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The Mental Health Needs of the Moderately Mentally Retarded Individual and the Family

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Recommended Citation

Baglin, Carol Ann, "The Mental Health Needs of the Moderately Mentally Retarded Individual and the Family" (1978). *Theses*. 345.
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THE MENTAL HEALTH NEEDS OF THE MODERATELY MENTALLY RETARDED INDIVIDUAL AND THE FAMILY

Submitted in partial fulfillment of the
Requirements for the degree of
Masters of Arts in Psychology,
Lindenwood College 4

Carol Ann Baglin
January, 1978

PREFACE

The general setting for this study was a typical special education site serving the severely handicapped in Los Angeles County, between the ages of three to twenty-one. The discussions refer to those individuals whose psychological evaluations, using the stanford-Binet Intelligience Scale, the Wechsler Intelligence Scale for Children Revised, or the Leiter International Intelligence Scale, place them within the range of the moderately retarded and cause them to warrant an educational setting that serves such individuals. The families reside in Los Angeles County and generally fall within the lower to middle economic strata, with approximately 55% qualifying for free lunch or Supplemental Social Security Income. The school is a daytime, public school facility that operates on a zero-reject philosophy. The pupils served are those that individual districts within Los Angeles County deem unservable within the district setting. They are referred to the County for their educational needs and related services.

L.A. County Schools, Division of Special Education, offers a unique opportunity for a study of the moderately mentally retarded of all types and their families. In functioning as a Program Specialist for the severely handicapped, I develop programs for the students and locate and provide support services for their families. In the six years I have been involved in these programs I have developed a keen awareness of the emotional problems of the moderately retarded and the problem of the home care and guidance of the mentally retarded child. The program to which I am presently assigned consists of approximately 160 trainable mentally retarded individuals, from ages 3 to 21. Two of the classes are for students that are both moderately retarded and visually handicapped. One class serves the moderately retarded deaf child. Four of the classes are in a specially funded program for the severely behaviorally disturbed individual.

The site has an active parent group that has facilitated the development of a unique awareness of their needs within myself and the local community.

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INTRODUCTION

Anyone who has worked or lived with mentally retarded persons is aware of how frequently their lives and those of their families are complicated by their emotional problems. In providing services for this population it is necessary to gain an overall understanding of mental retardation and resulting environmental effects. The determination of the unique features of mental retardation is difficult due to the diversity of conditions included under the label. The variety of unique factors which can result in retardation produce a distinctly individual profile affecting emotional development, potential intellectual functioning and descriptive etiology.

Mental retardation, as a concept, has not proven easy to define. A single definition has not been completely acceptable to all concerned. The recent trend toward integration into society of mentally retarded persons highlights the need for clarification of the conditions subsumed under the term "mental retardation" and an appropriate definition. The definition adopted by the Association of Mental Deficiency (AAMD) states mental retardation refers to significantly subaverage general intellectual functioning (two standard deviations below

I

INTRODUCTION

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Mental retardation, as a concept, has not proved easy to define. A single definition has not been completely acceptable to all concerned. The recent trend toward integration into society of mentally retarded persons highlights the need for clarification of the conditions subsumed under the term "mental retardation" and an appropriate definition. The definition adopted by the Association of Mental Deficiency (AAMD) states mental retardation refers to significantly subaverage general intellectual functioning (two standard deviations below the normal), existing concurrently with deficits in adaptive behavior, and manifested during the developmental period. Intellectual functioning conceptualizes intelligence as a measurable human trait expressed as an I.Q. score which is distributed along a continuum. In a normal distribution of a population the midpoint or mean I.Q. is 100 and the theoretical distribution of I.Q. scores in the population can be predicted statistically. About 16 percent of the total population (approximately 32,000,000 persons in the United States) falls below one standard deviation from the mean, having an I.Q. below 85 (President's Committee on Mental Retardation, 1976). Three percent of the population (approximately 6,000,000 persons) have I.Q. scores below 70. In California alone there would be approximately 600,000 affected individuals. The following chart (President's Committee on Mental Retardation, 1976) shows the major levels of mental retardation and the I.Q. ranges that apply to each level, from the two widely used intelligence tests.

	Obtained Intelligence Quotient	
Level of Mental Retardation	Stanford-Binet	Wechsler
Mild	52-68	55-69
Moderate	36-51	40-54
Severe	20-35	25-39
Profound	19&below	24&below

The measurement of mental retardation initially was concerned with an intelligence quotient. However, deficits in adaptive behavior are generally regarded as the first indications of a problem. "Adaptive behavior" refers to the way anindividual performs those tasks expected of someone his age in his culture. Due to the developmental component in retardation, adaptive behavior in an individual's growth and development is affected from birth to death, involving both physical growth and emotional and social development. It has many implications for intervention and the treatment of mental disorders throughout the developmental stages, which may adversely affect an individual's behavior and adjustment to that individual's unique environment, whatever it may be, can be substantially improved through learning appropriate skills and knowledge, and through an improved self-image.

Mental retardation is a condition, not a disease, and it is not possible in every case to identify the cause. In only a minority of cases can it be determined at birth that a person is, or ever will be, mentally retarded. Mental retardation is in many respects more perplexing than other handicaps for the family to adjust to, particularly when it occurs in the absence of demonstrable physical manifestations. Ross (1964) noted how, unlike a sensory or physical impairment, it is impossible to achieve any degree of empathy for the state of the mentally retarded. We cannot possibly suspend our higher mental processes or temporarily cancel everything we have learned. It is this quality of mental retardation which makes counseling the retarded and their families a difficult challenge.

The retarded child's emotional development is impaired by his limited abilities to perceive and respond adequately to his environment, and by the impact of the conscious and unconscious resentment, rejection and/or overprotection and unsuccessful competition he experiences. It is difficult to determine what a retarded individual's condition means for the family or to unweave the sometimes elaborate defense systems developed by the individual and the family to cope with the condition of retardation.

I have found that although the emotional impact of having a retarded child is great, the families are generally able to modigy their previous routines and existing values to maintain their marital, occupational and kinship committments. This process of adaptation and familial structural change would be more easily facilitated with community services and family therapy.

<u>Scope of the Problem</u> The mental health needs of the mentally retarded can be viewed in several ways. Initially the determination of retardation is made and it is at this

point, when the parents are given the diagnosis of mental deficiency, where constructive professional help has the best chance to facilitate parental acceptance. A negative experience can compound what is already a family tragedy. The physician is usually the individual who initially conveys information concerning retardation, in approximately 94% of cases (Abramson, et al., 1977). Following the diagnosis and the presentation of evaluative findings parents will experience a great deal of stress. Reactions to the very real trauma of recognizing retardation in one's own child differ for the parents, depending on their own personality. Skelton (1972) found that parents identified seven prime areas of concern: (1) training and education; (2) the retarded child interfering with family life; (3) family problems interfering with the ability to care for the retarded child; (4) physical care and protection; (5) a living situation for the retarded child; (6) recreation and companionship; and (7) the retarded child and the community. A treatment program for all areas will be needed to be worked out according to the family's financial, social and emotional situation. Evaluation of the child will be ongoing throughout the developmental stages and parents will be readjusting to the child's needs and their changing patterns.

The mentally retarded individual, as much as the normal individual, is greatly influenced by interpersonal relations and the total life environment. Philips (1966) stated that the emotional symptoms may be influenced by constitutional endowment, the retardation, and the special vulnerability of all retarded children to problems in personality development. Heber (1964, p. 169) stated that "it is apparent that the mentally retarded and particularly those who are institutionalized have a substantially higher prevalence of psychotic and psychoneurotic disorders than the general population." Chess (1966) noted the frequency with which professional workers whom families consult have avoided a diagnosis. Inherent in this problem is the significant relationship between the degree of intellectual retardation and the child's adaptive capacities and potential for coping interactions with the environment. It is uncommon to see a retarded child who presents no emotional maladjustments as part of his clinical picture. The whole gamut of mental illness has been identified among the retarded.

Families with a mentally handicapped child will often be in need of assistance from the moment of diagnosis, up to and following the point where provision for guardianship, other than parental, must be made. Parents are in need of professional guidance related to adjustment, general child care and special services for their handicapped child.

There is a direct need for mental health services including early diagnosis and evaluation, crisis intervention, individual counseling, group psychotherapy, behavior management and other treatment modalities. It is difficult to determine what mental health services are being provided on behalf of the mentally retarded. Some emotionally disturbed retarded individuals and their families are receiving services through specialized clinics or interested and understanding private practitioners. These are only a small fraction of those individuals requiring services. Every segment of the community should be involved in the planning, implementation, and evaluation of mental health services for the mentally retarded and their families. An understanding of mental retardation and the skill to provide mental health services to the retarded individual and his family is derived from the synthesis of medical, psychological and sociological knowledge. One approach to providing and improving the delivery of mental health services is to bring together current theory and treatments and apply this knowledge to one segment of the complex system of mental retardation.

This study attempts to (1) survey the literature regarding the treatment of the moderately retarded individual, his mental health needs and the needs of his family; (2) to apply a few selected treatment methods to both the retarded individual and to his family; (3) to survey in the Los Angeles area those community mental health services which are available; and (4) to suggest some utilization of these services for emotionally disturbed, moderately retarded individuals and their families.

Federal Government and the Handicapped Public Law 94-142, the Education for All Handicapped Children Act of 1975, has facilitated a new awareness for the parents of the handicapped and their children. Public Law 94-142, sometimes referred to as Civil Rights for the Handicapped, guarantees that: (1) all handicapped children have available to them a free and appropriate public education; (2) certain rights of handicapped children and their families are protected in the educational decision-making process; (3) a clear management process be established regarding education of the handicapped at all levels of government; and (4) financial assistance be provided to state and local governments for education of the handicapped. The relevance of this law to the moderately retarded individual and his family is that the total child is considered a responsibility of the educational system and the professionals therein. Qualifying as handicapped under the law are both the mentally retarded and the seriously emotionally disturbed. Included in the "education process" is specially designed instruction, including classroom instruction, instruction in physical education, home instruction and instruction in hospitals and other institutions. "Related services" means transportation and such developmental, corrective and supportive services required, including speech pathology and audiology, psychological services, physical and occupational therapy, recreation and medical and counseling services. Another aspect of the law relevant to the mental health needs of the moderately retarded is a provision for the "least restrictive environment." The law requires that handicapped children be educated with non-handicapped children. It is hoped that this will facilitate the normalization of these children and their acceptance by society as a whole. If the atmosphere was one of support the handicapped individual would develop an improved self-image. Many parents are fearful of such massive and immediate integration because of the effect on their children and themselves. The general public may not be at such a level of acceptance as to provide the vital support needed for these individuals. For the parent that has had a difficult adjustment to the limitations of their moderately retarded child this introduces a new dimension in expectancy levels that could serve to confuse an already tenuous acceptance of the mental retardation. When the handicapped child is thrust into an unfamiliar environment with increased stress of both change and the inherent fear of normal people, this moderately retarded individual, with severe deficits in adaptive behaviors and social skills can only experience a highlighted poor self-concept and a sense of failure.

