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THE IMPACT OF A MENTALLY RETARDED CHILD ON THE FAMILY

by
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A RESEARCH PAPER

SUBMITTED IN PARTIAL FULFILLMENT OF THE

REQUIREMENTS FOR THE DEGREE OF

MASTER OF ARTS IN EDUCATION (EDUCATION OF MENTALLY HANDICAPPED)

AT THE CARDINAL STRITCH COLLEGE

Milwaukee, Wisconsin

This research paper has been approved for the Graduate Committee of the Cardinal Stritch College by

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Date: July 29, 1968

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CHAPTER I

INTRODUCTION

The mentally retarded are children and adults, who, as a result of inadequately developed intelligence, are significantly impaired in their ability to learn, and to adopt to the demands of society.

The Problem

This paper is concerned with the personal adjustment problems of the parents of mentally retarded children and the family upsets that are caused by the presence of a retarded child. Most parents experience emotional upset and anxiety as the result of the birth of a retarded child. The presence of a retarded child in the family also tends to have a disrupting effect on family life.

The parents of average children have the resource of their own life experience as a basis for social, educational and career planning for their offspring. By contrast, parents of the mentally retarded must plan for their children, who are in some respects so deviant from average, that planning for them cannot follow patterns drawn from parental experience. As a result, parents of the retarded feel at a loss on a very realistic basis, and with this sense of inadequacy come feelings of guilt and anxiety.

The President's Panel on Mental Retardation, A National Planto Combat Mental Retardation (Washington, D.C.: U.S.Government Printing Office, 1962), p.1

²French, Anne C., Levbarg, M., and Michael-Smith, H., "Parent Counseling as a Means of Improving the Performance of a Mentally Retarded Boy: A Case Study Presentation," <u>American Journal of Deficiency</u> (1953) 58: 13-20.

DEFINITION OF TERMS

For the purpose of this paper, children with retarded mental development will be described as follows:

I.	Q. Range
Totally Dependent Mentally Retarded	0-25
Trainable Mentally Retarded	25 - 50
Educable Mentally Retarded	50 - 75

CHAPTER II

REVIEW OF LITERATURE

Various studies show that many parents of mentally retarded children suffer from feelings of guilt, projection, denial, over-protection, fear, bitterness, martyizing, and other behavior symptoms indicating personal maladjustment.

Parents' Personal Reaction to Retardation Guilt

The emotional reaction of guilt along with feelings of shame, frustration, and inner turmoil are some of the first and greatest challenges for parents of a mentally retarded child. The fact that their feelings are irrational and thoroughly illogicial, does not prevent the reaction. The parents are reacting as they are because they cannot do otherwise.

This is particularly true in their first period of tribulation when a few words have torn from them the dreams and ambitions of years. Parents are plagued with the haunting question, "Why did it have to happen to us?" Their initial reaction is that some fault or weakness in themselves is being publicly exposed. They cannot help accusing themselves. They see so many avenues of life closed to the child - avenues which have brought or would bring happiness to themselves and, therefore, they assume to their child.

A study by $Grebler^3$ of the problems of parents of mentally

³Grebler, Anne M., "Parental Attitudes Toward Mentally Retarded Children," American Journal of Mental Deficiency (1952) 56: 475-83.

retarded children shows that parents of retarded children are exposed to more trying experiences than parents of normal children. She states that:

- l. Many of the experiences of frustration by parents of the retarded are due to elements inherent in the child's condition and limitations imposed by the outside world.
- 2. These parents react to this frustration in terms of their own personality difficulties.
- 3. The parents' reaction to the condition of mental retardation is interwoven with their general attitude toward the child.
- 4. Those parents who react with feelings of guilt and condemn themselves show ambivalence to-wards the child.

Sheimo emphasizes that the attitudes and pressures from other children and neighbors toward the retarded child and his parents, add to and aggravate existing inner turmoil and sense of dissatisfaction. A guilt and anxiety-reducing approach to the parent would be for the person counseling the family to have the attitude that parents would have to be "superhuman" to derive the same degree of satisfaction from a more normal child.

