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BASIC CONCEPTS UNDERLYING THE ICF/MR REGULATIONS

Three fundamental concepts that underlie the ICF/MR regulations and are crucial to the implementation of the program are (1) its use of the developmental model; (2) its philosophical roots in the principle of normalization; and (3) the program's protection of recipients' civil and legal rights.

A Conceptual Framework for the Developmental Model

Wolfensberger[3] has advocated the developmental model as the most desirable concept of mental retardation, and he defines it by saying that the developmental model takes an optimistic view that behavior can be modified, and usually it does not invest the differences of mentally retarded persons with strong negative values. Persons with mental retardation, even if severe or profound, are perceived as being capable of growth, development and learning.

Underlying Assumptions

Three assumptions are fundamental to the developmental model:

1. Life is Change: Basic to the adoption of the developmental model is the premise that all human beings are in a constant state of flux. Thus, to view a human being as physiologically or psychologically static is essentially to deny his/her experience as a living organism.

[1]This material has been taken (and updated with certain modifications) from the SURVEYOR COURSE MANUAL FOR INTERMEDIATE CARE FACILITIES FOR THE MENTALLY RETARDED, developed at Tulane University by the Department of Health Services Administration, School of Public Health and Tropical Medicine, 1430 Tulane Avenue, New Orleans, Louisiana 70112, originally in October of 1974. The course was developed under contract from the Division of Provider Standards and Certification (then under DHEW) and sections thereof have also been utilized in the training of Michigan Department of Mental Health personnel for the development of a statewide program of community-based Intermediate Care Facilities in October of 1977. Revisions made are based on factors present in 1984 but a large part of the information provided was not significantly altered. Revised by J. Leismer, 1/84.

[2]This section was based on Phillip Roos, Gene E. Patterson, and Brian McCann's paper entitled "Expanding the Developmental Model." National Association for Retarded Citizens, Arlington, Texas.

[3]Wolf Wolfensberger, Principles of Normalization in Human Services. Canadian Association for the Mentally Retarded, Toronto, Ontario, 1972.

2. Development is Sequential: Related to the concept of life as change is the principle that human beings change in predictable, sequential ways, in compliance with specific stages, e.g., development is an orderly process.

3. Development is Pliable: Although the general sequence of developmental stages is established, individual differences in the details and the rate of development are considerable.

Of particular relevance to those concerned with programming for individuals with mental retardation is evidence that environmental variables, both physical and psycho-social, can significantly alter the rate and direction of individual development. Everything from the effects of nutritional factors upon neurological and intellectual functioning to the effects of sensory and experiential deprivation can be (and usually are) important factors which shape the composite make-up of an individual.

Implications of the Developmental Model

What are the implications of adopting this model in a residential program for persons with mental retardation? First of all, recognition of the fact that each child or adult (whether handicapped or not) is in a continual state of flux, subject to the influences of dynamic encounters with the environment, implies that those responsible for developing programs cannot avoid the responsibility for selecting some areas of change for acceleration, identifying others for deceleration and selectively modifying the direction of these changes.

A critical issue revolves around the criteria to be used in selecting the rate and direction of the changes sought. If survival is, in fact, the bottom line goal of all living things, then the developmental model should be utilized to insure the continuity of the individual. Unfortunately, one can go in either of two directions with survival the goal in each - either one sees survival as "preservation of life" or as "effective coping with the environment." In the former case, especially with respect to the care of mentally retarded persons, this has often meant the removal of as much risk as possible from the environment, promoting as much dependency as possible, thereby somehow insuring survival. The latter implication, though, suggests the taking of steps to enable the person to cope with the environment as effectively as possible, thereby increasing reliance upon his own resources for survival, which in the final analysis is believed to be the most productive and human approach to living. In view of these considerations, it is felt that the definition of survival as effective coping with the environment is more appropriate to the developmental model. On the basis of this definition, three principles emerge as basic to the selection of appropriate goals for the individual:

1. Increased Control Over the Environment: An important aspect of coping is the ability to control the environment and to make choices among alternatives. Persons with mental retardation should, therefore, be helped to develop behaviors which will extend their control over the environment, including other persons and themselves. In an ICF facility, for example, the ability

to feed oneself, or go from place-to-place alone, entertain oneself, protect possessions and to communicate, all contribute to more independent functioning and to more control over one's own existence.

2. Increased Complexity of Behavior: Effective coping with the environment involves the ability to proceed from simple to more complex behavior. The desirability of fostering complex patterns of behavior is based on the premise that such behaviors are in general more effective in coping with the environment than are rudimentary activities. For example, being able to use effective speech and language promotes better functioning than does gesturing and grunting.

