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Major Trends in Mental Retardation

GUEST EDITORS: PHILIP ROOS
BRIAN M. McCANN

member of

national association for
retarded citizens

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MAJOR TRENDS IN MENTAL RETARDATION

Guest Editors: PHILIP ROOS and BRIAN M. McCANN

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Progress and improvement in the lives and prospects of the nation's millions of mentally retarded individuals depend, ultimately, on how well the services they need are delivered. And how well the services are delivered depends primarily on the planning, efficiency and effectiveness of the state and community agencies that administer and furnish public programs and services for the handicapped... .

Although the retarded child of today has a far greater opportunity for a life of active adult citizenship than his predecessors, there are [still] major opportunities to meet and solve problems if the past is to be a prologue to a better future for the retarded individual. The task before us is to apply our current knowledge. . .

The President's Committee on
Mental Retardation (1971)
The decisive decade

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MAJOR TRENDS IN MENTAL RETARDATION

PHILIP ROOS and BRIAN M. McCANN

Human beings surpass all other life forms on earth in intelligence. Their capacity to reason, to conceptualize, to learn, and to manipulate time distinguishes them as unique. Most contemporary societies place high value on intelligence and tend to equate it with being human. Hence, individuals lacking in intelligence tend to be considered less human than others; typically, they have been stigmatized and denied full participation in society.

Defining Mental Retardation

Mental retardation is the current term used to refer to the many conditions characterized by difficulty in complying with cultural values regarding intellectual and social behavior. Although numerous definitions are in current use, there is general agreement that a diagnosis of mental retardation is based on multiple criteria, including measured intelligence (usually quantified as an Intelligence Quotient, or IQ), adaptive behavior level (sometimes quantified as a Social Quotient), and medical classification (Roos, 1973). In general, performance on a standard intelligence test falling within the lowest 3% of the population (at least two standard deviations below the mean) is considered essential — though not sufficient — for such a diagnosis (Grossman, 1973).

Mental retardation is no single entity, but rather the result of any one of a multitude of possible conditions, all of which have

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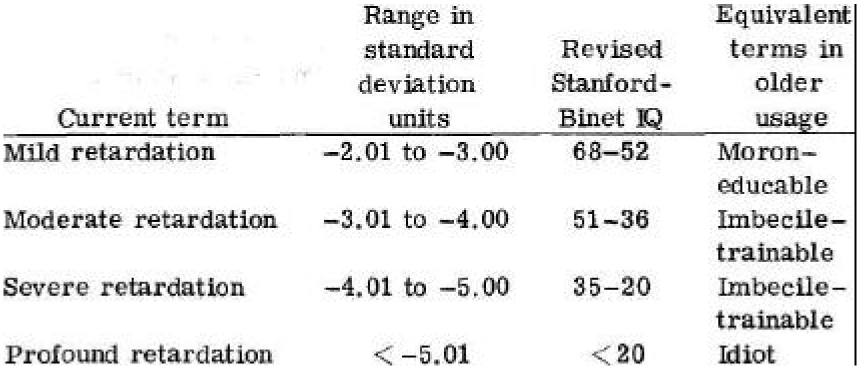
Philip Roos is Executive Director, National Association for Retarded Citizens, 2709 Avenue E East, P.O. Box 6109, Arlington, Texas 76011. Brian M. McCann is Director, Research and Demonstration Institute, NARC.

Levels of Measured Intelligence



Current term	Range in standard deviation units	Revised Stanford-Binet IQ	Equivalent terms in older usage
Mild retardation	−2.01 to −3.00	68−52	Moron-educable
Moderate retardation	−3.01 to −4.00	51−36	Imbecile-trainable
Severe retardation	−4.01 to −5.00	35−20	Imbecile-trainable
Profound retardation	< −5.01	< 20	Idiot

the common effect of significantly impairing intellectual functioning. The capacity to reason abstractly, to exercise judgment, and to learn are most obviously affected.

Although more than 250 causes of mental retardation have been identified to date, no specific cause can be determined in approximately 75% of cases (President's Committee on Mental Retardation, 1971).

Levels of retardation vary from extreme impairment rendering the individual practically helpless to relatively minor deviation from cultural norms. The American Association on Mental Deficiency (AAMD) recognizes four levels of mental retardation, based on the degree of deviation from the average functioning level. The levels of retardation, their approximate demarcation on the Revised Stanford-Binet Test (Terman & Merrill, 1960), a standard test of intelligence, and the old terminology still sometimes used are summarized in the table (based on Heber, 1961). Approximately 89% of retarded persons are mildly retarded, 6% are moderately retarded, and only 5% are severely and profoundly retarded.

