THE CASEWORKER'S RESPONSIBILITY TO THE RETARDED CHILD AND HIS PARENT*

by BERNHARD SCHER

Jewish Child Care Association of New York

IT is obvious that there is a new and and growing interest in the retarded child and his parents. Newspaper and magazine articles have made the whole country aware of the tremendous problems such children pose for every community. Unfortunately, while this new awareness of the retarded has taught the public that "retarded children can be helped," it has apparently been less effective in convincing a good many caseworkers of the same fact. Recently, for example, at a meeting in New York, it was maintained by one expert in community organization that only the exceptional individual with an I.Q. of 60 to 65 could be expected to mature socially and otherwise past the age of 18 and could remain in the community only so long as he continued to live with his family. It was seriously suggested that even such individuals would need to be institutionalized when their parents or relatives died, or became unable to aid them for other reasons.

The almost total irrelevance of these statements to the known facts could scarcely be clearer. Only about 10 per cent of all so-called defectives, children and adults with I.Q.'s below 75, are in institutions. Even this small percentage is, of course, heavily weighted with individuals of the most inferior capacity. Obviously, the great majority of the retarded are, and will remain, in the community with, or without, parental support. How great their capacity for successful community living will be, how great a community contribution they can make, and what personal adjustment they may achieve will depend directly on what the community, including professional workers, accepts as its responsibility for them.

Traditionally, the Jewish community has accepted responsibility for all its children, the retarded no less than others. In the service for Passover, for example, the simple son is included with the wise and the wicked sons and with the infant child, as deserving instruction. The Haggadah says that the simple son, on seeing the preparations for the festival, can only ask "What is this?" The child's parent is told to give him a direct and reassuring answer, "With a mighty hand the Lord brought *us* forth out of Egypt, from the house of bondage." That so primitive and poor a people should have recognized the limitations of the retarded child and yet sought ways to include him in the whole community is, in one sense, surprising. In another sense, it is completely in character that Judaism, which taught the basic concepts of human worth and human dignity to Western civilization, seems to have been the first to recognize its special responsibility to the retarded.

This reference may serve to point up how far our present practice, as Jewish professionals, is lagging behind the expressed ideas of an earlier and presumably less understanding period. The tragic fact is that, as a profession, casework has made only the smallest contribution to professional knowledge and practice in the field of retardation. Only recently, as part of the general reawakening to the problem, have caseworkers, as individuals, become active. But even the quickening of public interest in the retarded, which already has resulted in more progress in five years than was achieved in the previous twenty-five, has so far scarcely affected the practice of established social agencies. In New York City, which has done about as much as most large communities, the outstanding child guidance agencies still offer no special service to the seriously retarded child or to his family. Only two institutions offer specialized sectarian placement for retarded children. In every area of social service the picture is much the same. In general, it is only too accurate to say that the Jewish professional community has made little or no special provision for service to, or care of, the retarded. Even when the retarded are not specifically excluded they are not really included.

This situation is made even less comprehensible if one considers the size of the problem, the serious implications it has for both the child and the parent, and the need for the kind of organized pioneering efforts which private, sectarian social work has traditionally accepted as its proper and peculiar role. In the past, no doubt, agency apathy could be traced in part to public indifference and the lack of client pressure. Whether or not this explains why casework agencies, which traditionally have been pioneers, have failed to provide leadership in this field is surely debatable. In any case, it is no longer true that such factors need limit agency service to the retarded. The public is interested and sympathetic. It may even be doubted whether finances are, or need be, a major problem.

Our experience at the Edenwald School has led us to believe that negative attitudes towards the potential of the retarded are based, in part, at least, on the difficulty professional workers have in making primary identification with the retarded. We have found that each new worker on coming to the school has had serious initial difficulty in finding a personal basis for his interest and service. In many cases, workers have at first almost wholly denied the very fact of retardation as if, in order to form a helping relationship, they needed to make the children over, a little closer to their own self-image. It is extraordinarily difficult to identify with the retarded child in the personal terms essential to psychological helping. It is not too hard to conceive of oneself as crippled, blind, seriously neurotic or even psychotic. All of us have had experiences which, by extension, let us feel what it would be like to be handicapped in such ways, but few of us can imagine ourselves truly retarded.