Sheimo, S.L., "Problems in Helping Parent of Mentally Defective and Handicapped Children," Am. J. Ment. Def. (1951) 56: 46

Teska⁵ mentions that the subnormal child, especially during the pre-school and early school years, is so seldom a credit or source of joy to his parents, that this fact is likely to be at once the cause of his parents' frustration and humiliations and the recipient of the harmful effects.

Projection

Sometimes, the guilt of one parent is so intense that he or she resorts to "projection" - putting the blame that one feels onto someone else. In this case, the husband or the wife. "The bad strain is in your family, not mine, etc." This type of invalid attitude results in intensification of an irrational feeling, disruption of the family and damage to the child.

Walker 6 states that the emotional structure of the parent must be relatively sound in order to withstand psychiatric disturbance. The retarded child may arouse feelings of accusation in both parents which would greatly jeopardize the intactness of the home.

Denial

After some parents have been told that their child is mentally retarded they insist that the diagnosis is wrong. These

Teska, Percy T., "Some Problems in the Adjustment of the Mentally Handicapped," J. Counsulting Psychology (Sept. 1947) 11: 278.

Walker, Gale H., "Some Considerations of Parental Reactions to Institutionalization of Defective Children," Am. J. Ment. Def. (1949) 54: 112.

parents see what others see but because of their emotional state they interpret it differently. By denying or refusing to admit that their child is retarded they are spared the necessity of feeling guilty about it. This mechanism can take the form of an absolute denial - "There is nothing wrong with my child". Or it may lead to the consequent "doctor hunting" the reading of every new popular, sensational medical report, etc.

Wardell's studies show that parents who deny that their child is mentally retarded have a variety of reasons for the child's difficulties. They cling to the idea that their child's backwardness is a temporary thing and they constantly look for a spurt in his growth that will indicate that he is improving.

Overprotection

Even when the parents do superfically acknowledge the fact that their child is mentally retarded, other defense reactions are often brought out without their conscious recognition of the basic motivation. One is to overprotect the child--keep him in an infantile or regressive relationship in order to avoid the threat that increasing maturity would bring. The older the child grows, the wider will become the gap between him and his normal peers, the more apparent will become the problem, and the more obvious the parents' shame and heartache. Hence, the child must remain a baby.

⁷Wardell, Winifred, "The Mentally Retarded in Family and Community," <u>Am. J. Ment. Def.</u> (1952) 57: 234.

Levy⁸ designates the condition of maternal overprotection as being rather typical of the relationship of mothers with mentally retarded children.

Wardell has found that if a family is overprotecting the mentally retarded child, it is usually well fortified with reasons why it is doing so.

Fear

When the parents begin to face the fact that their child is retarded they become fearful of many things--What will their friends and neighbors think? Dare they have more children? Could they have prevented the retardation? They're fearful about the future of the child, about the effect on the rest of the family, about their own ability to handle the situation.

Mothers' understanding of their mentally retarded children was studied by means of a "directed" interview approach by Rosen 10. The mothers of thirty-six retarded children with I.Q.'s between 40 and 80 were chosen for the study after they had met the criteria of:

1. Being able to admit that their children were retarded.

⁸Levy, D.M., <u>Maternal Overprotection</u> (New York: Columbia University Press, 1943)

⁹Wardell, Winifred, "The Mentally Retarded in Family and Community," Am. J. Ment. Def. (1952) 57: 234

Rosen, Leonard, "Selected Aspects in the Development of the Mother's Understanding of Her Mentally Retarded Child," Am. J. Ment. Def. (1955) 59: 522-28.

- 2. No longer looking for a cure.
- 3. Trying to act constructively for their children's present and future welfare.

The majority of mothers in the study said that the fact of having a retarded child caused them to fear the recurrence of mental deficiency should they have more children.

Bitterness

Parents of mentally retarded children sometimes go through a period when they feel very bitter about what has happened to them. It is natural for them to feel sorry for themselves. They ask, "Why did our child have to be like this? Why did God inflict this punishment on us"? They may become antagonistic toward society in general and often tend to be oversensitive about what others think and say.

