American Handbook of Psychiatry

MENTAL RETARDATION

II. Care and Management

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Table of Contents

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II. Care and Management

Today, patterns of service in the area of mental retardation are undergoing a progressive change and differentiation which eventually may enable most persons considered handicapped to live in communities throughout most or all of their lives. Under the impact of the normalization principle and strong advocacy for the retarded at many levels, a range of family support services, training and educational options, domiciliary options, and work options is being developed. In many places, traditional residential institutions have redefined their programs, dispersed some of their functions among small specialized facilities in communities, and/or have become the hub of regional programs. All services are being ordered along a continuum which will allow progressive movement of the individual toward as much independence in adult life as the degree of normative skill development will permit.

Services

Two major groups of services may be considered within the emerging service system as follows: (1) those which are directed toward the maximum cognitive competency and adaptive behavioral outcomes of the developmental period; and (2) those which are directed toward the maintenance of functional and productive capacities in adult life.

Developmental Services

Training and education are the one constant feature of programming throughout the developmental period. During this time, all other professional services are titrated for their specificity against the assessed needs of the child and family.

If identification of developmental retardation occurs in early infancy, home-training programs may be instituted in order to provide parents with the knowledge of appropriate developmental and behavioral objectives and to assist them in acquiring effective techniques of support. These programs may be especially important if the infant or young child with mental retardation, cerebral palsy, or multiple disabilities presents unusual cues or stimuli to parents. In these instances, the automatic or untutored parental responses may be inappropriate, may impede effective learning progress, and may even reinforce maladaptive behaviors. During the preschool period, the

focus of training and education shifts to extrafamilial, developmental day-care programs, often with the continuation of a parent educational component. It is noteworthy that preschool programs, such as Head Start, are increasingly accepting children with mental retardation and other handicapping conditions into their services.

By school age, preparation begins for the range of social environments which may be open to the person in adult life. At this time, a few profoundly retarded or multiply handicapped children may be placed in medically oriented institutions or nursing-home programs, where they ideally will receive systematic stimulation, behavior shaping, care, and consistent social contacts. Other children, who are severely or moderately retarded, may enter self-contained special educational programs either in regular schools or in a segregated community facility. Children with mild retardation may receive a variety of educational programs in regular schools as follows: self-contained special education, split regular and special education, regular classroom with special resource teachers, regular classroom with tutors and programmed instructional aids, or regular classroom with no special supports. By the teen years, training and education are vocationally and work oriented and may terminally involve work-study experiences.

The family is viewed as the major resource for the care of the child with mental retardation during the developmental period. All necessary medical,

allied health, social, counseling, mental health, recreational, transportational, protective, legal, and other services must be available in order to support the continuation of community living in the nuclear family, if feasible and appropriate. Alternate living arrangements should also be available in foster homes or group homes on a short-or long-term basis, as indicated by the capacities of the nuclear family. Generic service agencies should include staff skills in the range of problems which may be associated with mental retardation.

Massive traditional institutions are now viewed as an option of last resort for developmental services for children with mental retardation. Many institutions at present, however, are integrating their activities with the continuum of community services. A range of services may be offered to the population of a region, for example, in support of continued family care. Specialized residential programs may be provided for multiply disabled children, especially for those from non-urban areas. For many profoundly retarded children with continuing medical needs, developmentally oriented nursing-care programs may be provided in residence. Habilitative residential programs may also be offered with the aim of returning the child to the family or community after specific developmental or behavioral objectives have been achieved. In some instances, a reverse flow is affected in which institutional residents receive all or most of their educational programming in the community. New residential facilities are being constructed in many parts

of the country which imaginatively exploit architectural possibilities for normalizing institutional environments. Recently, minimum institutional standards have been adopted for the accreditation of residential facilities which ensure a basic quality of professional care and service.

Ideally, the available range of domiciliary options, work options, and guardianship arrangements should permit parental responsibilities for the person with retardation to end when he reaches adult life. Except in a few instances, this ideal is not yet realized.

Adult Services for the Enhancement and Maintenance of Functional and Productive Capacities

The need for special adult services is determined by the amount of social structuring which the individual requires, i.e., whether independent or dependent living is possible. In either case, the usual generic human-service agencies and programs must be available on a need basis. Special consideration must be given to domiciliary arrangements, work provisions, heterosexual (or homosexual) activities, and legal rights. It is axiomatic that living and work arrangements should enable the person to approximate normative experiences as nearly as the behavioral potential permits.

