

Deciding what's best for your retarded child



by Katharine G. Ecob

Medical and nursing service provide for illness. Specialized training and education are designed to develop whatever capacities the child possesses. There is a planned recreation program. The child has plenty of companions with the same handicap, which encourages socialization. He does not have to compete with brighter children. The regularity of daily procedure stabilizes good habits. For the older, more able children, the farm, domestic work or shops give practice that may later lead to employment.

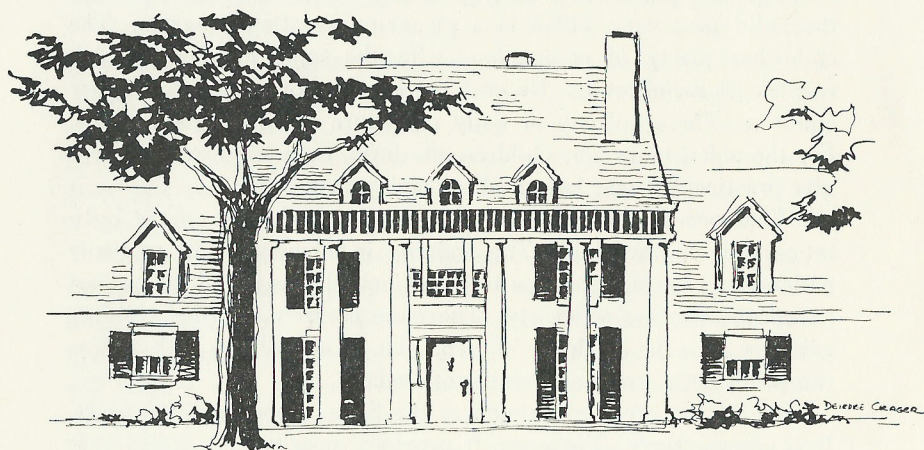
What benefit the child will gain depends not only on the institution, but on the child. The training is intended to fit as many patients as possible to return to the community as useful, or at least harmless, members of society. The more severely retarded children gain less than the brighter children, who, in accordance with ability, can profit more from the training offered.

One of the great advantages of the State School is permanence. It is always there. For some it provides security and skilled care for life. For others it may be a stepping stone to useful living in the community.

All institutions, however, have limitations. The care is kindly, but there is less of love and individual attention than in the home. Removal from the community breaks contacts the child would otherwise have. Overcrowding and shortage of personnel, in most State Schools, are so serious that the individual child may not receive all of the benefits the institution was planned to give.

The Institution to Which the Child Would Go

Usually parents do not have a choice as to where a child would go if they decide on care in a public institution. There may be only one in the state that receives retarded children. If there are several,



they are likely to be districted, or to receive only certain types. Parents, therefore, must think not of *an* institution, but of the particular institution to which their child would go.

There are great differences in institutions. Some offer little beyond custodial care. Others give constructive training and real preparation for life in the community. For the severely retarded child, and those with double handicaps, kindly custodial care may be what counts most. But for children able to profit by specialized training and education, the more progressive types of institutions will be sought by parents.

How far away is the institution? Is it so hard to reach that parents can seldom visit the child? It is important to keep the child in contact with the family, though, in some cases, the care the institution gives may be more important. Parents can partly make up for infrequent visits by sending letters and occasional small presents.

It is sometimes possible to arrange for the child to make home visits without losing his place in the institution.

Some State Schools have extensive programs for preparing patients to return to the community. Does the institution in question have "half-way stations," such as colonies or family care, to which the patient might progress, if he has benefited by training? Is there a program for helping the more able patients to find suitable work?

Expenses must be considered. State Schools accept patients without charge if the parents are unable to pay. Ability to pay is usually judged by the amount of family income and the number dependent upon it. There may be substantial charges. All patients are treated alike, whether relatives are able to pay for care or not.

There are several methods of admission, varying from voluntary placement to commitment by a court. None, however, precludes the possibility that the child may return to his home, since the superintendent has wide powers of discretion.