It is generally accepted that the mildly retarded are capable of economic self-sufficiency and that the moderately retarded can be economically productive in sheltered employment. Hence,with current technology, approximately 95% of retarded persons have the potential of being economic assets to society. Technological advances could, of course, increase the number.

The most widely held conclusion regarding the incidence of mental retardation in the United States is that 3% of the population will at some time in their life function in the mentally retarded range. Thus, more than 6 million Americans will fall within this group (Tarjan, Wright, Eyman, & Keeran, 1973). Probably no more than *1%* of the population, or 2 million Americans, are identified as mentally retarded at any given time (Tarjan et al., 1973). This discrepancy between incidence and prevalence is attributable to the fact that the diagnosis of mental retardation is related to age and that the mortality rate is higher for seriously retarded persons than for the average population. Hence, the peak period of identification is between the ages of 6 and 12 years, and about two-thirds of those diagnosed as mentally retarded lose this label during adolescence or early adulthood.

Historical Antecedents

Interest in humane care for the retarded is of recent origin, dating from the mid-1800s, whenafew pioneers regarded retarded persons with optimism and initiated services to educate and habilitate them. Following the well-known work of Itard, early workers established residential institutions as educational facilities designed to prepare their residents for productive life in society (Kanner, 1964). The goals of these early efforts were remarkably similar to contemporary philosophy regarding institutional services (Baumeister, 1970; Helsel, 1970; Kanner, 1964; Wolfensberger, 1969).

The historical development of residential institutions in the United States has been described in terms of changing approaches to deviancy (White & Wolfensberger, 1969; Wolfensberger, 1969). Such early pioneers as Seguin, Wilbur, and Home in the United States and Guggenbuhl in Switzerland developed programs to educate the retarded for return to society. This initial phase (1850-80) was characterized by efforts to make the deviant "undeviant."

The promised results failed to materialize, however, and institutions grew from the accumulation of a residue of nonhabilitated residents. The focus shifted from habilitation to effective isolation, economy of operation, and maximum use of resident labor (1870-90). The guiding philosophy became one of protecting the deviant from society.

This phase was soon replaced by custodial warehousing, designed to protect society from the deviant (1880-1925). Genetic studies allegedly linking retardation to antisocial behavior (Goddard, 1914) contributed to concern for controlling and containing the retarded. Services that would currently be characterized as dehumanizing were advocated by most leaders in the field, including Fernald, Powell, Carson, and Barr.

These early approaches to services for retarded persons generated destructive models of mental retardation, which still linger today and interfere with habilitation efforts and public acceptance of the retarded. These models, as described by Wolfensberger (1972), have included the subhuman organism, the menace, the object of pity, the eternal child, and the diseased organism. Each of these models generates destructive approaches to the retarded. For example, the diseased organism model depicts retarded persons as sick and in need of "treatment" and "hospitalization." Dependency, safety, cleanliness, and comfort are emphasized, the prevailing attitude being pervasively pessimistic as a result of the concept that mental retardation is "not curable" and therefore is "hopeless."

Current Trends

The past decade has witnessed significant, in some cases sweeping, changes in attitudes and philosophies regarding mental retardation. The new perspectives have resulted in a renewed wave of hope and optimism that, in turn, has been reflected in increased emphasis on the provision of individualized programs geared to meet the specific learning needs of mentally retarded clients.

The Developmental Model

A major stride has been the gradual erosion of the once prevalent destructive models of mental retardation in favor of a more positive view. For example, Wolfensberger (1969) advocates the replacement of these negative stereotypes with a developmental model of mental retardation, which he defines as follows: "The developmental model takes an optimistic view of the modifiability of behavior, and usually it does not invest the differences of the retardate with strong negative value. Retardates, even if severely retarded, are perceived as capable of growth, development and learning" (P. 81). This definition has been expanded by Roos, McCann, & Patterson,[1] who stress the programmatic implications of the concept:

> Programs for retarded persons based on the developmental model are designed for the express purpose of modifying the rate and direction of behavioral change. Recognition of the fact that each retarded child or adult is in a continual state of flux, subject to the influences of dynamic encounters with the environment, is basic to the concept. Goals or programs based on this model consist of selecting some changes for acceleration, identifying others for deceleration, and selectively modifying the direction of these changes.