It seems obvious that some such deep-seated factors are at work, since it is hard to conceive of a rational basis for such long-standing professional neglect of so large and serious a social problem. The size of the problem alone is impressive. A recent report by Mr. Roselle, the director of the admirable Southbury

---

* Presented at the Annual Meeting of the National Conference of Jewish Communal Service, Atlantic City, New Jersey, May 22, 1955.

Training School in Connecticut, underlines this fact. A special committee, after studying the situation in Connecticut, arrived at the conclusion that approximately two out of every one hundred children of school age were retarded enough to require special care. This is a most conservative figure. Estimates run as high as three and more per hundred. This finding may be seen in better perspective, if it is realized that it means that the number of retarded children is larger than the total number of children with polio crippling, heart conditions, cerebral palsy and blindness *added* together. Retardation is, in fact, a major and still almost untouched social problem.

It is, of course, a major individual problem for the child and his parent, as well. Few handicaps are as general in their consequences. For the child, retardation means a different way of life in every area. He matures differently, plays differently, lives differently. In many, perhaps most, cases, he learns his difference slowly and painfully, through failure and without help. His parents move from concern to fear and, finally, perhaps, to a painful endurance of a condition which is both total and continuous. The additional fact that retardation is genetically determined, in most cases, and exists as a congenital condition makes personal guilt almost inevitable in even the most enlightened parent. These problems are made more serious and painful because community resources and services are so few and so inadequate.

If there is new hope for the retarded child and for his parent, it is because parents have organized themselves in a unique and stirring revolt against community apathy and professional neglect. These relatively new groups have done an amazing amount in a very short time. They have made of retardation a live issue. They have made the public conscious of, and sympathetic to, the problems faced by such children and their families. They have affected state governments and obtained the support of the national Congress. They have established new facilities and secured the extension and improvement of older ones. Perhaps most significantly, they have given parents, as well as their children, new hope.

Inevitably, any movement as vital and dynamic as this has its limitations and blind spots. The associations for help to retarded children have been aware of this. They recognize that they have started projects for which they were not ready, or which they could not support. At least some of their leadership has recognized that there are serious dangers, for the retarded child, as well as for community planning as a whole, in the creation of totally new services rather than in the extension of existing ones. There is even recognition of the fact that such organizations have an almost inevitable, but dangerous, tendency to meet the most immediate and vocal needs of the membership even when this threatens the development of a consistent scheme of care.

There can be little doubt that such problems will become less frequent and serious as the parents' movement matures. The obvious readiness of such associations to use professional workers as guides and as executives is a sign that such growth already is taking place.

A more serious result of parent leadership, however, has been that the emphasis on external aids, such as play schools for the very young and sheltered workshop for the adolescent, has made for a relatively static and paradoxically unhopeful point of view regarding the nature of retardation. It has tended to stress retardation as a condition, determined by physical factors, rather than as the functional result of a great many factors, psychic as well as organic in origin. It is not hard to see why parents, burdened by guilt and harassed by the inadequacy of community facilities, have taken so static a view. It may be noted that this emphasis also reflects the fact that the parents' organizations have been most interested in the very seriously retarded child, where genetic and physical factors probably are relatively more significant than they are in the more mildly retarded.

While such a concept of retardation is both understandable and generally accepted, it is not clearly and firmly established as correct. Our experience at the Edenwald School, which serves the less seriously retarded child, has led us to the belief that retardation must be viewed as a mode of adjustment to, as well as a consequence of, physical limitations. During a ten year period, in which more than 150 cases have been seen and studied carefully, not a single child has been admitted of whom it might have been said that he was "retarded but otherwise normal." In every single case there was clear evidence of personality deviations ranging from relatively mild reactions to frank psychoses. This is, undoubtedly, a special group, as is true of the population in any placement agency, but the facts seem at least to suggest that there is need for further study of the reciprocal relationship between retardation and personality deviations.

