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Impact of a retarded child on his family and vice versa

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THE IMPACT OF A RETARDED CHILD ON HIS FAMILY
AND VICE VERSA

by

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A RESEARCH PAPER
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This research paper has been
approved for the Graduate Committee
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CHAPTER I

INTRODUCTION

"The child needs strength to lean on, a shoulder to cry on, and an example to learn from."¹

Every child must have love and security if he is to grow and develop properly. If a child is to accept himself and relate well to others, it is first necessary for others, especially the parents to accept the child for his worth as an individual. The needs of a retarded child are the same as those of a normal child, only more so. The manner in which a retarded child is accepted by his family from the very beginning will greatly affect his self-image, social adjustment and his acceptance of others. Of course, there is always the initial shock to the parents and their own adjustment to their child's condition. Most parents who have a mentally retarded child suffer from a chronic sorrow that has not always been recognized by the professional personnel who attempt to help them. This chronic sorrow will usually last throughout their lives regardless of whether the child is kept at home or is institutionalized. The sorrow will vary according to individual circumstances. When the parent is asked to "accept" the child's retardation, it is not clear to him just what he is being asked to do. In general,

¹H. H. Humphrey, (at the National Conference on Day Care Services, Washington, D.C., May, 1965), Children, XII (November-December, 1965), 234.

the parents do accept the fact of the child's handicap and try to meet his needs in a realistic manner. However, the parent cannot abandon his chronic sorrow even though he would like to do so. This sorrow is a natural response to a tragic fact. When the professional workers accept this as a natural, rather than a neurotic response, they can be more effective in helping the parents achieve the goal of increased comfort in living with and managing a mentally defective child.¹

Statement of the Problem

Mental Deficiency is a family tragedy, and whatever one may do or say, the tragedy remains.² In all cases, the problem remains first and foremost a family problem. You cannot regard and treat handicapped children in isolation. All members of the family need to have a clear and realistic understanding of the nature and extent of the child's condition.³ ". . . the deep, dependent relationship each family member has to all other family members is rarely understood. . . . In a family everyone is linked together for better or for worse, sometimes until death. The reciprocal interplay among family members is seen as a homeostatic process."⁴ Not only must the family members learn to handle

¹S. Olshansky, "Chronic Sorrow: A Response to Having a Mentally Defective Child," in Management of the Family of the Mentally Retarded, ed. by W. Wolfensberger and R. Kurtz (Parkinson Division, Follett Educational Corporation, 1969), pp. 116-119.

²S. Olshansky, "Parent Responses to a Mentally Defective Child," Mental Retardation, IV (August, 1966), 21.

³W. Kvarceus and E. N. Hayes, If Your Child is Handicapped (Boston: Porter Sargent Publisher, 1969), p. 399

⁴J. Baldwin, "Troubled Child--Troubled Family," Elementary School Journal, LXVIII (January, 1968), 179.

their own feelings of self-pity, shame, anger, hurt, frustration; they must learn effective ways of relating to and helping the damaged child. Diagnosis of the family as well as of the afflicted child is called for, and this is to be followed by family counseling and family therapy. The other children in the family must not be neglected and the parents must not wear themselves out in their efforts to help the one child. Jealous or embarrassed sisters and brothers and tired parents can prove to be a greater hazard to the child than the handicap itself. It is true, the family most certainly needs the help of professionals, but no matter how effective this help is, most of the support and reinforcement must come from the family members themselves if the child is to achieve optimal development and maximum use of his capacities. Also, the family interaction with the afflicted child will be either positive or negative-- never neutral. Without full cooperation and understanding on the part of the family as a whole, the handicapped child will be limited in his potential growth and development.¹

Considering what has been said, it can be clearly understood how important the family is to the retarded child's total development. In this paper the writer has attempted to review the research which has been done concerning the impact of a retarded child on his family and vice versa. Many studies have been done on family adjustment problems, reactions of parents, family acceptance, effect on the family unit, and on counseling the parents of the retarded. However, there is " . . . a

¹Kvareceus and Hayes, If Your Child is Handicapped, pp. 399-400.

disturbing lack of empirical underpinnings for past and present practices in the management of the family of the retarded."¹ One reason for this is the newness of the field as there was little family management in mental retardation before the mid 1940's. With change in family management of the retarded, the future will probably see changes in the impact which a retarded child will make on his family.

In the long run, management of the family of the retarded should, and undoubtedly will, become more continuous with education for parenthood in general. The rearing of children is one of the most significant and demanding tasks most of us confront in our lifetime. Yet, paradoxically, this is a task for which the average citizen has received little or no formal preparation. Even when the child has an unimpaired growth potential, and even where parents are highly intelligent, well-educated, and possessed of abundant material resources, child rearing is typically fraught with error, and frequently marked by failure. How much more problematic the situation then becomes when the child is handicapped!²

In view of these statements concerning the family problem which retardation presents, the writer has endeavored in her findings to determine its implications for the future.

Definition of Terms

For the sake of clarification it deems advisable to define the following terms:

Mental retardation refers to subaverage general intellectual

¹Wolfensberger and Kurtz, Management of the Family of the Retarded, p. 511.

²Ibid., pp. 517-18.

functioning which originates during the developmental period and is associated with impairment in adaptive behavior.

Heber stated that the "choice of the term 'mental retardation' was predicated on the basis that it appears, at present, to be the most preferred term among professional personnel of all disciplines concerned."¹

Mental deficiency - a term used as a synonym for mental retardation. Sometimes used in a more restricted sense to refer to those whose mental retardation is attributable to structural defect.²

Mentally handicapped - a term sometimes used as a synonym of mental retardation. It is also used to refer to a specific or segmental defect in intelligence or other aspect of behavior.³

Educable mentally retarded - a term used to refer to mentally retarded persons who are capable of some degree of achievement in traditional academic subjects such as reading and arithmetic. Also used to refer to those mentally retarded children who may be expected to maintain themselves independently in the community as adults, or to that group of mentally retarded obtaining IQ scores between 50 and 70, 75 or 80.⁴

Trainable mentally retarded - a term used to refer to mentally

¹R. Heber, "A Manual on Terminology and Classification in Mental Retardation," Monograph Supplement to American Journal of Mental Deficiency, LXIV (September, 1959), 3.

²Ibid., p. 90.

³Ibid., p. 93.

⁴Ibid., p. 98.

retarded persons whose disabilities are such that they are incapable of meaningful achievement in traditional academic subjects but who, nevertheless, are capable of profiting from programs of training in self-care, social, and simple job or vocational skills. Also used to refer to that group of mentally retarded obtaining IQ scores from 25 or 30 to 50.¹

Severely retarded - may be viewed as being above the level of total dependency throughout their lifetime. Many require intensive and extensive medical and nursing care; while others, because of organic brain damage, are somewhat difficult to control. Motor development is retarded, as are language and speech.²

Exceptional child - this term applies to all children who are handicapped physically, socially, and mentally, as well as gifted according to some scale of mental measurement.³

Mental retardate - a person who is mentally retarded.⁴

Adjustment - a state of harmony and adaptation, a relationship (as to the environment, other persons, etc.)⁵

¹Ibid., p. 98.