Martyrizing

Another attitude that is often taken on by parents of a retarded child is the "martyr" attitude, in which everything is centered on the child. The parents heap all their attention on their retarded child because they feel, or like to make themselves believe, that their normal children are well enough to "shift for themselves." "I have done this terrible thing to my child," is the unconscious feeling they have. "Therefore, I must suffer, I must sacrifice myself to him." As a result, other members of the family are denied their rights as individuals. Other children inevitably feel ignored, to the detriment of their

sound emotional growth. It is not surprising that, in such cases, resentment toward the retarded child frequently develops on the part of his brothers and sisters.

The Effect of a Retarded Child on the Entire Family

As was noted there is evidence that the presence of a mentally retarded child causes much personal maladjustment of the parents.

It has been stated many times that a mentally retarded child also tends to have a disrupting effect on the entire family.

Retarded Child at Home

Schonell and Watts' study of an Australian sample clearly shows the impact of a mentally retarded child on the family. However, because of the location and time of this study many problems were present then that would be considerably minimized today. For example, there are schools today for the severely retarded child. There is more knowledge, guidance, and help for the parents of retarded children. Experience shows that where facilities are available parents may be helped, and when a severely retarded child attends school, his social development improves. As a result conditions within the home improve.

Schonell and Watts studied fifty families living in Brisbane, Australia, who had a mentally retarded child with an I.Q. of 55 or under. All of the children in the study ranged

ll Schonell, F., & Watts, B.H., "A first Survey of the Effects of a Subnormal Child on the Family Unit," Amer. J. Ment. Def. (1952) 61: 210-219.

in ages from five to seventeen and lived at home. None of the children attended school of any kind. The occupations of the fathers ranged from farm laborers to professional and administrative workers. The sample was chosen from those families who had registered their retarded children with the Queensland Subnormal Children's Welfare Association. Interviews were conducted in the home of the selected families by research workers who had extensive social and psychological training. The results of the interviews and the questions asked the parents were as follows:

- was retarded? Most parents noticed some symptons of retardation in their children before the age of one year. It appeared that all had recognized the condition by the age of five years. In the majority of cases the mothers were the first to recognize signs of retardation (38 cases). In twelve of the cases the parent's attention was drawn to the child's state by either medical or outside observers. In very few cases did the parents rest content with the first diagnosis of retardation. Twenty-four families reported that they had incurred a great deal of expense (mainly medical) in trying to find amelioration for the child's condition.
- 2. What behavior difficulties did you experience with your retarded child during the pre-school years?

The majority of mothers in the study said that lack of social development and of emotional control, difficulties connected with feeding, disobedience, and lack of speech development had caused them considerable trouble.

- The majority of mothers had received no help of any kind. Most of the mothers were almost desperate in their plea for some help.

 Eighteen said they desired most to be able to have a sitter who could occasionally care for the retarded child in order to give them some relief from the constant care and worry.
- When the future of their children was discussed, the mothers showed evidence of extreme emotional tension and many wept. Twenty-seven reported that their most pressing worry was what would happen to the child in the eventuality of the death of one or both of the parents.
- 5. What are the effects of your retarded child on family plans? In fifty per cent of the cases, visits by the family to the homes of other people were curtailed. Perhaps the greatest inconvenience suffered by the mothers was in their shopping arrangements, where three out of every five mothers found that they had experienced difficulties. In many cases, the eating and

sleeping problems of the retarded child affected the whole family. Many mothers stated that plans, activities, discipline, and management of siblings suffered because of the presence of the retarded child.

Twenty*six per cent of the mothers reported that their normal children complained of adverse comments having been made at school about their retarded siblings.

- 6. What difficulties in housing and work did you encounter? Twenty-eight per cent of the families had moved to a different residential area because of the retarded child. This involved an upheaval and resettling process for the entire family. The reason for the move in seven cases was to bring the child to the metropolis in the hope that some training center might be available to them. Families moved to the capitol city from towns as far as 400 miles away. Three families moved for medical purposes.

