The Placement of the Mentally Retarded Child

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SUMMARY

A mentally handicapped child brings tremendous problems to his family. He may be rejected entirely, or he may be given an undue amount of attention to the detriment of the whole family. An attempt is made to point out an intermediate course which will give happiness to the child and yet not disrupt the family.

S. Afr. Med. J., **48**, 420 (1974).

This article was written at the request of the staff of a home for mentally retarded children, the staff of the Social Work Department, and the Mental Assessment Clinic of the Transvaal Memorial Hospital for Children.

To deprive a mentally retarded child of his inherent right to live at home, where he is loved by his parents, can, indeed be a major decision and should be taken only when the pros and cons have been fully discussed.

In the United States of America and Britain, authorities who care for mentally retarded people of all ages, are endeavouring to keep the more able at home, or in foster-care, and to admit to institutions only the severely mentally and physically handicapped. It is hoped that South Africa also will be able to do this, but to do so requires available and trained teams of workers to visit and advise on home care.

In making a decision, one has to consider: the mentally retarded children themselves; the parents and families; the available institutions; the public.

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Date received: 19 July 1973.

THE MENTALLY RETARDED CHILDREN

These children are born with all the rights of normal children. They need love, provision of the physical needs of food, shelter, medical care, and education and training to the fullest extent of which they are capable. They are almost certainly, happier at home, especially in their earlier years. It may be impossible to assess accurately the mental ability in infancy of a possibly retarded child. The child, though retarded, yet of reasonable intelligence, may not develop his full potential in a home for retarded children where there is a lack of the stimulation provided by normal siblings.

Examples of children in this group may be illustrative.

Johanna was certified at the age of 2 months and admitted to an institution for the mentally retarded. Her mother was a para-8, who absconded from the hospital after the birth of her infant. At the age of 2 years she appeared brighter than the other children in the home, and the reason for certification was hard to understand. She improved after a period in foster-care but testing revealed an IQ of 50. After much trouble her certification was set aside and she was taken into foster-care, and later adopted. She is now an entirely normal child doing

well in Grade 1 at a normal school.

How many Johannas have not been rescued from such an environment?

John was admitted to the same institution at an early age, suffering from convulsions and thought to be retarded. At the age of 4 years he also appeared brighter than the other children in the institution, yet was refused admission to another institution with a very good training scheme for retarded children, as being too backward. The IQ was assessed at 50. Six months' foster-care has made a remarkable difference. He has learned to talk, whereas before he could say nothing. He has a good chance of living a normal and useful life, though he may not succeed in an ordinary school. John, however, was lucky in that a suitable foster-mother was found for him. How much better off would he have been had he never been in an institution?

Home Care

Home care, however, may be impossible for one or more **reasons:**

1. Some children are so physically and mentally handicapped that they should be removed from their families. The family may be too upset by the state of the child to care for him in a rational manner, especially when feeding and other needs require special attention. Such children who need to be admitted to homes often cannot be placed.

2. The child's home may be unsuitable. Some mentally handicapped children are born to retarded parents, or parents who for other reasons are unable to care for them. Real neglect of, and hardship for, such children, are well known.

3. The parents may not be able to accept a handicapped child without a resulting disruption of the family. The decision in such an instance should never be taken lightly and, if possible, not soon after birth. With good counselling many families adjust themselves remarkably well and they should be given the opportunity to do so.

4. The family may be far from a big city where physiotherapy and training facilities are available. In such a case the child should be placed in foster-care, or, when at a suitable age, in an hostel. In either case he will be able to spend the holidays with his family, and if he has lived at home, he will know his family, and outings or spending the holidays with them will be pleasant and more likely to be successful.

THE PARENTS AND FAMILY

Initially the parents are appalled by the news that their child is retarded, but this is not a reason for advising them to get rid of the child as soon as possible, or that they should not see the child. It is important to realise that retarded babies are usually not more difficult to care for than are normal babies.

Mothers should be encouraged to look after their babies, especially when newborn. Should they find they cannot cope, after a reasonable attempt, they might ask for relief. In this way they are helped to accept their final decision whatever that may be. Should it not be possible for the baby to be kept at home, at least the mother will know that she has tried, and not shirked her responsibilities.

One hears much of the multidisciplinary approach to medical problems. Such an approach is vital in this situation. The best team would consist of a social worker, a district sister trained in this work, the family doctor, and a minister of religion. A paediatrician should advise on the diagnosis and any possible investigation of the child. If the child is old enough when the diagnosis is made or at a suitable age later, an assessment of speech, hearing, vision and intelligence should be made. The team could help by informing the parents of what can be done to help them and the child, and of the facilities available for helping them. It is vitally important that members of the team visit the home frequently in the earlier days, and regularly, but less frequently, later on, so that the family are always being helped, and especially during the bad time they have to face during the first few weeks after being told of the diagnosis. This is especially important in the case of the handicapped newborn.

It is felt that many children with Down's syndrome particularly, are admitted to institutions because such counselling is not readily available and the parents are advised to be rid of the children as soon as possible and, often, not to see them. With adequate counselling this sort of situation soon should not arise.