²H. Stevens, "Overview," in Mental Retardation, ed. by H. Stevens and R. Heber (Chicago: The University of Chicago Press, 1964), p. 4.

³A. O. Heck, Education of Exceptional Children (New York: McGraw-Hill Book Company, Inc., 1953), p. 4.

⁴Heber, "Manual on Terminology and Classification," p. 98.

⁵Ibid., p. 87.

Self-concept - is a global concept which, in general, refers to the sum total of all the characteristics a person attributes to himself, and the positive and negative values he attaches to these characteristics.¹

In this paper the writer has used the terms mentally retarded, mentally handicapped, mental deficiency and exceptional, interchangeably. In the cases where a distinction had to be made, the terms educable mentally retarded, trainable mentally retarded and severely retarded were used.

Summary

It can be concluded, therefore, that the retarded child cannot be treated in isolation. It is a family problem and must be treated as such for the best interests of all concerned.

¹Stevens and Heber, Mental Retardation, p. 146.

CHAPTER II

REVIEW OF LITERATURE

Overview

The writer has found many studies which have been done on the impact of a retarded child on his family, or on the family problem of retardation in general. Very few, however, have been found which have dealt with the influence of the family on the retarded child. Few sibling studies have been done because of the difficult nature of gathering such data. In the area of parent and family counseling for the family of the retarded much research is being done at the present time.

Effect on Family Unit

In the estimation of the writer, the two following studies seem to serve as "key studies" of the research done on the family problem of retardation.

The first was a study done in 1956 by Schonell and Watts¹ in Brisbane, Australia, to determine the extent of the effect which a sub-normal (trainable retarded) child had on his family unit. At that time not much had yet been done in this area. It had been believed that such

¹F. Schonell and B. H. Watts, "A First Survey of the Effects of a Subnormal Child on the Family Unit," American Journal of Mental Deficiency, LXI (July, 1956), 210-19.

a child had a disrupting effect on family life, but there had been little objective analysis to uphold or disprove which aspects of family life were affected.

The aim of this research was to determine the extent to which subnormal children influenced the family unit and to discover how family life was most affected. The children involved in the study were between 5 and 17 years of age and had to be living in the home and not attending a school of any kind. Their development was such that they were incapable of profiting from even a special school program as well as being seriously retarded socially.

It was found that the lack of knowledge on the part of the parents, their inability to formulate a program for the child, and their desperate plea for help led to much family tension. The parents had no help or guidance to ease the burden, and as a result, the normal family routine was constantly disrupted. The activities of the normal brothers and sisters were often impeded, the mental health of the mother was jeopardized, and thus the problem became one of the whole family unit and not merely of the individual retarded member.

It was concluded that these problems could at least be minimized if the parents could receive some type of guidance and if arrangements could be made to place the child in some kind of training center in order to improve his social development.

A follow-up study was done by Schonell and Rorke¹ in order to

¹P. Schonell and Meg Rorke, "A Second Survey of the Effects of a Subnormal Child on the Family Unit," American Journal of Mental Deficiency, LXIV (March, 1960), 862-68.

assess the changes within the family units after their subnormal children had attended a special day training center for at least six months.

It was found that 82 per cent of the parents interviewed agreed that it was helpful to meet and discuss with other parents because this enabled them to understand their problems better. In this study 75 per cent of the parents made mention of the fact that the social behavior of their children, particularly outside of the family group, was greatly improved after attending the training center.

A marked improvement had taken place in the child's adjustment in the following areas:

1. relationship with siblings and with visitors to the home
2. personal and safety routines
3. care of property
4. level and form of play and language development

The general conclusion reached was that the encouragement and help received from the center had helped parents to reach a calm acceptance of their problem and of all the responsibilities involved. The improved social adjustment of the retarded child greatly decreased the tension in the family circle and the disrupting effect that it had previously placed on all the family members.

In subsequent research the findings are quite consistent in their agreement that parents of severely retarded children are very much limited in their activities outside the home. In England Holt¹ found that 40 per

¹K. S. Holt, "The Home Care of the Severely Mentally Retarded," Pediatrics, Vol. XXII, (1958), cited by B. Farber, Mental Retardation: Its Social Context and Social Consequences (Boston: Houghton Mifflin Company, 1968), p. 160.

cent of the parents were unable to go out together and a smaller percentage were unable to take a vacation. Tizard and Grad¹ discovered that about half of their families with a retarded child living at home were limited by the presence of this child. Farber² found that many of the women of the families with severely retarded children often developed physical symptoms and many parents who spent considerable time in voluntary associations had low marital integration scores.

In a study done by Fowle³, however, it was found that the marital integration was not adversely affected by the presence of a severely retarded child in the home. It was also found that the role tension of the siblings in the family especially that of the oldest female tended to be higher when the retarded child was kept at home than when he had been institutionalized. The conclusion of this study, therefore, was that the welfare of the siblings should be taken into consideration when counseling the parents of severely retarded children.

Naturally, it can be easily understood that the realization that their child is retarded does not have the same impact on all families. It is possible for a parent's reaction to a retarded child to vary from complete acceptance to complete denial of his adequacy. Because

¹J. Tizard and J. C. Grad, The Mentally Handicapped and Their Families (New York: Oxford University Press, 1961), cited by B. Farber, Mental Retardation, p. 160.

²B. Farber, "Effects of a Severely Mentally Retarded Child on Family Integration," Monograph of the Society for Research in Child Development, 1959, No. 71, cited by Farber, Mental Retardation, p. 161.

³Carolyn M. Fowle, "The Effect of the Severely Mentally Retarded Child on His Family," American Journal of Mental Deficiency, LXXIII (November, 1968), 468-73.

of the many environmental and personal factors involved, the achievement of acceptance often requires much effort on the part of the parents of a retarded child.¹

When Begab² investigated the factors influencing parental reactions to their child's handicap, he discovered that the manner in which the individual parent adjusted to the problem was determined by a variety of considerations, in spite of the fact that there were some factors common to all. One of the considerations mentioned was the personal adjustment of the parent which included his physical, social, and emotional resources. With parents who were emotionally mature, financially able, and intelligent, the problem of acceptance seemed to be less severe than in the case of the less capable parent. The nature and degree of the child's deficiency and the presence of other children in the home were also found to influence the degree of parental acceptance. The personality of the parents and the manner in which the family members reacted in a time of crisis were found to be important factors, too, in determining how a retarded child will be accepted in a family unit. A retarded child could be the cause of greater unity in some families, whereas in others, his presence could be the cause of complete disintegration.

¹Marion J. Erickson, The Mentally Retarded Child in the Classroom (New York: The Macmillan Company, 1956), p. 103.

²M. Begab, "Factors in Counseling Parents of Retarded Children," American Journal of Mental Deficiency, LX (1956), 515-24.

