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COUNSELING PARENTS OF RETARDED CHILDREN

by

Sister Audrey Fontenot, M.S.C.

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

Lister Janne Marie Kiebhan (Adviser) Date <u>Feb. 8, 1972</u>

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CHAPTER I

INTRODUCTION

The growth and development of every child, be he normal or handicapped, is greatly influenced by the world with which he first comes in contact, namely his parents, siblings, and social environment. These factors that play such an important part in his life must always be kept in mind.

For many years much attention has been given to the retarded child. While the rapid increase of concern and interest of professionals for the child continues, it seems that the same interest of professionals for the parents has not kept pace. Thurston notes there has been a marked acceleration of interest in the field of retardation. However, he stresses the obligation of professionals to the parents of the retarded and the need for improvement in the counseling of these parents. He further states, "The parents of the handicapped child assume a vital role in planning effective treatment and habilitation. To understand and help the child, it is essential to understand fully the attitudes and emotional reactions of the parents toward him and his disability."¹

In May, 1954, Scher began his presentation at the Seventy-Eighth Annual Convention of American Association of Mental Deficiency with,

¹J. R. Thurston, "Counseling the Parents of Mentally Retarded Children," <u>Training School Bulletin</u>, 60-61 (November, 1963), 113.

"Study of recent professional literature shows that there has been a significant increase during the past few years in the attention given to direct work with parents of retarded children."¹ Yet, a study, published in 1971 by Justice, O'Connor and Warren, stated that parents did not receive assistance from public or private resources for most of their problems. It further stated that a large proportion of parents did not know of additional services which would help them with their problems.²

Therefore, it is clear that there is a need for improvement in the counseling of parents of the retardate. If one is to help this child realize his fullest potential, it is necessary to know the feelings and reactions of these parents in order to enable them to overcome any unfavorable attitudes, to help them cope with arising problems, and to guide them in all stages of their child's growth.

Definitions

Research has viewed this type of counseling in the light of different professions. Studies have also taken into consideration the classifications of the mentally handicapped, such as the custodial or severely, trainable, and educable mentally retarded. It is important to counsel the parents of any retardate, no matter what classification has been given this child. Since these factors and other variables determine the steps to be taken regarding this counseling, the following clarification was deemed essential.

¹B. Scher, "Help to Parents: An Integral Part of Service to the Retaded Child," <u>American Journal of Mental Deficiency</u>, IX (July, 1955), 169.

²R. S. Justice, Gail O'Connor, and N. Warren, "Problems Reported by Parents of Mentally Retarded Children--Who Helps?" <u>American Journal of</u> <u>Mental Deficiency</u>, 75 (1971) 685.

<u>Counseling</u>: Lewis notes that it is not surprising to find that there is no generally accepted definition of counseling due to the fact that counselors differ in their belief as to the most appropriate goals and means of counseling.¹ However, he says:

"From the viewpoint of society, counseling is a process by which one person helps another to deal more effectively with himself and the stresses imposed by his environment. In this sense, persons from a variety of professions may engage in counseling and be vitally concerned with understanding its nature."²

The above definition is favored by this writer.

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 I.Q. scores between 50 and 70, 75 or 80.³

<u>Trainable mentally retarded</u>: a term used to refer to mentally 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

¹E. Lewis, <u>The Psychology of Counseling</u>, (Chicago: Holt, Rinehart and Winston, Inc., 1970), p. 8.

²Ibid., pp. 4-5.

³R. Heber, "A Manual on Terminology and Classification in Mental Retardation," <u>Monograph Supplement to American Journal of Mental Defi</u> ciency, IXIV (September, 1959), 98.

group of mentally retarded obtaining I.Q. scores from 25 or 30 to 50.1

<u>Severely mentally retarded</u>: 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

Statement of the Problem

The purpose of this paper was to review available research, literature and observations concerning:

- 1. The importance of and the need for continuous counseling of parents of the retardate.
- 2. Techniques, methods and helpful hints used in different professions in counseling these parents.
- 3. The effect that parent counseling has on parental attitudes and on the growth and development of the child.

Summary

In this chapter it has been stated that parents, siblings and social environment play an important role in every child's growth and development. The rapid increase of interest of professionals for the retarded child seems to have surpassed the interest of professionals regarding the counseling of the parents of these children. The need

¹R. Heber, "A Manual on Terminology and Classification in Mental Retardation," <u>Monograph Supplement to American Journal of Mental Defi-</u> <u>ciency</u>, IXIV (September, 1959), 98.

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

for improvement in counseling of parents of the retardate has been clearly stated.

The definition of a few terms was given in order to clarify for the reader the meanings favored by the writer. The purpose of the present study was stated, namely to consider the importance, the need, techniques and the effects of counseling parents of retarded children.

It can be concluded that many individuals are aware that counseling for the parents of the mentally handicapped plays a vital role in the field of mental retardation. Lest this be just an awareness and not a reality, the following questions concerning this vital role should be answered:

What has been done? What is being done? What more can be done?

CHAPTER II

REVIEW OF LITERATURE

The Importance of and the Need for Continuous Counseling of Parents of the Retardate

As one reviews the early literature on mental retardation, one is surprised to find very little mention of parents and of the effects or impact upon them in first becoming aware of their child's deficiency. It seems that not until these parents, between the mid 1940's and 1950's, were beginning to band together and form organizations, that professionals in different fields also began to show their interest in and concern for parents as well as of the retarded child. More observations and studies regarding these parents began to be published. It is also gratifying to note in the past decade there has been an overflow of literature on this important topic. Since then the importance of the parents' role for the retarded child's development and adjustment in life has been highly recognized. Many have agreed with Weingold and Hormuth¹ that dealing with a child in isolation is unthinkable and work must be done with parents who play such an important role. As studies and interest for this child increase in leaps and bounds, the vital role of parents becomes more and more evident.