Propositions The following propositions formalized this study's organizational format.

1. There are available psychotherapeutic treatment modalities for the emotionally disturbed mentally retarded individual.

2. There is a need for mental health services for the moderately mentally retarded individual and for the family.

3. Ther services presently available in Los Angeles County are not readily available to the individual and the family. During a crisis there is little or no recognition of the immediate needs of the individual or the family, due to the elaborate bureaucratic maze of paperwork and long waiting lists.

4. There are clinics available that recognize the need for mental health services and attempt to provide community-oriented mental health services. They are overburdened and cannot meet the demand for services.

II

EMOTIONAL PROBLEMS OF THE MENTALLY RETARDED

Review of the Literature There is a sterotype that has been prevalent among many mental health professionals that no mentally retarded person can profit from mental health services such as counseling and psychotherapy. Because they are retarded these individuals have been regarded as outside the realm of normal treatment methods. This may be true for the small fraction of retarded whose handicapping consitions are so profound as to preclude even a minimal level of awareness. However, for the vast proportion of the moderately to mildly retarded, my experience does not indicate this to be true, nor does the literature support such s finding. Retarded persons can and do respond to counseling and psychotherapeutic interventions.

The mentally retarded child who demonstrate maladaptive emotional or social behavior needs the type of treatments usually included under the area of mental health services. Mentally retarded persons are generally not being provided with these services even though they are eligible.

Mental retardation is a clinical developmental syndrome (Webster, 1970). There are three basic features of retardation which have implications for the individual's personality development: an intellectual impairment which is associated with a unique type of intellectual growth; a slow rate of development; adaptational deficits and characteristic qualities in emotional growth, social adaptation, and personality traits. There is a tendency for clinical investigators to exclude cases of organic brain disorder and psychosis from clinical studies of the emotional aspects of mental retardation. While this is an understandable effort to attempt to obtain a pure case of emotional manifestations in mental retardation, the investigator might just as rationally exclude cases with known separation from the mother during infancy, and those with environmental deprivation (Webster, 1963).

The integration of the concepts of psychiatry, with a medical emphasis and those from psychology and education, as related to mental retardation, are still at an early stage. Most of the work has been done by clinical psychologists and special educators. Kirk (1958) and Blah (1966) placed an emphasis on the importance of personality and behavioral aspects in the education of the retarded. Heber (1964) contributed a comprehensive review of experimental research on mentally retarded persons and their personality. He noted the extreme paucity of data bearing on the relationship between personality variables and behavioral efficiency of the retarded individual, in view of the generally acknowledged importance of personality factors in problem solving.

There has been a conspicuous lack of dynamic psychiatry to provide any insights into the understanding of the emotional problems of the mentally retarded child. Clark (1933) stated,

> There is found in all mental defectives a weak ego structure in association with an impounding of libido within the personality and an inbinding of primary narcissism, thus limiting the psychic energy available for object relationships, which in turn dilutes the motivation for learning or acquisition. (p. 136)

Pearson (1957) described a defect in ego and superego, and the deep sense of worthlessness of the mentally retarded child. Webster, a psychiatrist, (1963) reported that in a group of 159 retardates three to six years old, not one child was simply retarded. He stated that

> the slow and incomplete unfolding of the personality is associated with partial fixations that result in an infantile or immature character structure. This particular style of ego development is accompanied by special descriptive features: a nonpsychotic autism, repetitiousness, inflexibility, passivity, and simplicity in emotional life. (p. 38)

In much of the psychiatric literature, deviant behavior of the retarded child tends to be attributed to retardation of ego development (e.g., Webster, 1970). This would suggest that some difficulties with both the executive function of the personality (the ego) and the conscience (the superego) are inevitable consequences of mental retardation. Development in the area of moral judgment in retarded children is somewhat slower than in normal children (Witkowski, 1967).

Chess (1970) noted that we do not have nearly enough systematic information on either the prevalence or specific etiology of behavioral disturbances in retarded children. Little work has been done on the possible effects of retardation upon psychological functioning and personality development. Chess (1970) cited the number of studies that are done in psychiatric hospitals or residential centers where the proportion of disturbed children is relatively high. In private practice the children referred are those whose behavior has been sufficiently troublesome to warrant referral. Chess was unable to identify any emotional or behavioral characteristics that are peculiarly and invariably associated with mentally retarded children. Slaughter (1960) supported through numerous studies such variability in behavioral components among the retarded. He noted that while there are some mentally retarded children who exhibit personality triats that seem to be linked to their deficiencies, there is no set of personality traits that may be regarded as symptomatic of mental deficiency. Mental retardates are, according to Slaughter (1960), as different from one another as are children as a whole. However, a mentally retarded person can never attain the full emotional maturity psychologists regard as the ideal for an adult. There is little definitive evidence to indicate, however, that any specific etiology could be developed to encompass the retarded individual's behavior. For every immature, obviously ego deficient retarded individual, there is another with similar cognitive skills who functions relatively adequately and establishes some relationships with others.

Menolascino (1970) reported on 1,025 young children whose ages ranged from 1.6 to 14.2 years, of which 256 were diagnosed emotionally disturbed and mentally retarded. He classified the four most frequent types of emotional disturbances as follows: chronic brain syndromes with behavioral and/or psychotic reactions (117 cases), functional psychosis (8 cases), adjustment reactions of childhood (39 cases), and psychiatric disturbances not otherwise specified (11 cases). This fourth group were all in the moderate range of retardation and commonly displayed frequent periods of general irritability against a personality of passivity, inflexibility and personal immaturity. He further noted that retarded children have a high frequency of special sensory and integrative disturbance, such as visual and motor problems. These problems influenced the capacity of these children to perceive environmental experiences and process information, thereby limiting their ability to use normal play as a means of problem solving. These sensory and integrative disturbances alter the mentally retarded child's view of reality and their body image, having implications for their unique personality development. These problems are magnified by the child's simplified understandings and his narrow repetoire of coping behaviors. Many retarded individuals have trouble thinking conceptually, and expressing their ideas in itself creates serious frustration and strengthens feelings of inadequacy and worthlessness. The retarded start out with major behavioral deficits and because they are retarded there are fewer behavioral alternatives available to them.

Personality Evaluation Once the diagnosis of retardation is made, a thorough evaluation of behavior and how the fact of retardation is related to the individual's overall adaptation is needed. Such differential diagnosis (Bialer, 1970) is primarily concerned with the attempt to isolate and identify all relevant factors in the case of a given individual who is functioning as a retardate, so as to enable the most effective treatment and planning for the individual. Patterns of behavior in a retarded child differ significantly from those observed in normal children of the same age. The behavior, while inappropriate for the child's chronological age, may be quite in unison with his mental age. It is also possible that the deviant behavior represents an underlying psychological disorder. As part of the diagnosis it is important to distinguish between a child's habitual level of functioning and his maximum capacity (Chess, 1970). Confusing a child's maximum and habitual levels of functioning may result in emotional problems, since overestimation of his capacities can lead to excessive demands and expectations.

It is extremely difficult to make a clear-cut delineation of the etiologic relationship between a deficiency in intellectual functioning and subsequent emotional problems in the retarded individual. An important source of information is the developmental history. Some retarded individuals may begin life normally and manifest intellectual retardation only after some traumatic event, such as infection, accident or a degenerative neurologic disease. A child, such as this, will not face the same demands as one who has functioned in the retarded range from birth.

There are several types of assessment procedures which can be utilized in the personality evaluation of the retarded individual. Certain tests of social and personal competency are "third person" tests, utilizing an individual other than the testee and the tester. The information is obtained mostly from a knowledgeable and credible person, who is interviewed by the psychologist, by observation or by actual administration of some test items. The physical condition of the child is not a consideration in the use of these procedures. It is important to note the motivation and relationship of the informant, so as to provide a context within which data can be interpreted.

The Vineland Social Maturity Scale or VSMS has been widely used for many years and is still frequently used. The items are grouped as an age scale from birth to twenty-five years, plus. The items assess self-help in general, in dressing and eating; locomotion; occupation; communication; self-direction; and socialization. The results are reported as Life Age and Social Quotient. Scoring criteria are provided in the manual. A shorter version of VSMS has 83 items as compared with 117 in the original. Devised by Mecham (1957), it focuses on communication skills from birth to sixteen years.

The Preschool Attainment Record or PAR, like the VSMS, obtains data from a knowledgeable informant or observation. The items are segregated for each category of developmental behavior. The eight categories are: ambulation, manipulation, rapport, communication, responsibility, information, ideation, and creativity. The raw scores are convertible into Attainment Age and Attainment Quotient.

The Gesell Developmental Schedule, Preliminary Behavior Inventory, surveys the growth of the child in motor, adaptive, language, and personal-social activities. It is applicable for infants and young children, four weeks to three years. It is an observational and informational checklist for three of the four areas of growth. The fourth, Adaptive, requires the tester to administer tasks to the child. The items are checked (+) if present or (-) if absent. The record form serves as a profile of levels attained in each of the four areas of activities in daily life.

The Cain-Levine Social Competency Scale is an interview procedure that was standardized on a moderately mentally retarded population between CA five and thirteen years, eleven months. The four subscales measure initiative, self-help, social skills, and communication. The psychologist checks one of four alternative statements for each of the forty-one items. Raw scores are transformed into percentile ratings for each subscale and for the total scale.

The Denver-Developmental Screening Test or DDST attempts to assess the rate and level of development of infants and preschool children from two weeks to six years.

The record form is divided into the four major areas of gross-motor, fine-motor-adaptive, language and personal-social development. The examiner draws a line across the face of the examination sheet at the point of the child's CA. As each item is passed or failed it is indicated "P" or "F". Each item is placed on the record sheet so as to show the ages at which the item was passed by 25, 50, 75 and 90 percent of the normal standardization population.

The Slosson Intelligence Test (SIT) has proved to be a useful screening instrument for both children and adults. It can be used by any responsible person who, in their professional work, often need to evaluate an individual's mental ability. The items selected for this screening test are similar in nature to the valid Stanford-Binet tasks. The test has a higher ceiling for adults and a lower base for children than the Stanford-Binet making it useful for children of suspected mental deficiency.

