COUNSELING PARENTS OF MENTALLY DEFICIENT CHILDREN

Report of a Round Table Discussion

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DIAGNOSIS

Diagnosis of mental retardation, which must precede counseling, is the responsibility of the pediatrician or family physician. In the absence of certain stigmata such as hydrocephalus, microcephaly or unmistakable signs of mongolism, the diagnosis can seldom be made in the neonatal period. The physician should have his suspicions aroused by failure of the newly born infant to suck, cry, exhibit Moro and tonic neck reflexes on proper stimulus. However, predictions based on behavior in the first days of postnatal existence are best kept in the physician's mind or, perhaps, carefully inscribed on the hospital chart. Cyanosis, twitchings or frank convulsions in the postnatal period are ominous, but not necessarily followed by permanent damage. The physician must be as certain as possible in medical prognostication before making parents aware of his fears for the future mental development of their child.

As the infant progresses through the first few months of life he will give clearly discernible signs of mental development if he is normal. By the second month he should be looking at objects, and soon thereafter be able to follow a moving object with his eyes. By the third month he should respond with some facial expressivity to words, to the usual "clucking" sounds or low whistles, commonly directed at small infants. Somewhere between the second and sixth months the physician should be able to detect retarded mental development, preferably before the mother suspects anything is wrong. Dr. Watson believes that the physician should confine his opinions to himself, or a few judicious words entered on the chart, until he is quite certain of the retardation or until the mother raises the question. He has found the most reliable evidence of promising mental development in the infant 2 to 4 months of age is an awareness of persons and objects nearby, and the ability to "grasp and hold" objects with the eyes, the longer the attention, the better. If one cannot get such an infant to look at and examine the observer, one should be worried about the mental development or vision.

When mothers do ask whether or not the baby's slowness is significant, the physician should meet the problem without evasiveness, and without attempting to stretch the boundaries of normal development too widely. The whole matter should not be put off with a statement such as, "Children vary so much in their developmental time tables that we have nothing to worry about. Give the baby time and all will be well." Although excellent advice when applicable, these words may rise up to plague the physician later when retardation becomes obvious to all, and when the distraught parents are looking for someone to blame or criticize. They might even come to the conclusion, rightly or wrongly, that the baby's development would have been better with early diagnosis and treatment.

Except as instances of mental retardation may be encountered in their own practice, pediatricians see these problems in consultation at a later date when diagnosis is relatively easy. Common referral complaints are: Failure to sit up, walk, or talk, or difficulty with school work. Dr. Watson
pointed out that the factual diagnosis is usually apparent, but determination of causes, degree, and prognosis may take considerable study. Counseling depends on as complete a diagnosis as possible. Several medical specialties and other facilities may have to be enlisted in the diagnostic study and subsequent counseling—the section of the following outline marked “team work” indicates some of the services often involved.

**ETIOLOGY**

Before discussing counseling Dr. Watson reviewed the causes of mental retardation. He followed an outline similar to that of Green and Richmond (Pediatric Diagnosis, Philadelphia, Saunders, 1954).

**Hereditary**
- Familial—genetic—common. Several genes involved.

**Rare—Single Genes**
- Phenylpyruvic oligophrenia
- Galactosemia
- Tuberous sclerosis
- Cerebral angiomnatosis
- Neurofibromatosis
- Sturge-Weber syndrome
- Friedreich’s ataxia
- Laurence-Moon-Biedle syndrome
- Gargovlism
- Tay Sach’s—cerebral lipoidosis

**Prenatal Factors**
- Infections—syphilis, toxoplasmosis, rubella
- Isoimmunization (kernicterus)
- Early maternal bleeding, toxemias, prematurity

**Metabolic Disorders**
- Hypothyroidism
- Hypoglycemia

**Other Causes**
- Mongolism—multiple etiology (anoxia)
- Primary amentia
- Epilepsy

**Cranial Maldevelopment**
- Microcephaly
- Craniostenosis
- Hypertelorism

**Cerebral Birth Injury**
- Natal
  - Hemorrhage
  - Anoxia
  - Subdural hematoma
- Postnatal
  - Poisoning
  - Infection
  - Post-infectious