Erickson¹ observes some additional factors. It has been noted that when the child is considered to be in the higher IQ range of retarded classification or when his behavior and appearance are acceptable, the parents are less inclined to accept the diagnosis of mental retardation.

These findings are borne out in the following quotation from Stevens.²

The nature and level of mental retardation of the child, the socio-economic status of the family, the emotional stability of the parents, the emotional climate the parents create in the home, as well as the level of community tolerance for the mentally retarded, all affect the manner in which the parents plan to meet the needs of their retarded child. These same factors will also determine how realistically the family accepts the child. Moreover, the constant presence in the home of a retarded child, who presents obvious physical stigmata, sometimes creates social rejection of the family by relatives and friends.

It must be recognized that the effect of family life on a profoundly retarded child reared in a high socio-economic status family will be totally different from that on a mildly retarded child reared in a family of low socio-economic status. The levels of aspiration of parents for their children greatly influence the attitudes the parents have for their children.

Adjustment of Parents and Siblings

An interesting study was done by Caldwell and Guze³ in order to determine what effect the living arrangements of the retarded child would have on the total family situation. It is never an easy decision to make

¹Erickson, The Mentally Retarded Child, p. 107.

²Stevens, "Overview," in Mental Retardation, ed. by Stevens and Heber, p. 6.

³Bettye Caldwell and S. Guze, "A Study of the Adjustment of Parents and Siblings of Institutionalized and Non-Institutionalized Retarded Children," American Journal of Mental Deficiency, LXIV (March, 1960), 845-61.

whether or not to institutionalize a retarded child. Besides considering the needs of the individual child, the needs of the entire family have to be taken into account. Two types of family structure were studied. Some of the families had a retarded child living in the home and the other families had their retarded child living in an institution. Two persons from each family were singled out for close scrutiny in this study--namely, the mother and one key sibling. The main purpose of the study was to see whether the mothers and siblings of one group differed very much in personal adjustment from those in the other group. The data did not reveal any striking differences between the two groups. Without exception, however, the siblings mirrored the decisions of the parents regarding the living arrangements of the retarded member. It was found, too, that the siblings of the retarded child were ordinarily very adaptable and that they could easily mold their value system in this matter and conform to the status quo of the family.

The findings of the Caldwell and Guze study should be of great importance to parents. Their reactions "set the stage" as it were, for the rest of the family. Once it has become an accepted fact that a child is retarded, there should also be parental acceptance. "Hope for the mentally retarded child rests with the hope and courage of his parents; a hope built on understanding, and a courage fortified by forthrightness."¹ The parent who truly loves his child will think of him as an individual with the right to become as fully mature as his potentialities permit. When the child's retardation is recognized, he is well on

¹Stella S. Slaughter, The Mentally Retarded Child and His Parents (New York: Harper and Row, 1960), p. 9.

his way toward making the adjustments necessary for a mentally retarded child to grow as rapidly and as normally as his limitations will permit and will not unwisely deter his maturing processes.¹ All this, of course, is not easy for parents, especially when they realize that their attitudes are going to influence the attitudes of their normal children towards the retarded brother or sister. The other children have to be taught that occasionally it is well to give way to the interests of the retarded individual and make some sacrifices for him. They will profit from the joy of giving and grow in maturity themselves. The sacrifices, however, should be reasonable. For example, it would not be wise for a parent to insist that a mentally retarded child be included in all of the activities of his brothers and sisters. Rather, brothers and sisters have to be taught to assume an attitude of understanding toward a retarded sibling. If they understand the nature and extent of his mental shortcomings, they will more readily be able to find and create situations where the retarded child can comfortably fit. Understanding the needs of a mentally retarded child necessitates understanding the needs of his siblings in their relationship to him.²

The process of bringing up a child is rarely entirely pleasant, although, in most cases, the rewards more than compensate for the hardships. Parents of bright, healthy youngsters also need a large measure of patience, understanding, ingenuity, and strength, but naturally, for

¹Ibid., pp. 2-4.

²Ibid., pp. 7-8.

the family of a retarded child, the situation is more complicated and hazardous.¹

It was interesting to note that in a study done by Gordon and Ullman² at the Morris J. Solomon Clinic for Retarded Children on the response of parents to young mongoloid children, it was found that the parents of retarded children, as well as those of normal children, could be classified into three groups with respect to social adjustment. One group consisted of those persons whose resources and balance enabled them to cope with the most excessive stresses in an effective and constructive manner. Family units where this situation prevails are in the minority. A greater number, by far, were those parents who have succeeded in making an adequate general adjustment but are, nevertheless, harassed and confused by the problems their children present. The third group is the one in which one or both parents show neurotic or psychotic dispositions and when extra burdens tax the limit of their resources, they are often unable to make any adjustment at all.

During the course of this study as the parents related to one another in group discussions, they discovered that many of their problems were the same as those faced by parents of normal children and that the problems that were unique to the mongoloids were far fewer than they had assumed. One of the problem areas, however, related to the resentment of

¹H. B. Robinson and Nancy M. Robinson, The Mentally Retarded Child (New York: McGraw-Hill Book Company, 1965), p. 506.

²E. Gordon and M. Ullman, "Reactions of Parents to Problems of Mental Retardation in Children," American Journal of Mental Deficiency, LXI (July, 1956), 158-63.

the other siblings at the amount of attention given to the mongoloid child and also to the handling of the attitudes and questions of the other children concerning the child's handicap. It was concluded that the example should be set by parental activity rather than by verbalization with regard to the handling of and general attitudes toward the retarded member. The parents could readily understand, especially after one example was cited of an older sibling who had an unusually quiet attitude toward her younger retarded sister and rarely, if ever, spoke of her problem. The sibling's behavior was clearly related to the mother's own stoical and self-contained attitude toward the retarded child.

Carr¹ states that many parents tend to be concerned with the handicap before perceiving the child who has a handicap, forgetting that this child, too, wants to be an individual. In order to become a well-adjusted individual, the child needs to accept his particular handicap, not in a passive and defeated manner, but with the peace of mind gained through some mastery over the environment. Parents can do much to alleviate many of their retarded child's negative feelings through love and understanding and by treating him as a normal child to a considered extent. The child does not have to have the fact of his retardation impressed upon him. Most retarded children have been dreadfully aware of that fact for many years. Parents, teachers, and other professionals can help them realize the implications of this fact for their future life by helping them to come to terms with their assests as well as their liabilities.²

¹Lela B. Carr, "Problems Confronting Parents of Children with Handicaps," Exceptional Children, XXV (February, 1959), 251-55.

²Robinson and Robinson, Mentally Retarded Child, p. 498.

Baum¹ mentions shame as being quite apparent in sibling relationships of the retarded child. This feeling toward the child stems from parental attitudes, too, as can be seen from the following example. A mother of a large family engaged a sitter for the first time to look after her attractive little mongoloid daughter. The sitter enjoyed playing with the child in the park and taking her for walks down the main street of the town. The sensitive mother then had to ask herself why the child's siblings, who often volunteered to amuse the little girl at home, had never appeared with her in public. It was evident that the mother's own feeling of shame regarding her retarded child had affected the feeling of her other children towards the handicapped member of the family.