¹J. T. Meingold and R. P.Hormuth, "Group Guidance of Parents of Mentally Retarded Children," Journal of Clinical Psychology, 9 (April, 1953), 118.

Bystrom stated "that services for the handicapped children are less than adequate unless parent adjustment is considered an integral part of the program and parents are allowed an equal part of the partnership in the struggle to provide adequate services."¹ This identical statement is repeated by Campanelle² in his publications. On the same continuum, it was Gardner and Misonger³ who indicated that "counseling needs of the parents of retarded children are manifold" and continues, "Ideally parent counseling should be an integral part of all programs providing service for the retarded child."

Professionals in all fields are becoming more aware that the first and crucial step to be taken to work successfully in the life of a retarded child is with those with whom he first begins life and with those with whom he continues to share his life.

Weingold and Harmuth deemed it necessary to stress what is often posed in theory and neglected in practice, that "no child stands alone; that a child is part of a family and a community; that what happens to the family affects the child and certainly the child affects the family."⁴

²T. C. Campanelle, <u>Counseling Parents of Mentally Retarded</u> <u>Children</u> (Milwaukee, Wis.: Bruce Publishing Company, 1965), p. 20.

³W. I. Gardner and H. W. Misonger, "Identification, Diagnosis, Treatment and Parent Counseling," <u>A Manual on Program Development in</u> <u>Mental Retardation--A Monograph Supplement to the American Journal of</u> <u>Mental Deficiency</u>, 66 (January, 1962), 81.

4J. T. Weingold and R. P. Hormuth, "Group Guidance of Parents of Mentally Retarded Children," Journal of Clinical Psychology, 9 (April, 1953), 118.

^{1.} W. Bystrom, "The Parent Counselor--An Emerging Professional Resource," <u>Counseling Parents of Children with Mental Handicaps, Pro-</u> ceedings of the <u>33rd Spring Conference of the Woods School</u> (Langhorne, Penn., 1958), p. 16.

The same point is clearly stated in Walker's belief, "that a child should have an opportunity to grow and develop physically, mentally, and emotionally to the full limitations that have been imposed upon him by nature and the fates. This is applicable regardless of the degree of mentality. To reach the end requires not only consideration of the treatment, modalities, but consideration of the environment and also consideration of those in contact with the child."¹

The birth of a retarded child, regardless of the degree of retardation, is a traumatic experience for all those concerned. The degree to which parents and siblings are able to cope with this situation will be the degree to which this child will be able to make life adjustments. Baroff,² Jordon,³ Bitter,⁴ Scher,⁵ Olskansky⁶ and no doubt many others, all agree that mental retardation is a family problem as well as an individual problem. These authors also agree that the nature of the family's response to the child will affect his emotional and cognitive development,

1G. Walker, "Treatment of the Mentally Retarded Pre-Adolescent Child," Proceedings of the 35th Conference of the Child Research Clinic of the School (1953), p. 21.

²G. Baroff, "Some Parent-Teacher Problems in Mental Retardation," <u>Training School Bulletin</u>, 60 (May, 1963), 38.

³T. Jordon, <u>The Mentally Retarded</u> (Columbus: Charles Merrill Books, Inc., 1961), p. 29.

4J. Bitter, "Attitude Change of Parents of Trainable Mentally Retarded Children as a Result of Group Discussion," <u>Exceptional Chil-</u> <u>dren</u>, XXX (December, 1963), 173.

⁵B. Scher, "Help to Parents: An Integral Part of Service to the Retarded Child," <u>American Journal of Mental Deficiency</u>, IX (July, 1955), 169.

6S. Olskansky, "Parent Responses to a Mentally Defective Child," <u>Mental Retardation</u>, 4 (August, 1966), 21. including his capacity to benefit from special educational programs.

In a study by Erickson,¹ the Minnesota Multiphasic Personality Inventory (used to assess the personality characteristics of emotionally disturbed children) was used to assess personality characteristics of parents of young retarded children. She notes that investigations of emotionally disturbed children stress the effects parents have on the child, while in the case of the retarded child more attention is given to the effects of the child on parents. Nevertheless, regardless of the way it may be, it is still obvious that the behavior and feelings of each can be affected by the other.

Since "no parent has a mentally defective child through choice," and no parent is ever prepared to face the birth of a handicapped child, it is vital that parents receive immediate and continued assistance in order to meet successfully problems of adjustments that will effect not only their lives but also the life of their child.²

Speaking of the staff's experiences at the Edenwalk School for Boys, Scher³ gives reasons why they believe the parents need equal counseling with their children, seeing that in some measure the relationships which have contributed to making the child what he is must be considered in order to make the required changes. The study showed that success comes only when both parents and child obtain continuous, skilled and intensive case work.

1_{M.} T. Erickson, "M. M.P. I. of Parents of Young Retarded Children," <u>American Journal of Mental Deficiency</u>, 73 (March, 1969), 728.

²J. Peck and W. Stephens, "A Study of the Relationship Between the Attitudes and Behavior of Parents and That of their Mentally Defective Child," <u>American Journal of Mental Deficiency</u>, IXIV (March, 1960), 839.

³B. Scher, "Help to Parents, An Integral Part of Service to the Retarded Child," <u>American Journal of Mental Deficiency</u>, LX (July, 1955), 175.