**Degenerative Disorders**
- Tay-Sach’s
- Heredodegenerative disease
- Hurler’s syndrome

**CAUSES OF PSEUDORETARDATION**

**Sensory Defects**
- Hearing—sight
- Language difficulties
- Aphasia—speech, reading
- Cerebral palsy
- Chronic illness
- Emotional disturbance
- Psychoses (schizophrenia)
- Unstimulated (environmental retardation)

Team work is necessary in diagnosis and management of mental deficiency. The principal professional services which may be called on for help are: The local chapter of the National Association for Retarded Children or similar organization of laymen interested in the retarded child and his family; family physician; psychologist; oto-laryngist and ophthalmologist; neurologist; speech pathologist; geneticist; social worker; and psychiatrist.

**COUNSELING**

There are certain attributes which a physician should have to counsel parents of retarded children. First, of course, is sufficient knowledge of causes of mental deficiency. Absolutely necessary is a sympathetic approach; an ability to understand the parental reactions which range from belliger-
ancy to anguish and despair. Parents must feel the physician's complete understanding and sincere desire to help.

Before opening the discussion of the topic, Dr. Watson called attention to the following material which has a bearing on the problem:

C. Anderson Aldrich in the American Journal of Mental Deficiency (52:127, 1947): "I am outlining here a technic which has been found successful in accomplishing separation of newborn mongols from the family, in the hope that it may help others in meeting this tragic situation.

1. When the diagnosis has been made in the newborn the mother is told that the baby is not strong enough to be brought to her at present and that he must remain in the nursery for a few days.

2. Next, the father is asked to meet the physician immediately, bringing with him any close relatives who are available in the neighborhood. At this conference, the nature of the problem is explained in detail, emphasizing its seriousness, the facts that no one is to blame, that future babies will be normal and that immediate placement outside the family provides the only hope of preventing a long series of family difficulties.

3. It may be advisable, in many instances, to enlist the aid of the clergyman closest to the family. This has been of great help to me several times, for often the pastor will be familiar with the unfortunate sequence of events which accompanies the birth of a mongol and may have dealt with such disrupted families in his church. He is often eager to prevent any repetition of such tragedies.

4. If the father and close relatives of the family can be made to accept outside placement as the solution of their problem, the physician and the husband, backed up by the family decision, report the whole situation to the mother. She is asked, not to make the decision, but to accept the one which has already been made by the close relatives. This has the advantage of tending to prevent the quite natural feelings of guilt which might otherwise plague her after surrendering the child to another's care.

4. Having obtained unanimous family permission, the physician must arrange for immediate placement of the infant. In some states this can be done through public agencies without delay. In others, a boarding home placement for the interval is necessary until the delays incident to commitment and finding institutional vacancies have been overcome.

"This method is, of course, not infallible, but in the past fifteen years it has failed me only two or three times. It means that the physician must take the lead in precipitating an immediate crisis in order to prevent much more serious difficulties later on. This is preventive medicine.

"I am presenting this report to you with the idea that it may stimulate interest in making available a rapid means of committing mongoloid infants in institutions. There is no doubt but that the social service load in any community could be lightened were cribs made available for immediate occupancy by newly born babies who were mongolian idiots."

Florence H. Stewart, Director, Lochland School, Geneva, New York (J. Pediat., 42:136, 1953): "My experience has convinced me that parents who keep such a child at home as a loved member of the family until he is three or four years of age are better able to accept his handicap and relinquish the later care of him with less pain because they have the satisfaction of having given him several years of tender care. . . . We are not referring here to the baby who shows gross physical stigmas but to those who show a developmental lag and possible mild cases of mongolism."