The AAMD or the Adaptive Behavior Scale is a behavior rating scale designed for mentally retarded, emotionally maladjusted, and developmentally disabled individuals. It is designed to provide objective descriptions and evaluations of an individual;s adaptive behaviors. In the moderate ranges of retardation the AAMD is an extremely effective means of determining the overall effectiveness of an individual's behavior. This scale has helped to eliminate the utilization of IQ tests to determine placement for students in the mild ranges of retardation. The adaptive deficits are considered to be more important determinants of success. The Scale consists of two parts. Part one is organized along developmental lines, and is designed to evaluate an individual;s skill and habits in ten behavior domains. Part two of the Scale is the product of a survey of the social expectations placed on retarded persons, in residential institutions and the community. There are fourteen domains and it is designed to provide measures of maladaptive behavior related to personality and behavior disorders. Information concerning the individual being evaluated should be obtained from that person who spends the greatest number of hours with the individual. There are 3 different types of administrative procedures: (1) 1st person assessment; (2) 3rd party assessment; and (3) interview method. A Profile Summary Sheet is provided.

There are checklists that cover a variety of activities similar to the other instruments. These are oriented to eliciting information that lends itself to yielding a personality evaluative picture. The Child Rating Scale which is similar to the above scales assesses the personality adjustment of primary grade school children who cannot read well enough to take the group psychological test. There are five areas rated: Self-adjustment, Home adjustment, Social adjustment, School adjustment and Physical adjustment. There are seventy-eight items on 9 scales of values between Yes (1) . . . to . . . No (6). The five scales yield a Personality Total Adjustment Score. The Devereux Elementary School Behavior Rating Scale or DESB consists of forty-seven items. The first twenty-six are checked by the rater on a five-point scale from Very Frequent (5) to Never (1). Items 27 to 47 are quantified on a seven-point scale from Extremely (7) to Not at All (1). There are eleven behavior factors and next to each are the particular scale items that contribute to it. The normative population did not include retarded individuals but can be used to appreciate the behavior and personality traits and discrepancies of the retarded. Burks' Behavior Rating Scales consist of 110 items in the Parent Form. The items are rated on a scale of 1 to 5, (1) you have not noticed this behavior at all . . . to . . . (5) you have noticed the behavior to a very large degree. Category scores in 19 areas are profiled indicating not significant to significant.

Testing procedures utilizing paper and pencil inventories are not generally feasible with the retarded because of poor visual-motor integration, reading difficulties (Cromwell, 1966) and limited verbal comprehension. Good substitutes for this kind of testing are interviews, observation, and case history (Allen & Cortazzo, 1976). These may be the major sources of valid and reliable information from which to derive a personality picture of the retardate. There remains the projective mode of evaluating personality. This procedure has been discussed by several authors (Jordan, 1966; Robinson & Robinson, 1965; and Sarason, 1953). Sarason (1953) indicated that the Rorschach Psychodiagnostic Inkblot Test is the most widely used with the retarded. Allen and Cortazzo (1970) supported the use of the Rorschach Test and its modifications with both the mildly and the moderately retarded child and adult. Any use of the variety of projective tests available (Draw-A-Person Test; the House-Tree-Person; or the Bender Gestalt) with the retarded makes the interpretation of the protocols extremely difficult due to the unique population, the dearth of research, intellectual limitations and language barriers.

Another area affecting the personality of the retarded is the degree of mental retardation. This is a significant factor in determining the child's capacity for coping with environmental pressures. In addition, the specific aspects of cognitive functioning, such as retentive memory and imitative ability, may be influential in determining adaptational abilities (Chess, 1970). The retarded child meets with failure frequently enough that he tends to look to others for guidance, leading to less effective behavior than mental capacity would seem to permit, much like normal children whose achievement falls below their potential for whatever reasons.

The general literature indicates that the retarded manifest higher levels of anxiety than do normal subjects. This could potentially be a positive trait in the personality of the retarded individual. Bialer (1970) indicated that level of manifest anxiety does not necessarily show a negative correlation with performance. It is possible that given life situations may evoke anxieties that will serve to either raise or lower the level of performance. However, from my subjective observations, the retarded respond negatively in performance to a raised level of anxiety. Perhaps due to overall behavioral deficiencies there are little adaptational responses available. For example, many moderately retarded individuals can be trained to perform certain simple tasks that enable them to participate in a sheltered work experience with other retarded adolescents and adults. When trained these individuals can perform the tasks adequately and are released to a workshop setting. Once at the setting, with increased numbers of people and an unstructured environment, they cannot maintain their behavior and frequently are unable to perform the task.

Another important factor in the child-environment interaction is temperament. From early infancy, individuals manifest striking differences in their characteristic reactions to varied stimuli. These temperamental qualities, which include rhythmicity of biological functions, activity level, positive or negative responses to new situations, sensory threshold, quality of mood, intensity of reactions, persistence, distractibility and attention span, affect the child's response to intrafamilial and extrafamilial demands. Certain patterns of temperament in relation to environmental stress may lead to disturbances in behavioral development (Thomas et al., 1968). Chess (1970) was able to identify a relationship between temperament and the retarded child's capacity to perform adaptive functions in ordinary life. Rejection of aid, often with overt anger, is related to temperament (Chess, 1970) and can grossly affect the retarded child's ability to profit from education.

Investigators have attempted to describe the self-concepts of the mentally retarded individual. Bialer (1970) summarized the research in this area: (1) the self-concept of the retarded cannot be characterized by a single set of patterns; (2) there is a consistently positive connection between level of intelligence and the positive/negative direction of self-appraisal; (3) there is a significantly positive association between self-attitude and school achievement; and (4) there appears to be a tendency for retarded subjects to overrate themselves on measures of self-estimation of either current or future performance. The retarded's conception of others can be conceptualized according to (1) his perception of other retarded individuals, (2) his concepts of non-retarded peers, and (3) his perception of the significant others in his environment.

General Behavioral Characteristics The mental retardation syndrome when complicated by a behavior disorder, includes disturbances in the psychological processes that are only recently becoming more clearly defined. In the literature there are several frequently cited behavior characteristics that are worth of separate discussion. Webster (1970) termed these psychological characteristics, that were more consistently associated with the degree of retardation, as "primary psychopathology of the mental-retardation syndrome." In his study the incidence of these features were observed to be roughly proportional to the degree of retardation present. In moderately to severely retarded children these features appeared commonly in all their records. Webster, in the same study, noted three basic features in the primary psychopathology: (1) the intellectual impairment; (2) the slow rate of development; and (3) the disturbance in the quality of emotional development. The third feature is characterized by poor differentiation of ego functions, poor development in the capacity to make emotionally significant distinctions between the familiar and the unfamiliar, difficulty in finding new solutions for old conflicts and frustrations and a tendency toward repetition and inflexibility in solving emotional problems.

Another trait was the simplicity of emotional life which is a manifestation of the undifferentiated ego. Webster (1970) differentiated the so called "autism" or isolation of mental retardation from the autism of psychotic children. The autism of the retarded was not the prominent feature, was not so highly developed as a defense, tended not to involve as much fragmentation of the ego functions, and coexisted with more appropriate responses to stimuli. In the same study, Webster delineated several secondary influences that complicated the effects of retardation. These included deprivation with the resulting flattened affect, disturbed ego development and physical effects. The second influence was overstimulation and its manifested anxieties. A third influence was that which occurred because of confused expectations on the part of the parents. A fourth type was observed in cases where the parents were still unable to accept a more realistic view of their child's handicap, resulting in erratic withdrawals of emotional investment from the child. Another common influence was the tendency of the parents to fuse their image of the child with their own partial image of themselves as defective persons. A sixth influence was reinforcement by the family of the infantilization of the child. A seventh common influence on emotional development was the frequent occurrence of emotional traumata, caused by illness, hospitalizations, surgeries, and seizures.

Chess (1970) reported a study of fifty-two retarded children of whom thirty were diagnosed as having a behavior disorder. She did not indicate the functional range of retardation. She reported the findings in clusters of patterns. The behavioral patterns the children exhibited included such bizarre behaviors often associated with childhood schizophrenia. A number of the children engaged in activity that was apparently aimless, including jumping, rocking, flapping of the arms, and eye blinking. Many interrupted their normal routines to perform these activities. Some engaged in stereotyped play activity, using toys or objects in a rigidly unmodified way. One-third of the children manifested an unusual seeking of sensory experiences, while others insisted on the repetition of certain environmental conditions. Aberrant behavior existed side by side with well-related and adaptive behavior. Language patterns, too, were repetitive, perservative, and stereotyped in many of these disturbed children. Of the thirty youngsters who were diagnosed in the study as having behavior problems, ten had difficulties that were direct symptoms of brain damage, eighteen had reactive behavior disorders (characterized by aggressive activity, overdependence, or fearfulness), one had a neurotic behavior disorder (exhibiting firmly fixed patterns reflective of anxiety or defenses against anxiety), and one was psychotic (Chess, 1970).

In a study of 18 children by Webster (1970), 66% of the children were rated as moderately to severely disturbed. They exhibited disorders of impulse and behavior, excessive shyness, fears and inhibitions, reaction to loss (depression), exaggerated negativism and compulsiveness, immaturity, a tendency for regression, precocious sociability, and infantile autism.

The prevalence of obvious behavioral disturbances in the moderately mentally retarded emphasizes the need for adequate services in the area of mental health for these individuals.

III

TREATMENT MODALITIES

In approaching the moderately mentally retarded individual in need of some form of mental health services, it is important to be flexible and creative in the method of treatment. The intellectual deficit of the mentally retarded has a number of implications for handling social and emotional problems. Limitations in abstraction are associated with limitations in language development, symbol formation, and imaginery play. To a large extent, the child's intellectual level and degree of disturbance will determine whether it is possible for the mentally retarded individual to be reached on a conceptual level, through relationship therapy or by the establishment of new patterns of behavior by conditioning.

Behavior Therapy The application of behavioral learning principles to the treatment of developmental and behavior problems has had a tremendous impact on the psychological aspects of retardation. It has frequently been demonstrated that to a certain degree the behavioral limittations of the retarded are due to a limited or inappropriate learning environment. The retarded child is not exposed to the amount or quality of experiences that a normal child is in development. The retarded child is limited in both receptive and expressive language. Both parents and siblings do not interact as frequently as with a normal child. If the retarded child has a physical anomalie, interaction with all individuals in the environment may be decreased.

Behavior therapy is particularly relevant for the severely and profoundly retarded, who for years have been neglected in the traditional psychotherapeutic modes of treatment. Through the systematic application of behavior modification procedures, these individuals have developed language, motor, perceptual, cognitive and social skills.