Domiciliary arrangements may involve institutions, half-way houses, hostels, or small group homes for individuals at moderately and mildly

retarded levels. Progression toward decreasing supervision within facilities should be possible as competence for work and independence increases. The psychological meaning of useful and remunerative work for the retarded is underscored here. Vocational rehabilitation services and a spectrum of settings for productive employment are necessary if community living is to succeed. Possibilities for heterosexual relationships and marriage are just beginning to be explored systematically in the face of long-standing social biases.

Edgerton has provided a poignant documentation of the quality of life associated with unsupervised community living for a number of individuals with mental retardation.

Identification

The responsibility for the identification of children with mental retardation is shared by all persons who are concerned with the development of the child, including the parents. Physicians are in a particularly strategic position to identify the children who come through medical channels. Presumptive identification may be achieved in medical office settings if sensorimotor, language, or social development deviates markedly from the norms of screening instruments such as the Denver Developmental Screening Test. Other infants and young children who do not receive care in physicians' offices may be identified in well-child clinics or in their own homes by public health nurses who are trained in developmental surveillance. Many other children are identified first in relation to the demands of day-care, nursery, or preschool programs. The importance of the schools as a source of identification of mild forms of retardation has been previously emphasized. Finally, developmental delay or mental retardation may be suspected first by parents, especially in high socioeconomic families, although even sophisticated parents occasionally overlook signs of difficulty for long periods of time.

Except for school identification, these activities serve chiefly to identify children with the most obvious manifestations of mental retardation. Other agencies, including physicians, may be somewhat less effective in identifying

mildly retarded children, especially in the absence of neurological or somatic abnormalities. Unless the objectives of identification are related to specific forms of intervention which can be immediately activated, however, *early labeling is a sterile exercise which may have harmful consequences for some children.* The state of the art in the area of screening and assessment of young children at developmental risk has been recently reviewed by Meier.

Evaluation

The "diagnosis" of mental retardation may have different connotations in different settings. It may refer to the formal labeling of a child through professional studies which identify the psychometric and adaptive behavioral criteria. It may refer to a medical evaluation for the identification of etiologies or remediable disorders which may be compounding the developmental and behavioral issues. In still other settings, it may refer to a comprehensive, interdisciplinary study of the child's functional characteristics for the purpose of identifying appropriate objectives for intervention, assigning professional responsibilities, or designating appropriate service resources. None of these "diagnostic" activities is necessarily confined to one location or a single discipline.

Medical Evaluation

The physician follows a definite agenda in the medical evaluation of children with mental retardation. He must identify associated medical disorders which are heritable, thereby permitting genetic counseling for the parents, amniocentesis for intrauterine diagnosis in subsequent pregnancies (where possible), or early recognition in subsequent offspring. In rare instances, a specific treatment may be available which will permit the amelioration or interruption of an underlying genetic disease. As noted in the preceding chapter, the clues which are presumptive of a specific medical

disease, including those which are heritable, are the following: (1) positive neurological signs; (2) neurological deterioration; (3) malformation clusters; (4) positive biochemical screening tests; (5) other physical signs, including macular degeneration, ectodermal lesions, and the like; and (6) prior family history of a heritable disorder. The physician must also identify remediable medical disorders which are actively inhibiting development through the restriction of response capabilities. Areas of concern here may include visual acuity, auditory function, convulsive activity, neuromuscular impairment, otologic, orthopedic, cardiac, or similar disorders. The physician may be assisted in this endeavor by a variety of medical specialists and allied health professionals. Many children with mental retardation will have additional disabilities which require treatment. The physician may also be assisted by social workers and psychologists in recognizing potentially remediable psychosocial factors which are actively interfering with cognitive growth and adaptive behavioral development.

Functional Evaluation

Present-day management of mental retardation during childhood is directed toward the production of specified changes in a child's competencies and adaptive behavior. Intervention of this type requires a definition of specific learning and behavioral objectives. A functional analysis of the child's current, observable behaviors is the necessary first step in defining these

objectives. Measures of intelligence which compare a child with a standardization group for the primary purpose of categorization have limited usefulness for this purpose; likewise, etiologic diagnoses are meaningless in this context.

