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by Ruth Freedman

A mentally retarded citizen searching for a home must explore beyond a simple structure. A physical abode itself does not assure successful and fulfilling community living. As Lotte Moise has described, a house in the community must first of all be a home. But a mentally retarded citizen must search for a *community* as well as a *home*—a community which accepts him as a fellow human being and which offers him the same opportunities, responsibilities, and risks offered to all citizens. This monograph has examined some of the essential characteristics in homes and communities which enable all persons to live as human beings. This final chapter will summarize some of the principles and goals set forth in this monograph and will then look at the role of mentally retarded citizens in determining where and how they shall live.

FUNDAMENTAL PRINCIPLES

Basic to all chapters, certain fundamental principles evidence this monograph's philosophy.

- The mentally retarded person can grow and change. The status of being retarded is open to change as is the level or *degree* of mental retardation. All persons have potential for development; the label and effects of mental retardation are not irreversible.
- A mentally retarded person's needs change as he grows and develops. Transitions from childhood to adolescence, to adulthood, and to old age are natural for all persons; and needs change at each stage.
- The needs of mentally retarded persons differ from individual to individual. Retarded persons, like all persons, have unique abilities and disabilities, likes, and dislikes. Each person grows, develops, and ages according to his own individual pattern; his needs reflect his uniqueness.
- All persons share certain universal needs. We all strive to meet our common needs for shelter, health, physical development, and personal and social growth. Disabled

persons' needs differ only in their capabilities to meet these needs.

All persons are entitled to certain human and civil rights. The rights to due process, to education, and to a life in the community have recently been in the forefront of the civil rights field. In addition, society takes for granted human rights to which even the most profoundly disabled persons are entitled—the right to respect, to dignity, to responsibility, to risk taking, and to individual life styles. These rights enable the mentally retarded individual to live as independent a life as is possible.

GOALS FOR A SYSTEM OF SERVICES

This monograph has attempted to translate the fundamental principles into goals for a system of services designed to meet the needs of mentally retarded persons. Some of the goals which have been emphasized include the following:

- Mentally retarded persons should receive generic services wherever possible. A system need not isolate the human needs of mentally retarded persons from the universal needs of all other persons.
- The system should provide a *continuum* of services, ranging from prevention programs to services for infants, children, adolescents, adults, and aging adults. Services should conform to the changing needs of mentally retarded persons and their families at these different stages of life.
- Services should be geared toward persons with *varying levels of capability.* No single service will meet the needs and abilities of all mentally retarded persons. In designing community residences, in particular, no one model will benefit everyone. There should be specialized community facilities for persons with severe disabilities, independent apartment units with little or no supervision for persons with minor disabilities, and a variety of living arrangements for persons between these two extremes. Similarly, at work, some individuals may require sheltered workshop settings, while others may be able to work in competitive employment settings.
- Services should be *individualized.* They should meet the needs of individuals, not the needs of a class of persons or the needs of the service system itself. Appropriate

diagnosis and ongoing evaluation, individual treatment plans, and periodic review procedures can help to assure individualization.

Services should be provided in a manner consistent with the *civil and human rights* shared by all citizens—the rights to dignity, respect, fair procedures, and equal protection under the law.

Services should strive to *integrate* clients into the mainstream of community life. Services should promote and ensure the participation of mentally retarded persons in normal community activities: educational, vocational, social, recreational, and religious.

Services should be *dispersed* geographically so that they are available to all. In urban areas, this requires placing services in areas convenient to the users, accessible by public and private transportation. In rural areas, where distances between population centers are great, transportation is a crucial factor. Either the client must go to the service or the service must come to the client. When necessary, the system should provide the transportation. Services must generate *community awareness* and *support.* Outreach models must be developed which inform community members of available resources and programs. Public education and legislative campaigns must be mounted to generate support for community programs for mentally retarded citizens. Services must be *accountable* to the clients. Providers of services must be continually monitored to ensure that they are meeting the needs of their clients. Associations and volunteer and advocacy groups can monitor and evaluate the overall service network to determine gaps in services and to press for the elimination of these inadequacies.

NEW DIRECTIONS

This monograph has discussed the philosophy, goals, and characteristics of community services for mentally retarded citizens. The authors do not presume, however, that the principles set forth here are permanent. Rather, we anticipate that new principles, goals and methods will emerge as the needs of mentally retarded persons in the community evolve. Evidently, mentally retarded persons will formulate and promote some of these new features. Too often we tend to view these citizens as the objects of services, rather than as primary actors in determining the kinds of services they need.