In keeping with the feeling of shame experienced by many parents of retarded children, Korke² reports a striking finding in her study. She found that because of the child's handicap, half of the families interviewed actually moved to a new neighborhood or seriously wanted to do so.

Sometimes the presence of a retarded child in the family results in greater unity among the members after the period of adjustment to the

¹Marian H. Baum, "Some Dynamic Factors Affecting Family Adjustment to the Handicapped Child," Exceptional Children, XXVIII (April, 1962), 387-92.

²Lenore Korke, "A Study of the Impact of Mentally Ill Children Upon Their Families," (A report of the findings of a research project sponsored by the Bureau of Research in Neurology and Psychiatry of the Department of Institutions and Agencies of the State of New Jersey, and conducted by Lenore Korke, during the period July 1, 1954 through June 30, 1955.) Division of State Library Archives and History, Trenton, N.J., p. 105. (Mimeographed)

child's handicapped condition has passed. Again, Korke¹ mentions several factors, stated by parents, which resulted in an increased sense of unity of purpose between husband and wife. The results of the study revealed that in some of the families where the child had been institutionalized, it was felt that the removal of the child from the home removed the source of tension and disagreement. Others felt that the presence of a handicapped child in the home resulted in changing their attitudes and values to such an extent that they began consciously to strive towards being a family that pulled together. Still others reported that the experience of having to cope with the child's problems was the cause of an increased sense of agreement between husband and wife in regard to important family plans.

In view of the research already cited, it can readily be seen that the picture need not always be a negative one. It is surprising how astonishingly well some families with retarded children are able to manage under adverse circumstances. In some cases, having a retarded child can give meaning and purpose to an otherwise bleak existence.²

An appropriate summing up of the findings which pertain to the adjustment of parents and siblings to a retarded child is stated very well by Carr.³

¹Ibid., p. 94.

²Report of a Conference on Social Sciences and Mental Retardation: Family Components, Michael J. Begab, chairman (Bethesda, Maryland: National Institute of Child Health and Human Development, January, 1968), p. 25.

³Carr, "Problems Confronting Parents," p. 255.

Parents are often puzzled about the relationship of other children in the family to the handicapped child. It is helpful to remember that all brothers and sisters can experience a certain amount of jealousy of each other. This is likely to be intensified when the mother must necessarily give more time and attention to the handicapped child. The other children cannot be expected to be entirely reasonable about this necessity because feelings are stronger than logic and reasoning power, both of which are intellectual qualities to be developed with growth. It is not easy to maintain a healthy balance of helping the other children to be especially considerate of a brother or sister less able than they, and at the same time not burden them or encroach upon their right to develop a healthy personality. No one can give pat answers as to what parents should do in this regard. It can only be suggested that a conscious awareness of these relationships and problems will in itself be a start in dealing with them judiciously. Love and acceptance, freedom to develop, control to protect, and good family relationships are the foundations for healthy personality development.

Acceptance, Self-Concept, and Labels

It is possible that some of the difficulties experienced by parents of a retarded child could stem from the way the handicap is diagnosed from the very beginning or from the label describing the condition. Although there is a lack of experimental data concerning the effects of labels on the attitudes of parents and teachers towards children, some professionals have concluded through clinical observations, that labels do influence the view taken towards a child's exceptionality.¹ According to Menninger² a label that is applied to an illness becomes almost

¹R. Combs and J. Harper, "Effects of Labels on Attitudes of Educators Toward Handicapped Children," Exceptional Children, XXXIII (February, 1967), 399.

²K. Menninger, "Psychiatrists Use Dangerous Words," The Saturday Evening Post, CCXXXVII, No. 16 (1964), 12-14.

as damaging as the illness itself and once applied, the label tends to mark a person as different, even after recovery. This is significant insofar as the reactions of parents are concerned when they learn that their child is handicapped, and, as McDonald¹ implies, this reaction is a result of confusion and misinformation on the part of the parents. It is true, that if parents are to accept the retarded child, they must be acquainted with the fact that their child differs from the average. However, the normal parent, even if he refuses to acknowledge the fact, is soon aware of any deviation in his own child.

The true meaning of acceptance for a parent is to accept what the child can do or learn right now--today, regardless of what his "label" says he can or cannot do. Today must come first and it must not be wasted in anticipation of tomorrow.² Most parents need time to adjust themselves to the tasks of the present with all of its realistic possibilities, instead of making foreboding statements about the distant future. Great care should be used in making long-range forecasts which very often can turn out to be wrong. When it is necessary to use a diagnostic label, the parents must receive help in exploring the true meaning of the term, otherwise the diagnosis would have a ring of finality about it. By encouraging parents to voice their fears at this time, they can be helped to be more realistic in facing their child.³

¹E. T. McDonald, Understand Those Feelings (Pittsburgh: Stanwix House, Inc., 1962), p. 11.

²Iris Major, "How Do We Accept the Handicapped?" Elementary School Journal, LXI (March, 1961), 328.

³Robinson and Robinson, Mentally Retarded Child, pp. 509-10.

As the writer mentioned earlier, the sorrow experienced by parents at the birth of a retarded child is a natural response to a tragic fact. The family, then, is placed in a cultural dilemma and spiritual crisis which will determine whether the child and the family will live together in peace, happiness, and security. According to Zuk¹, the pain experienced by the parents at this time depends to some degree on cultural factors. It is easy to understand that the parent who is extremely conscious of social standards of behavior will be most apt to have a difficult time. Zuk maintains that the religious background of the parents can powerfully determine the degree of family acceptance of handicap in the child. The first step in resolving the spiritual crisis is accepting the dilemma as inevitable. In spite of the cultural dilemma it has been observed that many families with handicapped children are able to maintain a religious attitude toward life. Holt² remarks, ". . . it is only some spark of hope or possibly faith, that enables these parents to bear their heavy burden year after year."

Important as acceptance is, it is not enough--it is a basic need. Parents have the responsibility of seeing that the child receives the opportunity to grow and develop according to his own pattern. This responsibility manifests itself in accepting the child "as is" and working with him from there. It is a big task to help a child to help himself,

¹G. H. Zuk, "The Cultural Dilemma and Spiritual Crisis of the Family With a Handicapped Child," Exceptional Children, XXVIII (April, 1962), 405-408.

²K. S. Holt, "The Home Care of Severely Retarded Children," Pediatrics, XXII (1958), 753, cited by Zuk, "Cultural Dilemma and Spiritual Crisis," 407.

but if it is accomplished he will feel good about himself and this is the sign of a positive self-image. The image of self in a child develops gradually through his experiences with other people.¹ Therefore, parents, siblings, teachers, and peers are all in a position to grant or withhold the child's need-satisfactions that will influence the development of his self-concept (or self-image) in either a positive or negative manner. The factors involved in the achievement of a positive self-concept are actually very few. These factors include one's native potential for adjusting to the demands of the environment, special talents or handicaps, and the opportunities for learning the skills necessary for successful adjustment. In the case of a handicapped individual, he certainly cannot be expected to form a positive self-concept in an environment which expects him to behave as if he were not handicapped.² It remains, then, for others to understand the problems of the handicapped child and to do what they can to help him achieve his potential without in any way demanding too much from him, or on the other hand, asking too little.