All questions about the particular institution to which the child would go, have to be considered in relation to what the home offers. Will he have his best chance in *this* home, or in *this* institution?

The Private Institution

The private institution can give more individual attention than the public institution, but does not usually have the extensive facilities of the latter.

There are even greater differences in private schools for the retarded than in State Schools. Some give good all around training. Others offer very little. Most of them limit admissions according to age, sex or the extent of retardation. The small school accommodating only a few children, often has a home-like atmosphere. The

larger school may emphasize education and have a larger teaching staff. A few have the cottage system, combining both advantages. The child's condition will determine which type of school is most suitable for him.

The rates in good private schools are beyond the means of most families. It can hardly be recommended that a retarded child be sent to an expensive school if it means that normal children in the family are seriously deprived.

The private school is, in some cases, a desirable solution of the problem of care and education. It is not, however, the child's only opportunity for development. For this reason, it does not justify extreme financial sacrifices.

The Severely Retarded Child

Parents are often advised to place a severely retarded child in an institution. For some, this may be advisable, but the degree of retardation is seldom the best basis for making a decision.

The child of very limited ability is not likely to benefit greatly by the training given in an institution. Good home care will serve him just as well. Some cities provide special classes for the severely retarded.

Conditions in the home, however, may warrant sending him away as a relief to the family. The severely retarded child needs nursery care far longer than others, and his presence at home may seriously disturb the family group. In general the more a child differs from the average in intelligence, behavior and appearance, the harder it is to absorb him into satisfactory home and community life.

The so-called Mongolian type is often singled out as being in need of institutional care. Many children of this type are of a

happy, affectionate disposition, and are not especially hard to manage at home. The considerations are the same as for other retarded children.

Changing Conditions

Nearly all the conditions affecting a retarded child may change from time to time. This fact adds to the difficulty of deciding whether or not to keep him at home, and is another reason for avoiding a hasty decision.

The mother, who has most of the care of the child, may become incapacitated. Other children may suffer chronic illness. The father, who supports the family, may lose his job so that the mother has to work. The death of either parent will alter the whole picture. Such serious changes often indicate institutional care.

There may be other changes that suggest home care. The child may be easier to manage as parents learn the "know-how" of daily training. When he reaches school age a special class may be available. His attendance at school will give some relief to the home, as well as advantages for him. Even the over-active child, usually hard to manage at home, may quiet down as he develops.

Varying conditions have to be judged according to their nature and probable permanence.

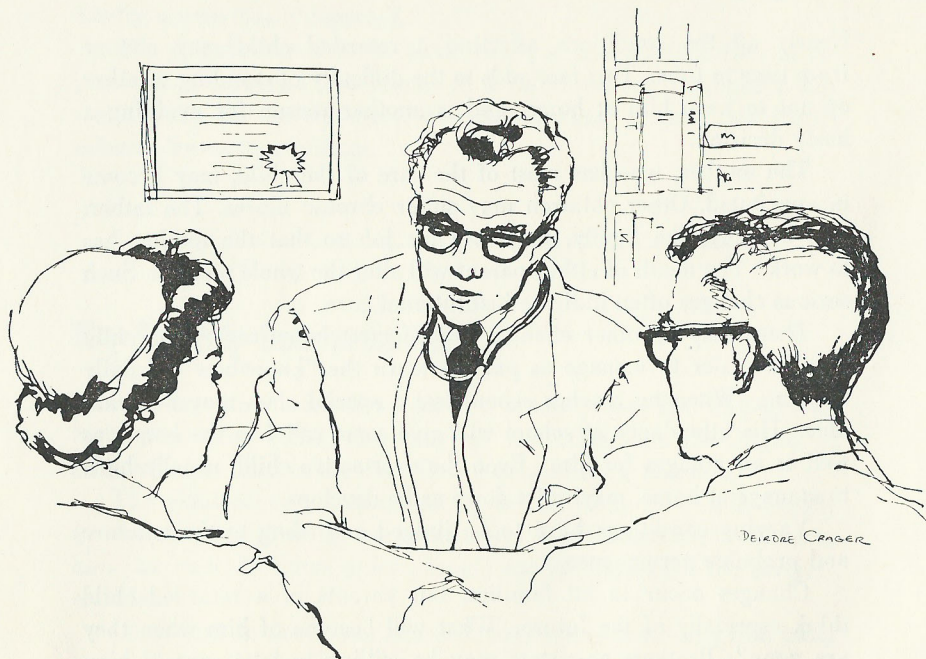
Changes occur in all families, but parents of a retarded child think especially of the future. What will become of him when they are gone? Brothers or sisters may be willing to take care of him, but it seems inadvisable for them to do so. They will have responsibilities for their own families.