Three criteria were proposed for assessing the legitimacy of goals for retarded individuals, it being stated that programs should be designed to: (1) increase the retarded person's control over his environment; (2) increase the complexity of his behavior; and (3) maximize his human qualities (i.e., those behaviors culturally defined as "human," "normal," or "desirable"). These criteria were subsequently incorporated in Section 1.1.1 of the Standards for residential facilities for the mentally retarded of the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (AC/MR-DD, 1971).

The Normalization Principle

Another major force in the ideological shift that began in the late 1960s was the normalization principle. This concept had its roots in Scandinavia, where it was reflected in programs for the mentally retarded long before the term was coined. Thus, normalization was incorporated in mental retardation legislation passed in Denmark in 1959 and in a comprehensive Swedish law enacted in 1967. However, the normalization principle was first systematically enunciated and elaborated upon by Nirje (1969), who defined the essence of the concept as ".. .making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (P. 181).

Nirje's treatise on normalization, which appeared as a chapter in a volume on residential services for the mentally retarded published by the President's Committee on Mental Retardation, was greeted with considerable acclaim by professionals and laymen involved in the mental retardation movement. Dybwad (1969), in a companion chapter, hailed Nirje's contribution as "without a doubt.. .the most important one in this book" and noted that the normalization principle was ".. .elegant in its simplicity and parsimony. It can be readily understood by everyone, and it has most far-reaching implications in practice" (P. 385).

Nirje's definition, which had a profound influence on American thinking, described normalization as a <u>process</u>, i.e., as an approach to programming for mentally retarded persons. This formulation seemed to be predicated on the critical <u>implicit</u> assumption that providing retarded individuals with normalized conditions would yield normative behavior. Subsequently, Wolfensberger (1972) presented a reformulation of the concept that dealt with not only process but also the goal of establishing and/or maintaining ".. .personal behaviors and characteristics which are as culturally normative as possible" (P. 28). This definition was more compatible with the developmental model, since it emphasized goals rather than means of reaching them.

An appropriate note of caution has been sounded by Grunewald (1974) regarding possible misinterpretations of this concept: "Normalization does not imply any denial of the retarded person's handicap. It involves rather exploiting his other mental and physical capacities, so that his handicap becomes less pronounced. It means also that the retarded person has the <u>same rights and obligations</u> as other people, so far as this is possible" (P. 5).

Individualization and Self-actualization

The growing acceptance of the developmental model and of the normalization principle has been paralleled by an increased emphasis upon individualization in programming for the retarded. A key ingredient is the individual program plan, developed on the basis of a thorough interdisciplinary evaluation and consisting of: (1) a specific statement of long- and short-term goals, stated in behavioral terms that will yield measurable indices of progress; (2) the programmatic strategies that will be utilized to attain these goals; (3) the persons responsible for carrying out the program and the training schedule to be followed; and (4) a statement of the data that are to be collected in order to assess progress. In the case of institutional residents, concrete postinstitutional plans are a fifth and critical element. It is encouraging to note that individual program plans are, in fact, a prerequisite for accreditation by the Accreditation Council.

In institutional settings, individualization is beginning to be reflected in a gradual move away from the dehumanization of traditional congregate care, which ignores the needs and desires of the individual and systematically strips him of human dignity and self-respect. For example, in some facilities, barren and depressing living environments are being modified to permit greater privacy, and colorful bedspreads and curtains, ordinary household furniture, and attractive wall decorations are being introduced; institutional clothing and standardized hairstyles are slowly giving way to greater latitude in dress and grooming; programs and activities are being based on individual rather than modal needs; and such debasing practices as "assembly line bathing" (Addison, Luckey, & McCann, 1972) are being supplanted by efforts to foster self-help skills. In most states, however, these changes are proceeding at a painfully slow pace.

A concomitant development is the increased opportunities for self-actualization that mentally retarded people are being afforded. This construct has been widely discussed, with varying degrees of abstraction, in the clinical literature (e.g., Goldstein, 1939; Rogers, 1951). For many retarded persons it is being translated into heretofore denied opportunities to have a voice in shaping their own destinies. In the case of the more severely impaired, this may involve relatively simple choices and decisions in such areas as food and dress. For the person whose handicap is less pervasive, it can mean the right to choose his lifestyle and place of residence.

Consumer Advocacy

Corporate advocacy on behalf of retarded citizens had its roots in the 1930s, when parents began to band together in small groups to seek improved services for their mentally retarded offspring.