In the behavior modicification model, all behaviors are seen as learned, including behaviors that are described as inadequate, inappropriate, neurotic, maladaptive, or pathological. The causes of the behavior are those environmental events which are effective in influencing the occurrence or non-occurrence of the behavior. This view places the major cause of inadequate behavior in the environment rather than on specific factors within the child. The behavior therapist seeks a specification of the problem behavior and the frequency of occurrence under specific environmental conditions. The focus of treatment is the overt behavior that is creating difficulty for those responsible for the retarded individual. The treatment goals are then stated in behavioral terms

(Gardner, 1970). The therapist seeks to identify those environmental events which have the effects of increasing or decreasing the occurrence of behavior. Social reinforcements in the form of praise, approval, smiles or attention, are effective. Non-social reinforcers, such as food, toys or favorite activities are more effective with some individuals, but should be paired with social reinforcements when administered. The effects of aversive or punishment consequences vary in effectiveness (Webster, 1970), but have been used with the more chronic behavior problems of the profoundly retarded.

The principle of extinction, frequently used in behavior therapy, suggests that behavior will decrease in strength upon the removal of those stimulus consequences which maintain it. There are serious limitations in the application of the extinction procedure when working with the retarded. It is difficult to identify those reinforcing events and then to control them once identified. This renders this procedure highly undesirable when behavior is dangerously disruptive or physically inimical to the client or to others. Time-out procedures are also frequently used in behavior therapy and consist of removing the individual from the presence of reinforcing individuals immediately after inappropriate attention-seeking behavior.

The following is a description of a federally funded project developed by L.A. County's Division of Special Education, Psychological Services. This program is based on behavior therapy principles that were developed to serve as a classroom model for moderately retarded/seriously behaviorally disturbed children. It illustrates a specific application of the principles of behavioral learning. It is being implemented at the school to which I am assigned by the psychologist, the program specialist (myself), and specially trained classroom teachers.

The purpose of the project was to find an appropriate public school program for seriously disturbed children functioning in the moderate to severe range of retardation. The behavioral or emotional problem had to be of such severity as to make their inclusion in classes for the trainable retarded so disrupting as to be precarious for themselves and to be a serious impediment to the learning of classmates. The focus of the study was to see if their behavior could be improved through the application of positive operant conditioning in a modified version of Hewett's (Robinson & Robinson, 1965) engineered classroom, with individualized learning programs for each child. If the behavior improved could a significant number of these children be returned to function adequately in and profit from a regular special education classroom. Many of these children are in the moderately mentally retarded range functionally, with their development and learning blocked by lack of inner behavior control conducive to accommodation and assimilation. The plan was proposed with the expectation that conditioning can bring a child to readiness for progress in developmental tasks, and to performance beyond their present demonstrated levels. This methodology, combined with smaller class size, increased teacher effectiveness and ability to use one-to-one intervention/attention procedure. The major emphasis is on pre-academic activities, with a stress on "attending", "responding", and "following directions." Children learn to respond appropriately, take turns, follow simple directions, get along with others and begin to develop the ability to function in small groups. They do not concentrate on academic written exercises, but rather focus on daily living skills, independence, development-motor, language/communication and self-image tasks.

Groups were matched in terms of the degree of retardation and the severity of behavior or emotional disturbances. Experimental and Contrast groups were equivalent in factors of sex, own vs. foster home placement, diagnosis and chronological age range. The treatment was effective in bringing many children to a level of awareness and responsiveness to their environment and to states of group interaction. Despite curriculum gains the children remained in the same range of retardation, making the most logical placement a program for the moderately retarded. The emotional problems were alleviated efficiently enough to allow profitable functioning only in a specialized public school setting.

The varied uses of behavior modification, as described in the literature, lends itself to the proliferation of treatment procedures. Altman and Talkington (1971) described the use of modeling techniques with the mentally retarded. Robinson and Robinson (1965) argued for the plausibility of modeling as an intervention technique. It should be used in conjunction with reinforcement principles. As the retarded individual makes successively accurate approximations of modeled behavior, reinforcements should follow. Gibson, Lawrence, and Nelson reported the use of three training procedures (1) modeling, (2) instructions and feedback, and (3) modeling, instructions and feedback, which were used to alter patterns of social responses. The most effective procedure was modeling, instructions, and feedback.

Drug Treatment Many drugs have been prescribed for treatment of the symptoms related to retardation and emotional problems. Share (1976) reviewed drug treatment for Down's syndrome individuals. Drugs have been used to modify behavior, as well as cognitive processes. It is essential that these drugs be used in conjunction with a well planned psychotherapeutic and educational program. Most of the symptoms frequently treated with drug therapy are: intellectual slowness, hyperactivity, isolation, sluggishness, obesity, short attention span, depression, irregular sleep, and so on. Hart (1969) described the use of some drugs that may facilitate the total psycholtherapy program, increasing the effectiveness of all treatment modalities.

Dextro-amphetamine (Dexedrine) is one of the drugs most helpful for the individual who is either hyperactive, or who seems depressed, frustrated, and withdrawn. The longacting form given early in the morning is a very convenient and often excellent media of symptomatic relief. Methylphenidate (Ritalin) also appears to be an excellent drug on occasions for the syptomatic relief of depression, isolation, and poor motivation.

With both these drugs the most frequent side-effects are interference with appetite and with sleep. Their use must be discontinued gradually over a 5-10 day span when the side-effects appear to a serious degree, causing insomia and weight-loss. The sudden withdrawal of either drug may lead to serious depression.

The use of tranquilizers is often productive of symptomatic relief in the shy, moody, withdrawn, or hyperactive and destructive individual. The drugs of the tranquilizer class most frequently used are: thioridazine (Mellaril), chlorprothixene (Taractan), trifluoperazine (Stelazine), diazepam (Valium), chlorpromazine (Thorazine) or chlordiazepoxide (Librium). Although the pharmacologic mechanism is unknown, an individual child will frequently respond to one drug much better than to another, even though they are very similar chemically. There is no practical way of predicting which drug or combination of drugs will be successful in any particular case. Most often the successful adjustment on a drug program is a matter of trial and error.

If a child is having frequent seizures, or if he has an electroencephalogram that suggests severe abnormalities of cerebral function, the use of anticonvulsant medications such as phenobarbital or diphenlhydantoin is often indicated.

Psychotherapy The techniques of psychotherapy with normal children need modification when applied to the retarded. The goals of treatment when the concentration is on personality change must be joined with an emphasis on resolving interpersonal and environmental difficulties in a more active manner for the retarded individual

(Katz, 1968). Psychotherapy with the mentally retarded requires combining a functional assessment with the traditional psychopathological model. When counseling is being considered for a retarded person, a flexible approach is necessary. Age differences and intellectual and functional variations will require individual assessment. Katz (1968) proposed that therapists considering the use of psychotherapeutic techniques with retarded children must ask themselves whether the investment of time is justified by the potential return. Depending on the degree of retardation the use of certain psychotherapeutic techniques is inappropriate. Many severely to moderately retarded individuals cannot make the changes necessary to benefit from this type of treatment. With adolescents and adults he states that psychotherapy should be considered if the retarded person is manifesting emotional or behavioral symptoms which are interfering with their adjustment or their ability to develop their intellectual, social or vocational potential. The primary treatment focus would involve a directive, structured approach, with acceptable treatment goals being to help the individual identify life elements that are sources of conflict and to help the client to find methods of resolving, minimizing or avoiding these conflicts.

Historically psychotherapy for the retarded individual has not been an acceptable treatment modality. Kanner (1957) discussed the goals of child psychiatry with the retarded to include training, special education and vocational guidance, sterilization and medical care. Rogers (1942) stated that non-directive methods of therapy are not indicated with the retarded since they lack the personality resources for resolving their problems. Thorne (1948) described a study he conducted where the basic objectives of counseling with the retarded included: (1) accepting the individual as being worthy in spite of his "defects", (2) permitting expression and clarification of emotional reactions, (3) patiently teaching methods for resisting frustration and achieving emotional control, (4) outline standards for acceptable conduct within the ability of each child, (5) building self-confidence and respect by providing experiences of success and (6) training the child to seek help with problems.

Lott (1970, p. 227) stated that

> psychotherapy, with due respect to its limitations and special indications, can be of assistance to the mentally retarded, especially those who are verbal and are aware of their handicaps. It is a mistake to assume that mental retardation, with its associated dimension of limited comprehension, is a firm barrier to the use of psychotherapy.

It seemed as I reviewed the literature that many authors were totally ignorant or chose to ignore the total personality of the retarded individual. The range of personality patterns and related behavioral disorders is the same as in a population with average intelligence. Singh (1972) found all sorts of disorders ranging from schizophrenic to neurotic problems of bed wetting, sexual perversions and sociopathic behavior disorders.

Tarachow (1962) suggested three principles as an overall conceptualization of all psychotherapeutic techniques. The first principle is an effort to supply the infantile object in reality. The therapist and the client retain each other as objects. The second principle is to supply displacements. The therapist selects the more ego-syntonic aspects of a problem, leaving the more troublesome areas undisturbed. The third principle is that of supplying stability, in support of defensive structures. Stability may be supplied by ego and superego support. The mentally retarded, as noted earlier, differ from the general population in the deficit functioning of their ego apparatur. Education and information enlarge the powers of the ego and so strengthen it. The retarded's need for psychotherapy is not a simply problem. It is compounded by an inadequate decision making process, environmental stress and a lack of committed motivation for behavior change. Psychotherapy can help in improving adjustments to the protective environment of the moderately retarded.

One of the objections to the use of psychotherapy with the mentally retarded has been their lack of verbal skills. Traditional psychoanalysis is not the only method of treatment. It is not necessary to be able to verbalize. Play therapy (Leland & Smith, 1972), dance (Lott, 1970), and painting can be used as a medium of expression to help the retarded work through their problems. In a normal child, play has been used to understand the psychodynamics of the child, even though the child is unable to verbalize thoughts and feelings. Non-verbal techniques (Sternlicht, 1966), including figure drawings, finger painting and music therapy, have also been used as a means of expression. Sternlicht also listed dance therapy as a medium for reducing tensions and providing for emotional expression of conflicts.

Some children may require treatment designed to give them maximum superimposition of structure on their behavior and their environment. The key to the psychotherapeutic process for these children is the manipulation and control of the environment that surrounds the child during the therapeutic process, by the therapist. Leland and Smith (1970) stressed that in dealing with that aspect of retarded behavior related to coping, the amount of organization and form which a therapist must use is closely related to the level of behavior that requires modification. As the child makes gains the therapist will supply less material and structure. They see the goals of therapy with the retarded as varied but generally centered aroung attempts to raise the level of functioning and to internally control behavior.