3. Maximization of Human Qualities: The third, and in some ways the most basic, principle for determining goals is the concept of maximizing the human qualities of each individual. In the present context, such qualities are defined as those which are culturally designated as "normal" and "human." Obviously, these characteristics differ from culture to culture and from era to era. Failure to comply with cultural standards may seriously impair the individual's ability to cope with the environment, sometimes resulting in rejection or isolation. Indeed, the institutionalizing of persons with mental retardation has often been a direct function of his or her failure to conform to accepted cultural values.

Activities which result in "humanizing" the individual include activities which foster spontaneity, enthusiasm, initiative in interpersonal relationships, and a myriad of other behavioral characteristics judged desirable by contemporary society.

Developmental goals for persons with or without mental retardation are basically the same. A truly developmental program should be individually conceived and designed. The underlying principles of the develomental model will hold, regardless of the individual's particular limitations. At any stage of development, therefore, the specific goals selected for the individual consist of target behaviors which would increase his "humanity," that is, behaviors which make him more autonomous would more closely approximate the cultural norm.

The Normalization Concept

The best means for implementing the developmental model in any service delivery system is within as culturally normative an environment as possible. Thus, the normalization concept refers specifically to the means for achieving the goal of maximizing culturally acceptable behavior. It means that individuals with mental retardation should, to the greatest extent possible, be treated as people first rather than as handicapped first. Emphasis should be first on their strengths and abilities. The implication is that this approach is likely to yield socially appropriate behavior, an assumption which appears generally acceptable both on theoretical and empirical grounds.

The normalization concept means that the pattersn of life for persons who have mental retardation should resemble a normal life style as closely as possible.

Much emphasis has been placed, and quite correctly, on homelike settings. According to the publication of the National Association for Retarded Citizens entitled "Residential Programming for Mentally Retarded Persons, Vol. II," some features of a normalized environment would be:

1. Normal rhythm of day, meaning that the daily rhythm for persons with mental retardation is like that for non-retarded persons, including opportunities for personal activities, privacy and the chance to do nothing from time-to-time.

2. Normal routines, meaning that the places where recreation occurs, where education takes place and where one works, are not the same places in which one lives. Patterns of routine movement should approximate the normal patterns found in ordinary life.

3. Normal rhythms of the year, meaning that persons with mental retardation benefit as much as anyone else from the cycles of events and seasons including vacations and celebrating their birthdays on their birthday.

4. Normal developmental experiences, meaning that in accordance with the developmental model, persons with mental retardation experience normal developmental stages, although delayed in varying degrees, which should be recognized and planned for, so that the person with mental retardation is not subjected to a socially imposed eternal childhood.

Also inherent in the normalization concept is the opportunity to make choices, to live in a heterosexual world, to be afforded basic financial privileges, and to be able to live in home settings which are normal in size and design. These features of a normalized environment are likewise attainable for multipli-handicapped non-ambulatory persons with sensory and motor disturbances.

One controversial aspect of the normalization principle involves the notion of risk. All children learn by assuming calculated risks in preparation for taking adult risks in an adult world. One of the most difficult things to come to terms with in the care of mentally retarded individuals is that they, too, must learn to assess and take risks. There is dignity in risk, but persons with mental retardation are often prevented from achieving such dignity by over-protection and infantalization that is imposed upon them by those responsible for providing services. Risk taking is a natural part of coping with the environment. Of course, the types and consequences of risk must be controlled, but the individual must experience it as part of growth and normal development. With such experience, in the long run, and within certain limits, the potential for effective risk taking and resolution will be greatly enhanced. The person with mental retardation will benefit and his accomplishments will be more his own, a goal that is worthy of anyone.

Although programs must be consistent with these two basic principles (the developmental model and normalization) in order to meet the requirements of the regulations, the regulations mandate only in general terms the use of specific program structures or modalities to meet the residents' needs. As was noted earlier, some program structures - particularly those used for limited

periods of time to achieve specific objectives for persons with mental retardation; i.e., for some persons who are seriously behaviorally involved - may be clearly non-normative within clear controls and time limitations. Such programs must be designed to achieve specific, time-limited, measurable, behavioral objectives that are consistent with the developmental model, with normalization, and with the primary needs of the individual.