Dr. Edward Shaw (Op. cit., p. 397): "I believe that the idea that the markedly subnormal child, especially the mongol, should be separated from the family at the earliest possible moment really stems from Doctor Brennemann who held most vociferously that it was the responsibility of the pediatrician to recognize this condition in early infancy and practically to demand that the mother should not take the child home from the hospital with her but should place it immediately in an institution. . . . Even in frank mongolism there is considerable difference in degree; some of these children progress to a certain point before they level off in their development and most pediatricians will be able to recall certain cases in which physical characteristics pointed to mongolism but in which the developmental pattern only gradually sustained the diagnosis indicated by the physical characteristics."
Dr. Stewart Clifford (Op. cit., p. 398): "I personally make every effort to have the obvious mongolian baby go to an institution from the obstetric hospital. When this is not possible, I try to have him institutionalized by the time he is two to four years of age. The group of physicians who are in charge of our state institutions take sharp issue with this policy of immediately institutionalizing mongol babies from the obstetric hospital. . . ."

Dr. Harry Bakwin (Op. cit., p. 399): "In the case of young parents, if a positive diagnosis of mental deficiency can be made at birth, as in the case of a mongol, I generally advise institutional or foster-home care if it can be arranged. . . . When hitherto childless parents in their middle years produce a defective baby the situation is quite different. . . . Often they do not plan to have more children and prefer a defective child to none at all. It has been my practice here not to interfere but rather to reinforce any decision which the parents seem inclined to make.

When parents who have already had several children have a defective child, a careful judgment is necessary on the basis of the desires of the parents, the age difference between the defective baby and the older siblings, the parents' appreciation of the effect of having a defective baby in the home on the older children. Though the effect on the older children is generally an adverse one, having a defective baby in the home can under certain circumstances be an ennobling experience for them. The parents' behavior toward the unfortunate member of the household may serve as a model for the other children and may engender in them a similar helpful attitude toward less fortunate members of society."

Dr. Harry Bakwin (J. Pediat., 49:486, 1956): "1) The parents should be told frankly and openly, yet kindly, about the mental condition of their child. 2) Certain offensive words like idiot, moron, cretin, mongol, and so on, should be avoided. 3) A few complimentary words about the child to help to lighten the blow. 4) Discussion should be designed to allay guilt and rejection feelings. 5) Topics which parents want discussed are etiology, heredity, subsequent children, future development of the patient. 6) The subject of institutional care should be approached carefully. 7) The parents should be assured of the continued interest of the physician."

Wolf and Lourie (Clin. Proc. Child. Hosp., January, 1953) state that an inquiry is in order into the impact on the family wherever there is a child with mental deficiency. The parents need help in thinking through what is involved in terms of: 1) Their own way of living. 2) How the other children in the family are involved. 3) What implications the defective child has in relation to the family's social standing. 4) Their position in their own families. 5) Their position with their neighbors. 6) What their role has been in creating the deficiency so that misconceptions about what they may feel is their fault can be corrected. 7) Guilt often is present if these issues are not clear and it can push parents into what seems to be illogical degrees of defense of themselves or overprotection of the child. 8) Families isolating themselves from all contacts or hiding the child.

GENETICS AND MENTAL DEFICIENCY

Whether or not heredity enters the counseling discussion will depend on the family, and the physician's judgment as to whether he should bring up the subject if the family does not. Usually the family will ask what the chances are for subsequent children being affected. The following material was presented for discussion:

Sorsby and Arnold (Clinical Genetics, St. Louis, Mosby, 1953, p. 324) state, "An appreciable fraction of mental defects are caused by specific genes. . . . This fraction has been estimated at anything from 80 to a few percent. It can be said with certainty that no less than 20 percent of the cases have a recognized environmental etiology and that the majority of the remaining 80 percent are highly suspicious of a basic genetic etiology," and (Op. cit., p. 330), "The overall incidence of mongolism among sibs of affected is about 1 percent; however, the risk for sibs born after the first affected is 4 percent. This, at least partially, is due to the fact that the risk of having a mongoloid child increases with the age of the mother. Any woman who becomes pregnant after the age of 40 years runs a statistical chance of 1 to 6 percent of having such a child," and (Op. cit., p. 331), "We do not at present have the necessary knowledge on the genetics of mental deficiency to assess precisely
the future effect of rigid program of sterilization."