Group therapy Psychotherapy for the mentally retarded is probably most valuable of all in the form of group therapy (Burton, 1954). It offers a unique technique for promoting socialization and adjustment, providing structure and opportunities for stimulation, modeling and feedback. Mowatt (1970) described a group of young adult clients, many of whom had speech handicaps. Some communicated only with grunts and facial expression, being virtually unintelligible to the leader. They were listened to attentively by the group. Neither inability nor non-readiness to talk was a contraindication for group treatment.

Group therapy for the retarded, screened for balance of group characteristics such as verbal level and degree of retardation, can be constructive if the therapist can constantly structure and revise individual goals (Astrachan,1955). It can provide the challenge of keeping to limits and observing routine rules. Relative control of impulsiveness can be learned in an atmosphere of mutual acceptance.

The principles of group therapy apply in mentally retarded groups as they do elsewhere. The retarded can profit from one another's experiences, as can typical people, and learn to modify deficit social skills in the group process. Group discussions fill vital needs for companionship and communication. They serve as an outlet for expression of feelings, and for developing increased confidence and motivation. The development of a more mature personality and positive adaptive behaviors require greater stimulation than the retarded individual normally receives in his everyday environment. Therapy can be an opportunity to gain an awareness and ownership of one's own feelings and an understanding of one's behaviors.

Group methods offer an excellent opportunity to observe basic ego mechanisms in the retarded. Slivkin and Berstein (1970) found that it requires a somewhat longer time to develop a group ego with retarded adolescents, indicating a need for lowered expectations and flexibility in the therapist. Group techniques can involve activity, reality reinforcing, clear limit setting and active teaching. Therapists have to play an active role if they wish to diminish the disorderliness of the group (Sternlicht, 1966). Innovative and imaginative efforts, such as modeling, puppetry and humor are required for developing a therapeutic alliance. In the early phases of therapy few probing comments are made. Instead there is an emphasis on feeling and clarification of the issues. The individual is given a chance to see that as a person he is not alone. Misconceptions can be corrected and opportunities to modify values by conforming to the group norm are available.

The following study is an application of some group therapy techniques with some moderately retarded adolescents conducted in a school setting. There were institutional aw well as parental restraints which limited the scope of the methods applied and the subject matter. The study was conducted at a day school program operated by the Los Angeles County Superintendent of Schools. The site differs from schools which serve "normal" children in that all the students there qualify as severely and often multiphy handicapped. There are approximately 250 severely handicapped students ranging in age from 3 to 21 years. The live either with their natural parents, with foster parents or in small group homes. The staff numbers more than 80 professional and paraprofessionals, including teachers, instructional aides, psychologists, program specialists, nurses, speech specialists, adaptive physical education specialists, physical therapists, custodial, secretarial and administrative personnel. The categories of severely to moderately handicapped served include the trainable mentally retarded, the development center student, multiply handicapped, deaf, blind and behaviorally disturbed. The primary objective set for each child is that of increased ability to function relatively independently in the world of work and leisure.

There is considerable variability between the individual learning and behavioral characteristics of the moderately to severely handicapped person. Most of the adolescents have behavior deficits or insufficient self-management skills to function without supervision. There are certain behavioral statements that are indicative of their adaptive behavior: 1) Severely to moderately retarded individuals usually have basic self-help skills but may have difficulty with those specifically requiring fine motor dexterity; 2) There are usually some deficits in attending skills and in imitation learning; 3) Language generally ranges from simple receptive communications with a few verbalizations to an adequate conversational vocabulary and syntactic structure; and 4) Cognitive skills, such as problem solving, concept formation, dealing with abstracts, is usually limited, consisting generally of a protective reading vocabulary and simple consumer math skills. The area most applicable to this study is that of cooperative social interaction. There will be limitations in the ability to interact for the retarded individual. They do not make generalizations easily or rapidly incorporate situational occurrences. Some behavior excess exists in the form of self-stimulatory body rocking and head-weaving, along with a variety of inappropriate verbal behaviors, such as squeals, grunts, and obscenities. Excessive putbursts of behavior and verbal responses may develop in response to frustrating situations or excessively demanding work task requirements.

The age of the site and the length of service of the teachers within the site has a significant effect on the social-awareness skills area of the curriculum. Many of the teachers were trained fifteen to twenty years ago and lack the exposure to recent trends and techniques available in the field of affective development. Many of the older students consistently manifest acting-out behaviors that inhibit productive interpersonal interactions. They, also, need some help in learning to deal with the new social situations confronting them as they leave the school and go into the community or workshop training. These retarded adolescents represent a unique and challenging area for counseling interventions. Behavioral approaches are usually recommended. However, I attempted a modified counseling and training approach to see how effective it might be with this population. The goals included: 1) to help mentally retarded adolescents to develop social skills necessary for successful peer-social interactions; 2) to develop alternative means of responding to stressful work and social interactions; 3) to develop appropriate self-control techniques; 4) to facilitate and participate in the preparation of appropriate transitioning experiences from the school to the least restrictive environment; and 5) to determine workable counseling techniques for behavioral interventions with a severely to moderately retarded population.

The subjects consisted of 8 adolescent students recommended by their teachers and support staff. The final list was selected according to the following criteria: 1) adequate level of receptive verbal language; 2) a means of expressive communication, i.e. signing, oral language, gesture; 3) no hearing or visual loss; 4) age (within the adolescent range); and 5) relatively high functioning in the moderate range. The procedures for conducting the group were based on the Human Development Program. This is a curricular approach, designed to give students an opportunity to become constructively involved in developing personal effectiveness, self-confidence and an understanding of the causes and effects of interpersonal relationships. It is usually conducted in a circle with a developmentally sequenced set of activities, designed to provide experiential lessons, for growth and personal success in the affective domain. The group met once a week for 45 minutes for twenty weeks. These guidelines were reviewed weekly: 1) each person gets a turn to speak; 2) a person may pass if they do not wish to speak; 3) listening is very important; and 4) the focus is on feelings. A count of expressive language was kept as much as possible for each student. After the first weeks it became obvious that this approach was not effective with the group. It required a certain level of abstraction that the students were unable to grasp. A great deal of time was spent trying to construct concrete situations but the students were unable to draw on their own experiences to meet the level of interaction necessary to participate. The number of interactions appeared to increase towards the end of the group meetings when we encouraged the students to generate their own topics and interact with more spontaneity and less structure. We decided to encourage the students to attempt to develop an unstructured awareness of the outside world, of their inside world and their fantasy activity. Coping with the physical environment was also stressed with emphasis on personal limitations and realistic goals.

Group approaches with the retarded do present many problems. However, as a treatment approach it seems to offer many advantages, including the opportunity for a variety of input sources including other group members and the therapist. Modeling, one of the most effective tools for behavior change with the retarded, is an excellent technique. The group participation fills vital needs for socialization and communication. It is the therapist's responsibility to remain flexible and try alternative approaches with the group.

IV

THE FAMILY OF THE MENTALLY RETARDED

Review of the Literature Parents report they experience extreme emotional upset and personal anxiety when they first learn that they have a mentally retarded child.

In every wanted pregnancy there is a sense of expectancy, intermingled with hope and apprehension. Parents-to-be have often unexpressed fantasies that their baby is their future, their dreams unfulfilled. This fantasy weaves through the delicate parent-child relationship, imposing on and altering what the child is and how he is to be perceived. These expectations may create for the parents an unrealistic image of an as yet unborn child that even under the best of circumstances is rarely met by the product of the birth. The birth of a handicapped child turns out to be a challenge to the mother and father, to the entire family constellation and ultimately to the entire family structure. Also effected is the fabric of the marriage itself. Many parents are not able to adjust these early fantasies with the presence of the handicapped child. The family is unable to absorb the impact of such an event with no preparation and little understanding after the fact. There appears to be little hope. When the handicap is chronic and the cure out of reach, the demands on the parents to cope are physically, emotionally and financially draining. Bewildered confusion is the first of many realistic responses through which they may pass, weaving in and out of a chronic sadness as they view their exceptional child.

Jordan (1961, p. 30) pointed out that "identification of mental retardation at birth comes at a time when parents are vulnerable physically and psychologically." The physician who first suspects the presence of mental retardation or who confirms a diagnosis is in a vital position to provide appropriate information and counseling for parents. Parents of handicapped children almost universally express dissatisfaction and manifest resentment towards the physician or psychologist who first confronts them with the diagnosis. No matter how it is presented, parental resentment ranges from "too much too soon" to "he told us he'll grow out of it." The physician who evaluates the child must recognize that although some parents realize the slowness of the child, they tend to consider it to be temporary (Cohen, 1972). It is the physician's responsibility to project the child's development into the future in such a manner as to enable parents to plan realistically. Abramson, Gravink, Abramson, and Sommers (1977) conducted a study on early intervention services and found that the average age of the child when retardation was suspected to be 6.17 months. Tizard and Grad (1961) found 45% of their sample was satisfied with the advice they received. Waskowitz (1959) found 25% of her sample satisfied. Pueschel and Murphy (1976) attempted to analyze 414 parents' perceptions of their experience at the birth of their child with Down's syndrome. They found while some physicians are skillful in conveying the diagnosis, many professionals do not respond appropriately to the needs of parents in this critical period of stress. Many parents stressed the fact that both parents should be present during the initial discussion with the physician, as they could offer support to one another. The physician should avoid having one parent bear the stressful load alone or even being responsible for telling the other spouse. Many parents requested a combined counseling effort of the obstetrician (with whom they were familiar) and the pediatrician, so as to relieve parental anxieties. The parents have a basic right to all available information and should be notified as soon as the diagnosis is made.

Drayer and Schlesinger (1961) discussed the techniques of the "informing interview." It is held following the initial diagnostic study of a child and is designed to provide parents and other members of the family with an opportunity to review the findings.

The workup that is presented includes a thorough review of development, social functioning, a specific history of the presenting problems, and psychiatric, pediatric, neurological and psychological examinations, including speech and hearing evaluations. An important responsibility of the informant is determining how much the family is prepared to know about their child. The discussions are, therefore, continually adjusted to the parents' readiness to deal with certain aspects of the findings. The informant utilizes the parents' own observations of the child's current level of functioning and rate of progress to help them come to a greater realization and understanding on their own. A program of management and treatment which keeps the total family situation in mind, needs to be developed. In view of Thurston's (1963) findings that only 4% of parents sampled understood the nature and cause of their child's handicap, the informing process must be thorough and ongoing.

In past decades, due to prevalent attitudes within society and due to teaching in medical schools (Pueschel & Murphy, 1976), physicians often recommended residential placement to the parents of a retarded child. It was argued that attachment of the mother to the child could be prevented by disallowing the maternal instincts to surface.