Sibling Studies

It is an accepted fact, as the writer previously explained, that the retarded child cannot be dealt with in isolation and that his siblings, as well as his parents, have an important influence on his total

¹Gladys G. Jenkins, Helping Children Reach Their Potential (Chicago: Scott, Foresman and Company, 1961), pp. 14, 35.

²C. C. Nelson, "Developing a Positive Self-Concept in the Mentally Retarded," Mental Retardation, I (February, 1963), 28-34.

pattern of development. Irish states, "While the bonds between parents and children are customarily strong within our nuclear family system, the ties between and among siblings will in most homes generally also be close, being second in strength only to the former."¹

Since this aspect of sibling interaction is so important, one wonders why there is such a lack of empirical studies which have focused primarily on sibling relations. Statistical studies to explore the significance that brothers and sisters have for each other have rarely been attempted by social scientists. Again, Irish² cites some practical reasons for the scarcity of such studies. It would be impossible to examine the effects of and changes in sibling interaction through time because of the variations in the ages of the siblings. The very youngest would not yet be able to talk, some would not yet have been born, and still others would already have left home. It would be difficult to reach a sufficient number of child subjects from a large number of families which would be required for statistical studies, and furthermore, the prevalency of remarriages involving children would introduce complicated sub-groups. Also, children are not as physically accessible or as socially amenable to study as sibling groups as they would be as separate individuals who could be easily reached in an ordinary school setting.

Despite the scarcity of research concerning direct sibling interaction, there are, nevertheless, some studies which show how a retarded

¹D. Irish, "Sibling Interaction: A Neglected Aspect in Family Life Research." in Sourcebook in Marriage and the Family, ed. by Marvin B. Sussman (Boston: Houghton Mifflin Co., 1968), p. 295.

²Ibid., pp. 299-300.

child influences his siblings. For example, in Farber's¹ study of 240 Chicago area families with several retarded children, he investigated characteristics of those normal siblings who were closest in age to the retarded child. He found that the retarded child's siblings were affected by his high degree of dependency which had adverse effects on the normal siblings' relationships with the mother. It was, apparently, not the mere presence of a retarded brother or sister which constituted the adverse factor, but the amount of the responsibility assumed by the normal siblings. Much of the housework evidently fell on the normal sisters who were expected, also, to serve as babysitters, thus relieving the mothers of a great deal of the burden. The normal girls who interacted frequently with their retarded sibling were found to experience more tense relationships with their mothers than those who had little to do with the retarded child. The presence of a retarded child also had adverse effects on the happiness of his siblings when the retarded sibling claimed so much of the parents' attention that there was not enough left for the normal children. However, many of these adverse conditions could have been caused not so much by the realistic demands made by the retarded child, but more so by the irrational manner of the parents' behavior toward them which, naturally, would work hardships upon the nonhandicapped child. In this connection, Korke's² reports that many parents endeavor to withhold the urge to express anger or

¹Farber, Mental Retardation, pp. 159-62.

²Korke's, "A Study of the Impact of Mentally Ill Children," p. 83.

impatience towards the handicapped member for fear of producing disorder in the child or causing unfavorable behavior. When this occurs, the normal sibling then has the additional problem of being pressured to curb feelings of resentment toward the retardate which might be normally expected toward any competitor for parental attention.

Adjustment to the retarded child also means a revision in the birth-order roles in a family life cycle. Naturally, when the children were very young, the interaction between the normal and retarded siblings tended to be on an equalitarian basis. As they grew older, the normal children automatically assumed a superior position in the relationship, whereas the retarded sibling, no matter what his age might be, will never mature socially and will eventually become the youngest child of the family.¹

It is interesting to note the contrast in the findings of Graliker, Fishler, and Koch² in their investigation on the reactions of teenage boys and girls to their younger, retarded siblings. They found that the retarded child had little influence on siblings who were at least ten years older than themselves. As a result of their study it can be seen that when the normal siblings are considerably older than the retarded member, there is little need to modify the birth-order roles in the family. It follows, then, that without this re-

¹Farber, Mental Retardation, pp. 153-65.

²Betty Graliker, Karol Fishler, R. Koch, "Teenage Reaction to a Mentally Retarded Sibling," American Journal of Mental Deficiency, LXVI (May, 1962), 838-43.

vision of birth-order roles, the normal siblings are not profoundly affected by the presence of the retarded child.

Farber and Jenné conducted a study to determine how interaction with retarded siblings affected the life goals of the normal children in the family. It was found that both boys and girls who had a high level of interaction with their retarded siblings emphasized as life goals devotion to a worthwhile cause or making a contribution to mankind. Those who had a low level of interaction were more concerned with success in personal relations and interested in social-emotional goals. This study would suggest that normal siblings who sustain daily interaction with their retarded siblings regard this as a duty and as a result they learn to accept and live with hardships and also to direct their life careers towards a profession requiring much dedication and sacrifice.¹

In order to help parents who expressed concern over their normal adolescents' feelings of being overburdened by the care of their retarded siblings and their expressions of hostility and resentment toward them, the staff of the Association for the Help of Retarded Children in New York conducted a guided group experience for adolescent siblings of the retarded.² The staff considered various ways and means of helping such young people in their efforts to strengthen family life. Group

¹B. Farber and W. Jenné, "Interaction With Retarded Siblings and Life Goals of Children," in Perspectives in Mental Retardation, ed. by T. Jordan (Carbondale and Edwardsville: Southern Illinois University Press, 1966), pp. 30-33.

²M. Schreiber and Mary Feeley, "Siblings of the Retarded: Part I—A Guided Group Experience," Children, XII (November-December, 1965), 221-25.

sessions were held every two weeks to discuss their problems and feelings as related to their retarded brothers and sisters and to the total life situation. The staff members were impressed by the large numbers of the normal adolescents who already had given evidence of being able to cope with the fact of their sibling's retardation. The experiences during the 8-month period were successful, not in so much that basic attitudes were modified or changed, but in that the participants began to realize that others had similar problems. Through the group discussions, as time went on, they seemed to be able to look at the broader implications of mental retardation not only for themselves but for others who also had retarded brothers and sisters. It was found, through their experiences, that the young people involved had developed greater maturity, tolerance, patience, and responsibility than is ordinarily found in children of their age. The young person with positive family relationships is often capable of enduring the emotional hurt and anxiety of having a retarded brother or sister without serious disruptions in his family and social life. The more clearly the normal children can understand the realities of their particular situation, the better they are able to cope with them.