Murray,¹ a parent of a retardate, reminds professionals that counseling for parents is not only imperative in meeting the problems of the moment but for always.

As one reviews the literature one finds different views regarding the effects of the retarded child on the family. Olshansky² spoke of the problem as a "chronic problem" that lasts as long as the child lives, while on the opposite continuum Begad³ believes retardation may be merely another problem among many others in the daily struggle.

Campanelle⁴ also reports the variety of meanings that mental retardation has for different families and how each family responds to it differently. Regardless of the viewpoint held by researchers throughout readings, opinions, and investigations, all agree on the need and importance of counseling parents. Statements similar to that found in Thurston's survey is present in most writings.

It should be further emphasized, however, that it is very important to be concerned about the adjustment of the parents in and of itself. The responsibility for a handicapped or a retarded youngster is deeply disturbing to the parents. While it is obvious that the handicapped child deserves first consideration and attention, the effect upon the parents should in no way be neglected.⁵

¹Mrs. Maxy A. Murray, "Needs of Parents of Mentally Retarded Children," <u>American Journal of Mental Deficiency</u>, 63 (May, 1959), 1082.

²S. Olshansky, "Parent Responses to a Mentally Defective Child," <u>Mental Retardation</u>, 4 (August, 1966), 23.

³M. Begad, "The Mentally Retarded and the Family," <u>Prevention and</u> <u>Treatment of the Mentally Retarded</u>, edited by Irving Phillips, Basic Books, Inc., New York, 1966, 71-83.

⁴T. Campanelle, <u>Counseling Parents of Mentally Retarded Children</u>. (Milwaukee: Bruce Publishing Co., 1965), p. 20.

⁵J. Thurnston, "Counseling the Parents of Mentally Retarded Children," <u>Training School Balletin</u>, 60-61 (November, 1963), 113. In contrast to the early literature in which there was an absence of interest and concern for parents the present data show a complete turnover. It would appear that this is due to the fact that parents themselves have not only made known their needs and their desire for help but continue to plead for aid. Some have publicly expressed these needs and these feelings, while others have done so privately. But one must realize that this is a very small percentage among the many who are less fortunate. What about those who know not where to turn and who have no one to turn to?

Even though researchers are aware of the importance of parent counseling in view of the fact that parents face many problems of social, emotional and educational implications this awareness can only become a reality through the various professions. The contributions that have been made by researchers are definite avenues from which these professionals can obtain valuable information.

Barsch¹ says that a sizable list of professionals with whom parents of handicapped children have come into contact some time or other could easily include the pediatrician, neurologist, psychiatrist, obstetrician, otologist, opthalmologist, osteopath, orthopedic, surgeon, audiologist, clinical psychologist, school psychologist, physical therapist, occupational therapist, speech therapist, social worker, nursery teacher, and classroom teacher. Whether the counselor be a physician, psychiatrist, social worker, psychologist, educator, or other he must be knowledgable about mental retardation, and especially about the feelings, attitudes and capacities of the parents.

Ray Barsch, The Farent of the Handicapped Child (Springfield: Charles C. Thomas, 1968), p. 14.

Barsch seems to be distressed that while these professionals have had specialized training in their respective fields and each has learned something about these children, still

One may look hard and long before any listing of courses devoted to understanding of parenthood of a handicapped child is found to be a formal part of the professional preparation. Not only do professionals from hundreds of university programs holding varying and differing orientations enter the fields of rehabilitation and special education each year but they also enter the fields with little or no preparations for their encounters with parents.¹

It can be concluded that parent counseling is an integral part in the field of mental retardation. Since there are many factors involved in this area one can begin by investigating: What has been done? What is being done? What more can be done?

<u>Techniques, Methods, and Helpful Hints Used in</u> <u>Different Professions in Counseling Farents</u>

There have been so many approaches taken by researchers and authors attempting to explain parental attitudes, factors determining the impact of child on parent, and developmental stages in the parent's life of these children, that one easily becomes confused in reviewing the literature. The overlapping of these stages and factors and the disagreement in the definitions of terminology make it confusing even to professionals. This may be the reason Barsch² strongly urges more education regarding these points. Since professionals will exert some degree of influence upon the parent of the handicapped child, it is necessary that

¹Ray Barsch, <u>The Parent of the Handicapped Child</u> (Springfield: Charles C. Thomas, 1968), pp. 14-15.

²Ibid., p. 15.

there be an agreement among them. The lack of agreement is a cause of distress and confusion to parents.

While it is true that parents alone know the real meaning of being the parent of a retarded child, nevertheless, counselors should strive to the utmost for the virtue of empathy. One might arrive at this after one becomes familiar with the many reactions which occur during the different stages in these parents' lives. With the understanding of the variety of reactions of parents toward mental retardation, Campanelle¹ speaks of effective parent counseling as the prime means for obtaining good from all the frustrations, anxieties, guilt feelings and hostilities which so often burden these parents. The contributions researchers have made concerning these certainly would seem to be one of the resources to draw from in order to become familiar with the stages and the emotions parents experience.

Reviewers have commented on the disagreement and confusion of the studies done. In finding hundreds of publications in the field of counseling parents of the retarded, Wolfensberger says "Despite the many testable hypotheses that have been advanced or that can be derived from these publications only a small number of experimental studies have been conducted." He further states that only a small number meet the criteria of most good experimental work.²

In examining previous related research studies to his study, Rosen commented that more attention is devoted to the retarded child than to

^{17.} C. Campanelle, <u>Counseling Parents of Mentally Retarded Children</u> (Milwaukee: Bruce Publishing Co., 1965), p. 20.