The attending physician will not recognize the mourning process and all that it involves. He may express a wish to send the child to an institution before the mother has even seen the child, reacting only to his own feelings of helplessness and feelings of failure. This, also, helps to emphasize the loss of the normal child. This inhibits the process of acceptance. Acceptance cannot be hurried and will proceed only if the mother's capabilities to think, feel and talk about her feelings and disappointments are at their best. Her growth can be impaired by the attitudes of those professional persons to whom she goes for help, physicians, nurses, educators and therapists. If the handicap is not apparent at birth the mourning reaction or grief response is less acute but follows similar stages. The realities of acceptance may be extended over a longer period of time with a greater denial of the child's defective development.

Physicians today are better informed of the nonavailability, the poor quality, and the high cost of institutionalization (Farrell, 1956). It is of extreme importance that professionals should never make the decision for the parents to place a child or influence parents so they feel they have no other choice. Now, only 4 percent of the retarded population live in institutions (Cohen, 1972). There is an increasing emphasis on having the retarded child live within his family.

Professional literature presents a variety of approaches dealing with the topic of parental trauma and needs arising from the birth of a child with a chronic, handicapping condition. It is, after all, the parents who suffer the direct emotional crisis. They are faced with the daily impact of the care and the continuing dependency of the child and it is the parents who must assume the responsibility for the child's needs.

One of the more important considerations in counseling the family is the chronological position of the parents in their overall life experiences. Farber (1960) described families as going through seven stages of family development: (1) with no children, (2) with infant children, (3) with preschool children, (4) with elementary children, (6) with college-age children, (7) with children out of the home (no children again, stage 1). Each stage is important in the family development because it is characterized by its own particular stresses and rewards. Also important is the anticipation with which the family meets the next stage to follow. What is important for the counselor to recognize is that the family with a chronically handicapped child is frozen at one of these stages, causing the stresses of that period to be intensified and prolonged, relegating the rewards to a minimal level. Frequently the sibling order is reversed so that the retarded child will functionally become the youngest sibling and the others, though chronologically younger, will assume the roles of older children. This can impose an increased burden upon the other children, especially the oldest, normal female child, who will assist with and assume the responsibility for caring for the younger children and the exceptional child. Caldwell and Guze (1960) found, however, that mothers and siblings of retarded children living at home were not significantly better adjusted than were mothers and siblings of retarded children who have been removed from the home and placed in an institution. In examination of family attitudes, their findings seem to suggest that adolescents and pre-adolescents who have had the experience of a retarded child in the family are generally adaptable and they can mold their value systems to conform to the family status quo. Siblings are affected, not so much by their own direct interactions with the retarded sister or brother, but more indirectly through the effect the retarded sibling may have on the two parents. The siblings may suffer from relative maternal deprivation because of the depletion of the mother's energies by the care of the retarded child (Pecci, 1972). They may be pushed to premature independence from a variety of internally imposed conflicts. In contrast Graliker, Fishler, and Koch (1962) studied twenty-one teenagers, from 13 to 18 years of age, older siblings of mentally retarded children. The results suggest that these teenagers, on the whole, lead a normal life with adequate social outlets and positive relationships with their peers. The presence of a young retarded child in the home did not seem to have an adverse effect on teenage siblings.

Another factor to assess when counseling a family with a handicapped child is the degree of family integration (Miller, 1973). This is defined as the degree of agreement between the parents regarding their life goals and values. Closely related is the family orientation, whether the parents are career-oriented, family-oriented, or child-oriented. The age of the parents, the length of the marriage and previous childrearing experience may greatly affect family responses to a handicapped child and their ability to benefit from counseling. When the first-born child is handicapped, the family unit is less solidified and the younger parents are less experienced in child-rearing practices. Since the first-born represents the initial attempt to reproduce themselves, the effect of a handicapped child can be much more devastating than one born later, when the parents have achieved production of normal children and had a normal experience in child-rearing. Another consideration is that when a handicapped child is born to a family with several children, there may be no further anxiety about future pregnancies since ordinarily this would be the last child. In a family with no other children there is an inordinate amount of anxiety regarding the outcome of future pregnancies that even adequate genetic counseling cannot eliminate since many problems are still not predictable.

In addition to considering the family as a unit, the counselor must attend to and understand the reactions of the individual parents. Olshandsky coined the phrase "chronic sorrow" to describe the parental reaction to a retarded child. Chronic sorrow is a natural reaction to a lifelong handicap, such as retardation. The intensity may be influenced by personality, religion, and social factors, varying from time to time for the same person and from one family to another. This pervasive psychological reaction is intertwined with feelings of guilt over producing a defective child, especially if the marriage itself or the baby had any unusual underlying factors. There is a profound frustration in being blocked in the normal fulfillment of reproducing successfully and bringing about a normal life cycle. The parent may berate the Fates for what has been done to them. At any level there may be an acute feeling of embarrassment over being the parents who produced a defective child. The counselor should be cognizant of the intense, personal reaction of the parents individually. Both parents experience psychological reaction, usually more acutely in the mother because of her role in the pregnancy and childbirth. Part of the usual psychological preparation for a new child during pregnancy involves the wish for a perfect child and the nagging fear of a damaged child. In most cases there will be a disparity between the desired child and the actual child. Resolving this disparity becomes one of the developmental tasks of motherhood in the establishment of a normal and healthy mother-child relationship (Miller, 1973). In the process of normal pregnancy, labor and delivery, psychological readjustments and achievements are part of the developmental advances leading to the early adoption of the motherhood role, influenced at first by the appearance of the baby and later by the baby's responses. All parents become disillusioned in their early expectations of a perfect child but are rewarded by the reality of success experiences as the child grows. This adaptive, developmental process is interrupted by the birth of a defective child. The mother of the handicapped child is faced with conflicting tasks--grieving for the loss of the expected child and adjusting to the presence and needs of the defective child. The grieving process is never completed as it would be with the death of a normal child with the passage of time.

The mother of a handicapped child is continually confronted by the object of her sorrow, hence, the chronic sadness. At the time the mother is prepared to begin nurturing her bundle of joy, she is faced with someone in which she failed to create what she intended. The irretrievable nature of the handicap adds to the mother's trapped feeling. The mother may counter the pressure of irrational guilt by an oversolicitous and overprotective attitude, termed the vulnerable child syndrome (Green & Solnit, 1964). The symptomatology includes difficulty with separation, infantilization, bodily overconcerns, and school underachievement. The mother may attempt to ward off feelings of grief by establishing a guilt, depressed attachment to the child. In doing so she may fail to relate adequately to other members of the family because she feels that she must give all her time and energy to the damaged child. There may be an underlying identification of the mother with her defective child, adding to her own sense of deficiency and failure. Each parent may fear discussing the child, the diagnosis and their reactions to it for fear of criticism and their own tremendous guilt. The parents are overwhelmed, unable to guage their reactions to the child, his development or their own unexpressed anxieties and depression. The adaptive process of coping with the outer reality of a child with a congenital defect and the inner reality of feeling the tremendous loss of the desired normal child requires an inordinate amount of effort. It proceeds through the repeated discharge of intense feelings, usually enabling the parent to recognize and align their perceptions with the realities of the handicapped child.

Leydorf and other grief specialists suggested stages a parent of a chronically handicapped child may experience in a fairly predictable order. (1) The bewildered confusion of parents is the first of many realistic responses through which they pass. This is a reality before the diagnosis is made. Frequently physicians and professionals require a planned time interval for study of the child. It is best, at this point in dealing with the parent, to encourage the establishment of a firm diagnosis, with informed confirmations as quickly as possible. If this is not possible encourage them to obtain a full explanation as to why a waiting period is necessary. (2) Denial of diagnosis is often the first response of the parent to the physician or psychologist who poses the diagnosis. This need for defense against the dreaded diagnosis is a reflection of the need to deny the disappointed hopes the parents held as they awaited the birth of this child. For the parent there may be a momentary relief from the anxiety aroused by not knowing. Relief is quickly replaced by the anxiety aroused from the realization that this devastating truth will not go away or be refuted. The best approach is to refer the parents to a specialist for a thorough, full examination and supportive laboratory studies. It is best for the diagnosis to be presented to both parents at the same time, taking adequate time to answer all questions and discuss parental feelings and reactions. (3) Denial provokes anger and guilt because the denial is not completely successful. The child is a constant reminder that he is not developing as he should. The aggressive out-going parent will direct his dismay outward at the professional who made the diagnosis. The anger may be discharged in many directions, towards the spouse, towards the self (guilt) and towards the child. This also provokes guilt, for the anger contains blame, generating the need for even stronger defenses. It is hard to look at the child and ask why did you have to be born, what did I do to deserve you? The treatment for the parent at this stage is to point out the realities. Deal with the feelings, allow them to be verbalized, thereby reducing the impact. Point out that the parents did not do anything wrong if this is a reality. If they have contributed, i.e., child beating, work through and treat this aspect of it. (4) Understanding of the diagnosis does not necessarily imply the acceptance of the prognosis. Hope weaves in and out.

Even the smallest success the child achieves evokes unrealistic hopes for the future. They may be continued excessive hope for a miracle. It is at this stage that there may be frantic searching from doctor to doctor, without even the benefit of consistent treatment. Parents are particularly vulnerable to quackery and should be confronted with as much clear cut data available to assure them that they are receiving the correct treatment. They should be clearly notified of any known con programs in existence. The parents need to be encouraged to explore the source of their hope and the rational limitations of the existing situation. (5) Cognitive understanding of the diagnosis does not necessarily connote a healthy adjustment. A resigned attitude may provoke depression simply because no resolving solution is available. The anger is turned inward and defended against by the depressive refusal to act. The reaction may range from withdrawal to an attempt to guide the child. This may be the first indication that the diagnosis is beginning to be accepted. Now is the time to begin a group program for the parents. They can share their reactions with other parents of handicapped children. (6) Acceptance does not necessarily mean a complete accommodation of oneself with the diagnosis and the child. This is a beginning and will be a function of what is real for this parent. The parent will begin to realize both the normal and abnormal areas of life with this child. There is the beginning of a coming to grips with the prognosis, reflecting the child's limitations, and also the willingness of society to recognize the child and fulfill his needs out of human awareness, not potential economic return. This is a time of rapid progress in treatment. The parent has now joined the team in offering a comprehensive program dealing with the total child. Potential is great for success at this stage. Understanding the conflicts within the parents helps them to understand the relationship between themselves and the child. Parents of the normal child go through many trials and disappointments but are able to look forward to the day when the child will be a self-sufficient adult. Parents of the handicapped child will usually always be burdened by the child's dependency, but what can be a burden can become a source of strengthening. Parents of handicapped children can be encouraged to find some resolution, comfort and outlet of frustration in having been advocates of their children, whatever the end level of capability may be.

