National Association for Retarded Children
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Within the last decade there has been vast development and rapid progress in the total area of mental retardation—more and better resources; specialized clinical and counseling services; training, educational, and recreational facilities; medical research; and financial aid. Concomitantly, there has been widespread interest in professional circles as well as in the community, increased understanding, acceptance, and tolerance of the mentally retarded child and his family.

Much of the credit for the impetus to this important movement belongs to the parents of retarded children who, because of their persistence; perseverance, and courage, have shown the way. It is the parents themselves who have given us clues about their own capacity and strength to find the solutions and resolutions to their problems.

Although much has been accomplished, one area that is a constant source of difficulty is that of communication between parents and professional personnel. Frequently the parents of a retarded child go away from a contact with a physician, psychologist, or social worker with a good deal of justifiable dissatisfaction. This is not an isolated occurrence but tends to be rather widespread and, as professional persons, we must assume the responsibility and blame for these difficulties. The services that are offered can and should be improved. As a means of improving these services, the author enlisted the participation of the Maryland Society for Mentally Retarded Children and interviewed the parents in the following exploratory study.

With the approval of the officers and members of the Society, a letter was sent to every fourth member stating
the purpose of the study. A questionnaire was developed as a general guide, with the full knowledge that this study would produce qualitative material of importance although not statistically impressive.

In general, the guide fell into the following categories: (1) identifying data, (2) when retardation was first suspected by parents, (3) consultations by specialists, (4) counseling by professional persons and parents' reactions to counseling, and (5) value of group organization to the parents.

Interviews were held by the author in the Harriet Lane Psychiatric Clinic, the average length of interview time was approximately 1 hour and, with few exceptions, it was the mother who came for the interview. Of a group of 50 to whom letters were sent and follow-up contacts made, 40 were seen; of the 10 remaining, the majority could not be reached and only 3 refused to participate. It should be noted that the group was a highly selected one, and the material is based on recall; therefore, the study does not lend itself to usual statistical methods.

In general, the parents can be described as an intelligent group of young and middle-aged people, with small families of 2 and 3 children, of the white race, and the middle socio-economic class. Diagnostically, the children could be placed into the following categories; 19 mongoloid, 15 brain damaged, 1 epileptic, 1 seriously emotionally disturbed, and 4 of unexplained etiology. There was 1 instance of a family with two retarded children.

Answers to the factual questions of "When did you first suspect something was wrong?" "Was someone professionally consulted at that time?" and "Who really told you your child was retarded?" produced difficulty in pinpointing answers. One explanation is the time lapse and the problem of recall, since this material was gathered from several months to many years after the patient was diagnosed as retarded. However, other factors that bear consideration are (1) problems in diagnosing, and (2) the parents' reactions to the seriousness of the problem of retardation, to their feeling of difference from other parents, and the resultant feelings of fear and anxiety.
Often there is much uncertainty around diagnosis because many different factors must be weighed and evaluated such as (1) physical, (2) emotional, and (3) limitations in the tests themselves and the difficulties surrounding the testing, particularly of young children. The process of considering physical factors that complicate accurate evaluation frequently involves referral to many different specialists with their variety of opinions and, certainly, their uniquely different ways of handling the parents.

It was not unusual to hear such expressions as: “My doctor did not know whether his slowness was due to his mental condition or to his physical sickness.” “The doctor was confused as to whether the child could hear.” “The doctor’s first impression was muscular dystrophy and then in another examination he thought he was just retarded.” Occasionally the influence of emotional factors must be considered, which necessitates intensive involvement of the parents in recapitulation of bitter life experiences.

The limitations of the tests themselves, just in terms of evaluating intelligence, lend another element of doubt. Certainly the innumerable difficulties in having the child perform at his best and obtaining as much as possible from him create questions and doubts. In other words, are the test results representative of the child’s intelligence? And, lastly, the adequacy and skill of the tester add another problem to the welter of confusion.

Mention of retardation creates a serious impact on parents, which is understandable in view of the attitude of society and the problems of the intellectually limited child achieving a safe, secure place in our culture. The very practical aspects of everyday living, training, schooling, recreation and, lastly, occupation and self-support have been almost insurmountable.