²W. Wolfensberger, "Counseling the Parents of the Retarded," in A. Baumeister, <u>Mental Retardation Appraisal, Education and Rehabilitation</u> (Chicago: Aldine Publishing Co., 1967), p. 329.

his parents. He, too, noticed that writings in the field of mental retardation are mostly opinions and experiences of authors instead of organized studies. Apparently he spoke of his own study when he said: "When the parents are the subject of study, adequate counseling techniques are stressed. To date there has been only one systematic study of parents of retarded children. That study was concerned with the acceptance of the retarded child by his parents."¹

Tretskoff² also notes that many studies reported on the value of counseling parents come from objective observation and not controlled experiments.

In a review of an analysis of the results of fifteen studies made regarding the needs of parents having a retardate, Ramsey reported that studies were so poorly designed he felt that "reproduction of them appears not warranted."³

Lest one becomes discouraged or begins to feel by these remarks and criticisms that progress has not been made, it would be wise to look at the positive side. To the new beginner in special education, it may seem that little advancement is being made in this area, while others who have been in this field for a longer period of time have seen much progress in the past decade. Viewing the role of a school psychologist Felsenthal⁴

L. Rosen, "Selected Aspects in the Development of the Mother's Understanding of Her Mentally Retarded Child," <u>American Journal of Mental De-</u> <u>ficiency</u>, 59 (January, 1955), 522.

²M. Tretskoff, "Counseling Parents of Handicapped Children--A Review," <u>Mental Retardation</u>, 7 (August, 1969), 33.

³G. Ramsey, "Review of Group Methods with Parents of the Mentally Retarded," <u>American Journal of Mental Deficiency</u>, 71 (March, 1967), 857.

⁴H. Felsenthal, "Role of the School Fsychologist in Counseling Parents of the Mentally Retarded," <u>Training School Bulletin</u>, 65 (May, 1968), 29-35.

feels that even though little research has been completed in this area, useful information is available concerning the family's response to mental retardation.

Even though Wolfensberger¹ did say that he had found few controlled and experimental works, he too admits that there is much valuable information from observations made by intelligent, sensitive and astute observers which can be as valid as and more profound than information gathered from controlled and empirical methods.

In Barsch's latest study he emphasized: "It is important to recognize that the bewildered parents searching for guidance in this new role as the parent of a handicapped child must contend with the available rehabilitation milieu. While a great deal of professional knowledge exists, the availability of that knowledge to the parent as he or she seeks to efficiently rear a handicapped child is dependent upon many factors."²

It is here that the professionals can come into this milieu. They can become sources of great assistance to parents of handicapped children if they become familiar with these many factors. By taking a good look at the available information compiled by reviewers, observers, and researchers, they can find the important variables, factors and developmental stages that determine the methods and techniques to be considered in parental counseling.

Yet, as professionals examine all this available material they might become confused by the various viewpoints, classifications, and approaches taken in explaining these variables, factors and developmental stages.

Wolfensberger, op. cit., p. 329.

²Barsch, <u>op</u>. <u>cit</u>., pp. 13-14.

Nevertheless, there seems to be an agreement that the effect on any family facing the problem of mental retardation is unique in each situation. Every member reacts differently and therefore must be studied and treated individually.

Watts sees where there is no one systematic technique of family therapy because there is no single systematic theory of family process. Inevitably, in any family faced with mental retardation, each member is affected. This basic social unit is not a static entity but a vital living organism and "The dynamics of each family can only be understood in terms of its unique structure, the inter-relationship between its individual members and methods of communication."¹

In attempting to deal with the particular individual or family problems concerned with a retarded child, Watts considered three concepts as applicable.

First, family values based upon cultural, religion and socioeconomic factors are important for professionals to assess in order to help parents plan for the child's future.

The second concept that should be sought is role identification. Knowing how the retarded child and other members are used in the family structure is very important to the person working with the family.

Thirdly, family interpersonal relationship is the principle by which the conscious and unconscious behavioral manifestations are brought out. How and why each member relates to each other and understanding the feelings of all members toward the retarded individual is essential in family

¹Watts, E. M., "Family Therapy: Its Use in Mental Retardation," <u>Mental Retardation</u> (October, 1969), p. 41. counseling. Empathy with the parents and siblings is vital in helping the family.

In this same report two examples illustrated family therapy on the basis of these three concepts. Both cases showed how each individual member was helped and came to a better understanding of each other.¹

Jordan,² too, is concerned about mental retardation as it affects human lives, the careers of retarded individuals and the careers of those who live with them. He feels that while it is indeed a public issue, this issue is of secondary significance to its significance as a family issue. Accepting the idea that the impact of mental retardation on a family is severe, he deems it appropriate to discuss reality factors to which parents adjust and to analyze the strategies which they adopt.

Under the reality factors four points are considered. The first practical problem to be considered is who will assume the responsibility of the handicapped person in the future. Second, the severity of retardation has to be considered in planning for this individual. A third related point is the possibility of other handicaps that may be present. The fourth factor calls for an insight into the available facilities offered in the area for the specific case.

It is interesting to note the pattern of adaptation used to cope with these factors. Probably one of the most systematic researches in this field is that of Farber's.³ This work suggested that the presence

¹E. Watts, "Family Therapy: Its Use in Mental Retardation," <u>Mental</u> <u>Retardation</u> (Outober, 1969), pp. 41-44.