Civil and Legal Rights and the Developmental Model

The history of how society has provided for its members with retardation gives ample clues to the very limited extent to which the rights of those members have been asserted and protected. Only in recent times have persons with retardation even been thought of as having a right to human rights. Again, concurrently with other advances in the field of mental retardation, the area of rights has emerged and is now receiving major consideration. It is remarkable how often it is necessary to repeat that all people have the same basic rights. Lists of rights of citizens with mental retardation have to specify rights that the average citizen does not even have to think about.

A worldwide impact was made in 1968 when the International League of Societies for the Mentally Handicapped published its "Declaration of General and Special Rights of the Mentally Retarded." A partial reprint of that declaration follows:

Declaration of General and Special Rights of the Mentally Retarded

Whereas the universal declaration of human rights, adopted by the United Nations, proclaims that all of the human family, without distinction of any kind, have equal and inalienable rights of human dignity and freedom;

Whereas the declaration of the rights of the child, adopted by the United Nations, proclaims the rights of the physically, mentally or socially handicapped child to special treatment, education, and care required by his particular condition.

Now Therefore,

The International League of Societies for the Mentally Handicapped expresses the general and special rights of the mentally retarded as follows:

ARTICLE I

The mentally retarded person has the same basic rights as other citizens of the same country and same age.

ARTICLE II

The mentally retarded person has a right to proper medical care and physical restoration and to such education, training, habilitation and guidance as will enable him to develop his ability and potential to the fullest possible extent, no matter how severe his degree of disability. No mentally handicapped person should be deprived of such services by reason of the costs involved.

ARTICLE III

The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to productive work or to other meaningful occupation.

ARTICLE IV

The mentally retarded person has a right to live with his own family or with foster parents; to participate in all aspects of community life, and to be provided with appropriate leisure time activities.

ABOVE ALL
THE MENTALLY RETARDED PERSON
HAS THE RIGHT TO RESPECT[4]

Using almost identical wording, the United Nations General Assembly adopted a "Declaration on the Rights of Mentally Retarded Persons," in 1971, lending the weight of that international body to the cause. Since then, the American Association on Mental Deficiency has amplified these declarations, resulting in several policy statements concerning the rights of persons with mental retardation.[5]

Rights to Treatment

As previously mentioned, the law now states that if the state offers free, public education to any of its school-age citizens, it must offer such services to all, including those who are developmentally disabled. It is now common knowledge that even the most seriously retarded persons can benefit from a properly-designed program of education and training. Increasingly, schools and day activity programs for adults have adopted a "zero reject" policy, which means that they serve every individual. Obviously, such a policy is consistent with the developmental model's precepts that each individual is capable of learning, of growth and development, if provided appropriate opportunities. Mandatory special education legislation is strongly justified by the experience realized in each state.

[4] The International League of Societies for the Mentally Handicapped, October 24, 1968.

[5] Mental Retardation, October, 1973 and June, 1974.

There is also a growing trend to assert that, in addition to the rights that they share with all other citizens, persons with mental retardation or other developmental disabilities have a right to those services which are necessary to ensure their fullest development. Persons have often been committed to institutions in order to receive treatment and training when, in fact, the institution was unable to or did not provide such services. Increasingly, experience has shown that everything that could be provided in an institution could be provided in a small residential setting and that often it could be provided better in the smaller setting if it was appropriately developed, supported and monitored. Every person with mental retardation, no matter how seriously disabled, can benefit from a properly designed program of treatment and training. This has been endorsed by the courts and confirmed by the experience of many persons nationally.

An additional and related right is the concept of the "least restrictive alternative." Under this concept, the disabled person is entitled to receive care and treatment in the least restrictive setting feasible that can meet his or her needs. If the disabled person is unable to remain in his/her own home, placement in a foster or substitute home should be sought. If such a placement will not meet his/her needs, a community small-group home should be considered, and so on. A centralized institution would be more restrictive than a community-based alternative method of providing residential services. The least restrictive principle also applies to program methodologies, with results like those implicit in the normalization principle. The program utilized must be the least restrictive (that is, the most normative) one that can produce achievement of the behavioral objectives.

If the right to grow, to develop and to lead a "normal" life is basic to all human life, then it is logical that one has the right to the kind of treatment which will insure that the individual will be able to lead as "normal" a life as is possible. If habilitation is associated with an abiding respect for human dignity, then active treatment is an assertion of the resident's rights as a human being, not merely an ICF requirement. The key to adherence with ICF regulations entails compliance with the stipulations but also suggests compliance with the spirit of the regulations. It is this added dimension of compliance with the underlying concepts that brings meaning to the intent and that assures further improvements in the quality of life for those persons affected by the guidelines.