It is no wonder then that usual responses were: “It’s like someone came to you and told you your child was dead.” “When we were told, it was a terrible shock—you stop living.” “I was on the verge of a nervous breakdown.” It was not surprising, therefore, that these reactions were followed by acute feelings of “aloneness,” “difference,” being set apart from the rest of the world, rejection, and lack of in-
interest in the children and their problems.

This is vividly illustrated by such comments as: "None of the doctors said anything to me; I couldn't even get any schooling for him." "We got so nervous — everywhere we went nobody would help us." "We then thought it was God's will and we did not go anywhere." "I feel the doctors brushed me off." "I feel that the medical profession did not want to be bothered, were impatient and annoyed." "We did not find anyone who sat down and told us what the problem was." "They just push you from one person to another."

Is it any wonder then that there were expressions of anxiety, embarrassment, and guilt? As one parent said, "The doctor did not want to be bothered. I was embarrassed to go to his office. I had to sit with other people's children. I was always treated with the attitude: 'Here comes this woman with this child.' The doctor did not like him and did not mince any words about it." Another said, "The majority of professional people we dealt with left us with the feeling that if you had a child who wasn't normal you should be ashamed of it."

Of the total group of 40, in 30 of the cases studied the parents suspected or were aware of retardation in the first year of life. Of the mongoloid group of 19, in 13 instances the parents were aware of and/or were told of the serious deficiency within the first month. The brain damaged and the etiologically unspecified cases of mental retardation took longer to diagnose.

In the brain damaged group, 12 were suspected of retardation under 1 year of age (3 of whom were known under the age of 1 month) and the remaining 3 took up to 3 years to diagnose. In the cases where no specific cause of retardation was known, 1 was diagnosed at age 20 days, 1 at 8 months, 1 at 1 year, and 1 at 18 months.

In the two remaining cases, the epileptic was diagnosed at 10 months and the other was diagnosed as questionable retardation due to emotional factors. Therefore, we must conclude that mental retardation was serious enough to be detected reasonably early in this group of children.
As one would expect, it was the pediatrician who was most frequently consulted first (in 25 instances). This was followed, in order of frequency, by the family doctor in 7 instances, the obstetrician in 3, the neurologist in 1, and the child guidance clinic in 1. In 3 instances the parents "just knew" and did not consult anyone at the time.

"Were others consulted and at what ages?" prompted a succession of medical specialists too numerous to record. Illustrative is one parent's comment. "I must have had Billy to over 100 different doctors." Another replied, "I must have spent over $8,000.00 for various consultations to no avail."

Unfortunately, parents did not seem to obtain the help they needed early enough to prevent the trauma of endless pursuit of answers to their problems. Perhaps, significant is the fact that the "end of the road" seems to be the child guidance clinic, psychologist, or psychiatrist, whom the parents finally seek in desperation, usually after the child is 2 years of age. Also significant is the fact that one-half of these patients finally reached these specialists.

"Who really told you?" produced only one significant point, namely, many parents "just knew" or suspected serious pathology long before affirmation by specialists. The author has found that it is not an unusual occurrence in clinical work for a parent to be able to state fairly accurately the intellectual level at which his child is functioning at the time he is seen. What the parents are really asking for is not just a diagnosis, but total handling of the problem.

The question "How were you told your child was retarded?" evoked the most intense responses indicative of the traumatic experiences suffered by so many of these parents. The striking thing that permeated this section was that the different reactions to what parents considered good and poor handling varied according to their own individual needs, so that one is forced to conclude that the most important consideration is the ability of the counselor to individualize, to be sensitive to where the parents are emotionally at a particular time, in other words to empathize with the parents.

Some parents wanted to be told directly as soon as
retardation was suspected. A typical comment was, “The
to be prepared gradually, as follows: “The doctor was very
tactful. He implied things right along. At first he said she
not holding her head up, not sitting up, etc. Not until
two or three years later did he really tell me the child was
seriously defective and had to be in an institution. He pre-
pared me well.”

Another parent reported, “A pediatrician told us the
called things in the nicest way it could be explained. He told us it was far too early to say how much
he would progress. We returned for visits frequently. As the
child grew older, we were told what the future held.”