A functional analysis of the child's behavior may involve any or all of the following: (1) a determination of his current developmental locus (i.e., his learned behaviors); (2) observation of his learning behaviors or processes; (3) observation and specification of his maladaptive behaviors; (4) observation of the environmental consequences (and possibly antecedents) of his maladaptive behaviors; and (5) delineation of the limitations which are imposed by medical findings on his response capabilities under specific demand situations.

The identification of the child's present locus in a known developmental sequence automatically defines his next developmental steps and delineates appropriate objectives for intervention. In recent years, studies in cognitive psychology, psycholinguistics, and social adaptive behavior (among children with mental retardation) have refined our knowledge of the hierarchical sequences of development, and, in some instances, have contributed to the construction of ordinal or other scales for the purpose of assessment (See references 21, 22, 25, 26, 28, and 29). It is now possible to specify a child's locus in any of several developmental streams with considerable precision.

Likewise, a child's educational locus and learning behaviors can be analyzed through psychoeducational instruments and educational observations. Again, the child's locus and functional characteristics delineate the appropriate educational objectives and approaches.

Maladaptive behaviors and those which are inappropriate and unacceptable in particular settings may also be observed and specified. When defined with sufficient precision, maladaptive behaviors can be rank-ordered in terms of importance, counted, and specified as potential targets for modification. The target behaviors which are selected for modification are usually determined in consultation with parents or other involved persons. The attempt to change adaptive behavior requires an analysis of the environmental consequences of the child's behavior as well. Consequent parental behavior and that of other significant persons with whom the child interacts must be specified in this context as simultaneous targets for modification.

Prescriptive Programming

From the preceding discussion, it is apparent that a new model has evolved in community and residential facilities for professional intervention with children with mental retardation. Prescriptive programming is the keystone of intervention within this model. A prescription is based upon the results of the analysis of a child's current, observable, functional characteristics. When all objectives have been identified and clearly specified, appropriate techniques for intervention can be prescribed, either in the area of training and adaptive behavior, or education. Behavior principles and modern educational concepts supply the technology for intervention of this type. Some features of behavior modification and effective educational programming were noted briefly in the preceding chapter.

A pragmatic test is an essential ingredient of prescriptive intervention. The program which is prescribed must finally be shown to be feasible for implementation within the home, the community facility, or the school, and to have demonstrable efficacy in the production of movement toward the specified objectives. If neither feasible nor effective, the objectives or the techniques of intervention, or both, must be modified.

Interdisciplinary Model

The interdisciplinary model is an organizational structure through which professional services are delivered to persons with mental retardation. The model is based upon the assumption that the complexities of the problems of the individual with mental retardation exceed the resolving power of any single discipline. The professional composition of the interdisciplinary group varies according to the forms and severity of the problems and the age of the person. The professional group at one time or another and in different circumstances may include some combination of the following: psychologists, educators, audiologists and speech pathologists, social workers, vocational counselors and rehabilitationists, allied health professionals, physicians from any of several specialties, including psychiatry, and care staff members. The contributions of each discipline are determined by the match between its specific skills, the functional characteristics of the person, and the priorities for intervention which are established through the interdisciplinary group process. Except for the continuing importance of education during childhood, the contributions of other disciplines may vary from person to person and at different points in the life of the same person.

The interdisciplinary model ensures the availability of appropriate professional skills for the person. In addition, it minimizes professional redundancy by requiring each discipline to define clearly its special expertise

vis-a-vis other disciplines. Through the interdisciplinary group process, the disciplines frequently generate a multifaceted view of the person, his problems, and the objectives for intervention which can rarely be duplicated by professionals who work independently.

Parental Involvement

Many early-infant educational projects have included a subsidiary parent-educational component, and several have worked primarily with parents in the home. These programs have demonstrated that specific direction of the maternal transactions with an infant or young child can influence developmental outcome under the conditions of the studies. In addition, the growing literature in the field of behavior modification has indicated that parents can be effective agents for intervention in relation to a wide spectrum of behavioral phenomena if provided with knowledge of appropriate objectives and techniques. It has now been recognized that parents can be taught to be effective teachers, that they can profit from formal specific child-rearing education, and that they can modify their behavior to some degree if they are reinforcing maladaptive behavior.