²Jordan, op. cit., pp. 35-79.

³B. Farber, "Family Organization and Crisis: Maintenance of Integration in Families with a Severely Mentally Retarded Child," <u>Mono-</u> graphs of the Society for Research in Child Development, 25 (1960).

of a retarded child can arrest the ordinary family cycle. In this study he sought to discover what might account for the marital integrations. He also studied the strategies that are used to deal with the reality factors. These strategies he called "child oriented," "parent oriented," or "home oriented." His study indicated that a combination of the severity of the crisis situation and the strategies used determines the degree of marital integration. The factors of religion, socio-economic status, birth order and sex are also taken into consideration when speaking of the strategies. These findings were based on a study of families with trainable and severely retarded children. Whether or not these findings would be applicable to families of educable retarded children is still unanswered.

Following the same vein of thought as above and discussing almost the same points regarding variables complexing mental retardation, Rychman and Henderson¹ have discussed them according to: parental variables, retarded child variables, sibling variables, and community variables. Practical insights for counselors can be derived from this study.

In much the same way as the above mentioned studies Begad² explored similar factors. He feels that the understanding of these is a prerequisite for those who work with the rehabilitation and adjustment of

¹D. Rychman and R. Henderson, "The Meaning of a Retarded Child for His Parents," <u>Mental Retardation</u>, 3, (August, 1965), 4-7.

²Begad, M., "Factors in Counseling Parents of Retarded Children," <u>American Journal of Mental Deficiency</u> (January, 1956), pp. 515-524.

the child and parents. Recognizing that these factors in many instances are inter-related or inter-dependent, he describes them in these broad categories:

1. Factors Related to the Environment.

2. Social Attitudes

3. Factors Related to the Child

4. Factors Related to the Parents

He stressed the importance of evaluating the inter-relationship of all factors--internal and external--in order to understand the motivation of parents and then begin to counsel them effectively.

Other investigations made that can be of much assistance to parent counseling are those studying parents' developmental stages of acceptance, degree of parental awareness of retardation, parental attitudes and reactions. Many parents develop an understanding, acceptance and awareness of their child's deficiency in a gradual and painful manner.

Wolfensberger has noted: "A number of writers believe that if parents ever learn to adjust to the impact of a retarded child, they do so in orderly and predictable stages."¹

At the time when parents come to consult with physicians, clinical personnel, or educators, they are aware of a problem that they can not face realistically. They come for help and understanding. The process of helping these parents must begin at the present level of the parents' understanding and awareness of their problem.

Stone,² an earlier writer, lists parental adjustments in terms of

Wolfensberger, op. cit., p. 347.

2_{M. M.} Stone, "Parental Attitudes to Retardation," <u>American Journal</u> of Mental Deficiency, 53 (1948), 363. the degree of awareness of the child's condition as follows:

Considerable Awareness

- 1. The parent states that the child is retarded.
- 2. The parent recognizes the limitations of any treatment.
- 3. The parent requests information about suitable care and training, usually placement in an institution.

Partial Awareness

- 1. The parent described the symptoms of retardation with questions about the causes.
- 2. The parent hopes for improvement, but fears that treatment will not be successful.
- 3. The parent questions his own ability to cope with the problems.
- 4. The worker evaluates him as having partial awareness of the child's real problem.

Minimal Awareness

- 1. The parent refuses to recognize that certain characteristic behavior is abnormal.
- 2. The parent blames causes other than retardation for the symptoms.
- 3. The parent believes that treatment will produce a normal child.
- 4. The worker evaluates the parent as having minimal awareness.1

Usually, this evaluation is done in a clinical setting and is passed on to those workers who are helping the parents.

Kenner² is another who sees three levels of adjustments in the parents' acknowledgment of their child's retardation. The first level shows complete inability to face reality; the second, there is much effort in disguising this reality; and the third level shows a mature

1_{M. M. Stone, <u>op</u>. <u>cit</u>., p. 363.}

²L. Kanner, "Parents' Feelings About Retarded Children," <u>American</u> <u>Journal of Mental Deficiency</u>, 57 (January, 1953), 375-383. facing up to the fact that the child is retarded.

Through his long experience with parents Kannar has found that parents have offered practical and valid materials for logical steps for counseling by the questions they asked. "There are worthwhile compilations of questions asked by them, indicating specific areas of puzzlement, needs for clarification, etiological quandries, unrealistic expectations, attitudes of ambivalence, disillusionment and guilt, over and above the desire for an unequivocal, easily comprehended appraisal of the child's condition in terms of domestic, scholastic, and communal relationships."¹

For further discussion and suggestions he speaks of parental curiosities and divides these in five groups:

- 1. Diagnostic Formulation
- 2. Problems of Etiology
- 3. Prognostic Guidance
- 4. Family Structure
- 5. Therapeutic Planning²

These are steps counselors could use for a systematic program in helping parents, child and family.

Another similar contribution is Rosen's³ exploratory study designed to present in a systematic way various phases of development in the

²Kanner, <u>loc</u>. <u>cit</u>., pp. 453-461.

³Rosen, <u>op</u>. <u>cit</u>., pp. 522-528.