Apropos of this discussion, it should be pointed out that
frequently parents inadvertently mentioned the names of
the doctors they had consulted (in spite of the request that
no names be mentioned). It is of interest to note that a par-
ent would condemn a doctor while another would highly
praise the same doctor.

This obviously casts no reflection on the doctor but
emphasizes the need to individualize each situation. An-
other observation is that in almost every record there is an
admixture of good as well as poor handling, which again
emphasizes the premise to handle each situation
individually.

Important to note is that, when questioned specifically,
questions were answered, particularly those relating to im-
portant factor in this regard was that these parents were
counseled not only sensitively and directly, but also their
future.

A typical expression was, “Our family doctor was won-
derful. He talked to us for about an hour. He said our child
was a dull boy and to give him regular care, but to give him
a little bit of extra love. He answered all my questions and told me just what to do. He prepared me well for the future.”

Another stated, “A psychiatrist told me for the first time my child was retarded. It was a shock, a bitter disappointment, but it was accepted. He told us what to expect and gave us wonderful advice.”

Another 8 also indicated they were told directly, frankly, tactfully, sensitively, or slowly, but in most instances, questions pertaining to implications for the future were not answered. In 3 cases parents were not informed by anyone, “they just knew.”

In 16 instances parents clearly described how poorly they were told with such adjectives as cruel, abrupt, confused, blunt, upsetting, contradictory. The adjectives the parents used are graphically illustrative of descriptions of their experiences, and they reacted to them with such comments as: “They tell you your child is an idiot and everything else. There should be a nice way to tell parents. When they told us roughly, we stopped going.” “The doctor said he will never be any good to you or to himself. I told him I was raised with the feeling where there’s life, there’s hope.” “I was told my child was mongoloid without any preparation for it. I thought he was perfectly normal, and it came as a complete surprise. We had just stopped in for a checkup. The doctor said I should have him in an institution because it would be better for the child and everybody else. All I wanted was to get out, I was stunned. My husband was overseas at the time, which certainly did not help. When you think back, you can’t believe anyone could be so blunt.”

Two parents commented that they were told over the telephone: “My husband was told over the telephone that the child was a mongoloid when the child was 4 days of age.” “The doctor said our child was a mongolian idiot over the telephone. He acted as though it was your problem, buddy.”

Numerous references were made to examinations which were considered too hasty and careless: “It was an assembly line fashion.” “The interview was not at all satisfactory. He saw us very quickly and did not even give us the results of the electroencephalogram. He sent us a note and suggested we buy a book he wrote. Good God, we still don’t
know whether he is epileptic or not." "I didn't have the feeling wherever we took her that they thoroughly examined the child." "The doctor gave her a 3-minute examination and said she was brain injured and threw her out." "The mother knows first of all what the child is. She's around the child all the time. She knows him thoroughly. How can a doctor, who sees a child for one-half an hour, know about the child?"

One other complaint, that was outstanding in the study, was a tendency on the part of professional persons to evade the issue. As one parent said, "The doctors gave me no clue that anything was amiss. In fact, they assured everything was going to be all right."

Other complaints pertained to complicated medical terminology.

As indicated in the preceding section, there are certain generalities that can be made, namely, that parents would want to be handled gently and warmly at all times, in language that they can understand, without evasiveness, after thorough examination and with enough time to digest the significance of such important material. This was reinforced by the parents in response to the question: "What type of service would you advise for people who are faced with this problem and are just beginning?"

The material indicates that they need gentler, more sensitive handling than the usual patient. This is supported quite vividly, as they expressed intense feelings and reactions. Particularly they stressed that their "children be treated as individuals" and that the counselor be interested in their problems. What they seemed to be expressing is the need for more responsible, integrated services in this field.

Professional people are becoming aware of this, as special diagnostic centers are developing in various parts of the country. Parents are able and willing to accept the uncertainty involved in diagnosis in an area which is not cut-and-dried if they could depend on a centralized resource rather than to be left to shift for themselves in an endless search for answers which are not possible.

In the instances where parents indicated the wish for frank, direct diagnosis as early as possible, they felt they
could accept the worst if the counselor was compassionate and respected them as parents with strength and dignity. They needed time to take in the extent of their problem and they needed to work on questions step by step. Questions did not arise in an organized, crystallized fashion, but gradually as the child grew. As one parent put it, "This is a lifetime thing."