Present approaches to the education of parents of children with mental retardation often emphasize instruction in the techniques of behavior modification. Although few studies have been designed to date with sufficient rigor to permit an objective evaluation of this approach, the education of parents in specific techniques to support the development of their own children has a strong intrinsic appeal. When the education of parents involves the use of the techniques of behavior modification, the parent becomes a contributing and participating member of the professional team concerned

with intervention. The parent may then be regarded as a manpower resource for the conduct of the child's program in the natural setting of the home. In the process of generating a prescription for intervention in conjunction with professionals, parents can learn appropriate developmental objectives, participate in the delineation of maladaptive behaviors, and acquire techniques and behaviors through which to fulfill a supportive and effective role with the child. Under these circumstances, the parental role acquires direction and specificity, and the parent assumes an active rather than a passive stance in relation to the child's problems.

Obviously, the educational approach to parents need not be limited to indoctrination in the techniques of behavior modification. The latter may lead at times to the delineation of objectives which are too narrowly defined from a comprehensive perspective. Any additional combination of the following techniques may be employed in working with parents: individual educational discussions, informational classes, group work, modeling experiences, feedback experiences—possibly with immediate cueing or delayed videotape viewing—and insight counseling.

Family Support

It is easy to overgeneralize concerning the psychological adaptations of parents, siblings, and the retarded child or adult. Often discussions concerning these adaptations are based upon stereotypes derived from experiences limited to high socioeconomic-status parents who have a severely retarded child. Obviously, the psychological adaptations of parents may vary according to multiple idiosyncratic factors as follows: the severity of mental retardation and the extent of the child's deviancy in behavior and appearance; age of the child; sex of the child and of the parent; age of the parent; sociocultural background; investment in the child for achieving unfulfilled parental ambitions; duration of the marriage and its mutuality and stability; presence or absence of other normal children in the family; religious orientation; orientation toward achievement; past experiences in dealing with adversity; previous attitudes toward handicaps and minority groups; need for social approval; need for utilization of the child in neurotic patterns which may defeat professional efforts for change or improvement.

In general, the adaptational problems of parents reflect anticipated psychological responses to the degree of realistic stress which the child poses. If the child is severely impaired, parents may exhibit a predictable sequence of reactions leading eventually to adjustment in accord with crisis theory. A phase of initial stress, shock, grief, and disorganization may be followed by a

prolonged phase of reintegration in which feelings of denial and guilt may be associated with the observed behavioral patterns. Eventually, an adaptation is reached which will permit internal comfort and constructive action by most parents. The passage of time and a prolonged expenditure of effort in behalf of the child may be necessary before the latter stage of resolution is reached. During the interim period, specific instruction and concrete assistance for increasing parental effectiveness with the child may be at least as important for psychological movement as the gaining of psychological insight.

Within the broad phases of adaptation, points may occur at which psychological stresses are intensified for parents in association with the maturation of the child. After initial recognition, these points may include: (1) the period at which the child's chronological age ordinarily would permit school attendance; (2) the period of pubescence with increased physical growth, sexual maturity, and sexual or erotic interests; and (3) the period of entry into adult life with the necessity for decisions concerning provisions for living and supervision.

Although the psychological reactions of parents may be homeostatic for them, the overt behavioral correlates of these reactions may be maladaptive for the support of the cognitive and adaptive growth of the child. Management goals are required for parents and the child, therefore, which are both separate and interrelated. In general, the dual objectives can be met most

effectively in the context of the child's program setting. Under these circumstances, it is least likely that the professional focus upon the child will be subordinated to an interest in the psychodynamic reactions of the parents. The experienced professional will observe the course of parental adaptations with time, however, as indications of denial, guilt, dependency, and projection are revealed. Individual psychotherapeutic efforts for parents, when indicated, should occur in facilities appropriate for them.

It is inevitable that some of the difficulties associated with the presence of a retarded child in the family, especially at severe levels, will impinge upon the normal siblings and create adjustment problems for them. Again, their problems may be seen as anticipated responses to stress which can usually be assimilated without major disruptive effects. Professional counseling for the parents or the normal siblings may be helpful at times in support of the adaptational processes. The fact that an affected child was born into the family may raise doubts for teenagers regarding their own capacity for parenthood. The provision of accurate information in clear, objective terms will be helpful in dispelling these apprehensions.

