

CHAPTER V

THE GOAL OF INDEPENDENCE

by Jennifer Howse¹

As a nation of pioneers we come from a tradition built on conquering new territory. Essential to the pioneer spirit is the will to set difficult and high-reaching goals and to apply human energy, time, and resources until the promised goal is achieved. This process has been repeated again and again in our history, and in most cases a goal, once established and agreed upon, is accomplished. Examples of recent success in goal achievement can be found in the fields of aerospace, corporate industry, and military weapons development.

In human services the same pioneer spirit appears in national goals such as conquering polio and cancer, providing medical services and income maintenance for the poor, aged, and disabled, and equalizing educational opportunities for handicapped children.

The field of mental retardation is now responding to a national goal of deinstitutionalization. This goal mandates that the community should possess service programs which will eventually eliminate placing retarded individuals in state institutions. This goal also calls for returning mentally retarded individuals from large institutions to their respective communities.

A change in service location does not, however, necessarily guarantee greater well being. Concomitant with the goal of deinstitutionalization, current expectations about the potential of retarded persons must be examined: toward what ultimate state of well-being are retarded citizens being directed in the community? This most crucial question demands dramatic changes in the expectations of the public and of many persons in the field of retardation. These expectations concern the quality of life we allow ourselves to envision for the retarded. Stated in a different way, what dreams and plans do we have for those people on whose behalf we have chosen to advocate? What ultimate goal do we envision for retarded individuals?

An examination of many of today's institutional and

¹ The author wishes to express her indebtedness to Mr. Kingsley Ross for many of the concepts in the paper.

community programs suggests that maintaining the status quo is about the extent of our vision. Using a status quo model of services has three major philosophical implications, all negative. The model's nature argues against change and development. Further, a status quo model nurtures a focus on disability, since the disability of retardation is the reason for providing services. Finally, for reasons of efficiency and economy the model allows for the fewest services to be delivered to large groups of institutionalized clients. Because a service system designed to maintain the status quo *will* maintain the status quo, this model of services dictates a goal of dependence for clients. Therefore, persons who ever needed services would always need them.

If we are going to shed this entrapment which can occur just as well in a community setting as in an institutional setting, a new national goal must be shaped, articulated, and applied for retarded citizens. This goal must carry a new set of assumptions upon which to build a service delivery model, and it must point toward future actions and directions.

A NEW NATIONAL GOAL

What ultimate goal should we advocate for mentally retarded persons? *Independence*. The same independence we take for granted.

For us, such independence means being able to

- participate in a variety of physical activities and sports including swimming, bowling, volleyball, and skating
- eat our meals with relatives and friends in a family style atmosphere
- eat in a restaurant whenever we choose without receiving assistance in ordering and paying for our meals
- choose and purchase our own clothing and make decisions about appropriate sizes, color, style, and cost
- assume responsibility for paying our rent or mortgage
- pay federal, state and local taxes
- enter into relationships with others and have an opportunity to share feelings with friends
- work competitively with others in a factory, office, or work environment
- earn at least a minimum wage to be self-supporting
- use the public transportation available in our community
- plan for and take vacations
- know when to call a police officer for assistance

- arrange for medical and dental checkups when necessary and to provide for our own medication
- read newspapers, periodicals, and watch television news programs to follow current events.
- exercise our basic rights including the right to vote.

ACHIEVING A GOAL OF INDEPENDENCE FOR RETARDED INDIVIDUALS

If we adopt the proposed goal, we must also establish a method to account for the progress of retarded individuals toward the goal. This method must recognize that retarded individuals function at different levels of capacity for independence. These levels may range along a continuum from complete incapacity to a full capacity for independence.

Although these levels of capability are difficult to define, one can project a desired level of independence for any person in relation to his physical, economic, and social functioning.

(1) Physical Functioning—Mobility:

The fully capable mentally retarded person will independently use all available public and private transportation without assistance.

The less capable retarded person can use public and private transportation but may depend upon some occasional supervision and direction.

A person with quite limited capability can use public and private transportation with supervision.

The least capable retarded person can be helped to him use public and private transportation.

(2) Economic Functioning—Work Skills:

A fully capable retarded person can engage independently in competitive employment and earn a living wage.

The marginally capable retarded person can work in a sheltered employment situation and may earn a living wage.

A less capable retarded person can participate in work and earn some wages, depending on his productive ability, in a workshop or activity program.

The least capable retarded person can be helped to perform some rewarding tasks.

Such a classification allows one to identify distinctive levels of physical, social, and economic functioning among all mentally retarded persons. One must take into account these varying levels as starting points but must, at the same time, stress that almost

any person's current level of functioning can develop toward a more independent level.

Accounting for an individual's progress toward the goal of independence must, however, occur in more detail than a simple assessment as above. An individual's current level of capacity for independence must be assessed in terms of the separate skills that constitute his current level of social, economic, and physical functioning. All three of those areas should be considered equally since they are interrelated and can all affect a person's ability to live independently.