Most institutions, because of over-crowding, have waiting lists which delay admissions. But in an emergency they are usually able to receive a child immediately. Some States permit advance commitments.

Conflicts

The deciding factors do not always point one way. There are usually reasons both for and against keeping a retarded child at home.

Advice from different quarters is often conflicting. The thinking of those who know most about the child and family should prevail, namely, parents and doctor or clinic.



Some emotional relief is gained by deciding not on the basis of feeling, but according to best judgment after all factors have been considered. Parents are helped also by the fact that their decision either way need not be final. Their choice is made for the present and immediate future, not necessarily for life.

Aids in Deciding

The following steps may aid in a decision:

1. Seek information on mental retardation.

Many books and pamphlets are available.

2. Review the child's progress at home.

Is he developing in self-help and behavior?

If not, can methods of management be improved?

3. Review the welfare of the family as a whole.

*Can other members lead a fairly normal life,
if the child is at home?*

4. Study the neighborhood.

*What are the resources for education, recreation,
companionship, training for self help and
employment?*

5. Consider advice of doctor or clinic.

What is expected in the future?

6. Talk with parents of other retarded children.

*Their problems will be different, but their experi-
ences may help.*

7. Visit the institution to which the child would go if sent to any.

*Consult a staff member on your own problem.
Do the children look happy and well cared for?
Is the program progressive?*

8. Become an active member of the nearest unit of the National Association for Mental Health, 1790 Broadway, New York 19, N. Y., and the National Association for Retarded Children, 99 University Place, New York 3, N. Y. These voluntary organizations provide an excellent opportunity for education and service... education and information about mental retardation and volunteer service to help improve community resources for the care and training of the mentally retarded.

Summary

No two homes or families are alike. No two cases of retardation are the same, and even in the same case conditions often change.

Some retarded children require institutional care for their own good, or for the welfare of the family or of society. Few general rules can be made as to the type of child who should be sent to an institution. Each case must be studied on an individual basis, and may need reconsideration at some future time. No solution is entirely satisfactory.

The principal questions are these: Do the parents want to keep their child at home? Can they do it without serious detriment to other children? Are there opportunities for growth in the neighborhood?

If the family wants the child and is willing to make sacrifices for his development, the decision is for them to make.

A companion booklet entitled "The Retarded Child in the Community" by Katharine G. Ecob may be purchased from the New York State Society for Mental Health.

The New York State Society for Mental Health

STATE CHARITIES AID ASSOCIATION

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The New York State Society for Mental Health is honored to publish this work of Katharine G. Ecob, nationally known authority on mental retardation, who for many years pioneered and served as Executive Secretary of the New York State Committee on Mental Hygiene of the State Charities Aid Association.

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Foreword

Most parents of a retarded child are faced at some time by a hard decision. Shall they place the child in a residential school or keep him at home? The emotions are deeply involved, and the decision is all the more difficult because no answer fits every case. Each child and each family are different, and the question must be studied on an individual basis.

Often parents mistakenly feel that they are to blame for the child's condition. Mental retardation has been known since the earliest times. It may occur in any family, rich or poor. Some relief from the unwarranted sense of guilt, and from anxiety about the child's care, may be found by making a thoughtful study of the needs both of the child and of the family.