In Queries and Minor Notes (J.A.M.A., Sept. 21, 1957), it was stated, "The occurrence of repeat monstrosities in the same family is not unusual. According to Murphy (Congenital Malformations: Study of Parental Characteristics with Special Reference to the Reproductive Process, 2nd Ed. Philadelphia, Lippincott, 1947), gross congenital malformations, as recorded upon death certificates, afflict approximately 1 in every 213 individuals who are born alive. About 25% of congenitally malformed persons are stillborn. In families already possessing a malformed child, the birth of a subsequent malformed offspring takes place with a frequency which is in the neighborhood of 25 times greater than that of the general population. In families containing two malformed siblings, the subsequent defective child is more likely to be born later in the family than it is to be the next child in order of birth to the first defective sibling. In families possessing two or more malformed siblings, the defect in the subsequent offspring has been identical with that in the previous defective sibling in approximately 50% of instances."

The following table is after Halperin (Am. J. Ment. Deficiency, 51:153, 1946.)

<table>
<thead>
<tr>
<th>Parents</th>
<th>Number of Children</th>
<th>Distribution of Mental Status of Siblings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Defective</td>
</tr>
<tr>
<td>Defective×defective</td>
<td>111</td>
<td>57%</td>
</tr>
<tr>
<td>Defective×inferior</td>
<td>51</td>
<td>35%</td>
</tr>
<tr>
<td>Inferior×inferior</td>
<td>274</td>
<td>15%</td>
</tr>
<tr>
<td>Inferior×average</td>
<td>93</td>
<td>3%</td>
</tr>
</tbody>
</table>

**DISCUSSION**

**Dr. Lawrence Richdorff, Minneapolis:** I estimate the number of significantly retarded children to be 1 to 2% of the population in Minnesota. No more than a tenth of these could be accommodated in institutions. To attempt to take care of all of them in special schools is financially impossible. Therefore, in addition to careful selection of those to be institutionalized, the physician should support development of facilities for education or training of these children in the home or community.

**Dr. Randall, Cleveland:** I believe that much more adequate provision of residential homes in the community would be possible if the problem were properly presented to the people. It should be made a community project. I believe that the child should retain a connection with his family if possible. The parents should certainly pay a part of the cost of these special homes within the community, but money might also be obtained from taxes or voluntary sources. These special homes should, of course, be licensed by the State or other agency.

**Dr. Delia White, Chicago:** I think that you will be interested in the community-supported venture that is being made just outside Chicago. We call this project the "Little City." We plan to take children of all I.Q. levels and from birth to 24 years. Some of these children will be able to go out into the community to work but will actually have their home in "Little City." It is planned that research work will be carried out in this unit and that the homey, pleasant atmosphere of the cottage unit system can be used.

**Dr. Segall, Youngstown, Ohio:** What are the requirements for admission to Little City?

**Dr. White:** We will take children with multiple handicaps so long as they are also mentally retarded. We hope to have a fairly low percentage of children who are custodial only. We plan to have a well rounded environment for these children and to have their families come to visit them frequently.

**Dr. Segall:** We cannot place a child in one of our state homes under 5 years of age. This is a state law. Has the American
Academy of Pediatrics gone into a study of the various state laws regarding the institutionalization of mentally retarded children?

**Dr. Watson:** Apparently no such study has been made.

**Dr. Jaslow, Chambersburg, Pa.** Regarding the location of homes for mentally retarded children, my experience indicates that a fairly critical problem in the maintenance of homes is the availability of lay help. The labor supply is better in the country, and salaries are usually not so high. Also, it is my feeling that persons from rural areas are more likely to be sympathetic and to be able to establish warm relationships with the children.

**Dr. Watson:** I think this coincides with my own experience, and I would add that the mentally retarded child is much more easily accommodated in his own home if it is a rural one. For the most part the city is a very cold and unresponsive place for the mentally retarded child.