 Ten per cent of the fathers had found it necessary to change their occupations because the family had moved on the child's account. One professional man had sacrificed promotion in order to bring his child to the city.
- 7. <u>Leisure time</u>. There was a very definite curtailment of daily and evening social activities.

In some cases the mother and father could rarely attend an evening's entertainment together because the child could not be taken and there was no one to care for him at home. Twenty-eight per cent of the families reported an effect on evening leisure time and fifty-two per cent mentioned the impossibility of indulging in daily social activities. This fact certainly interfered with the communal life of the families and deprived the mothers of those outings which contribute to the social pleasures of life, and thus to the maintenance of their mental health.

8. Family upsets. Fifteen of the mothers reported family upsets which while not severe, yet had an ill effect on the family's functioning, and well being. Usual comments were, "We all get irritable at times." One mother said, "There's tension all the time, and I'm right in the middle of it." Thirty four of the fathers were reported to be worried about the child; of these, twenty-three were affected to a considerable degree.

It is clear from the evidence collected in this study that the effects of a retarded child on the family may be of an economic, social, or emotional kind and that they may be far reaching and intensely restrictive and disruptive in nature. Farber 12 investigated the impact of a mentally retarded child on the family. Two hundred and forty families in the Chicago area who had a severely mentally retarded child sixteen years of age or younger were studied. One hundred and seventy-five of the families studied had the retarded child at home. Sixty-five of the families had the retarded child institution-alized. Approximately forty-five per cent of the families were Protestant, forty per cent were Catholic and fifteen per cent were Jewish. Two interviewers visited each family in their home at an appointed time. Both parents were given a written and oral interview. Some of the results of this study are:

- l. The presence of a mentally retarded boy in lower class families had a greater impact on the parents' marriage than the presence of a mentally retarded girl. The reason for this is probably because there is more expected of a normal boy than a normal girl. A boy is expected to achieve status in the community at least equal to that of his father. A girl is expected to marry, do housework, etc. Therefore, a severely retarded girl is better able to conform generally to the parents' expectations than a retarded boy.
- 2. In middle class families marital integration of parents of retarded boys is not significantly

¹² Farber, Bernard, "Effects of a Severely Mentally Retarded Child on Family Integration", University of Illinois, Monographs of the Society for Research in Child Development, Vol. 24, No. 2, Serial No. 71, 1959.

different from the marital integration of parents of retarded girls. Middle class families usually expect their normal girls to go on to college, achieve socially, etc. Therefore, the impact of a retarded girl would be equally as great as that of a retarded boy.

- 3. The mothers' over-protection of the retarded child adversely influenced the adjustment of the normal siblings. This was especially true of older sisters who were expected to assume responsibilities for caring for and protecting the young retarded child. However, this dependence of the retarded child did not affect the marital integration of the parents.
- 4. Younger retarded children affected the adjustment of their normal siblings more than older retarded children did. However, parents were more affected by their older retarded children, especially older retarded boys.
- 5. Contrary to findings on the marital integration of parents, the retarded child's sex and the family's social status did not influence the adjustment of normal siblings to their family roles.
- 6. Catholic parents appeared to receive a greater degree of emotional support from their religion and tended to accept their retarded child better than non-Catholic parents.

Institutionalization of the Retarded Child

Bringing a retarded child into the world is one of the most bitter experiences a parent can have. Bringing him to an institution is almost as bitter for the majority of them. 13

As was stated, one of the most common miseries of parents of a retarded child is a guilt complex. This complex often reaches its zenith at the time of institutionalization. Studies have been made to determine what types of families institutionalization, and the effects that the institutionalization has on the families.

Farber 14 reports the following findings:

- 1. The institutionalization of a retarded child, regardless of the sex, had a beneficial influence on the marriages of middle class parents.
- 2. Generally, parents of older institutionalized retarded boys had a high marital integration than parents whose older retarded boys were living at home.
- 3. Normal sisters were better adjusted at home when the young retarded sibling was institutionalized. This was especially true when the normal sisters were expected to help care for the

¹³Bauer, Charles E., <u>Institutions Are People</u> (New York: The John Day Company, 1966), p. 103

¹⁴ Farber, Bernard, "Effects of a Severely Mentally Retarded Child on Family Integration," Univ. of Illinois, Monographs of the Society for Research in Child Development, Vol. 24, No. 2; Serial No. 71, 1959.

retarded child. When the retarded sibling was older it had little effect on the normal sisters whether he lived at home or in an institution.

