can occur in both the prenatal and postnatal periods. In the prenatal group are included rubella, toxoplasmosis, syphilis, and others. The postnatal infections are any of those that affect the brain, such as encephalitis, meningitis, or brain abscess of whatever etiology.

Toxic factors include toxemia of pregnancy, kernicterus, and other maternal intoxications. Investigations are being carried out on these toxic factors as shown in one report that suggests that the pigments in erythroblastosis do not affect the brain unless liver damage is present. This in turn suggests that if the liver damage can be prevented, the brain will not be affected.

The traumatic episodes that may cause mental retardation may occur in the prenatal period; at birth, when the trauma may be a mechanical injury, or secondary to asphyxia; or in a small number of cases, as postnatal cerebral injuries.

Many metabolic agents may cause mental retardations, some of which, if diagnosed early enough, can be treated and the retardation prevented. The latter include phenylketonuria, galactosemia, and some cases of hypothyroidism. Cerebral lipoidosis, arachnodactyly, and lipochondrodystrophy are also included under metabolic disturbances, but the specific factors involved are not yet clearly defined.

New growths as etiological factors in mental retardation are not common. They include such growths as neurofibromatosis and angiomasosis. Tuberous sclerosis is also listed in this group.

The next major biological group, those due to unknown prenatal influences, is represented by Mongolism. The recent studies of chromosomal pathology and its relationship to Mongolism indicates the value of classification for further clarification and possible prevention of these disorders.

The final biological group includes those conditions where cerebral pathological lesions are observable but the specific etiology is uncertain. Demyelinating and hypermyelinating diseases, as well as cerebellar degeneration, fall into this class.

The second large category of clinical entities is that group which is primarily environmental in its etiology. Many of these children fall into the mildly retarded group, which is not the primary consideration of this report. This category includes socio-cultural factors as well as psychological disturbances.

The concept "mental retardation" can be largely a cultural label. In many communities certain children may be classified as mentally retarded primarily because they fail to meet the expectations of their particular school culture. Social factors, such as physical and psychological deprivations, are also important in the etiology of mild mental retardation. Current studies on deprivation indicate that it is impossible to develop normally if there is inadequate emotional and intellectual stimulation. The work in imprinting in animals indicates that even such previously considered instinctual behavior as nest building does not develop in birds that have not been stimulated sufficiently.

Psychological factors that can cause a child to function on a mentally retarded level range from severe anxiety to early infantile autism. The developmental history of such children gives evidence of original intellectual potential, but the longer the psychological stress continues, the more the child may become indistinguishable from those with biological mental retardation.

As a separate category may be listed an intermediate group that falls between the biological and the emotional and that undoubtedly involves both factors. Childhood schizophrenia probably falls into this intermediate group, including as it does some cases that seem genetic or constitutional, with psychological factors tipping the balance. Here again, although these children may actually have good intellectual potential, they are markedly handicapped and can function only on what appears to be a mentally retarded level. A similar condition may occur in children with sensory organ defects, especially hearing, where the child is unable to make adequate contact with his environment and therefore appears to be retarded.

Undoubtedly further research into all entities of mental retardation will result in shifts from one group to another. This entire classification, therefore, should be considered fluid and interconnected.
APPENDIX 2.

SUGGESTED READING LIST FOR PHYSICIANS
AND PROFESSIONAL WORKERS


Group for the Advancement of Psychiatry: Basic Considerations in Mental Retardation: A Preliminary Report, GAP Report No. 43, December, 1959.


APPENDIX 3.

SUGGESTED READING LIST FOR PARENTS


DIRECTORY OF CAMPERS FOR THE HANDICAPPED. Copies are available from the American Camping Association, Bradford Woods, Martinsville, Ind., and the National Society for Crippled Children and Adults, Inc., 2033 Ogden Ave., Chicago, III. 60612. 1959, 68 pp., 50¢.


LIVING IN PUBLIC AND PRIVATE SCHOOLS AND HOMES FOR THE RETARDED—APPENDIX A, DIRECTORY OF THE AMERICAN ASSOCIATION ON MENTAL DEFICIENCY, AAMD Business Office, F. O. Box 96, Williamsport, Penn. 1962, 207 pp., $1.00.

SELF-HELP CLOTHING FOR HANDICAPPED CHILDREN AND ADULTS, The National Society for Crippled Children and Adults, Inc., 2023 West Ogden Ave., Chicago, Ill. 1962, 84 pp., 50¢.


Acknowledgments

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Three bound volumes of reports and symposiums, covering the years 1947 to 1962, are also available and include reports that are now out of print and unavailable in any other form.