These efforts coalesced into a nationwide movement in 1950,when 42 parents representing several local organizations banded together to form the National Association for Retarded Citizens (NARC), originally called the National Association of Parents and Friends of Mentally Retarded Children (National Association for Retarded Children, 1966). Today this organization has some 250,000 members, in nearly 1,900 state and local units. Over the past 27 years, the membership of the NARC has broadened considerably. Composed largely of parents at the time of its founding, approximately 20% of the NARCs members are now professionals, and some 25% are concerned citizens (National Association for Retarded Citizens, 1976b).

The history and accomplishments of this national advocacy movement, which have been discussed in detail elsewhere (e.g., Roos, 1970), have included concerted efforts to improve the quality of life for retarded individuals through legislative reform, research, public education, programmatic leadership, and, in some instances, the provision of direct services in order to demonstrate the feasibility of previously untried approaches (e.g., community-based residential alternatives) or to fill voids in publicly supported service systems (e.g., education and training programs for the severely and profoundly retarded).

A new dimension was added to organized advocacy efforts in 1967 with the founding of Youth-NARC, which stresses direct personal involvement of its members with retarded persons (National Association for Retarded Citizens, 1974). This division of the NARC, composed of young people ranging in age from 13 to 25, has now grown to approximately 20,000 members, in 600 units.

A more recent development has been organized self-advocacy by mentally retarded people themselves. This trend is exemplified by People First, founded in Oregon, which recently held a convention attended by more than 600 participants (National Association for Retarded Citizens, 1976a).

Another exciting development on the advocacy front has been the introduction of the citizen advocacy model, by Wolfensberger,[2] who defines the essence of this approach as "a mature, competent citizen volunteer representing, as if they were his own, the interests of another citizen who is impaired in his instrumental (practical problem solving) competencies, or who has major expressive (relationship and/or affectional) needs which are unmet and which are likely to remain unmet without special intervention" (P. 4). The rationale underlying citizen advocacy is that many people are handicapped or disadvantaged in such a way or to such a degree that they cannot effectively represent their own interests in our rapidly changing society.

The first citizen advocacy program was established by the Capitol Association for Retarded Children,[3] in Lincoln, Nebraska, in early 1970 and was awarded a commendation by the President of the United States the following year. With funding from three agencies within the U.S. Department of Health, Education, and Welfare, the NARC initiated a national program in 1972 to catalyze the development of a nationwide network of citizen advocacy programs (Copeland, Addison, & McCann, 1974). According to a recent study (Addison, 1977), there are currently 142 local citizen advocacy programs operating in 32 states and an additional 10 state citizen advocacy offices, which provide backup services. These local programs involve some 5,000 one-to-one advocate-protege relationships. Approximately 75% of the programs surveyed were administered and operated by Associations for Retarded Citizens (Addison, 1976).

Perhaps the most dramatic advance in advocacy in the 1970s has been the use of class-action suits to safeguard the rights of retarded citizens and to obtain improved or new types of services for them. For example, the national component of the NARC and a number of its state and local units, together with a variety of other public and private groups (e.g., the U. S. Department of Justice, the Mental Health Law Project, and the National Center for Law and the Handicapped), have participated in litigation involving several key issues, including the "right to treatment" (e.g., <u>North Carolina Association for Retarded Children v. State of North Carolina</u>; <u>Wyatt v. Stickney</u>; and <u>Ricci v. Greenblatt)</u> and the "right to education" (e.g., <u>Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania</u> and <u>Mills v. Board of Education of the District of Columbia</u>). Decisions in the former area have been instrumental in eradicating some of the abuses that have characterized public institutions for the retarded. Suits concerning the right of all school-age persons to a free, public education have, in turn, succeeded in opening the doors of the public schools to severely and profoundly retarded children In a number of states. This "zero reject" approach has been codified in the Education for All Handicapped Children Act (P.L. 94-142), enacted by Congress in 1975.

Some Emerging Issues

Implementing the Normalization Principle

The value of normalization has now been generally recognized, and the principle is being widely applied and reflected in laws, court decisions, federal regulations, and accreditation standards. Yet even as the principle's popularity continues to increase, serious questions are being raised about its universal applicability.

Although the assumption that application of normalized approaches will yield culturally desirable behavior seems generally valid on both theoretical and empirical grounds, there may be situations in which non-normative procedures may prove more successful in reaching developmental goals. As noted by Roos, McCann, & Patterson:[4] "The fact that a given approach has become culturally normative does not insure that it is the most effective procedure for modifying the rate and direction of individual change in retarded persons, or — for that matter — in persons of normal intelligence" (P. 8).