L. Kanner, "Parent Counseling," in J. Rothstein, <u>Mental Retarda-</u> tion: <u>Readings and Resources</u>, (New York: Holt, Rinehart and Winston, 1961), p. 453.

mother's understanding of her retarded child. Using the adaptation of John Dewey's "Steps in Thinking" he follows a similar pattern of organization called the "Outline of Developmental Phases." With the understanding that there is an overlapping of time and degree in these phases he places them in the following order for clarity sake:

- 1. Awareness of the problem
- 2. Recognition of the problem
- 3. Seeking for the cause
- 4. Seeking for the solution
- 5. Acceptance of the problem

This study concluded that the mothers showed a marked similarity in attitudes and opinions toward their child's retardation. They seem to follow a general pattern of development with individual differences and seemed to be affected very little by intellectual factors. Mothers seek to accept but at the same time resist acceptance of their child's disabilities. It was noted in this study that the school can be a beneficial and sustaining influence for the mother during these trying times.

The data obtained from this study showed that the medical profession needs to be enlightened in the problem of mental retardation. As a result, from the methods used by physicians in telling mothers of their child, most mothers showed unfavorable attitude towards the medical profession.

From the reports given by these mothers the public lacks an understanding attitude of mental retardation.

Rosen feels the major contributions from this study, if used prudently, can serve as a guide for anyone working with mothers of retarded children.

Thurston¹ and Blodgett² seem to agree with other experts on three stages in the effective counseling of parents by presenting these three stages:

1. Acceptance of the disability

2. Setting some rather long-range plans

3. Counseling the parents about attitudes and feelings

If there really are orderly stages of parental coping, Wolfensberger questions the order of the above. He wonders if these stages of Thurston and Blodgett should not be totally or partially reversed, putting counseling first, planning next, and acceptance last.³

In searching for information and knowledge on the topic of counseling parents one cannot overlook the literature on parental attitudes and reactions. The list of emotional reactions and attitudes of parents described in the literature seems to be almost infinite according to Wolfensberger's list:

alarm, ambivalence, anger, anguish, anxiety, avoidance, bewilderment, bitterness, catastrophic reaction, confusion,

1John Thurston, "Counseling the Parents of Mentally Retarded Children," <u>Training School Bulletin</u>, 60 (November, 1963), 113-117.

2H. E. Blodgett, "Helping Parents in the Community Setting," 33rd Spring Conference of the Woods School (Minneapolis, 1958), p. 347.

Wolfensberger, "Counseling the Parents of the Retarded" in Baumeister, <u>Mental Retardation Appraisal</u>, <u>Education and Rehabilitation</u>, (New York: Holt, Rinehart and Winston, 1961), p. 347. death wishes, denial, depression, despair, disappointment, disbelief, dissociation, embarrassment, envy, fear, financial worries, frustration, grief, guilt, helplessness, hopelessness, identification, immobility, impulses to destroy the child, lethargy, mourning, over-identification, pain, projection, puzzlement, regret, rejection, remorse, self-blame, self-pity, shame, shock, sorrow, suicidal impulses, trauma, etc.

While many writers have stated that guilt is the most prevalent reaction, Grebler² has suggested in her study of parental attitudes that perhaps frustration is the common denominator of all the unique problems.

Another author has approached the emotional reaction of parents in the light of grief and anger. Before parents can reach the point of truly accepting the child's handicap, Cohen finds that they have to work through a series of difficult stages:

(1) experiencing a period of grief; (2) acknowledging and learning to handle their anger; (3) dealing with the anxieties aroused by the impact of the child's handicap on their usual adaptive patterns; and (4) making certain adjustments in their way of life that will affect not only the handicapped child but the total family unit.³

These adjustments should be understood by any counselor who will be of assistance.

Based on Olshansky, personal and professional experiences and that of the Children's Development Clinic staff in counseling parents of severely retarded children, Olshansky has shown that most parents of a

Wolf Wolfensberger, "Counseling the Parents of the Retarded," in A. Baumeister, <u>Mental Retardation Appraisal, Education and Rehabilita-</u> tion (Chicago: Aldine Publishing Co., 1967), p. 330.

²Anna Marie Grebler, "Parental Attitudes toward Mentally Retarded Children," American Journal of Mental Deficiency, LVI (January, 1952), 475.

³Pauline C. Cohen, "The Impact of the Handicapped Child on the Family," <u>Social Casework</u>, XLIII, (March, 1962), 137.

mentally retarded child suffer a "chronic sorrow" which has not always been recognized by professional personnel who work with them. Parent personality, ethnic group, religion, and social class are factors which influence the intensity of this sorrow. Counselors often over-emphasize acceptance. His suggestions to counselors are:

First, the professional worker should abandon the simplistic and static concept of parental acceptance. Every parent--whether he has a normal or a mentally defective child--accepts his child and rejects his child at various times and in various situations.

Second, the professional person's perceptions of the parent will be different if he accepts the idea that chronic sorrow is a natural, rather than a neurotic reaction.

He feels that if the validity of chronic sorrow is recognized the counselor will counsel parents in the light of helping them to increase their comfortableness in living with and managing the child.

In reference to the variety of reactions described by the preceding and other experts, Barsch pointed out in his study that: "The general tendency to characterize parents of handicapped children as guiltridden, anxiety-laden, overprotective and rejecting beings is unfortunate. While it is true that such cases exist, the majority of the parents are unduly stigmatized by this generalization."²

It seems that this may suggest to counselors that caution should be taken in putting labels on parents. Many of these traditional adjectives which have been applied to this population are not inevitable consequences of having a handicapped child.

^{15.} Olshansky, "Chronic Sorrow: A Response to Having a Mentally Defective Child," <u>Social Casework</u>, XLIII (4 April, 1962), 192.

²Ray H. Barsch, <u>The Parent of the Handicapped Child</u> (Springfield: Charles C. Thomas, 1968), p. 342.