Similar findings are reported by Adams.¹ She states that when problems arise with the siblings of the retarded, it is nothing but a normal response to a highly stressful situation and professional help could prevent the situation from becoming worse. She also reports that

¹Margaret Adams, "Siblings of the Retarded: Their Problems and Treatment," in Management of the Family of the Mentally Retarded, ed. by W. Wolfensberger and R. Kurtz, pp. 445, 452.

even though the advent of a retarded child is a tragic and painful experience, most families have sufficient resources to cope with its problems if they are given help. The help offered by social workers and other professionals in the field will greatly aid in ensuring that the positive resources of strength and good will are maintained within the entire family.

In keeping with the above findings, an interesting and significant Head Start program for younger siblings of retardates is reported by Kaplan and Colombatto.¹ This program was undertaken at the New Haven, Connecticut, Regional Center, in cooperation with the Yale Psycho-Educational Clinic in order to identify the problems of the siblings and suggest preventive measures that might be taken. It was believed that such children often have serious problems arising from living in a home with a retarded brother or sister. The children involved in the program were from culturally disadvantaged families and there was a high probability that the environment could be detrimental to the intellectual and emotional development of the other children in the family. Another factor, however, was that psychological problems often confront a child when there is an older retarded sibling in the family, regardless of the cultural-familial background. It was found that out of ten children, at least half were already showing signs of being mildly defective. Those who were found within the average range were the youngest of the group. It was thus suggested that the retarding effects of the culturally dis-

¹Frances Kaplan and J.J. Colombatto, "Head Start Program for Siblings of Mentally Retarded Children," Mental Retardation, III-IV (December, 1966), 30-32.

advantaged background on these children would become progressively more serious as long as they remained in that environment. The following quotation adequately sums up the important implications of this study:

Extensive clinical experience with families of retarded children suggests the following hypothesis. Some problems of siblings seem to be a direct consequence of living in a home with a retarded child. For example, bringing friends home after school might be more difficult or embarrassing with such a sibling. However, another potential source of great difficulty lies in the changed attitudes of parents towards their children once they know they have a retarded child. Very frequently, parents fear that the child born after the retarded one will be defective; or they begin to depend on the "normal" siblings to make up to them for all the things the retardate cannot achieve. The possibilities are endless, but all have serious implications for the normal boy or girl.¹

As a result of the findings of the above studies, the writer has concluded that a retarded child can react on his normal siblings in various ways. Much seems to depend on the ages of all the children concerned and on the socio-economic background of the family. Finally, Robinson² offers the following succinct statement:

The evidence suggests that most children can adapt themselves to the presence of a retarded brother or sister and that they tend to adopt the attitudes of their parents toward the family situation. Only when they are pushed aside or expected to assume maturity and responsibility beyond their years are they likely to suffer serious consequences.

¹Ibid., p. 32

²Robinson and Robinson, Mentally Retarded Child, p. 523.

Impact of the Family on the Retarded Child

Much of the retardation research has focused on the impact of the problem on family life--the intrafamily dynamics it brings into play and the changing role patterns and adaptive strategies that develop. The converse proposition, the impact of the family on the retarded child's development, personality, and emotional status has received less attention. The impact of the child's constitutional endowment on parent-child interactions, the role of the family in the socialization of the child, and the effects of parental attitudes and child management techniques are all critical in this context. And, of course, families are not islands unto themselves. Each is subject to a host of ethnic, religious, socio-economic and cultural values which affect how they perceive and cope with the problem.¹

In the light of the above quotation it can readily be seen why the present writer has had difficulty in locating articles or studies that have dealt precisely with the influence of families on retarded children. Many references have been made to the importance of this influence, as, for example: "The attitudes of parents and siblings toward the retarded child are the most crucial to family adjustment . . ." ² Also, "The handicapped child's attitudes regarding himself and his handicap are in major part determined by parental reactions toward the child and his disability. Anyone who has worked with handicapped children and their parents is well aware of this fact. Whether the handicap is a

¹Begab (chairman), Report of a Conference on Social Sciences and Mental Retardation, p. 3.

²M. Begab, "The Mentally Retarded and the Family," (pamphlet) reprinted from Prevention and Treatment of Mental Retardation, ed. by I. Philips (Basic Books Inc., Publishers, 1966), p. 76.

mental one or a physical one, the way in which the parents respond to it and to the child is a major factor in deciding the child's own self-attitude."¹

Heilman further states the following:

Observed parental behavior seems to bear a close relationship to observed child behavior. Although the majority of the cases seen in clinical practice are not so clearly drawn as the ones reported, there is usually an observable similarity between the kinds of behavior which the parents exhibit and the ways in which the child behaves.

In planning services for handicapped children, perhaps more emphasis should be placed on expanding therapeutic services to parents, as being one of the best ways of assisting the child to achieve the optimum emotional and social adjustment.²

The article by Heilman is important not only for its teaching value but also because of its historical significance. According to Wolfensberger and Kurtz,³ Heilman was one of the few persons, who, as early as 1950 recognized that one of the best ways to help the child was to provide help for the parent.

According to Ross, "The child can only be helped if the responsible adults around him are able to come to terms with his deficit on the basis of a realistic recognition of his strengths and his handicaps."⁴ Ross explains further that retarded children are more dependent on pa-

¹Ann E. Heilman, "Parental Adjustment to the Dull Handicapped Child," American Journal of Mental Deficiency, LIV (1950), 556.

²Ibid., p. 562.

³Wolfensberger and Kurtz, Management of the Family, p. 415.

⁴A. O. Ross, The Exceptional Child in the Family (New York: Grune and Stratton, Inc., 1964), p. 70.

rental care and remain dependent for a far longer period of time than normal children. Because of the greater intensity of parent-child interaction, it is imperative that parental conflicts and anxieties do not disrupt the relationship, as this could play havoc with the child's emotional stability, since the child's self-image is derived from the attitudes that those around him hold and manifest toward him.¹

Ross' findings are borne out by Worchel and Worchel² in their study in which parents of retarded children rated the personality traits of their own retarded child, their idea of the "ideal" child, and of the average child. They found out that there is greater parental rejection of the retarded child than of the normal one, and in view of the findings, plead for efforts directed toward developing better attitudes on the part of parents.

It has already been mentioned in this paper that siblings of the retarded child do tend to imitate their parents' attitudes toward him. This fact is again brought out in a study by Barsch³ in which he stresses the importance of parental attitudes by explaining that an undesirable home environment can be highly conducive to creating emotional complications for the defective child.

¹Ibid., p. 562.

²Tillie Worchel and P. Worchel, "The Parental Concept of the Mentally Retarded Child," American Journal of Mental Deficiency, LXV (May, 1961), 782-88.

³R. Barsch, "Explanations Offered by Parents and Siblings of Brain-Damaged Children," Exceptional Children, XXVI (January, 1960), 271-74.

Denhoff¹ explains how parents of exceptional children have dynamic impacts on the growth and development of their children. Parents very often have reactions about their children which may be influenced deeply by hidden psychological factors about which they have little understanding or control. Especially in the case of parents of handicapped children, many mixed emotions are present which are quite psychologically involved. Much of the difficulty stems from how early the diagnosis of the handicap is made, because it has been discovered that the longer time it takes a parent to find out, the greater the internal conflict about it will be.