As a hypothesis for study, it is suggested that retardation almost inevitably affects both the child's capacity to relate and the attitudes of his parents both directly and deeply. It therefore and equally inevitably prevents normal personality development. This hypothesis, that retardation is a mode of adjustment, is in full accord with what we have learned about the special group of retarded children and their families whom we have studied at the Edenwald School.

It is a valuable hypothesis, if for no other reason than that it makes possible, and even necessary, an optimistic, mental hygiene approach to the individual retarded child. In this connection it may be noted that the traditional concept of retardation as a limiting "condition" almost inevitably leads to concentration on providing "opportunities" for training. The concept of retardation as a mode of adjustment leads to equal emphasis on psychological help to the individual and his family. Whereas the first approach will give more immediate relief to parents and the child and better use of what we know, the second promises deeper understanding and more adequate research.

For the present and in the foreseeable future both these approaches will be needed. There is obvious need for the energy, courage and vision of the associations of parents. There is equal need for patient, detailed professional work with retarded individuals who may thus be helped to make better use of whatever community facilities there are or may be as well as better use of whatever strength they may have.

In this field, where basic facts and basic facilities are almost equally lacking, there surely is place for both parents and professional workers. It would be most unfortunate if effective partnership is not achieved because of failure on either side. It is clearly a sign of increasing maturity and security on the part of these organizations that they have been seeking professional leadership, as well as professional advice. However, it would be destructive, perhaps disastrous, if, at this hopeful moment, the parents' organizations were to give up, or lose, what is uniquely theirs to give and become a kind of specialized Child Study League. It is from the parents that the energy and anxiety necessary for progress must come.

Casework, as a profession, and caseworkers, as individuals, have a dual responsibility to the parents of the retarded child. They need to accept responsibility for the almost complete failure of private social work to make its own unique contribution. They also need to assume an important role within the parents' organizations, while accepting the unique and essentially non-professional character of such groups.

Social work has a special role to play in the associations for retarded children not because it has become expert in the field, for it has not, but because it, alone among the professions, has the background to see the child, as a whole, within a family, and within a community. Such a total point of view is essential, both theoretically and administratively, for retardation is almost unique in the way it affects total behavior and total potential.

The experience of caseworkers in the development of child care and in child placement has given to casework a special competence and a special responsibility. For example, the parents' associations and their expert advisors alike are struggling with the hard questions involved in policy regarding the use of placement for retarded children—when they are not trying to avoid such questions as altogether too unpleasant to contemplate. Caseworkers dealing with dependent and disturbed children have come to understand and accept the fact that placement is right for *certain* children and *certain* families at *certain* times and under *certain* conditions. They have come to accept the fact that placement, like any other form of treatment, is right when it is needed, rather than a desperate last resort. This kind of knowledge of the needs of the child, as they relate to the needs of the family, is unique to social work. It is only fair to add, however, that the problems involved in work with the retarded are greater and more complex, because of the total nature of retardation, than they are in work with the normal dependent or disturbed child. In practice, this will mean that the caseworker going into the field of retardation has much to learn.

The caseworker therefore has a special responsibility to the parents of the retarded child, as part of an association of such parents. His second, and perhaps even greater, responsibility is to the parent of the retarded child as an individual with a serious personal problem. Improved diagnostic facilities, extension of school facilities and of shelter workshops undoubtedly will relieve parents of some of the burden they have had to carry but will not, by themselves, be enough. Parents still will have the agonizing need to accept the fact that their child is retarded, will have to face the difficult decision whether to keep or place their child, and will have to learn how their own reactions may help or hinder their child. Working with individuals with such problems has traditionally been the obligation of the private sectarian social agency in the United States.

Many arguments have been advanced to explain agency inaction in the area of work with the retarded. It is frequently claimed that such children will always need custodial care, and are therefore a proper charge on the state rather than on philanthrophy, for example. This is a conclusion based on the flimsiest evidence and contradicted by every new development in the field. The fact is that the social adjustment of the retarded is determined in part by their genetic capacity, in part by their rearing, in part by their education, in part by their work training, and in largest part by community attitudes and acceptance.