Some of the comments of the parents are indicative of their keen feelings of anxiety and guilt, and it is important to emphasize that this is not resolved simply by articulating it for the parent. One parent said, "I got angry at people who told me not to feel guilty. It only made me feel guiltier."

There seems little question that, for many parents, the highest degree of specialized skill is indicated in the area of counseling. If we, as professional persons, really listen to what parents of mentally retarded children say, we can take our clues from them. It was not unusual to find parents express relief as they learned their children could at least be toilet trained and could express such simple needs as to ask for water, etc.

As one parent said, "I used to lie awake and pray that my child could say a little word like 'water' because I was so afraid he would be thirsty and could not help himself." It is interesting to note that two parents spontaneously commented that they were relieved in "spilling over to me," although they had innumerable, previous opportunities to talk about their problem.

Two observations worthy of mention were related to terminology. One is that parents showed severe reaction to such terms as idiot, imbecile, and moron, and hoped for terminology that would avoid such negative connotation. Another is their request for simpler explanations in terms they could understand, particularly, practical, tangible suggestions relative to everyday living.

Perhaps we need a greater appreciation of the little achievements of the retarded child and its meaning to their parents. Still another request was for clearer explanations, the full meaning of which they could take in. Parents often interpret such terms as "the child is slow" to mean that the child "will catch up in due time." In my clinical experi-
ence I have found that a better way of helping parents to understand what is really meant is to use the word "behind," connoting that the child will not catch up.

A discussion of the material would be incomplete without giving some illustrations of the continuous history of the parents’ search for help. Comments taken out of context and categorized cannot possibly present the full meaning of the total impact of accumulated frustrations on the parents on the one hand, and their strength and capacity to handle their problems on the other. Only as we can appreciate and accept this can we be fully helpful in developing adequate services.

Two records have been selected to illustrate this: the first one concerns a child diagnosed as mongoloid and the second one a child diagnosed as brain damaged.

Mrs. Martin, the mother of five children, is a warm, motherly person, of limited educational background but, nevertheless, of good intelligence. She is a thoughtful, sincere individual.

She begins as follows: “I knew Johnny was a slow child, but I thought he was a sick child. During infancy he slept for the most part and we couldn’t awaken him.” Early he was taken to the clinic; however, no mention was made of retardation. “They said he was just sick. He was not a well baby, but would probably pick up, but they never gave me a reason.” However, an attendant kept repeating, “If only I had your faith.” Apparently this comment seemed so inappropriate at the time that it made an impression on the mother.

When Johnny was about 2 years of age, a doctor was called about another sibling and casually commented that Johnny was mentally retarded. The doctor referred him to the hospital where the opinion was that the child was a mongoloid, very retarded, and that the best thing for us to do was to put him in an institution because he would forget us very quickly and if we had other children, it would have an effect on the whole family, particularly that our children would be embarrassed because of Johnny. On this statement, Mrs. Martin comments, “I thought that was abrupt and cruel.”

Mrs. Martin continued, indicating her upsetness over
this experience. She said, “After I got home, I wanted to know how retarded he was because I was too upset to ask any questions while I was at the hospital.” She returned to her pediatrician because apparently she had a warm relationship with him. He disagreed with the opinion of institutionalization, suggesting that it was the parents prerogative to decide such a drastic move.

His opinion was that the child needed the love which could not be received in an institution. He explained Johnny’s mentality, cautioning her not to spend any money on Johnny, but to center her financial resources on the other children. The doctor’s most meaningful comment, and Mrs. Martin says this with much warm feeling, was, “Remember, when your other children have left, you will always have Johnny.” (In response to the question, “Who gave you the most help?” Mrs. Martin unequivocally said it was this pediatrician.)

The parents explored every school possibility without any success until he was 10 years of age when he was accepted in a special class in the public school. He stayed there four years and was withdrawn when the center closed, and was then placed in another school. According to the mother, considering his limitations, he has made a good adjustment at school. He mixes well with the other children who have encouraged him in this respect. He even writes, spells, and does a little arithmetic. Mrs. Martin feels that the school has been instrumental in giving Johnny confidence, and enabling him to do some of the things normal children are doing. She glowingly describes her relationship with the teacher as “wonderful,” particularly the help to the parents in allowing them to sit in class, observe, and learn.