4. The normal brothers had a better home adjustment when their young retarded siblings lived at home. The mother's time and attention were taken up by the retarded child; therefore, the normal brothers had more time for their own activities. After the young retardate was institutionalized, more attention was given to the normal brothers and they were faced with many demands that they had escaped earlier.

Downey¹⁵ did a study to determine parents' reasons for institutionalizing their severely mentally retarded children. He studied sixty-nine families in the Chicago area who had a retarded child in an institution. His findings showed that:

- 1. Education of the parents determine when and why a retarded child is placed in an institution.
- 2. Well educated families place their retarded children in institutions when they are young.

 It appeared that the well educated family is a companionship family. The mother has a commitment to
 a democratic maternal division of labor. She feels
 she could divide her time more or less equally among

Downey, Kenneth J., "Parents Reasons for Institutionalizing Severely Mentally Retarded Children," <u>Journal of Health and Human</u> Behavior (1965) 6: 163-69.

all her children. The additional care required by the retarded child would prevent her from doing this. Therefore, the retarded child is placed in an institution at an early age so that the mother can better meet the needs of the rest of her children and because of the indirect effects of the retarded child on his siblings. The well-educated parents demonstrate low interest in the child after institutionalization.

3. The less-educated families place their retarded children in institutions when they are older. The less-educated family is likely to be an institutional family. The mother adheres to age-grading criteria in the maternal division of labor and divides her time among the children according to their ages with the youngest receiving the most attention. The retarded child, regardless of his chronological age, remains the "baby" of the family. Therefore, the less educated mother gives more attention to the retarded child and does not feel that she is neglecting her other children. Vocational and academic training and fear that the older retarded child may get into trouble in the neighborhood are reasons that these parents give for placing their older retarded children in institutions. These parents demonstrate high interest in the retarded child - visit him often, take him home for visits, participate in the institution's activities for parents, etc.

4. The advice of doctors is an important factor in institutionalization. Ninety-one per cent of the parents stated that doctors advised them to institutionalize their retarded child. It is believed that placement of younger children is more influenced by doctor's advice than the placement of older children.

The type and severity of behavior problems that a mentally retarded child has before he enters an institution are likely to determine whether the family will reaccept him back into the family circle after institutionalization.

Mercer 16 explored the relationship between the pattern of crisis experienced by a family before a retarded member is placed in an institution and the likelihood that that member will be released to his family following institutionalization. Her study centered on 133 retardates, half of whom were released from the Pacific State Hospital for the Retarded, Pomona, California, during the fiscal years 1957, 1958, and 1959. The other half of the group of retardates were still residents of the hospital. Both groups were matched for intelligence, sex, ethnic group, age, and length of hospitalization. One hundred and twenty-four of the

Mercer, Jane, "Patterns of Family Crisis Related to Reacceptance of the Retardate," <u>American Journal of Mental Deficiency</u> (July 1966) 71: 19-32.

subjects were under 20 years of age. Information from the hospital records and from interviews with the families were analyzied.

Three major findings were reported:

- 1. Resident patients produced more severe pre-institutional crisis than the discharged retardates did. This crisis affected other family members and was disruptive in nature.
- 2. The families of both groups suffered from inter-personal tension and conflict, fear for the welfare of the retarded child and structural stress. In addition to this, the families of the resident retardates had physical care problems--exhaustion of the mother, cost of support, medical care, frequent seizures, and the burden of constant supervision.
- frequently felt that placement in an institution was the only solution to the pre-institutional crisis. Almost half of the families of the released retardates were either divided or unanimously opposed to institutionalization as a solution to the pre-institutional crisis.

 Thirteen of the released retardates were placed in the institution over the protests of the family, usually by police or welfare agencies.