Holiday care should be arranged so that the family has a break from the child at least once a year, and soon as he is old enough, arrangements should be made for him to attend an institution for physiotherapy and training; where there is no institution much can be achieved by several mothers helping each other by taking, say, 5 children on any one morning.

Sessions in which parents of handicapped children meet each other and receive counselling, are most important. When the team of advisers feels there is jeopardy for the family, caused by the handicapped child being at home and that this outweighs the advantage to the child, then there should be no hesitation in seeking institutional care, and the parents should have no feelings of guilt. Feelings of guilt are, in fact, much less common in parents who have made an effort to look after their children.

The following are cases illustrative of children placed too early:

Baby A has Down's syndrome. At birth her parents were advised to have her placed as soon as possible. The social worker at the institution which had accepted the child, visited the parents, who were delighted at the advice given, and relieved to know that they did not necessarily have to part from their baby. She is now safely at home and the social worker visits the family regularly. When she is older the child will be taken daily to an institution for training.

Baby B, also with Down's syndrome and an IQ of possibly 70, or even higher, was in hospital for surgery in his earlier months. At the age of 2 years he was too bright for the institution, but his parents were appalled at the idea of a 2-year-old stranger coming home, although

with proper home care he might have developed to a more normal level. Now he will have to be taken either into foster-care, if suitable people can be found, or be transferred to an institution for more normal children.

Baby C, another baby with Down's syndrome, was born to an extremely wealthy family. When the diagnosis was made at 5 days the obstetrician advised the parents that they would be unable to look after the child, and so he was institutionalised when newborn. The child would surely have been happy on the family farm and it is doubtful whether any family disruption would have occurred.

THE INSTITUTION

An ideal institution would have small groups of children in the care of a housemother; these would be in separate houses or in separate units in a big institution. Adequate medical care, physiotherapy, and training facilities would be readily available.

The institution would also provide holiday care. Such institutions are few, all are full, and most have limited finances. It is essential not to overstrain them.

We should have far more day centres, where more children could be trained and more parents helped. It is particularly important that we provide such facilities for retarded Black children.

THE PUBLIC

The public needs consideration and education. There should be no distaste for mentally retarded children, nor should they be kept away from normal children.

The mother of a handicapped child is helped greatly when the child is accepted by the neighbours, allowed to mix with their children, and even cared for occasionally by them.

It is a sad situation where there is affection for a physically handicapped child, but aversion to one who is mentally handicapped. Very few mentally retarded children are harmful in any way, and most of them respond quickly to love and affection.

We, therefore, appeal to doctors to dissuade parents from placing handicapped children in institutions too early. This has become a problem with Down's syndrome, which is so easily diagnosed at birth. Much as one may sympathise with the parents, many precious places in homes are wastefully given to newborns with Down's syndrome, who can almost always be helped at home for some years, and so more institutional vacancies could be made available for the many children who urgently need help. There are naturally infants with Down's syndrome who need early admission, but in most cases the parents are not given the opportunity to recover from the shock and cope with the situation.

Let us consider some examples of children who cannot be admitted due to lack of accommodation.

Baby D has Down's syndrome with severe congenital heart disease. He was the second child of a young unmarried mother, but she is now married to his father. It was believed that she would have a better chance of making a successful marriage if the child were suitably placed; but no place is available.

Baby B was a normal, healthy baby until he was injected with his first triple vaccine. He convulsed for several hours after this and now has severe brain damage. He was an only child and at 9 months he could not sit, hold up his head, nor respond to any stimulus. It was several months before a place could be found for him.

Baby C is a severely retarded, spastic hydrocephalic, the first child of an 18-year-old mother.

Baby D has Down's syndrome, and is the only child of divorced young parents. The mother works hard all day and spends her evenings and weekends caring for the baby.

These are a few of the very many tragic cases on the long waiting lists of every institution.

CONCLUSION

The vast amount of work being done on the prevention of mental retardation, which is the most hopeful aspect of the problem, is outside the scope of this article. It is essential that every child be fully investigated, so that the cause, can be discovered, if possible. This is essential to prevent further cases occurring in the same family.

In conclusion, may it be suggested that the following points be considered in any approach to mentally retarded children, especially those with reasonable intelligence and appearance:

1. Mothers should be encouraged to keep the children at home, at least during the early years.

2. All possible help, control and guidance should be offered the family to help solve the many problems which occur.

3. Endeavour should be made to provide centres with physiotherapy, speech teaching, special teaching, occupational therapy, and educational facilities for all mentally retarded children in the country and accomodation should be reserved for the severely handicapped. Hostel- or foster-care should be offered to those who need it, especially country children.

4. Every attempt should be made to encourage foster-parents to accept these children.

5. Counselling is available. The Mental Health Society, the Transvaal Society of Parents and Friends of the Mentally Handicapped, the Social Work Department and the Psychiatric Department of the Transvaal Memorial Hospital for Children, Tara, the Children's Clinic and the District Service, can all provide help. Most of the homes for the mentally retarded have excellent social workers. The child should be referred to one of these or similar bodies for care and the family for guidance and introduction of parents to other parents at special group meetings.

I should like to thank Matron Dodson, Sister Mackie and Mrs Benjamin of the Woodside Home, and Mrs Schnier of the Transvaal Memorial Children's Hospital.