In response to the question “Do you feel that your contact with professional people had been satisfactory?” Mrs. Martin’s first point was, “Parents need all the kindness you can give them.”

She also felt that parents should know exactly what is wrong as early as possible. If known at birth, it should be told at that time because one can be more helpful to the child. She regretted the information being withheld from her. She described it as “not fair.” “It’s yours, your baby, you want to know right at the beginning.” Mrs. Martin had
the feeling that everyone knew that her child was mongoloid except herself. It bears emphasis that she was not informed that the child was a mongol until he was 2 years of age.

She further emphasized that “if there is a ray of light, it should be told.” When the pediatrician told her Johnny could reach the mental age of 8, it was helpful to her. “Every word we took hold of.”

Still another area of importance is to handle questions pertaining to heredity. The Martins were very much concerned whether to have additional children, and it was with great relief that after repeated contacts with professional people, she finally got her questions answered.

“What type of service would you advise for people who are faced with this problem and are just beginning?” brought forth the seriously traumatic experience of first being told bluntly and insensitively. “I felt it could have been handled a little more kindly. If you can speak to anyone in the medical profession for a while, it’s wonderful. If they can’t help the child, maybe they can help the parent.”

About institutionalization, she commented, “I think too many children like this are put in institutions. It frightens the parents to think of institutions. I don’t think an institution should be mentioned at first. Couldn’t it wait to see how a child progresses before it is mentioned? I am truly as proud of Johnny as I am of my boy who graduated from college.”

The second record is as follows:

This is one of the few situations in which both parents participated in the interview. The Allans are intelligent, fairly young people, in their middle thirties, and have a family of three children. In spite of all of their struggles, their charm and zest for living comes through.

Bobby was about 7 months of age when they had some vague suspicion that all did not seem quite right. They consulted their pediatrician who said that he was a little slow—not responding, not sitting up. “But the pediatrician said nothing to allay my fears, he said Bobby would be all right.” Then, with much feeling, Mrs. Allan adds, “He didn’t say this because he didn’t know—he did know.”

After much “badgering,” on the mother’s part, and insistence that there must be something wrong they were
referred to a neurologist. Bobby was about 1 year of age by this time. The examination showed that he was nearsighted.

Further consultation with two doctors indicated that there was nothing wrong. Mrs. Allan said, “I thought I would work harder and teach him more. Then began the most frustrating period of my life. Trying to teach a child when it was not possible to teach him was like knocking my head against a stone wall. My heart just aches when I think what we have been through. I pushed him. I spent a lot of time with him. I would try to feed and toilet train him and we got just no place.”

The Allans returned to the pediatrician, whereupon they were referred to an orthopedic man. At that time, Bobby was about 1½ years old, and Mrs. Allan estimates his intelligence at about 1 year. The orthopedic man found his feet were quite flat and suggested corrective shoes. He also offered the following advice, “He will catch up, he will be all right.” Mrs. Allan, however, felt all was not so rosy because she mentions that at 19 months he was beginning to walk but “still there was not a flicker anywhere else.”

When Bobby was 2 years of age, the family was referred to a psychiatric clinic. Here she describes her experience as “wonderful.” The doctor spoke to her at some length and “it was almost a relief for me to hear it. At least I knew where I stood.” By this, Mrs. Allan means she had her suspicions confirmed, namely, that Bobby was retarded. However, he was described as being only mildly retarded, with a good prognosis, but the years have proved otherwise. At least she knew she didn’t have a normal child.

Mrs. Allan described meeting her pediatrician on the street and berated him for not telling her the truth. His comment was, “You couldn’t have done anything about it anyway. I knew that you would find out soon enough.” Mrs. Allan emphasized how deeply disturbed she was during that time.

Although Mrs. Allan felt she was reasonably well handled by the psychiatrist, her questions were not answered. When questions arose regarding other children, Mrs. Allan consulted her pediatrician and he advised her against having
another child. Their obstetrician, however, encouraged her to have another one. She subsequently became pregnant, and describes this period as one of great fear of having another retarded child. In the sixth month of pregnancy she contracted mumps, and "nearly went crazy." "The baby was wonderful. Anyway it had a happy ending."