Parents have a direct influence, either favorably or adversely, on an exceptional child's ability to adjust into society. Naturally, a handicapped child will never achieve the same excellence of performance as a non-handicapped child, and a mildly handicapped child will most certainly perform better than a moderately handicapped one. But it follows that a well-motivated, efficient, happy handicapped child will excel the performance of a normal child who is careless, anxious, and poorly motivated. This is where the proper, accepting, parental attitudes, especially if they have been present since the child's early life, have a great impact on a child's adjustment.

The following is an interesting and thought-provoking statement made by Denhoff in his study:

¹E. Denhoff, "The Impact of Parents on the Growth of Exceptional Children," Exceptional Children, XXVI (January, 1960), 271-74.

In early infancy it is hard to predetermine which babies will make good students. Thus, by initiating a total treatment plan early in life, and by integrating what we have learned about parent attitudes with what we know about growth and development of children, it seems that severely or moderately handicapped children appear to become mildly handicapped. Similarly, the mildly handicapped children seem to end up--in the eyes of their parents--without a handicap at all. It is true that there is a high casualty list during the pre-school years. Some handicapped children are destined to remain babies. Others are so distorted behaviorally by the impact of parents with attitudes so adversely influenced, that there is little that can be done to change them. It has been found that physical handicap alone has never been a deterrent to normal adjustment. Emotionally healthy families have happy and well adjusted exceptional children.¹

In later school years, too, it was found that the key to "good" school adjustment is family understanding and acceptance. Good medical treatment and psychological evaluation are both necessary, but the family is of the first importance in the impact made on the child. The parents must have a sympathetic understanding of the child's needs if they are to profit from the concrete and realistic suggestions given by the professionals for their child's well-being and progress.²

The importance of the influence of the family continues on into adolescence when the mentally handicapped child is even more in need of the support of his environment. At this time of his life he needs the feeling of security and belonging in order to wean himself safely from

¹Ibid., p. 274.

²E. Denhoff and R. H. Holden, "Family Influence on Successful School Adjustment of Cerebral Palsied Children," Exceptional Children, XXI (October, 1954), 5-7.

his family when he finds himself in a new and mature relationship outside the home. Rejection of such a child by his parents and a neurotic atmosphere in the home would only impose a neurotic behavior pattern in addition to the difficulties that the handicapped child already had.¹

In general, the results of the studies seem to indicate an agreement among the writers of the tremendous impact made by the families on the total development and adjustment of their retarded children.

As a concluding remark, Robinson states:

There is an obvious reciprocal relationship between a retarded child and his family. The more favorable the relationship, the more stable, tractable, and self-possessed the child will be and the greater will be the happiness and stability of those who live with him. In turn, he will be more likely to gain the affection and support he needs to enhance his healthy adjustment.²

Counseling and Guidance

In the light of all the foregoing remarks, it is only logical to conclude that since the impact of parents on the adjustment of a retarded child is of such critical importance, it must naturally follow that parents are in desperate need of help, guidance, and counseling as soon as they are aware of the fact that their child is handicapped. The earlier this help is received, the better it will be for all concerned.

¹Martha Foale, "The Special Difficulties of the High Grade Mental Defective Adolescent," American Journal of Mental Deficiency, LX (April, 1956), 867-77.

²Robinson and Robinson, Mentally Retarded Child, p. 513.

Ross explains the importance of help for parents by saying:

Yet a plea to parents that they adopt realistic attitudes toward a child's defect or handicap is quite useless, since the person with unrealistic attitudes is unaware of holding them. Unconscious mechanisms are exceedingly powerful forces and such defenses as reaction formation or denial do not yield to exhortation. Because of this the understanding, skilled help of the professionals with whom the parents come into contact takes on tremendous importance. The parents themselves do not know that they are distorting reality. It is the professional outsider who must be prepared to help them toward a realistic appreciation of the child's condition. With sensitivity and understanding most parents can be helped to cope with their crisis and its consequences in a realistic manner, especially if professional help is available right from the time when the child's exceptional condition is first discovered.¹

The mother of an exceptional child wrote the following: "Our greatest need: Constructive professional counseling at various stages in the child's life which will enable us as parents to find the answers to our own individual problems to a reasonably satisfactory degree."²

Even though this plea for help seems to be very simple, the very simplicity of it can be misleading. This type of help is not so easy to provide. "It is, in fact, very difficult to provide, for, as Spock (1961) so honestly admits, telling parents that their child has a handicap or defect is one of the tasks most repugnant to the physician."³

¹Ross, Exceptional Child in the Family, p. 70.

²Mrs. Max A. Murray, "Needs of Parents of Mentally Retarded Children," American Journal of Mental Deficiency, LXIII (May, 1959), 1087.

³Ross, Exceptional Child in the Family, p. 73, quoting B. Spock, On Being a Parent of a Handicapped Child (Chicago: National Society for Crippled Children and Adults, 1961).

That this is a difficult task is understandable. Despite the fact that it is, however, guidance for parents is imperative. According to Begab:

Guidance for the parents is no less vital than for the child himself, for it is within the orbit of family life that the child is taught the "socialmindedness" characteristic of later life. Here he learns right from wrong, consideration of others, respect for property, and how to share. To create an atmosphere most congenial to this development, parents need education as well as therapeutic services to help them carry out their child-rearing functions. Attention to these problems in the early phases of family adjustment can prevent more serious difficulties later in life.¹

Even though early help for parents is highly recommended, the situation becomes a little different in the case of a mildly retarded child. Severely retarded children are usually detected at birth and it is at this time that the parents seem to need the most intensive help. On the other hand, mildly retarded children are often not suspected until a number of years have elapsed and evidence begins to accumulate that the child is "slow". The child, too, may not have any physical appearances that would indicate any retardation. Under these circumstances, the parents are frequently reluctant to accept the fact and often try to deny it or hope for a change. Parents' belated realization of the retardation leads to a depression which has a "double edge" on it because the child may be well aware of the fact that his parents are disappointed in him. This, of course, results in a poor parent-child relationship. The parents, then, need guidance in order to restore an effective relationship with the child and to help them

¹Begab, "The Mentally Retarded and the Family," (pamphlet) p. 79.

realize that the child can become a contented and contributing member of society.¹

The need for some type of guidance or counseling for the parents has already been explained. However, the group approach has become increasingly important for its therapeutic value. When group therapy methods were first introduced, it was a matter of efficiency in treating several persons at a given time. As time went on, certain unique social advantages of group treatment over individual methods came to be realized. In a group of parents with similar problems, their grief may come to expression and they begin to help one another to resolve their inner conflicts. The therapeutic goal of such a group is to help the parents themselves to adjust to their situation, to understand themselves and also their attitudes and feelings toward the retarded child.²

From the above remarks, the conclusion may be reached that it is highly imperative that parents receive professional help as soon as their child is recognized as being retarded. The guidance is needed to help the parents to get over the initial shock and to get through the period of mourning that naturally accompanies the diagnosis. Early diagnosis is important, but in the case of belated recognition of the retardation, guidance is still needed, although it may be along slightly different lines. The professional adviser, according to Zuk, has a dual

¹Juanita Dalton and Helene Epstein, "Counseling Parents of Mildly Retarded Children," in Management of the Family of the Mentally Retarded, ed. by Wolfensberger and Kurtz, pp. 415-20.