May we now turn our attention to two problems which are extremely important. One of these is how best to handle the immediate problem occasioned by the birth of a defective child, especially one designated a mongolian imbecile. The second problem is how best to proceed in counseling the family when the physician is convinced that a given child should be placed in a state home and training school or other similar institution. May I have your thoughts on the first problem—informing the parents that their newly born infant is mentally defective?

**Dr. Appel, Flushing, New York:** I have lived through that period when we followed Aldrich's advice of not even allowing the mother to see her newly born mongoloid child. I came to the conclusion that this was not the best way to handle the matter. I believe that the mother should be told as early as the physician's judgment indicates. Just who tells the mother depends upon several factors; sometimes it is her husband, sometimes the obstetrician, sometimes the pediatrician. The matter of the desirability of ultimate institutionalization may come up during these early talks or it may be delayed to a later date, again depending upon how much the parents understand the true nature of their problem.

**Dr. Shaffer, Norristown, Pennsylvania:** I speak as a practicing physician in the community. I believe final solution of the problem of the severely retarded child must wait until the parents have fully accepted the facts. The father should always be fully informed and present at all important discussions regarding the child. I believe that the child should have a place in the home until it becomes evident to the parents that the time has come for a transfer out of the home.

**Dr. Nelson, San Francisco, California:** Many physicians feel that it is their duty to decide for the parents just what shall be done with the severely retarded child. Unless the parents understand the basis for such a decision and really make it themselves there is the possibility of feelings of guilt later on.

**Dr. Watson:** I think I agree that the parents are the ones who must actually make final decisions, but the physician not only acquaints them with the facts but also should let them know definitely what we advise. Sometimes the parents will, in a sense, be able to make the physician's advice their own final decision, and perhaps escape misgivings, doubts and guilty feelings after they have decided to place their child in custodial care.

**Dr. McKitterick, Burlington, Iowa:** We should not forget that each child in the home is in competition with his siblings for parental love, affection, etc. Our thinking about the defective child should include measures to shield him from unfair competition and from the future unfavorable effects of parental rejection.

**Dr. Segall:** I interviewed 40 mothers, mostly between 25 and 40 years of age, who had given birth to mongoloid children. None knew at birth that their child was mongoloid—all said later that they wished they had been told at birth. Most of them had floundered for several months, bothered...
by a feeling that there was something seriously wrong with the child but not having the benefit of a solid diagnosis and an understanding of just what it meant.

**Dr. A. P. Rauber, Decatur, Georgia:**
One of the main things that we can do is to be a friend to the family. I think that they should be told of the fact that they have a defective child as soon as the diagnosis is a certainty. The first days are the best for explaining.

**Dr. R. B. Jessup, Palo Alto, California:**
I would like to have some expressions of opinion concerning the problem presented by a threatened abortion. How many of our severely retarded children may be due to a pregnancy saved by “heroic measures” which certainly, in retrospect, would better have been allowed to go ahead and miscarry?

**Dr. Watson:** Since we are all pediatricians I doubt that any of us is in a position to have an authoritative opinion in this matter. Certainly the thought that you raise has occurred to almost every physician who has seen grossly defective children resulting from these abnormal pregnancies. On the other hand, we have all seen a pregnancy exhibit alarming signs of impending disaster and then go on to term with a normal child resulting. It takes a great deal of wisdom and courage to know which pregnancies to allow to terminate spontaneously and which to fight hard to save.

**Dr. Robert Warner, Buffalo, New York:** I worked with Warkany for 1 year, and in taking the histories of siblings of retarded children I found that other pregnancies (which resulted in normal children) had almost exactly the same incidence of bleeding or toxemia as those which resulted in retarded children.

**Dr. Watson:** I believe that physicians who have worked directly with retarded children in an institutional setting are pretty much of the opinion that there is a great deal of advantage to the child to stay in his own home for the first 4 or 5 years of life even though he may be placed in an institution thereafter.

Can we now have some discussion concerning the time at which the severely retarded child should be separated from his home and family for the benefit of all concerned?