Professionals would be lacking in their search for information if the comments and publications of parents were overlooked. There have been many concerned parents who have expressed their views, needs, and advice to professionals.

Papish¹ obtained opinions of a representative cross-section of parents' group membership of the National Association for Retarded Children. It represented the views of men and women from every section of the United States. From the professionals, namely physicians, psychologists and social workers, parents want frankness and truth. From educators they expect leadership in educating the public in the field of mental retardation. From the community they want a place of dignity in society for their child.

After summarizing major problems of parents Murray states their greatest need, "Constructive professional counseling at various stages in the child's life will enable us as parents to find the answers to our own individual problems to a reasonably satisfactory degree."²

From Patterson one can use the following suggestions:

- 1. Tell us the nature of our problem as soon as possible.
- 2. Always see both parents.
- 3. Watch your language.
- 4. Help us to see this is OUR problem.
- 5. Help us to understand our problem.

²Mrs. Max A. Murray, "Needs of Farents of Mentally Retarded Children," <u>American Journal of Mental Deficiency</u>, 63 (May, 1959), 1087.

¹M. Papish, "Understanding the Needs and Desires of the Parents of the Retarded Child," <u>Proceedings of the 35th Conference of the Child</u> <u>Research Clinics of the Woods Schools</u> (Langhore, Penn., 1953), pp. 53-55.

- 6. Know your resources.
- 7. Never put us on the defensive.
- 8. Remember that parents of retarded children are just people.
- 9. Remember that we are parents and that you are professionals.
- 10. Remember the importance of your attitude toward us.

In parallel to Patterson's comments, Jordan has suggested ten commandments for counselors:

- 1. Be honest in your appraisal of the situation and explain it without unnecessary delay.
- 2. Deal with both parents, since they are a natural unit.
- 3. Be precise, but do not be unnecessarily technical in your explanation.
- 4. Point out who must be responsible ultimately.
- 5. Help the parents grasp the issues.
- 6. Keep in mind the referral agencies that can be of assistance.
- 7. Avoid precipitating ego defensive reactions in the parents.
- 8. Do not expect too much too soon from the parents.
- 9. Allow parents their quota of concern and uncertainty.
- 10. Try to crystallize positive attitudes at the outset by using good counseling techniques.²

These studies and publications reveal that parents are seeking for help but finding little.

One can conclude that there have been many opinions, publications and observations regarding the factors determining the techniques and methods for counseling parents. It has also been stated that much has been written on parental attitudes and reactions to a retarded child. Helpful hints and advice from parents have been given to professionals.

These resources can be useful to all professionals concerned in order to proceed with the next important step that should be taken-effective parent counseling.

L. L. Patterson, "Some Pointers for Professionals," <u>Children</u>, 3 (February, 1956), 15.

²Jordan, <u>op</u>. <u>cit</u>., p. 66.

The Effect That Parent Counseling Has on Parental Attitudes and on the Growth and Development of This Child

Investigators have noted that studies reporting on the value and effect of counseling parents of handicapped children come mostly from objective observation, and personal experiences, rather than controlled experimental studies. Even though this is so, one would be lacking in research if these were overlooked, whether they be clinical observations, experiences from personal observation, or experimental studies.

Tizard and Grad's¹ social survey showed that families of the mentally defective have greatly benefitted especially from the help and advice given by the social worker. The cry for more help from the medical services seem to express the value of counseling that could be derived from early counseling of parents.

Similar findings indicating the need for early education of retarded children and assistance to their parents are found in Kirk's² experimental study. His findings show that the greater the changes are in the environment the greater are the changes in the rate of growth of the child. It was noted that where there was consistent training and cooperation of parents the preschool children accelerated their rate of growth. This study made an attempt to point out specific parental attitudes and behavior which may affect the growth or lack of growth in

¹J. Tizard and J. C. Grad, <u>The Mentally Handicapped and Their</u> <u>Families</u> (New York: Oxford University Press, 1961), pp. 120-131.

²S. Kirk, Early Education of the Mentally Retarded (Urbana: University of Illinois Press, 1958), pp. 207-208.

children of certain families but no clear-cut generalizations were possible.

One of the major, elaborate studies of child rearing practices, made by Barsch, had no intention of being of therapeutic significance. Yet one of the observations was: "The total investigation sequence had therapeutic significance for most of the parents."¹ Many of the parents reported that the questionnaires and clinical interviews helped them reevaluate their methods of dealing with their child. Some admitted that this was the first time that they had stopped to review their actions and attitudes. Fathers and mothers were able to talk things over with each other. It has been suggested since the therapeutic effect was so impressive that these questionnaires be considered by clinicians in rehabilitation settings.

There have been negative effects that initial counseling interviews have had on parents. Since this interview may be the greatest emotional crisis of a lifetime it should be treated with much consideration and empathy. Many parents now look unfavorably upon the medical profession because of lack of tact and empathy during the first stage of awareness of their child's retardation. Yet, Thurston² gives a reminder, "It is far too easy to cast blame upon the physician; it is far harder to understand the difficulties he faces." He feels that there should be more research regarding the parent-physician relationship.

¹R. Barsch, <u>The Parent of the Handicapped Child</u> (Springfield, Illinois: Charles C. Thomas, 1968), p. 352.

²J. Thurston, "Counseling the Parents of Mentally Retarded Children," <u>Training School Bulletin</u>, 6 November, 1963), 114. Parental counseling has been seen in forms of group therapy. Olshansky¹ considers counseling as a means to provide parents with the opportunity to air their feelings of sorrow, guilt and anguish, and at the same time to get the support that these feelings are understood by others and are legitimate. Bitter's² study, whose purpose was to determine the effectiveness of a series of parent group discussions, indicated change in attitudes which helped parents, child and family.