Different levels of functioning may be viewed as a composite of a person's acquisition of certain skills. Therefore, to chart the movement of a retarded client from one level of functioning to the next, one must chart the existence and acquisition of certain skills. In this way one can develop and monitor a meaningful plan of service for each individual. Further, services provided to retarded clients can be accounted for in terms of what changes occur in the client.

After a person's level of functioning has been assessed, the skills he needs to function independently can be identified, and appropriate services to develop those skills may begin. Through this approach, one can identify and develop those social, economic, and physical skills necessary to move a person from a level of dependence, semi-dependence, or marginal independence to a level of complete independence.

STATE EFFORTS TO ACHIEVE THE GOAL OF INDEPENDENCE

Several states, including California, Florida,² and Nebraska, are currently trying various methods to measure the effect of services in changing client skills. The assessment efforts center on the concept that retarded persons need to acquire certain abilities to perform certain functions necessary for a successful existence in society. Therefore, a meaningful service program should identify the skills which a client lacks and develop those skills to the fullest extent possible. Inherent in the approach of each of these states is a goal of independence, and further, the implication of a developmental model. The California ap-

² For information about the Florida model, write for "*The Directions for Florida's Retarded Citizens*", Division of Retardation, Florida Department of Health and Rehabilitative Services, Tallahassee, Florida.

proach³ was developed on the premise that current methods and standards of evaluating services for retarded persons are inadequate. These methods fail to specify whether a program successfully solves a specific problem and what progress the individual makes.

The California method perceives mental retardation as a continuum of functioning ranging from complete dependency to independent functioning. Dependency is characterized by the need for total specialized services such as for profoundly retarded, non-ambulatory persons receiving 24-hour care in a state institution. The other end of the continuum is characterized by completely independent functioning which reveals no functional or behavioral difference between a person once identified as retarded and a "normal" person.

The California approach has attempted to identify those skills and functions necessary for independent functioning. These areas include self-help skills such as ambulation, eating, dressing, and personal hygiene; communication skills, community living skills such as money management, use of transportation, and participation in recreational activities; and behavior problems such as aggressive or destructive behavior, withdrawal, and excessive dependency.

By defining those skills necessary for independent functioning, this approach provides a method of setting goals for each retarded person and then of evaluating the results of program efforts. The skills necessary for independent living which an individual does not yet have can be identified, and goals for developing those skills can be established.

Nebraska has developed a similar approach to the evaluation of services provided for mentally retarded persons. This approach is designed to measure how well the needs of clients are being met and to determine how well service providers are functioning.

The Nebraska method, like the California approach, defines those behaviors or skills necessary for independent living. These include self-management skills such as grooming, eating, and personal hygiene; communication skills, interpersonal skills such as group participation and interaction with others; environmental structuring skills such as meal preparation and money management; environmental access skills including using

³ The California method is called "Individualized Data Base," and information may be obtained by writing to Alan Boroskin, Ph.D., Pacific State Hospital Research Group, P.O. Box 100-R, Pomona, California, 91766.

⁴ Community Regional Services developed the "Nebraska Client Progress System" under the direction of the State Office of Mental Retardation, Nebraska Department of Public Institutions, Lincoln, Nebraska.

the telephone and public transportation, and employment skills including work quality and persistence.

This method assesses each person in terms of his ability to function in each of the areas defined as necessary for independent living. As a result of this assessment, the method identifies areas of need and begins appropriate programs to develop those skills. This approach can identify gaps in services and duplication of efforts and can objectively measure and evaluate the effect of programs on individuals.

IMPLICATIONS OF ADOPTING THE GOAL OF INDEPENDENCE

An approach which identifies and develops those skills necessary for independent living can help a retarded person toward the goal of independence. National adoption of this goal would affect the planning of services on federal and state levels and the delivery of services in local communities; most important, it would increase the ability of retarded individuals to participate as independent members of a community.

Deemphasis on the Need for Life Support Services. This approach would obviate programs which provide *only* life support services. Instead, all programs would aim toward growth and development of those skills necessary to achieve independence. For the retarded individual, this approach means that the services he receives will be designed to increase his level of functioning rather than maintain him on a certain and often permanent level of activity.

Reduction in the Labeling Process. An approach which assesses those criteria necessary to achieve independence does not use a relative IQ score to determine potential level of functioning. Instead, the method focuses primarily on those social, economic, and physical skills which individuals have or will need to achieve independence. Plans for a retarded person's future development will not be based on an IQ level, which often implies a static condition with negative expectations. Instead, each retarded person will be recognized as having varying degrees of abilities and having individual needs which can be developed to achieve independence.