At about 3½ years of age, Bobby had his first convulsion, his condition was followed at the seizure clinic, where he was put on medicine for convulsions. The parents were told nothing about his condition, and were critical of the fact that he did not have a complete work-up. They "... were not even told what the EEG showed."

There was further pursuit of medical exploration until finally they consulted a psychiatrist. The psychiatric consultation was described as being reasonably satisfactory, although the psychiatrist was cold, he told us the brutal facts. At least I could start living after that rather than just hoping. Even so, he was optimistic. He recommended institutionalization, but the parents indicated their disapproval of this with much vehemence. The psychiatrist also pointed out that they were concentrating too much on the retarded child to the exclusion of the normal sibling. The indications are that they could accept this.

In answer to the question, "Was your contact with professional persons satisfactory?" the response was "absolutely not." Then they added, "In fact, we have lost a great deal of respect for the medical profession; we have had nothing but frustration every place we have turned."

"What type of services would you advise for people who are faced with this problem and are just beginning?" brought the immediate response, "Gently, but the truth." Mr. Allan felt that the counselor should evaluate the type of parent and the intellectual capacity of the parent, have a few visits with them if necessary, and handle them accordingly. They both agreed that the parents should be informed just as soon as the doctor knows. He said, "The attitude is of paramount importance. If the parents sense sympathy in the professional person and willingness to understand, this has a great deal of meaning. After all, most parents want to respect their doctor."
One further comment revealed the magnitude of the burden for parents when Mr. Allan said, "After all, you have a whole lifetime to worry about this, and you can only take it by degrees."

The discussion of the questions of institutionalization produced much negative response on the part of the parents, especially when the counselor had no direct knowledge of the resources but, even more important, little understanding of the family and indiscriminately advised it as a solution.

Illustrative are such comments as: "They all spoke of institutional care as though that was the only thing we could do. They acted as though we had no choice." "If the child can be cared for at home and is not a burden on other members of the family, then they should keep him. I look at the happiness Billy has given us—he is so sweet and kind. The other children in the family adore him." "I honestly think that Tommy would not have gotten anywhere in an institution. There is no difficulty in having him at home."

Without exception these parents wanted what was best for their children. They wanted to know whether the resources would help their children to achieve their capacities, however meager, and help them grow up as well as possible considering their handicaps. When necessary, they can come to terms with institutional care if that is the soundest way of helping their children. They asked whether their children need more than their share to enable them to assimilate whatever training and education are available.

Also, they are able to provide the tender, loving care to make this possible. So many parents cannot be interviewed without the interviewer being greatly impressed with their love for their retarded children and their ability to accept and handle frustration. It is important to note that in 21 of the cases institutional care was recommended early, but in only one was it followed through. The obvious conclusion is that they were not ready or interested in this solution to their problem.

It is significant to note that there is important research going on in the field on the families who can best use institutional care for their retarded children. One study, still in
progress, considers the effects of a severely retarded child on family integration, the results of which can be of help to counselors in evaluating the kind of family who can keep their child with them and those who might best be directed toward institutionalization.

Apparently there has been more change in the attitudes of society toward retarded persons than we realize. The prevalent assumption has been that families cannot accept too much difference and that the higher the cultural and intellectual achievement, the less possibility there is for the retarded child to be cared for at home. This is not supported by this study. On the contrary, a place has been found for these children in their families, neighborhoods, and schools. I do not believe that it is being too omniscient to say that many of these children have gotten as good a start in life as is possible under the circumstances. I should doubt that anyone would challenge the fact that the institutionalized child does not have his emotional needs met.

Needless to say, parents spoke glowingly of the local state Society for Retarded Children. They have found a way to share their experiences, to be supportive to each other, to resolve their feelings of difference, and, most important, to speak for retarded children and crusade in their interest.

This has been an invaluable group therapeutic experience for many parents, an important factor in enabling families to live more comfortably with these children and to be helpful to them. They have proved parents need to be no longer isolated as individuals and families, with the serious emotional problems which set them apart from the rest of the world.

These parents have paved the way for community understanding and acceptance of the problem, and have achieved an important role in community welfare by spearheading the need for specialized services in education, recreation, parent education facilities, and in programs of financial aid. They have discovered so much for themselves that they want to share their experiences and to be helpful to others.