This study shows that behavior problems are important factors in institutionalizing a mentally retarded individual. Whether the families accept the retarded child back into the home after institutionalization depends on how the retarded individual's behavior affected them. If the retardate's behavior caused physical and emotional stress to family members and if his presence in the home caused excessive physical care, it is less likely that the family will want him returned to the home.

Parents' Attitudes Toward Retardation

Although a great deal has been done for parents of mentally retarded children in order to help them accept their problem of retardation, there still seems to be a discrepancy between what the professionals think and the attitudes that parents have toward mental retardation. There is evidence of this discrepancy in the literature.

Condell 17 conducted a study of parental attitudes toward mental retardation. Parents whose children had been at the Four-County Project for Retarded Children in rural Western Minnesota for evaluation, were the subjects of the study. The Thurston Sentence Completion Forms were mailed to 152 families in order to find out the reactions and concerns of parents of retarded children. Some of the results of this study are:

1. Most of the parents found it hard to

¹⁷Condell, James F., "Parental Attitudes Toward Mental Retardation," American Journal of Mental Deficiency (July 1966) 71: 85-92.

accept the presence of retardation and wanted help in getting more knowledge of their child's condition. Initial comforting did not diminish their desire to know how and why their children became retarded. It appeared that the question of cause and the nature of retardation continue to be of apparent concern to parents for many years. The largest number of parents said that they still continue to wish that their child could be normal.

- 2. Parents of retarded children have a good deal of concern, anxiety about the future. What happens to them determines, in part, what happens to the child.
- 3. Most parents of retarded children like to talk to other parents of retarded children since this creates a type of common bond and there can be an exchange of ideas.
- 4. Forty-five per cent of the sample felt that education was the best thing that happened to their retarded child. Professionals tend to prefer for the child such activities as work-shop opportunities, day care activities, etc., which are seen by parents as "substitutes" for education. Parents have to be helped to understand what is being provided.

CHAPTER III

SUMMARY OF RESEARCH FINDINGS

The review of literature indicates that the birth of a retarded child is generally looked upon as a tragic experience by most parents, and that many parents suffer personal maladjustments as a result of having a retarded child. There is also evidence that the presence of a retarded child in the home has an adverse effect on the entire family.

Despite the fact that the presence of a mentally retarded child in the family is a heart-breaking situation, one that demands enormous adjustment, most parents are able to pick up the shattered pieces of their hopes and plans and deal with the situation effectively. Many not only deal with their particular child but find the strength to go on to "How can I help others in the same situation." It is the parents of retarded children who through their organized activities have helped improve the welfare of the retarded child at home, in institutions, and in all types of schools. The parents' efforts have also helped to implement and promote legislature, and to further research in the field of mental retardation. Because of the parents' concern society's attitude toward mental retardation has changed greatly in the last decade. No longer is the retarded child considered a forgotten child.

CHAPTER IV

CONCLUSION

The findings of this paper indicate that there is a need for further research in the area of counseling for the parents of mentally retarded children. It appears that most parents of retarded children need help in dealing with their own emotions, attitudes, and personal feelings toward mental retardation. If this counseling could be given immediately after the initial diagnosis of retardation it might help the parents stabilize their reactions. It appears that most of them need to hear an authoritative and sympathetic endorsement of themselves, of their human and parental competence, of their right not to blame themselves for what has happened.

Research findings also indicate the need by physicians to know more about the problem of mental retardation. This research shows that many parents of mentally retarded children turn to physicians for help. Some mothers of retarded children feel that the majority of physicians reflect evasiveness, disregard for their feelings, or lack of knowledge regarding mental retardation.

There is evidence that sibling tensions are often involved in families with retarded children. This may indicate that family therapy may be more productive than the individual and group therapy which have been generally practiced heretofore.

There is an indication for the need for more research in the area of future care for older retardates, when the parents can no longer care for them in their own homes. Parents of mentally retarded children have a great deal of concern -- anxiety about the future. What happens to them determines, in part, what happens to their retarded child. An opportunity is needed for them to explore the unknown.

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