This flexible application of normalization is reflected in a recent study (Almore & Roos. In press) evaluating predictions of future residential services in the United States during the next 20 years. A majority (69%) of the participating experts predicted that over 50% of settings housing profoundly and multiply handicapped retarded persons will deviate from normalized homelike settings and will capitalize on concepts of human engineering and specialized environments.

Recently, concern has been expressed that rigid adherence to normalization may have certain inherent dangers (e.g., Roos. In press). It may, for example, lead to supersimplification, in that some may assume that by furnishing a "normal" environment for retarded persons, program goals will be automatically reached. Obviously, normalization is no substitute for systematic, individualized programming.

Another potential danger is confusing means with ends and assuming that "normal" procedures will necessarily produce "normal" behavior. Although this assumption may often prove to be valid, there will no doubt be many significant exceptions.

An additional potential pitfall of normalization is that rigid adherence to the principle is likely to impede exploration of novel approaches that deviate from normative procedures. It would be most regrettable if experimentation with new methods, such as application of space technology, were discouraged because of departures from normative practices. In view of these considerations, the following conclusion appears warranted, on the basis of current knowledge:

> In general, normalized procedures and settings should be used. Deviations from normalized approaches are acceptable only when alternatives are more successful in reaching developmental goals. Departures from normalized approaches are not acceptable... for improved efficiency... or for ease of administration. .. . However, should a prosthetic environment that looks in noway like a home prove to be more successful in developing language in a severely retarded child than a normalized approach, it would be a desirable deviation from normalization. (Roos. In press)

Hedonism

Fostering happiness of retarded persons continues to be a popular objective. Indeed, hedonism has been generally adopted as a pervasive cultural value, as is evident from the increasing emphasis on "doing one's own thing," "sexual freedom," "consciousness raising," the "drug culture," and so forth.

Some have maintained that retarded people would be happier if not "pushed" to "achieve beyond" their capacity. This argument has been used to justify custodial care rather than active programming and to retain people in institutions in spite of their potential for functioning in society. Conversely, it has been argued that:

> If retarded children and adults are to be granted the same basic rights as their non-retarded peers, it is clear that developmental goals must take priority over hedonistic considerations, for this is precisely the situation which prevails with individuals of normal intelligence. That is, in the socialization of the non-retarded, "happiness" is sacrificed in favor of developing behavior which is adaptive and culturally sanctioned.[5]

Of course, "happiness" is an ambiguous concept, and at least part of the difficulty in applying it to services for the retarded is that it has both immediate and long-term components. Hence, it can be argued that developmental programming may interfere with immediate pleasure while it increases the individual's capacity to derive future happiness, since achieving developmental goals will increase his ability to control his destiny and enhance his social acceptability. Viewed from this vantage point, it can be claimed that the individual's long-term happiness will be increased as the result of developmental programming, even though immediate pleasure may be curtailed.

On the other hand, the premise that all retarded persons should develop "to their maximum potential" can be attacked as unrealistic and unfair, in that few nonhandicapped persons achieve this level of development. The normative pattern seems to consist of a compromise between a level of functioning that is minimally socially acceptable and the hypothetical maximum potential level of functioning. It would seem that this same pattern is appropriate for retarded persons. Hence, every retarded individual should be assisted to develop to that level of functioning which meets minimally acceptable social standards. Having reached that level of development, retarded people should be granted the same degree of freedom as the nonretarded. They should be allowed the choice of whether or not to develop further, and be given ample opportunities to do so. Hence, the goal of programming for retarded persons might be defined as assisting the individual to reach and maintain his optimum level of functioning rather than his maximum level of functioning (Roos. In press).

Least Restrictive Alternative

The legal principle of the least restrictive alternative ".. .declares that when government does have a legitimate communal goal to serve, it should act through means that curtail individual freedom to no greater extent than is essential for securing the goal" (Chambers, 1973. P. 993). This principle has been used to press for viable community-based residential alternatives to large multipurpose institutions. The rationale is predicated on the assumption that community-based residential services are less restrictive than institutions, so that, if they are able to furnish services meeting retarded persons' needs at least as successfully as institutions, they must be the alternative of choice. Although compelling research findings comparing the effectiveness of different residential models are yet to be obtained, the available evidence suggests that community-based residential services are indeed at least as effective as institutional services for the vast majority, and quite possibly for all retarded persons. It can also be argued that, on an a priori basis, institutions are categorically more restrictive than community-based residential facilities. However, this premise may not necessarily be valid in all situations for all retarded people. Restrictiveness applies not only to physical curtailment of freedom but to psychological and sociological constraints as well. Hence, there may be situations in which retarded persons residing in community-based settings may be living in extreme social and psychological isolation, whereas those living in some institutions may be living in a less restrictive situation in terms of being participating members of an accepting subcommunity. Restrictiveness is obviously a relative concept, to be evaluated in terms of the individual retarded person and the degree to which specific settings provide him or her with freedom.