The management of erotic feelings and sexual behavior generates more uncertainty and concerns in relation to the child or adult with mental retardation than any other aspect of behavior. Many individuals with retardation reach puberty and adult life without adequate information,

understanding, or opportunities to learn appropriate mechanisms for coping with sexual feelings. Parents and professionals alike may systematically avoid specific preparatory efforts in these areas. Parental concerns at adolescence often focus upon unconcealed masturbation, sexual exploitation (either heterosexually or homosexually), pregnancy, and lack of control of sexual impulses. The recent emphasis upon normalization and the increased movement of individuals with retardation in society has highlighted the potential sexual risks. At least at an academic level, attention is now being directed toward the necessity for instituting curricula and training programs for the preparation of children to fill adult social (including sexual) roles. Parental instruction is almost universally needed as a means of enabling them to provide appropriate support for developmental growth in this area.

Professional Decorum

The overt behavior which the professional person manifests in fulfilling his specific responsibilities for the child may have powerful, nonspecific side effects for families. In utilizing himself as an instrument for parental support, the professional person should demonstrate technical competence, provide an appropriate behavioral model with the child, and demonstrate a constancy of interest in the child and family. He should also maintain an expectation of developmental movement in the child in line with the prevailing optimism surrounding present-day approaches to intervention and in recognition of the shaping effect of expectations. Finally, he should respond positively to appropriate parental behaviors and neutrally to inappropriate behaviors as a means of reinforcing parental strengths and attenuating weaknesses. The professional person should be aware, however, of the emotional turmoil which parents may feel and the range of behavioral responses which they may exhibit in relation to a child with severe mental retardation. He may then provide an important, nonspecific source of comfort, if needed, through his listening skills.

Drug Treatment

The physician may be an instrument for increasing the effectiveness of learning and behavioral intervention for some children by prescribing neuropharmacological agents which may modify distracted behavior or control seizures. In these instances, the choice of an appropriate agent and dosage requires the joint participation of educators and other disciplines as objective observers of behavioral effects through the use of rating scales and other quantitative measures. Drug therapy, however, cannot substitute for appropriate educational or intervention programs. At times, the behaviors, which a physician is asked to modify through drug treatment, represent behavioral responses to inappropriate or nonindividualized programs or to maladaptive parental behavior. Appropriate program prescriptions should always precede medicinal prescriptions. Neuropharmacological agents do not have the potentiality for modifying basic behavioral patterns or learning characteristics. Only appropriate behavioral programming can accomplish the objective of basic behavioral change.

When prescribing neuropharmacological agents, the physician may be advised to follow the format of a behavior-modification prescription. Thus, the behavior(s) to be modified should be clearly defined and specified in concrete terms. The frequency of the target behavior should be counted with and without medication in the child's home and/or school setting. Measurable

changes in school-learning behavior should likewise be demonstrated if academic objectives are the defined targets. *Since neuropharmacological agents are potent drugs with significant potential side effects, treatment should be discontinued if it fails to produce quantitative evidence for the intended behavioral effects.*

Ethical, Moral, and Legal Issues

Mental retardation pinpoints sharply many ethical, moral, and legal dilemmas for the professions and society at large. Judgments concerning the withholding of life-saving medical treatments in individuals who are demonstrably retarded; human experimentation in retarded populations with attendant issues concerning risks and consent; sterilization procedures on the indication of retardation alone; marital prohibitions; institutional commitment procedures; denial of rights and unequal treatment before the law; all and many more discriminatory practices are currently being questioned and sharply attacked. The values and fabric of our society are threatened as long as these inequities are permitted to exist. Strong advocacy for individuals with mental retardation has become a major responsibility for all who are concerned with human life, dignity, and pluralism.

Conclusion

Within the recent past, major changes have occurred, and are continuing to occur, in concepts and practices related to intervention with children and adults with mental retardation. These changes have generated an expectation that the developmental velocity and adaptive behaviors of all children can be modified through specified forms of environmental intervention. During the developmental period, community services in support of family care have supplanted the large institution as a major resource for service and care. In adult life, the thrust toward normalization has led to a variety of living and work options which have contributed to a clarification of the ultimate objectives for developmental interventions. To an important extent, social changes have occurred which have increased the options for a retarded person even when the possibilities for individual change are sharply limited. But communities must be conscious of the extent of the commitment which is required to build a spectrum of community-based services (integrated with institutional services) in order to make these options realistic. Without the commitment of adequate resources, community programs risk the same disenchantment which historically overtook residential institutions.

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