Parents who send their child to an institution love him as much as do parents who keep theirs at home. It is not a question of love or duty, but of expediency. What is best for all concerned?

There is time to think

Usually there need be no hurry about deciding whether to keep a retarded child at home or place him in an institution. Except in rare cases of emergency, there is no reason for hasty action, and a decision either way need not be final. The child can remain at home unless developments show that institutional care is needed. Even if a child has been placed, the institution will, in most cases, release him if reasonable home care is provided, and he is not likely to be a danger to himself or others.

Many factors enter and they vary from time to time. But in most cases it is unwise to seek institutional care, until after home care has been tried and both parents agree on placement.

The Three Main Questions

The three basic considerations are:

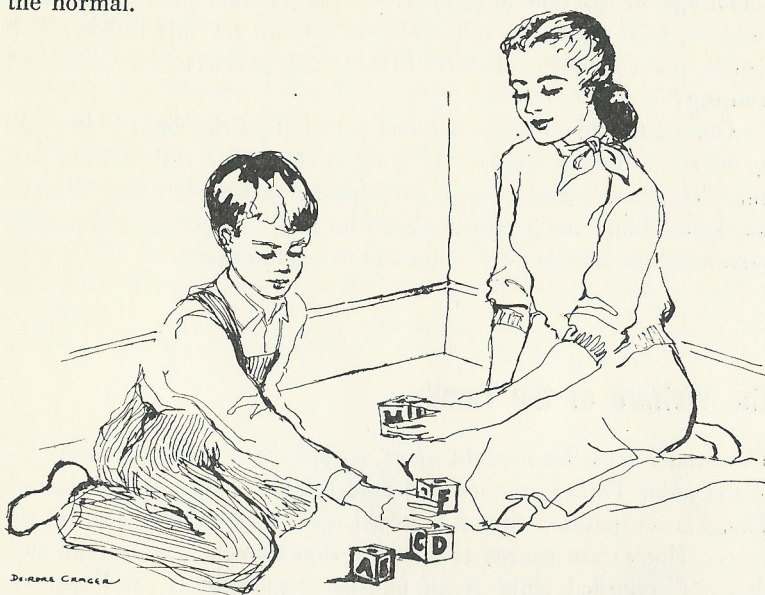
1. The welfare of the retarded child.
2. The welfare of the family.
3. The welfare of society.

The good of society need not be thought of if the child is well managed at home. Retardation in itself is not a danger to the community. The retarded child is, in most cases, docile and harmless. With good training he may even contribute to the welfare of family and community.

Institutional care for the purpose of protecting others, is needed only if a child has become unmanageable or delinquent.

The Welfare of the Child

Whether a retarded child will do better at home or in an institution depends on conditions in the home, family and neighborhood. The home gives more affection and individual attention than any institution can supply. These are as important to the retarded child as to the normal.



Do the parents want to keep their child at home? Can they accept him as he is, whatever the handicap? If so, they expect to provide such essentials as food and clothing. But these are not enough. Are they able and willing to help the child reach his fullest development by patient training and constant supervision over many years?

The objective is to make the child's life happy, and as useful as the condition permits. In every home there are many means of training for self-help and the qualities that may lead to self-support later.

The home, at its best, gives more opportunity than is possible in an institution for developing wholesome personality, which is one of the greatest assets a retarded child can have.

The home includes the neighborhood. Does the community provide facilities for helping the child to develop his capacities? Is there a special class where the child may be accepted when he reaches school age, or can one be formed? Are there other children, perhaps younger, with whom he can play? Are there safe places for play? Can he often go out of doors? Is there any provision for vocational training?

One of the advantages of home care is that the child is brought up in the world of reality. He mingles constantly with normal persons. This may occasion some hardship by making him feel inferior. But in the long run it is better for him to learn to adjust to normal surroundings, if he is ever to live in the community.