Glimpses of the Future

Recent trends in mental retardation reflect rapid and dramatic changes in philosophical and technological developments. Progress during the past 20 years has probably been greater than the gains on behalf of retarded people during all of previous recorded history. If this rate of acceleration continues, the next two decades should bring advances in the care of retarded citizens that can hardly be anticipated. Perhaps the only safe prediction that can be made at this time is that the future promises to be vastly different from the past, and that the fate of our retarded citizens will be inextricably bound to social and technological developments.

Toffler's (1970) analysis of the future in terms of the dimensions of transcience, novelty, and diversity is useful in relating current developments to probable changes in the field of mental retardation (Roos, 1972).

Certain anticipated changes in basic aspects of society suggest that mentally retarded persons are likely to benefit. For example, there are those who predict that society will shift from an economy of scarcity to an economy of abundance. If this shift occurs, it will probably entail a change in emphasis from economic productiveness to an emphasis on humanistic values and personal fulfillment. Such a shift would very probably foster a more tolerant and caring attitude toward people who deviate from cultural norms.

A shift from a society based on competitiveness to one based on cooperation, which is predicted by Gorney (1972), would likewise tend to have positive consequences for retarded persons, since it would generate a more positive attitude toward the handicapped and encourage their acceptance as participating members of society. For example, it is probable that children may be systematically rewarded for assisting less competent peers and that students may work on projects as cooperative teams that include retarded and other handicapped pupils.

Greater diversity is expected in approaches to meeting basic human needs. Hence, increasing alternatives to the nuclear family can be anticipated, including multiple marriages, communes, and professional parents. Such alternative lifestyles will probably become equally socially acceptable, and may provide viable possibilities for retarded persons, including those who may be incapable of achieving economic self-sufficiency.

Technological developments during the next 20 years are also expected to greatly improve conditions for retarded persons. For example, educational techniques using prosthetic devices and procedures capitalizing on right-cerebral-hemisphere functions hold great promise, particularly for severely handicapped pupils. Refinements of behavior modification, including direct electric stimulation of the brain, should likewise do much for the education and training of the retarded. Applications of space technology, prosthetic environments, telemetry, and biofeedback may also benefit the lives of handicapped persons.

In the biomedical area, memory-enhancing drugs are expected within the next 10 to 20 years, followed shortly by drugs that will enhance intellectual functioning. Regeneration of neurons may be possible within the next 30 years. Significant advances in the prevention of mental retardation are also expected, including developments in the identification and correction of inborn errors of metabolism, modification of genes through molecular manipulation, and further advances in nutrition.

The specific impact of such technological developments is impossible to assess, but obviously it will be considerable. As expanding technology provides greater control over human destiny, new moral and ethical issues will become increasingly compelling. Hence, the current concerns regarding human experimentation, psychotechnology, sterilization, abortion, parental rights, right to life, and genetic engineering will soon become major moral and ethical issues, not just with regard to handicapped persons but with regard to all people.

The future is more than a recapitulation of the past and more than an extrapolation of current trends. Man is not a helpless victim of what lies ahead, for he has the unique capacity to mold the future and to shape his own destiny. The future of retarded persons will certainly be strongly influenced by sociocultural and technological changes. Yet it will also be a function of the actions of individuals — professionals, administrators, parents, attorneys, legislators — who care deeply about their handicapped fellow human beings.

NOTES

[1] P. Roos, B. McCann, & G. Patterson (1970) Expanding the developmental model. Arlington, Texas: National Association for Retarded Children. Unpublished paper.

[2] W. Wolfensberger (1970) Toward citizen advocacy for the handicapped. Omaha, Neb.: Nebraska Psychiatric Institute, University of Nebraska Medical Center. Unpublished paper.

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[4] Roos, McCann, & Patterson, op. cit.

[5] Ibid.

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