HELPING THE MENTALLY RETARDED

I—Counselling with Parents of the Mentally Retarded Children - (1)

By

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The problem of helping the mentally retarded child is a stupendous one, but it is worth all our effort, enthusiasm and zealous pursuit, for its solution. A mentally retarded child, it is agreed by all now, needs to enjoy the fundamental rights of existence, care, education and other opportunities for intellectual, emotional and social adjustment in his family and outside, as much as any normal child.

A mentally retarded child shows a condition of incomplete or less than normal mental development. He has a limited capacity to understand, to learn, to think, to reason, to judge and to discriminate. He cannot, therefore, profit much, from his experiences or ordinary schooling (Bhatia)*. This is then the first problem that he presents—the problem of intellectual deficiency resulting in poor educability. Poor educability, in most cases, leads to the problem of social inadequacy and immaturity and the consequent social maladjustment. Both these problems are accentuated by non-acceptance or rejection at the hands of his parents and siblings—the attitudes that foster a sense of insecurity in the child. Other accentuating factors are feelings of intense guilt in parents and an atmosphere of frustration, conflict and unhappiness in the home. If these parental feelings and attitudes persist, all efforts to improve the functioning and performance of the mentally retarded child can prove abortive and useless. Hence the need for counselling with parents of the mentally retarded. "It is recognised more and more that professional and at the same

At a recent seminar on "Helping the Mentally Retarded", held under the auspices of the Child Guidance Clinic, College of Nursing, Ministry of Health, New Delhi, and opened by the Health Minister, the following problems were stressed:

1. to focus the attention of the public on the source, etiology and problems of mental retardation in our country, with a view to changing the present attitude of neglect and ostracism.

2. to suggest some preventive measures in the light of knowledge of etiology of mental retardation.

3. to highlight the importance of co-operation between the parents and all workers in the field of training and education towards rehabilitation of the mentally retarded.

4. to impress on the public that the mentally retarded can be trained, educated and thus rehabilitated within limitations, and, therefore, should not be considered as doomed to lead a life of inactivity and usefulness.

Two articles are being published on this series. The first article on Counselling with Parents of the Mentally Retarded Children by Mr. B. Dev Bhatia, is useful to all nurses, not only public health nurses. Since two to three per cent of the total population is estimated to suffer mental retardation, perhaps one family out of every thirty, needs help in this area. But the socially unacceptable health or disease condition, is one which we meet daily. We are dealing continually with the same problem in relation to scarring, deformity, disfigurement as in leprosy, tuberculosis, psychiatric conditions, cancer, venereal disease, etc. What are the questions the relatives and the patient ask us? How can we understand their feelings? Mr. Bhatia's article helps us to understand how to help a family to function; how can we give emotional support; how we can help get expert diagnosis, counselling, and help towards training and education and rehabilitation of the affected members of the family.

The second article on "The Role of a Nurse in helping the Mentally Retarded" deals directly with the role of the nurse in prevention of mental retardation, as well as her part in helping diagnosis, counselling the family and supporting them so that the family can function and the other children grow and develop normally.

Also included in the series is a list of Child Guidance Clinics at present organised in different parts of the country, to which we may refer parents of mentally retarded children, for help, diagnosis and counselling.

—Editor

* Bhatia, B.D., Helping the child who is mentally retarded. Child Guidance Clinic, College of Nursing, New Delhi.

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whose sole function is to dole out advice; and the parent does not feel that he is forced to accept what he has been told. On the other hand, the parent feels that he has played an equally active role with the practising clinician toward an understanding and solution of his problems. Merely enabling him to have an idea of the present intellectual status and the admonition that the child should be placed in a special school, if any, or in an occupational therapy institute, is not enough. No matter how expertly and conscientiously this is done, it somehow does not take in the whole magnitude of the problem.

Thus counselling with parents of mental retardates WILL HAVE THE FOLLOWING PURPOSES:

(a) Clarifying issues involved in mental retardation, such as what it means in terms of present conditions and future expectations.