The Welfare of the Family

The family must be thought of as a whole, and a normal home life is the goal. Father, mother and other children must be considered. There is no question that a retarded child is a great burden to the home. Homes are geared to average, sometimes above average children. A retarded child is an unusual responsibility, and requires many family adjustments. How much he will disturb family life depends on many factors, some of which can be controlled by good management.

Some conditions make satisfactory living for the family almost impossible. If such conditions exist and are not likely to improve, then institutional care is indicated for the greatest good of the greatest number.

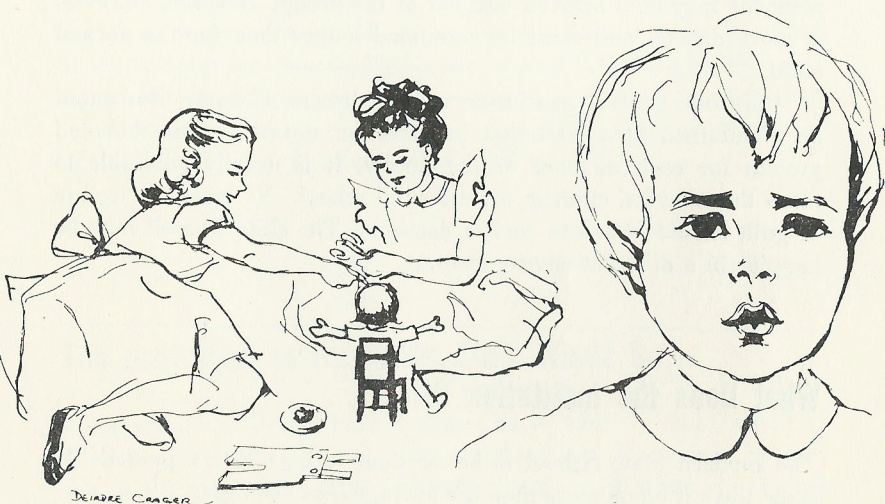
The retarded child may need so much care that the mother cannot have a normal life, nor give proper attention to other members

of the family. The over-active child, the destructive child and those with physical handicaps in addition to retardation, may be in this class.

Physical care is not the only problem. Presence of a retarded child may interfere with the social relationships of parents and other children. A mental disability cannot be compared to a physical handicap. While the latter calls forth compassion, the former is more likely to create fear. This attitude is slowly yielding to better understanding by the public, but is still something to contend with. Often, however, the retarded child fits readily into the neighborhood. His acceptance depends chiefly on personality, behavior and appearance.

In the home, a retarded child may cause constant quarreling and sometimes serious disagreement between the parents, or between them and normal children. The emotional effect on brothers or sisters may be very severe. On the other hand, sometimes the family is drawn closer together in the common effort to help a weaker member.

The attitude of parents has a strong influence on the feeling in



both family and neighborhood. When parents accept and love their retarded child they have paved the way for his acceptance by others.

Circumstances may make it easier or harder to keep the retarded child at home. Suitable living quarters make it easier by giving others in the family more freedom. Crowded conditions add to friction. In a country or suburban home, care is usually easier than in a city. Whether the child is older or younger than the other children may make a difference either way, as well as the size of the family group.

Sometimes there is financial stress because of a retarded child. In their anxiety to do their best for him, parents may spend more than they can afford in the hopeless search for a cure. This is a difficulty that can be avoided. At present no treatment is known that will make a child bright. Financial sacrifices will not help the child, and put an unnecessary strain on the family.

One cannot say that a retarded child always threatens the welfare of other members of the family. This is especially true if he is an only child. Depending on his condition and on good management, he may be a beloved member of the group. His care, however, is more difficult and must be continued longer than for the normal child.

Only one general conclusion can be drawn. If home life cannot be maintained at a level that provides for normal satisfaction and growth for each member of the family, it is usually advisable to place the retarded child in a residential school. No blame or feeling of guilt should attach to such a decision. The child himself may be happier in a different environment.

What Does the Institution Offer?

The modern State School is better than is popularly supposed. In some ways it offers more than the average home can give.