In this community movement retarded citizens must have a say about which services are developed and how they are delivered. Their voices can clarify planning and aid service delivery. And even more importantly, to deny them meaningful participation is to devalue them as human beings. As Ann Shearer has stated:

> If participation is to develop strongly it requires all of us to see 'mentally handicapped' people as equal human beings to the rest of society; with a positive contribution to make to that society; who need and are entitled to be listened to; who receive services as a right because of their citizenship in our society and not from a sense of charity for lesser beings; who like everyone else respond to the way they are treated; and who have a right to respect. Only in these circumstances with these conditions accepted, does participation become an important, indeed an essential element of services, because it is only in these circumstances that recipients and providers of services can come together in a way that ensures participation.[1]

Participation of mentally retarded persons in decision making is not merely a forecast for the future. Already, we are witnessing the beginning stages of this movement. Both in this country and in others, mentally retarded persons have come together to voice their concerns and to organize support. Since 1968, the Swedish Association for Retarded Children has sponsored a series of conferences for young mentally retarded adults. At one of these meetings in 1970, the participants themselves drew up a position paper which expressed their concerns about leisure-time activities, vacation, living conditions, education, employment, and wages. Although the document is too lengthy to present in its entirety here, the following excerpt on "living conditions" shows the types of conclusions which were reached.

Living Conditions:

> *We wish to have an apartment of our own and not be coddled by personnel; therefore we want courses in cooking, budgeting, etc.*
>
> *We want to have a right to our own apartment but without priority on the waiting list (In Sweden, one may have to sign up for an apartment well in advance).*

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[1] Ann Shearer, *Listen* (London: Campaign for the Mentally Handicapped, 1973).

> *We want the right to move together with the other sex when we feel ready for it, and we also want the right to marry when we ourselves find the time is right.*
>
> *We who live in institutions and boarding homes have found that:*
>
> > *The homes should be small.*
> > *We want to choose our own furniture, and have our own furniture in the room.*
> > *We will absolutely not have specific hours to follow in terms of going out, returning, etc.*
>
> *We want to have more personal freedom, and not as it is now in certain institutions and boarding homes where you have to ask permission to shop for fruit, newspapers, tobacco, etc.*
>
> *We want the right to invite other youngsters to our hostels.*
>
> *One should not have food coupons in institutions and hostels even if it has practical advantages; we want to pay with our own money.*
>
> *When we are living in institutions, we want social training to be able to move out into society and manage on our own. Even in institutions, we want to be able to go steady and live together with the other sex without having the personnel interfering with our private lives.*
>
> *We who live at home have found that:*
>
> > *It is largely good, but one ought to move out when the time is right to a service sheltered apartment or hostel; one cannot for his whole life be dependent on his parents. We want, however, to have our own key when we live at home.*[2]

Similarly, in Britain, two major conferences have been held **for** and with mentally retarded persons, sponsored by the Campaign for the Mentally Handicapped. In 1973, providers of services as well as consumers attended LISTEN, the second conference. The purpose of LISTEN was to give the mentally retarded consumers an opportunity to present their views on needed services. In the discussions held on living, working, and leisure—the need for choice, independence, and participation emerged as the major themes. Conference participants hoped that such meetings would pave the way for more direct involvement of consumers in the planning and development of services.

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[2] Bengt Nirje, *"Report on a Conference of Retarded Young Adults in Malmo"* 1968. (Mimeographed.)

In the United States, mentally retarded citizens have also organized on their own behalf. Several state conventions for mentally retarded adults have met, for example in Massachusetts and Rhode Island, in which delegates have discussed such issues as dehumanization and restriction of civil rights. Mentally retarded persons have also formed advocacy groups to provide public education to community groups and consultation to agencies planning and providing community services.

The formation of these self-advocacy groups suggests that consumer participation may soon be strengthened. Without meaningful opportunities for this participation, mentally retarded persons lack full citizenship. After spending 25 years in the institution and now pushing for community placement, one resident of a Massachusetts state school said:

> *I want to be a citizen. I want to do what every citizen can do. Citizenship means voting. Citizenship means working, it means helping others. It also means that we are able to make important decisions for ourselves. Our families and the people who work with us can help us, but if citizenship is to mean anything we must make the final decision.*

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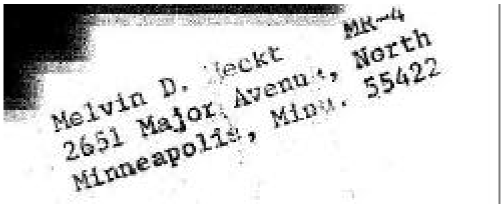

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