(b) Clarifying issues in regard to family and community relationships, the effect on other siblings and the effect of sibs on the mentally retarded child.

(c) Getting the parents to accept EMOTIONALLY, the child’s retardation, by enabling them to see that the creation of a defective child need not be considered a badge of dishonour or failure.

(d) Getting the parents to accept emotionally the child’s academic limitations.

(e) Getting the parents to dispel feelings of shame, embarrassment, disappointment, guilt and personal responsibility, by resolving their conflicts.

(f) Getting the parents to realise that in some measure they are as much a problem as their child.

(g) Getting the parents to live more harmoniously with each other and their child.

The Counsellor

These objectives or aims of counselling are undoubtedly difficult to accomplish, but they may be realised, to a great extent, if the counsellor is sympathetic, patient, tactful, understanding and sensitive. This implies that he understands that parents go through many reactions in the rearing of a retarded child and in their struggle with their misfortune. He realises the feelings and attitude of parents and does not merely scoff at them.

Feelings and attitudes of parents

It will be pertinent here to describe these parental feelings. Most parents experience feelings of confusion, shock, disbelief, guilt, bitterness and envy.

Although most parents suspect that something is wrong with their child and even have tangible proof of the fact, many of them are afraid to face the truth. They fear reality, and instead of meeting the situation and consulting some expert, go through a lot of wishful thinking. “It can’t be! I am sure he will outgrow it...” They are bewildered, and confusion or bewilderment is prolonged, on account of relatives supporting their wishful thinking. Most of the Indian parents, fortunately or unfortunately are blissfully ignorant of mental retardation. Hence, for a long time they do not take any particular notice of the phenomenon.

When parents are informed that their child is mentally handicapped, they are terribly shocked. The blow is really hard! Although the doctor’s pronouncement has merely confirmed a suspicion they have had for a long time, they just cannot take it.

After the initial shock, other reactions set in. Some parents are so tense, that discussing the problem with them is out of question. Others seem outwardly but remain pent up till they ‘collapse’. Quite a large number of parents at first refuse to accept the diagnosis of the doctor—that their child is mentally handicapped.

They disbelieve the doctor and hope that he may be wrong. They even try to convince him that there is nothing wrong with their child, that he is just not understood. They try to convince themselves that they have known other children who have been similar to their child in early childhood but who later grew to be normal. This disbelief is bolstered up by relatives and friends. It is because of this refusal to accept the doctor’s verdict, that they look for some one who will tell them that the child is normal, and that, even though he shows certain signs of retardation, he will grow out of it in the near future. Lurking behind this ‘disbelief’, is the realisation that something is wrong with the child. This paradoxical reaction causes conflict.

Once the parents accept the verdict, their worry increases. Many questions arise that they cannot answer. “What will be his future?” “What will his friends and neighbours think?” They are filled with ‘shame’ at this thought. Often they blame themselves or each other. They feel guilty. “They dig up all the skeletons in their family closet in their anxiety to find the source of their trouble...” (Levinson). At this stage the need between the parents may arise. Quarrels, arguments become a daily routine. The family life gets impaired.

The guilt feeling may be accompanied by a sense of inferiority, of inadequacy and of failure. This may result in withdrawal from society. “The mother or the father who may have been a very sociable person previously, shuts herself, or himself, up with the retarded child. She becomes a recluse, refusing to see or to be seen by friends and neighbours” (Levinson).

Withdrawal from society or social contacts, may lead to parents devoting all their time to the retarded child. In the process, other members of the family may be neglected. Some parents on the other hand, may react in the opposite way and pull away from the confusion and uncertainty by becoming deeply involved in outside activities, that keep them away from home. This is particularly true of fathers of the upper middle class in our country.

Another outstanding reaction on the part of many parents is one of bitterness, resentment and envy. They often exclaim, “Why does our child have to be like this? Why did God inflict this punishment on us? Why is everybody else’s child normal? Why can’t our society or State do something about such children?”

(Contd. on page 173)