W. Wolfensberger (1967) offered a somewhat similar continuum of possible parental reactions, suggesting that parents may experience one or more of three types of crisis experiences: (1) novelty shock crisis--in which a disorganization results from a "demolition of expectation," the discrepancy that results between the type of expected child and the nature of the child that was born (these parents need basic information about the nature of the condition and emotional, physical and financial support); (2) value crisis--in which the child is either overtly or passively rejected to some degree because of the parents' belief in what is valuable, desirable, or acceptable; the parental reaction may be viewed as relatively extreme, ranging from total denial and immediate institutionalization of the child, to over-sensitization which might result in guilt due to the parents not feeling they can provide adequate care for the child (parents need intensive personal counseling); or (3) reality crisis--resulting from a realization on the part of the parents that they no longer are able to provide for control, or effectively deal with the multitude of problems the child presents (parents are forced to see realistic and practical assistance from community agencies, professional groups, medical specialists, residential centers).

Leo Kanner (1953) has described parent reactions to mental retardation as variants of three specific types:

1. A recognition and an understanding of the condition and acceptance of the child;
2. Disguises of the child's problem or condition with a search for either scapegoats upon which to project blame or for magic cures;

3. Complete denial of the existence of the condition of retardation in their child.

The effects of a mentally retarded child upon the family life can be a major study in and of itself. Tizard and Grad (1964) found in their study that there were few families that did not comment on the sense of humiliation they felt. Neighbors and friends, though sometimes sympathetic, were often indifferent. Some women could only do the housework after the retarded child had been put to bed. Some had to get shopping done by neighbors. Many were unable to go out to work and could not find babysitters under any circumstances. Some families cut themselves off from social contacts completely following the birth of a retarded child.

Psychiatric management of families of the retarded has sometimes ignored the realistic burdens associated with rearing an atypical child.

Murray (1959) was one of the first to advocate the concept of lifelong counseling. As the child develops, new problems and crises arise, each calling for further counseling. There are seven crisis points at which the diagnosis may be made or where further counseling needs will arise: (1) birth, (2) developmental delay, (3) school entrance, (4) adolescence, (5) vocational planning, (6) death of a parent, and (7) institutional placement.

The American Medical Association identifies 12 crisis periods: (1) the first suspicions of retardation, (2) final diagnosis, (3) school entrance, (4) rejection by peers, (5) sibling relationships, (6) acute illness, (7) general family crises, (8) sexual problems at puberty, (9) vocational adjustment, (10) marriages, (11) decision on placement, and (12) separation following placement.

The concept of parent counseling should be regarded as an important component of any program that deals with handicapped children. Unfortunately the concept is given little more than bureaucratic lip service. A commitment to serve handicapped children carries the responsibility of providing assistance to parents, both in dealing with the child and with their feelings about the child and themselves. Raising children and caring for their needs are tremendous responsibilities. Resolving conflicts and problems are what all parents do. These problems are magnified for the parents of handicapped children. We live in a society that is geared to the needs of the average person with average needs. What do we do with the handicapped child and overwhelming parental needs? During the past fifty years a variety of agencies and programs have been established to meet the need. Two particular actions have been influential in the establishment of these programs: the Mental Health Act signed into law by President Truman in 1946, and the message delivered by President Kennedy to Congress in 1963. Many special programs for both children and their parents came with this recognition of the rights of handicapped children and the needs of their parents. Parents may be at any stage in their ability to deal with their children and this has important implications for the counselor who must be sensitive to the acceptance level demonstrated by the parents.

Counseling parents of handicapped children can take a variety of forms depending on the type of the handicap, the nature of the problem, and the profession of the individual providing the counseling service, i.e., physician, teacher, school psychologist or therapist. Auerbach (1961) stated that the goal of counseling these parents is to help them explore all aspects of the family and their situation with their child, to gain greater knowledge and understanding of the child's physical and emotional development, to look at their role as parents, and to become aware of the special complexities of their parent-child relations. Research seems to indicate that group counseling can be especially effective with parents of handicapped children. They seem to be more amenable to information obtained in a group situation where all their mutual problems are shared. There is a certain amount of support that comes from sharing with other families who have the same problems or worse. The counseling situation should include both parents, in the natural environment if possible, to avoid the absent parent from undermining the growth made by the attending parent and thereby defeating the counseling effort. Group counseling was found by Appell, Williams, and Fishell (1964) to be the most effective in promoting and assisting the parent to deal with the realities of their child and the impact on the family.

The approach to parent counseling depends on the agency providing the service. MdCowell (1976) suggested three strategies: informational, psychotherapeutic and parent training. The approach used will depend on the entry level of the parents seeking assistance. The informational stage is usually when the family is still trying to move towards acceptance. It provides facts, evaluations and suggestions for alternatives available for the family. The psychotherapeutic approach is to assist the parents in dealing with their feelings and the conflicts which bring about emotional difficulties for both parents, the siblings and the affected child. The third strategy is aimed at developing effective interaction techniques for managing the child's behavior with the emphasis on communication. The most well known of these is Parent-Effectiveness-Training Program which was developed by Gordon (1970). Most parent intervention programs are working at this level, providing the parents with the training and skills to be an effective part of a multifaceted approach to working with the handicapped child.

Counseling of the family, specifically the parents, must be a continuous process to be effective. As the family moves through a variety of stages, interacting with the handicapped child's developmental process, many new problems must be confronted and dealt with in the process. Too often there is some service provided at the birth of the child but the parents are then left on their own with minimal information and the reality of the child. Another frequent point of community intervention is the entry into school crisis. What do we do with this child becomes the problem of the parents and the educators. Once an appropriate educational setting is found very little else is done. Unless of course puberty brings with it problems for the retarded individual and for the parents. Many parents are perplexed by this body of a young adult and mind of a child. The parents will soon find few "experts" will agree on the appropriate interventions. When this young adult is out of school and ready for some type of vocational program very little will be available and its appropriateness will depend on the individual. The point of this discussion is to indicate that parents of retarded children do not experience a difficult stage. A counselor working with the family of a retarded individual needs to be aware of the possible points for intervention. Without continual counseling the entire life process is difficult, threatening to tear apart the protective fabric of the family. Parents of the handicapped have to cope with different feelings about themselves, their child, and the community where they live.

The impact of retardation is felt by all members of the family unit. There are a greater number of problems in such areas as individual and marital adjustment, childrearing practices, and sibling relationships. A primary consideration for those serving the retarded is to deal with how the problem of mental retardation affects human lives, and the development of the retarded person and those who live with them.

At a site the size of where I work there are continual requests from the parents to provide counseling and information. It is impractical to attempt to provide this service on an individual basis, so a group was formed. The goals of the group were: 1) to help the parents of the mentally retarded to gain a greater knowledge and understanding of their child's physical and emotional development; 2) to provide information on basic behavior management techniques for the home and assist in their implementation; 3) to provide information on community services and agencies; and 4) to acquaint the parents/caretakers with the school and its role in their lives and the development of their child. A letter was sent home to the parents relating the concept of the group and requesting parent participation. Follow-up phone calls were made. (Fifty-four responses were received after the notice had been sent twice. Forty-nine were received from natural or step-parents. Four were received from foster parents. One was received from a group-home caretaker. Three were fathers.) Transportation was arranged for some parents through an existing Parent Organization. At the first meeting the parents were encouraged to express what they wanted from the group. The following is the list of expressed concerns: 1) what to do when my child reaches adult age; 2) sex education; 3) how to help and deal with a hyperactive child; 4) what to do when my child throws a plate of food on the floor; 5) respite care weekends relief-babysitting; 6) foul language; 7) help to understand how my child perceives things; and 8) possible places to put my child when I can no longer take proper care of him. A "Parent Day" was organized to acquaint parents with the school and the services offered. A packet was developed that provided a variety of program schedules, a map of the site (14 acres) a history of the school, class assignments and community affiliated programs. The group met on a twice-weekly basis for 10 weeks. Frequently a community speaker came and addressed the group on their concerns. At various times throughout the weeks certain information was solicited. The following tables were developed after parents were asked to indicate how they were notified about their child's condition.

Attendance was a problem in this group and similar parent groups. Although parents verbalized an appreciation of the group I felt that many of their more personal problems, critical to their life situations, were not dealt with as adequately as they would be in a clinic or family counseling setting.

Table 1

Person(s) First Notified by Professionals of the Child's Diagnosis

Person	Number of Respondents
Both parents	11
Mother alone	18
Father alone	4
Grandparents	1
Sibling	-
Other relatives	-

N = 34

Table 2

Person Who Notified Mother/Father

of the Child's Diagnosis

Person Notifying	Number of Respondents
Family physician	7
Obstetrician	5
Pediatrician	16
Nurse	-
Social worker	1
Spouse	4
Relative	-
Other	-
N = 33	

V

COMMUNITY MENTAL HEALTH SERVICES

Many parents in their quest for some help in dealing with their handicapped child look to a mass of professionals and community agencies. There are a wide range of services available in many local communities. These services are available from a variety of professions and organizations that assist in the care of the retarded during their lifetime. Families with a mentally retarded and handicapped child often will be in need of assistance in making adequate adjustment to their personal and community life (Olshansky, 1966). The mentally retarded individual resides with his family, in a community of systems. Both the individual and his family is influenced by the continuous interaction of these intricate systems. There is presently a growing awareness of the handicapped and their rights within the community. Families are demanding more understanding from the community and acceptance of their child. As mentally retarded persons do become a more visible segment of our everyday society, there will be a growing awareness of the need for a coordination of both our time, resources and public funds, particularly by the school and community agencies, to promote acceptance. The more severely retarded are likely to be noticeable in terms of behavior, appearance, speech and physical defects. Gottlieb and Siperstein (1976) studied what characteristics about people who were mentally retarded could influence attitudes toward them. They found surprisingly that mentally retarded children were not rated more favorably than mentally retarded adults.

One of the goals of the President's Committee on Mental Retardation is adequate, humane service systems, in the areas of physical, social, educational, economic and residential needs of persons who are mentally retarded. There are several ways in which mental health services for the mentally retarded can be classified. Such services are grouped as "direct" and "indirect."

"Direct" services include early case finding and evaluation, crisis intervention, individual counseling and psychotherapy, group psychotherapy, behavior modification, and other treatment modalities, including the use of drugs. "Indirect" or "supportive" services include manpower development and utilization, research, mental health consultation, and community organization of services.