Appell reports on a two-year group counseling project which brought out these points:

- 1. In general, the counseling served as a catharsis for the parents.
- 2. Parents indicated initial confusion on diagnosis, but after counseling, were more willing to accept and less to insist on self-discovery of retardation.
- 3. There was a freer and more realistic discussion on retardation and a better understanding.
- 4. Counseling helped them to see others were sympathetic and not merely curious and pitying.
- 5. Their goal orientation changed.
- 6. Counseling enhanced the Day Care Center as a helpful resource.
- 7. There was greater optimism related to the child's future.³

It is evident through these observations of parent counseling, whether they be from elaborate experimental designs, clinical

¹S. Olshansky, "Parental Responses to a Mentally Defective Child," <u>Mental Retardation</u>, 4 (August, 1966), 21-23.

²James A. Bitter, "Attitude Change By Parent of Trainable Mentally Retarded Children as a Result of Group Discussion," <u>Exceptional Children</u>, XXX (December, 1963), 173-177.

³M. Appell, "Changes in Attitude of Parents of Retarded Children Effected Through Group Counseling," <u>American Journal of Mental Defi</u> <u>ciency</u>, IXVIII (May, 1964), 812. observations or personal experiences, that there is a definite effect on parents, child and family, no matter what form or method is used.

Summary

This review of literature clearly indicated that there is an awareness of an agreement regarding the importance and need of parent counseling of retarded children. There seems to be no doubt in the writings that parent counseling is definitely an integral part in the field of mental retardation. In order that this awareness become a reality it is up to professionals working with parents to make use of the available contributions already made, especially in this past decade.

A few controlled experimental studies, with many clinical observations and personal experiences are resources counselors can draw from in order to determine the most appropriate techniques and methods for counseling in a specific situation. Since each parent and family is unique and must be treated as individuals there can be no single systematic theory of counseling. A vast amount of useful information was found in the literature regarding parental attitude, variables, factors and developmental stages of parents faced with retardation. The helpful hints and advice to professionals from parents was not overlooked. Using these resources wisely one is able to proceed to effective parent counseling.

Frequently stated is the fact that there have been few controlled studies on the effectiveness of parent counseling. Nevertheless, it was noted by a few elaborate experimental projects, clinical observations, and personal experiences that effective parent counseling, no matter what techniques or methods are used, shows growth and development for all concerned.

CHAPTER III

CONC LUS ION

It has been highly recognized especially in the past decade by many observers that: 1) parental attitudes and emotions greatly influence the life of their retarded child; 2) the degree to which parents are able to cope with the situation will be the degree to which the child will make adjustments in life; 3) the nature of the family's response to the child will affect his emotional and cognitive development; 4) the success of working with the child depends on the continuous, skilled and intensive work with parents; and 5) parents not only need assistance but are searching and pleading for help when mental retardation is introduced into their life. These facts have been investigated and demonstrated in many ways. In these studies and illustrations there seems to be a prevailing conclusion. Each author concludes with a statement of clear need of additional empirical research.

Since it is obvious that parents constitute a large portion of their child's environment and the need for parent counseling is apparent, it seems that more definite steps should be taken in the field of mental retardation. Those who are concerned about the education and counseling of parents of retarded children should make more effort to have parent counseling become an integral part of the child's whole development.

There is a great need for all professional fields to include in their education the study of parents of retarded children. Many researchers have strongly supported both early and continuous counseling of parents. This education should begin in the medical field and should progress to all other areas.

Another step that should be considered is one in the field of education. There has been a lack of cooperation between school and home, which may have caused more problems to parents. Many educators have freely expressed their views and complaints about parents' lack of understanding and acceptance of their child. How many administrators and teachers have actually made these parents an integral part of the child's education? A major project that seems to be necessary in special education is the parent-teacher relationship.

Another observation in this review was the lack of programs for the education of parent counselors of retarded children. There is need for universities and colleges to offer training programs or courses pertaining to parents of handicapped children. If this need were met, parent counseling might become a reality rather than just an awareness.

There is no doubt that more research would be of great value but the available research and information should be steps to greater work in effective parent counseling. The cry for help from parents is urgent and is expressed by Barsch:

The parents of handicapped children conveyed the message in hundreds of ways throughout the study--and the chorus is clear. If our nation wishes to optimize the development of its handicapped children, increase their potential for contribution, strengthen the family model and insure a condition of health--the plea of these parents should be heeded. A way must be found to understand and help. There is no choice.¹

Summary

Many authors have stated that parents, siblings and social environments play an important role in a child's life. With this in mind there are many factors that could arrest the growth and development of a retarded child. The parents' role in the life of a handicapped child needs prior consideration.

In the early literature on mental retardation there was much written about the retarded child and very little mention of the parents. In the past decade studies and observations have shown a growing interest and concern for these parents. Through these studies and observations the need and importance of parent counseling has been realized. It is frequently stated that parent counseling should be an integral part of the field of mental retardation.

Many writers and investigators have studied parental attitudes and reactions to a retarded child. There have been opinions, publications and observations regarding factors that determine the methods and techniques to be used in parent counseling. A few studies have shown the effects that parent counseling has on the parents', child's and siblings' adjustment and development.

With all the available information in the literature concerning parents of retarded children and the emphasis on the great need of these parents definite steps for more work in effective parent counseling should be taken.

¹Barsch, op. cit., p. 373.

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