Unfortunately, this erroneous, static conception of a fixed relationship between capacity and adjustment skill is being used to justify the exclusion of retarded children from agency programs. As a result, children have been denied an opportunity to develop to the limit of their capacity and workers have failed to learn more about the nature and dynamics of retardation. Thus a vicious cycle has been set up, in which misconception has led to neglect and neglect to further misconceptions.

It is the responsibility of caseworkers and of casework administrators, in particular, to change this situation, to make agency facilities available for help to retarded children and their parents. Our experience at the Edenwald School has been that Board leadership in the development of such services may be expected if the problems and needs are clearly presented and if adequate study is encouraged. Public interest in the retarded has been sufficiently general for Boards to be at least sympathetic to the need, in our experience. Naturally, the very size of the problem and the serious gaps in service will make Board members cautious, but such caution is most proper to professionals in this field as well.

The opportunity for service is practically without limit. Almost every type of social agency has a special service to offer if it will develop the additional knowledge and methods needed to fit its present skills to the different needs of the retarded.

For example, child guidance agencies could rapidly develop the kind of diagnostic service which is so urgently needed by parents of retarded children. The few diagnostic clinics presently operating in New York City have waiting lists of a year and more. It is true that diagnosis in retardation is not a simple or easy process. It needs the pooled skills of many experts and study of many areas. The process is, however, not basically different from that which is required in work with seriously disturbed children, where medical and psychiatric advice are used to supplement the findings of the social worker and psychologist. The great advantage of creating diagnostic services for the retarded within child guidance agencies, rather than in hospitals, would be that diagnosis would be fully integrated, from the very first, with help to the parents. Such agencies already are oriented to recognize the parents' problem in accepting such hard facts and know that help to the child and parent will depend, in good part, on attitudes, rather than in the facts alone. If diagnosis does not lead to helping the parent accept the fact of his child's retardation and to see how his attitudes may help or hinder, it is of only partial value, at best.

If child guidance workers will accept responsibility for diagnostic aid, they will almost inevitably need to face the even greater challenge and opportunity for therapy for such parents and their children. It is still far from certain whether orthodox methods are useful in work with the retarded or whether such individuals are, in fact, available for therapy at all. However, evidence has been accumulating slowly which makes it probable that therapy is as valid for the retarded as for other children and that it need not be too different in form from accepted methods. The need of parents for detailed, specialized help in the training and rearing of their children could be met by such agencies as well. The mental hygiene values of such help are almost incalculable.

Child placement agencies also have an obvious and special role to fill. It is unfortunate but true that, as general standards for placement have risen, it has become even more common for agencies to exclude the dull from care. Paradoxically, therefor, standards for service to such children have tended to decline while standards for others have been improved. Such exclusion of the retarded has been based, in good part, on the old misconception regarding the fixed relationship between capacity and social adjustment, which has already been discussed. More validly, agencies have questioned their ability to serve such children within established institutional programs for the more normal child. Such questions are less justified today, however, since specialized programs have become the rule, rather than the exception. The increase in social services for children in their own homes, the growth of foster home care, and the extension of professional services in the field of placement have combined to reduce the total number of children in placement very sharply, in progressive agencies, at least. As a result, there has been a shift in emphasis towards specialized treatment units, designed to meet the need of seriously disturbed children. It would be no less appropriate or socially useful to establish such units, dedicated to the service of retarded children needing placement. The content of program would need to be different, of course, but the basic concepts of care would be very similar. Our experience at the Edenwald School has made it clear how real are the opportunities for valid professional service in this area. It should be noted that the demonstration values of such placement units are particularly great, since the standards of public care for the seriously retarded will depend, in part, on what is proved possible and effective in private agencies.

Similar opportunities await exploitation by family service, group work and vocational training agencies. Only the smallest beginnings have been made and most areas of service still lie virtually untouched. The social benefits and the relief of individuals which such casework service might provide are almost unlimited. The very size and value of these benefits place a heavy responsibility on the caseworker. Only if caseworkers will accept this responsibility, and help their agencies to accept them, will it be possible to bring the simple son, who is also worthy of our best efforts, out of the house bondage, out of despair and into hope.