Activation of a Developmental Model. Programs aimed at achieving independence use a developmental approach in providing services to mentally retarded persons. They will be viewed within a framework which recognizes and encourages the poten-

tial for growth. A dynamic and growth-oriented approach thus replaces traditional models which often implied inabilities and limitations. Such an approach will affect the way a retarded person views himself as well as the way family members and the general community perceive him. If an individual lacks certain skills to be independent, the approach aims to develop them so that the retarded person can achieve the highest level of independence.

Motivation and Direction for the Retarded Individual. An ultimate goal of independence can motivate and direct a retarded individual and lend a sense of purpose to his family and friends. The stated goal implies that retarded individuals can develop skills to live more independently if they receive appropriate resources. The goal clearly defines a purpose for each program and provides direction for our efforts. This clearly defined approach shows the retarded individual and his family the level on which he is functioning and what skills need to be developed for independence. Programs of services thus become more understandable and purposeful because the family and the individual know what they are working toward.

Recognition of Individual Competence. This approach replaces the more traditional attitude of incompetence associated with retarded persons and recognizes the abilities that a retarded person has or can develop. Thus, the adoption of this goal will replace a negative attitude with a growth-oriented one which leaves room for and indeed encourages active participation by the retarded person in decision-making.

IMPLICATIONS FOR COMMUNITY AGENCIES

An approach which can assess an individual's level of functioning and can identify those areas needing development to achieve independence has direct implications for community agencies involved in providing services to retarded persons. When one considers some of the constraints on serving individual clients, such an approach seems especially important.

These constraints mostly relate to the types of funding and to categorical resource allocation patterns that have emerged over the last decade. The current problem of resource allocation arises from the administrative realities of dealing with special target groups and the models that have evolved for categorical funding. For example, administrative reality may be based on population characteristics such as urban, rural, or

suburban. But homogeneity of population characteristics does not mean a homogeneity of problems. Special problems associated with this model of reality are characterized as "ghetto" or rural-isolated, and service project funding depends on meeting the needs of individuals in these settings.

Income level of clients provides another type of administrative reality, because of the categorical emphasis on using funds for services to low-income clients. From this model arises a dual service system, especially in the area of medical services for clients who can afford medical treatment and those who cannot. Anyone who compares public health services to those offered by private physicians can see the inequality of this system.

Another type of administrative reality is based on neighborhood, city, or county boundaries or agency delineation of service areas or districts, in which these zones may impose criteria for eligibility for services.

Superimposed on these criteria for services are the types of constraints associated with the way agencies traditionally evaluate and account for services. Specifically, agencies account for services in terms of dollars spent, types of persons employed, types of facilities used, and number of clients served. Yet none of these indicators really identifies what happens to the client after he receives the service. The implementation of the goal of independence will affect the way a local agency assesses retarded persons, the method by which it provides services, and the manner in which agency efforts are evaluated.

Developing More Individualized Programs. To implement the goal of independence, community agencies will begin by assessing an individual's needs and the skills he requires to function independently. After identifying these needs, the local agencies can plan appropriate individual services aimed at developing skills. These services will recognize retarded persons as individuals with varying degrees of skills and provide for the development of abilities essential to independent living. Thus, the valuable services provided by the agency will be individualized services rather than broad, generalized programs directed at groups of clients.

Better Decision-Making Agency Administrators. This approach should allow administrators of community programs to make decisions more effectively, as they receive ongoing data relating to the individual client's needs and abilities. By being able to identify individual needs and progress, the administrator should be able to recognize gaps in programs and services. Therefore, he should be able to make more appropriate decisions

about allocation of manpower and resources and the direction of future program development.

More Effective Evaluation Methods for Local Agencies. The method implied in the goal of independence for mentally retarded persons will require that agencies identify all measurable skills necessary for independent living. Evaluation of local program efforts will then focus on the number of individuals who have achieved independent living and the number of skills necessary for independent living which have been developed. Through this improved method of evaluation, program administrators can identify those areas of programs providing effective services and those areas not achieving their objectives. The improved method of evaluation will result in the development of improved services for retarded persons.

Clearer Direction for Local Agency Efforts. If a local agency adopts an ultimate goal of independence, it must objectively consider and plan individual programs and allocate its resources effectively so that it can carry out the programs. All programs will have a specific purpose and will be directed toward the same goal of achieving independence for retarded persons.

SUMMARY

We are currently responding to a national goal which calls for deinstitutionalizing retarded individuals and subsequently returning them to the community. No one can deny the importance of such a goal and its potential effect on the life of a retarded person. But this return to the community should be guided by the promise of new opportunities for positive growth and change for the individual. The goal of independence will afford such opportunities and can bring many positive results for program development, management, and evaluation. Through the skill assessment approach suggested earlier, information on each individual client can help in building individual prescriptions and managing programs. Further, programs can be evaluated in their most important dimensions; What changes are occurring in the client as a result of the program?

Above all, the goal of independence promises far-reaching benefits for the retarded persons themselves: Within a framework of independence the retarded person must be viewed as an individual with certain skills at his own level of competence who, like most of us, is working toward a goal that will bring about a better quality of life.