

THE RIGHT TO HABILITATION FOR PERSONS WHO ARE MENTALLY RETARDED

I Introduction

Over the past twenty years, American society has learned that any serious attempt to ameliorate the consequences of mental retardation, of necessity, must involve the synchronized efforts of a variety of health, education and social service specialties. Providing this wide array of needed services in a comprehensive, balanced system, however, has proven to be an elusive goal.

Fragmentation of services and lack of proper interagency coordination continue to be major problems in many states and communities, despite the oft-documented failure of traditional, isolated systems to offer an adequate range of service needs among the client population. Denial of the basic legal and human rights of retarded persons frequently is grounded in the failure of society to develop service delivery systems which are multi-faceted, make available to the retarded a wide range of generic and specialized health, education and social services and build in workable mechanisms for client-centered case management and interagency cooperation.

It is important to recognize that attempts to deliver direct services to mentally retarded clients often involve the real or potential denial of one or more of the individual's rights or prerogatives. For this reason, it is incumbent on responsible professionals to employ intervention strategies which minimize the degree of infringement on the client's rights without sacrificing the likelihood of positive outcomes.¹

Inherent in this emphasis on minimal intervention are several important, underlying assumptions, on the part of the American Association on Mental Deficiency, about mental retardation and society's responses to the problem. First, no right or privilege should be withheld from any citizen without a convincing justification; at the same time, denying mentally retarded individuals access to appropriate services on rigid civil libertarian grounds is no solution to the problem. Indeed, inaction may be a cruel form of inhumanity to an individual desperately in need of assistance. Second, in view of the complexity and diversity of the assistance needed by persons classified as mentally retarded, habilitation services must be individually tailored and packaged to meet the needs of each particular client. No restriction should be placed on a client's rights or privileges by a service agency or individual practitioner unless it can be clearly demonstrated that the restriction is an essential prerequisite to accomplishing an approved service goal. The fact that it may be necessary to limit the exercise of a particular right of a client in an effort to achieve a service goal, however, is insufficient grounds for withholding

¹ In the legal context, this principle is often referred to as the "least restrictive alternative." Over the past few years, as the result of a flurry of federal and state lawsuits asserting the "right to treatment" and the "right to education" for all mentally retarded individuals, the concept of the least restrictive alternative has been added to the lexicon of most professionals in the field. However, the meaning of the term itself frequently has been confined to physical restrictions on an individual's freedom, whether in an inappropriate educational setting (e.g., a segregated classroom) or in a residential milieu (e.g., a sterile, custodial institution). It should be made clear that the concept of minimal intervention, as it is used in this position statement, applies equally to the service or treatment modalities selected by the program staff as well as the physical environment in which the program takes place.

any other right or privilege of that individual. Finally, the impact of mental retardation is dynamic in nature and, therefore, often will have differential effects at various points in the retarded individual's life. The service delivery system must be flexible enough to adjust to such changes and restore individual rights and privileges as soon as they can be properly exercised by the client. The purpose of this statement is to specify the service rights of mentally retarded individuals and to articulate the views of AAMD concerning the principles underlying an effective, balanced and comprehensive approach to delivering a full range of habilitative services to such persons.

II The Individual's Right to Service

As the Association stressed in an earlier position statement, "mentally retarded individuals have the right to a publicly supported and administered comprehensive and integrated set of habilitative programs and services designed to minimize handicap or handicaps."² Among the service rights specifically recognized by the Association are:

- A. The right to a free public education appropriate to the individual's needs;
- B. The right to quality medical care;
- C. The right, in accordance with a written, individualized program plan, to such training, rehabilitation, habilitation, therapeutic and counseling services as will assist the individual to develop to his or her maximum potential;
- D. The right to engage in productive labor or other meaningful activities to the extent of his or her capabilities;
- E. The right to assistance in securing access to appropriate services and exercising his or her full rights as citizens;
- F. The right of the retarded individual to exercise freedom of choice in the selection of services, to the extent of his or her capability;
- G. The right to a physical and social environment conducive to the development and growth of the individual and the full exercise of the rights listed above.
- H. The right of the client or his or her parent, guardian or legal representative to have access to all personal service records, data and information maintained by any service agency.

An effective service delivery system should be designed to secure and safeguard the above rights.

² See Rights of Mentally Retarded Persons.