**Dr. Robert Kugel, Iowa City, Iowa:**
We are attempting to provide in the community special classes for retarded children. There are several benefits from such classes, particularly if there can be some medical supervision with a view to therapy of any causative factors that are known.

**Dr. Anderson, Billings, Montana:** I work in a center which was a cerebral palsy unit but now handles mentally retarded. In our set-up for the cerebral palsied we had speech therapists. Do the mentally retarded need speech therapy?

**Dr. Kugel:** Speech therapy often is beneficial in helping the child adjust socially. Also the speech therapist may help in a diagnostic way. (Example: Aphasia or dystonia. We had a retarded child, 13 years of age, who mainly as a result of speech-correction therapy had an apparent rise in I.Q. from approximately 60 to 95.) There are many such cases where I believe speech therapy to be a useful adjunct in a well-rounded program for the mentally retarded.

**Dr. J. H. Root, Jr., Waterbury, Conn.:** I agree that the speech therapist should be part of the “team.” We should also not forget the point of view of the birthright of the retarded child. It is not fair to regard the mongolian child as a “cute little thing,” namely as a pet. We are likely to come to regard them as pets, not human beings. I believe that there are three prime areas which should be kept in mind in our decisions concerning the retarded child. The infant is usually well accommodated in his own home and of no great concern except as his parents worry about his future. The period from 1 to 6 years is the period in which the difference between the retarded child and the normal becomes more and more obvious. Sometimes during this period, pressures within the family may influence the decision to transfer the child out of the home. Beyond the age of 6 years the child

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becomes harder to handle because of his physical size and because of his many maladjustments.

**Dr. Anderson:** These defective children who have spent the first several years at home are certainly better off at the time they enter an institution than if they have been institutionalized since infancy. However, we find that after 2 or 3 years it is difficult to see any real difference in behavior between the children of these two groups.

**Dr. V. Fisher, Baltimore:** Before recommending institutionalization we should certainly know what sort of institution the child is to enter. In some states, to place a child in a state institution is to abandon him, for little or no training is to be had. When the I.Q. approaches the idiot zone the child cannot be trained no matter how good the facilities.

**Dr. Watson:** Before our time runs out we must discuss the relationship of genetics to the problem of mental retardation. This, of course, has two facets: The first is presented to the physician when the parents ask, "If we have more children is this likely to happen again?" The second problem is the question of sterilization of the mentally defective to prevent propagation of more mentally defectives. This, of course, applies only to those whose retardation is on a genetic basis and not the result of brain injury, deprivation, etc.

**Dr. Kugel:** I know of two mongoloid females who have produced children. One of these produced a mongoloid child and the other a child who was apparently normal. I would like to put forth one thought relative to the sterilization of mentally defective children, particularly girls. In the typical state home and training school these children are taught absolute obedience. This is likely to place them in some added jeopardy when released from the school, because they are unable to realize when they are disobeying and are likely to follow any suggestion.

**Dr. J. H. Root:** I think that there are two reasons for sterilization: The first has been mentioned, i.e., the likely outcome of the pregnancy; we know that mentally defectives tend to produce mentally defectives. The second consideration is, of course, the fact that the mentally defective person is not able to provide the kind of care and family life suitable for the up-bringing of a child.

**Dr. Watson:** The physician must proceed with considerable caution when broaching the subject of sterilization. I recently learned that we could not get a court order to sterilize a child who had a diagnosis of cretinism in infancy and in addition had had one sibling with cretinism and one with tuberous sclerosis, both of these siblings dying in infancy. Treatment with thyroid extract since infancy had enabled the patient to have entirely normal physical growth and development. Her I.Q. was approximately 65. An informal court opinion, obtained before actually raising the issue, informed me that the I.Q. was not low enough to legally justify sterilization. Nor could it be justified on the basis of the possible inheritance of tuberous sclerosis and cretinism. I confess I was a little disappointed because in my opinion, this good-natured, trusting girl was not entirely able to look after herself.
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