Olshansky (1966) recommended providing concrete services, such as: (1) a good clinic, which provides diagnostic services, social case work, and public health nursing services; (2) Pre-school nurseries to improve and accelerate the process of socialization; (3) Baby-sitting services so mothers can be able to go out for a change, or just take a nap; (4) High quality institutions for both temporary and permanent care; (5) an adequate program of education; and (6) sheltered workshops. I would like to add that the admission to institutions should be based on need, with provision for "immediate" emergency admissions. Education should be provided beyond the current mandated age of 18 years. Many retarded persons return to spending their days in front of television when school is over. Sheltered workshops need to be federally subsidized in order for the moderately retarded individual to be kept in them. As private organizations dependent on the Department of Rehabilitation, they tend to discount the moderately-retarded adult in favor of the referral for the drug or delinquent youth, who will ultimately produce more. Activity centers need to be available for those retarded individuals unable to even minimally participate in a work setting. Other alternative employment possibilities, coupled with intensive counseling, need to be available to all retarded individuals.

It must be kept in mind that the emotionally maladapted retarded individual is essentially powerless to act. They need a community based mental health program with strong advocates to support mental health services on their behalf. There is a serious dearth of valid and reliable information through which to present an accurate picture of the available services for mentally retarded people. I feel comfortable in stating that there are not enough, and what is available is difficult to locate, disability specific, expensive and has long waiting lists.

The following is a cursory overview of the most commonly suggested services for the mentally retarded.

1. Regional Center Programs:

California's Regional Center Program is specifically designed to help individuals with developmental disabilities and to assist their families.

The program, operating through a statewide network of private non-profit community agencies under contract with the State Department of Health, provides a focal point within the community to which developmental disabilities individuals and their families can turn and receive assistance in achieving their potential.

Services of a diagnostic, counseling, and coordinating nature are generally provided directly by the Regional Center personnel. Among the most common services are:

Information and referral
Diagnosis and evaluation
Counseling
Admission to and discharge from state hospitals

Court ordered evaluation

Guardianship

Consultation to other organizations

Community education regarding developmental disabilities

Advocacy

The Regional Center makes available through generic agencies, or purchases, other services deemed appropriate for each client.

Many of the parents, at my site, had only vague notions as to the services offered and many were not registered. Frequently funds are not available when parents apply for services. There are volumes of paper work involved in any application for services.

2. Closer Look

CLOSER LOOK, the National Information Center for the Handicapped, is set up to provide practical advice on how to find educational programs and other kinds of special services for handicapped children and youth.

If you want ideas for dealing with the needs of a mentally, physically or emotionally disabled child or young adult--write to CLOSER LOOK. Please tell as much as you can about the kind of help you are looking for. Include facts about a person's handicapping condition (known or suspected), age, and current school or job problems.

The staff will respond with an information packet that includes background pamphlets, suggestions on steps to take to locate services, facts you should know about laws affecting the handicapped, lists of helpful organizations, suggested reading and other down-to-earth information.

CLOSER LOOK's service has been designed to give parents as much guidance as possible. Professionals who are trying to help handicapped children and their families will find the information packets useful, too.

3. COPH

The Coalition of Parents for Handicapped see the development of a resource pool as a tool for bringing about a more equitable situation for disabled persons. The full utilization of this tool will provide a means to supplement and rectify existing limitations. COPH is a volunteer organization whose objective is to bring together representatives from special disability interests for the purpose of sharing information pertinent to all exceptionalities.

4. National Association for Retarded Citizens

Most of the members of the association are parents who have lived through many of the adjustments and challenges of the retarded, and can draw on their own experience to help.

5. A.L.M.A.

ALMA MENTAL HEALTH is a licensed Outpatient Psychiatric Clinic focusing in Pre-Care and After-Care services for the Developmentally Disabled. The clinic specializes in mental health services for the Developmentally Disabled and their families. This type of counseling makes ALMA Mental Health unique in that it is the only direct service center for the developmentally disabled offering specific mental health services in the area, possibly in the state, and some have said in the entire nation. ALMA provides bi-lingual and bi-cultural services to the Spanish-speaking.

6. NPI: Neuropsychiatric Institute, UCLA has a Child's Department.

The Child Outpatient Department (OPD) is part of the UCLA Mental Retardation and Child Psychiatry Program. It is operated jointly by the University and State of California with some support from the U.S. Department of Health, Education and Welfare. The Clinic is an integral part of the teaching and research program for medical and paramedical professionals in the fields of mental retardation and child mental health.

Following an initial screening process, patients are evaluated by the Clinic Team. Once this evaluation is completed, appropriate recommendations are made.

Of the five children's wards, two are for adolescents: one which has a short-term intensive treatment program for mildly retarded adolescents and another follows a rather traditional psychotherapeutic approach for disturbed adolescents. There is a third ward for retarded and autistic children utilizing a behavior modification program, and a fourth for latency-age children with psychiatric problems uses a somewhat eclectic approach. The fifth ward is a pediatric ward for developmentally disabled children with concomitant psychiatric problems. Rated bed capacity of wards varies from 16-20 patients. Most children on these wards have had significant school learning or behavior problems prior to admission. Their average length of hospitalization is about eight months and ranges from two weeks to well over a year. There is also a day treatment program in which selected patients attend essentially the same daily activities as children assigned to the wards, including school.

I have yet to get a child admitted for services. It took two days to convince them that an initial interview was appropriate for one student that was having a psychotic episode. They refused to admit him on the basis of moderate retardation and sensory impairment.

7. S.S.I.--Supplemental Security Income

This is provided for those disabled individuals unable to participate in the job market on a competitive basis. The hardest problem with S.S.I. is convincing them that you are a disabled individual, especially if you are not registered with Regional Center. There are also a variety of income restrictions that further confuse eligibility.

8. The Los Angeles Regional Family Planning Council, Inc. A plan to provide services to persons with Mental Retardation

Since 1968, the Los Angeles Regional Family Planning Council, Inc. (LARFPC) has been providing family planning services to persons of low and moderate income and to young persons of all economic levels. These services enable clients to have greater control over their family size, their lives, and their bodies. As such, these services improve individual and social functioning.

There are many people with "developmental disabilities": mental retardation, cerebral palsy, epilepsy, autism, neurological disabilities, and other, similar conditions. Because of a combination of disability and lack of service, they are handicapped in the areas of family planning, family life education, and sexuality. The conditions themselves vary widely in their response to treatment, and the individuals' social functioning varies tremendously--often independently of their disability.

The LARFPC Board of Directors recognized that this group, which could use and was requesting family planning services, was not receiving them. A reconnaissance survey was performed to identify the current level of family planning services available to persons with mental retardation--the largest subgroup of persons with developmental disabilities. The study demonstrated that family planning services and sex education services were sorely needed, and underlined the sensitivity of the issues.

In response to this report, LARFPC included in its 1975 work program provisions for a comprehensive plan to provide appropriate services to persons with mental retardation.

9. Community Health Centers:

Throughout the Los Angeles area there are a variety of communit mental health centers that offer counseling services to the families of the mentally retarded. I visited several and was somewhat surprised by the lack of understanding of the impact of such a child in the family. One agency felt it was the same type of crisis "like losing a job." Nearly all of these agencies had long waiting lists. Payments could be made on a sliding scale basis.

In summary, obviously I have only addressed a few issues in the area of community mental health care for the retarded individual and his family. There are services available. They are difficult to locate. Once located, you have to be persistent and demanding. So many families need so much help. Follow-up calls must be made. Frequently parents call me in desperation when they have not received the services or information requested. When I call the agency they have no record, have an incomplete file or assume that the parents have dropped the request. It is imperative for parents to understand their rights and be strong advocates for the mentally retarded individual in their family, regardless of age.

VI

SUMMARY STATEMENT

In a descriptive study of this length it is important to review the propositions that formulate the basis for the information presented. The first proposition stated that there are available psychotherapeutic treatment modalities for the emotionally disturbed mentally retarded individual. The information indicates a variety of methods available to those working with such a unique population. These methods include: behavior therapy, the utilization of drug treatments, and psychotherapeutic interventions such as counseling, play therapy, art, dance, and group therapy.

The second proposition indicated that there is a need for mental health services for the moderately mentally retarded individual and for the family. This is supported by a variety of studies cited and by direct parent contacts. The effects of a mentally retarded child on the family are well-known in the community and educational systems that serve these children and their families. A variety of agencies have been established to meet the ongoing needs of the family.

The third and fourth propositions indicate that there are services presently available in Los Angeles County that recognize the need for mental health services to the retarded and their families but they are overburdened and cannot meet the demand for these services. During a crisis there is little or no recognition of the immediate needs of the individual or the family, due for the most part to the elaborate bureaucratic maze of paper work and long waiting lists.

Through the years I have become aware of the limited treatment interventions utilized with the moderately retarded individual and how scarce and inadequate are the available community services to meet the ever-growing needs. As some parents become too frustrated, too disabled by the continued burden of an emotionally disturbed/ mentally retarded adult/child, their only alternatives frequently become institutionalization or foster home placement. Inherent in either of these choices is a sense of guilt and failure. In recent years, however, these choices are not even available to the parent. In California, under Governor Reagan's Administration, there was a move to place the retarded child and adult back into the community. However, as I have all too frequently discovered there are few placements available in the community and the quality of the care received is sometimes not even adequate. The community is presently ill-prepared for the influx of the retarded, let alone those retarded individuals with emotional problems. The threat inferent in the deinstitutionalization movement is that these retarded persons will not be accepted by the community into which they are placed. As the mentally retarded person, with his emotional problems and deficits in adaptive behaviors, becomes a more visible segment of our society, emphasis needs to be on promotion of more positive attitudes and the provision of the meeded mental health services to the individual, his family and the community.

If we are to create a climate conducive to developing these needed services, there will be a need for massive re-education of the general public to the nature of mental retardation and its manifestations. On a limited basis there is a growing acceptance of the retarded individual and his needs. It is "normal" for the retarded to desire companionship, to have sexual contact, and to have emotional problems. The federal government can legislate through PL 94-142 the rights of the handicapped but this will be difficult to enforce unless it is also able to remove the physical and societal barriers to the retarded. There needs to be adequate and equal funding of community services for the retarded and his family, especially in the area of mental health services.

The phenomenon of the mentally retarded individual and his emotional needs are difficult to comprehend despite the advances in medical knowledge and innovative approaches in the social and behavioral sciences. Perhaps the most significant factor that can influence the probability of a better adjusted retarded individual ia a flexible and creative attitude of those who come in contact with the retarded. If an approach or treatment is tried with no apparent results do not throw out the individual, discard the treatment. Then, re-assess the individual and his needs and develop a new approach.

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