²Wolfensberger and Kurtz, Management of the Family of the Mentally Retarded, pp. 226-28.

responsibility, " . . . to prepare the family for day-to-day problems and to strengthen its spiritual qualities in order to help it sustain itself in the trials through which, inevitably, it shall pass."¹

And finally, the value of group therapy is not to be underestimated. The mutual support and encouragement of parents to each other in group guidance and counseling is of significant importance.

Summary

The tragedy of mental retardation remains a family problem. The studies reviewed reveal the tremendous impact that this problem has on each and every family member. Because of the delicacy of the problem and of the importance of helping the handicapped member to successfully cope with life's tasks, both parent and professional must work together to help him achieve a measure of independence and to see himself as a worthy and valued member of the community.²

¹Zuk, "Cultural Dilemma and Spiritual Crisis of the Family," p. 408.

²Kvareceus and Hayes, If Your Child is Handicapped, p. 408.

CHAPTER III

CONCLUSION

Implications for the Future

As an outgrowth of the studies reviewed, several implications for the future can be deduced. One is the importance of early diagnosis on the part of the physician or professional worker upon whom it falls to inform the parents that they have a handicapped child. To delay, under the pretense of upsetting the parents, or hoping that it may not be so, only gives them false hope and makes the shock greater in the end. The earlier the parents receive guidance and help in this matter, the better for themselves and for the child, too.

Not only guidance and counseling for the parents as individuals, but also in groups is becoming more imperative in coping with the family problem of retardation. The group approach in family management possesses unique social treatment advantages, and the utilitarian aspects of group treatment should not be minimized.

Dybwad, the former executive director of the National Association for Retarded Children sees an urgent need for systematic efforts toward, a) a clearer conceptualization of various group approaches for parents, b) clear recognition of appropriate training of managers of group problems, and c) the development of research designed to assess the effectiveness of such programs.¹

¹Wolfensberger and Kurtz, Management of the Family of the Mentally Retarded, p. 229.

With changes in family management of the retarded, the future will probably see changes in the impact which a retarded child makes on his family.

In the future, more should be done to try to reach the parents of mildly retarded children. The developmental potential is the greatest for this group, yet it is the group for which the least has been done. Most services have been geared towards helping those with severe retardation and the same emphasis seems to prevail in parents' groups.¹

Also, according to Begab:

Up to the present time, there has been an unexplained gap in mental retardation research. Many psychological, educational and biomedical studies have been done, but few sociological studies. This is particularly strange since priorities for sociological research center around family interaction and the interplay between sociological variables and family functioning--areas which have enormous significance in relation to mental retardation. They need to be explored as a basis for assessing the relative contributions of genetic factors, minor neurological deficits, and social forces in the etiology of mental retardation.²

In this conference the point was made that perhaps if the label "mental retardation" were changed to "social retardation", the sociological aspects of the problem could more easily be stressed and sociologists could more readily see its relevance to the field of social sciences. It was mentioned, too, that perhaps the most important point for sociologists to center their attention upon would be on the manner

¹Begab, (chairman), Report of a Conference on Social Sciences and Mental Retardation, p. 22.

²Ibid., p. 26.

in which mental retardation can be used to illuminate other relationships within the family.¹

It seems reasonable to assume that in the future much more will be done in the field of social sciences about the problem of mental retardation, since anything that makes such an impact on the family certainly makes an impact on society in general.

Summary

Mental retardation is a family problem; therefore, the retarded child cannot be dealt with in isolation. Family problems require family solutions. The trauma and shock which families experience with the advent of a retarded child is a normal response to an extremely stressful situation, and professional help is needed to prevent the situation from becoming worse. The retarded child makes a tremendous impact on the life of the other family members, and, by the same token, the attitudes and reactions of the family towards him greatly affect his total development. The most crucial aspect of any child's environment is his family. The attitudes shown by the parents are important because the normal siblings largely reflect the feelings of their parents towards the retarded member. The secure parents, then, who aim at developing positive attitudes towards the child and accepting him as he is for his worth as an individual, are well-equipped to provide a healthy climate in which the retarded child may flourish. Professional help is needed, however, to enable the parents and siblings to achieve such a goal.

¹Ibid., pp. 27-28.

Begab sums up the problem very well in the following manner:

Mental retardation as a family problem is, then, as diverse as the many causes that produce this condition and the differences in family and community situations that contribute to it. Each situation must be evaluated carefully. Only as the nature of the problem and the dynamics underlying it are fully recognized can appropriate solutions be undertaken and the retarded person's potentials realized. As the child progresses through life, his needs and those of his family assume new dimensions, calling for different services or professional skills. To the extent that these are adequately provided and properly coordinated, the mentally retarded will prove to be less of a threat to family stability. In time, society will be more than repaid for its investment.¹

Concluding Remarks

As a fitting conclusion to all that has been written in this paper, the following quotations seem to be appropriate:

I would urge any parent or relative of a retarded child not to despair. The retarded are capable of great love and great joy. In us, they can create a meaning and purpose beyond the normal. Above all else, we must love them, but as people, not as objects. If the retarded are taught, they can learn; if they are encouraged, they can succeed; if they are trained, they can work. And if they are given our respect as persons, they will return that respect, not only for us but for themselves. This is the greatest gift we can bestow, and they, in turn, can bestow on us a glorious enrichment of our lives.²

¹Begab, "The Mentally Retarded and the Family," (pamphlet), p. 83.

²Rose Kennedy, "New Hope for the Mentally Retarded," Sign Magazine, June, 1970, p. 26.

In conclusion, may we leave you with the thought that even though we as parents of retarded children are faced with a multitude of problems, many unanswerable questions and a great deal of grief, yet we do have our compensations. . . . It has been my privilege to have talked with hundreds of parents of retarded children. One of the favorite themes which permeates our conversation is how much our children have meant to us. This thought runs like a bright golden thread through the dark tapestry of our sorrow. We learn so much from our children; retarded children are wonderful teachers if we are not too proud to learn from them and the grief of parents leaves little room for pride. We learn so much in patience, in humility, in gratitude for other blessings we had accepted before as a matter of course; so much in tolerance; so much in faith--believing and trusting where we cannot see; so much in compassion for our fellowman, and yes, even so much in wisdom about the eternal values of life because deep agony of spirit is the one thing which can turn us from superficialities of life to those things that really matter. We also gain much in developing a strange kind of courage which enables us to face life without cringing because in one sense we have borne the ultimate that life has to offer in sorrow and pain.

Where in all of this wide, wide world could we go to learn such lessons as these--lessons dealing with the real meaning of life?

Where else could we ever learn so much from those who know so little?¹

¹Murray, "Needs of Parents of Mentally Retarded Children," pp. 1087-88.

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