Independence: The Ultimate Goal of Rehabilitation for Spinal Cord-Injured Persons

Lex Frieden, Jean A. Cole

During the late 1960s and early 1970s, a new concept related to rehabilitation and improvements in quality of life began to emerge and be expressed by people with spinal cord injuries and other disabilities. This concept, independent living, is the foundation of the independent living movement, which has helped to overcome the barriers to a higher quality of life for disabled people. Of the many organizations and programs set up to provide support for disabled people living in the community, the independent living program seems to be comparatively successful at facilitating independence by people with spinal cord injuries. Independent living programs provide the kind of community-based support services necessary to expand the range of living options for disabled people beyond those traditionally available in most communities.

The role of occupational therapists in the independent living stage of the rehabilitation process can be similar in some respects to their role during earlier phases of medical rehabilitation. However, the definition of independence as a "mind process" leads to considerable expansion of the therapist's role beyond the focus on physical skills, which are usually key priorities during medical rehabilitation. Occupational therapists typically possess knowledge and skills that equip them well for assisting clients in the independent living stage of the rehabilitation process.

The question is often asked, "What are the long-term goals of spinal cord-injured individuals after rehabilitation?" The answer is, more likely than not, that the goals of spinal cord-injured individuals are generally the same as those for anyone else. Most people want to have a family, a home, a car, a job, and recreational opportunities.

In the past, some rehabilitation professionals, friends, and family members have discouraged people with spinal cord injuries from adopting or seeking these goals.

Lex Frieden, MA, is Executive Director, National Council on the Handicapped, Washington, DC 20591. At the time of this study he was Director, Independent Living Research Utilization Project, The Institute for Rehabilitation and Research, Houston, TX, and Assistant Professor of Rehabilitation at Baylor College of Medicine, Houston, TX.

Jean A. Cole, PhD, is a master's candidate, School of Occupational Therapy, Texas Woman's University; she also is Assistant Professor of Rehabilitation at Baylor College of Medicine, Houston, TX, 77030.
The injured people were led to believe that such goals were unrealistic and that they should be satisfied and happy to be alive. Little hope was given for spinal cord-injured people to achieve near-normal lives; in fact, the general public's expectations of life for spinal cord-injured people could be weighed on a different scale of normality than was their own. What was considered a normal life-style for the general population was not considered normal for people with spinal cord injury. As a result of these attitudes, many spinal cord-injured people adopted restricted goals and lowered their expectations.

During the late 1960s and early 1970s, a new concept related to rehabilitation and improvements in quality of life began to emerge and was expressed by people with spinal cord injuries and other disabilities. This concept is called independent living and is defined as follows:

Control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, and making decisions that lead to self-determination and the minimization of physical or psychological dependence upon others (1).

At first, it was a reaction to repression. Some disabled people felt their lives were unnecessarily restricted by their disabilities. They acknowledged that the barriers to goals of independence that exist for everyone were complicated by disability, but they believed the barriers could be overcome. They felt that supportive programs could be established and environmental accommodations made that would allow them to have opportunities and seek goals open to the general public. They rejected the notion, often expressed by professionals, that they should be confined to institutional care. They rejected the assumption that they had fewer rights than nondisabled people, and they rejected the idea that government's obligation to them was limited by their disability.

These people began to assert themselves in public forums. They organized and formed lobbying groups. They claimed equal rights as citizens to public services like transportation, housing, education, and employment and demanded to vote. Although most of these rights were not denied intentionally or directly, they were indirectly denied by virtue of the fact that most of the public services and the public offices and polls were inaccessible to them.

From the concept of independence, a movement emerged to overcome the barriers to a higher quality of life for disabled people. Called the independent living movement, it is defined as follows:

The process of translating into reality the theory that, given appropriate supportive services, accessible environments, and pertinent information and skills, severely disabled individuals may actively participate in all aspects of society (1).

This movement was joined by disabled people, their family members, friends, and neighbors, rehabilitation professionals, politicians, opinion leaders, policy makers, and people throughout society. The movement led to new laws that asserted equality and protected the rights of disabled people. It led to new or adapted accommodations, making housing, transportation, public places, schools, and job sites accessible to people with disabilities. It also led to new, more positive attitudes by the general public toward people with disabilities and of disabled people toward themselves. Perhaps most important, it led to new opportunities for severely disabled people, including those with spinal cord injuries, to seek independence, to enjoy the benefits of their labors, and to enjoy the high standards and quality of life that society offers (2).

As a result of the independent living movement and the changes that have occurred during the past few years, people with spinal cord injury may now realistically seek goals that were once limited to nondisabled people. In fact, the limits imposed by spinal cord injury may be less important in determining the achievement of a person's goals than are certain other demographic and socioeconomic variables not related to the disability. Many disabled people now go directly from the rehabilitation center to independent living arrangements in the community. Others do so after a temporary respite with their families, and still others do so after participating in extended vocational rehabilitation or transitional living programs.

Overcoming Barriers

The principal barriers to achieving goals of independence that spinal cord-injured people face may be categorized into three groups: environmental, personal, and economic. Environmental barriers are independent of and often beyond immediate control of the individual (e.g., curbs, steps, and narrow doorways). Environmental barriers may also be the societal attitudes that project disabled people as incapable and pathetic. Personal barriers relate directly to individuals and, more likely than not, can be affected by them. Examples of such barriers include negative
attitudes, low self-esteem, feelings of dependence, unreasonable insecurity, unwillingness to take risks, preoccupations with cure, the inability to organize and plan, poor self-image, and unnecessarily limited expectations and goals. Economic barriers relate to an inability to purchase needed equipment, supplies, and services. Economic barriers may confound a person's ability to overcome both environmental and personal barriers because they restrict the range of possible solutions.

There are more solutions now than ever before to overcoming the barriers to independence, including purchasing or making adaptive equipment and devices. For example, high-level quadriplegic persons may purchase electrically powered wheelchairs that are controlled by either making slight movements of the chin or by sipping and puffing into a straw. Sophisticated remote-control devices and primitive robots are also available. In addition, there are broader, more systematic solutions, such as the mandated use of mass transportation vehicles made accessible by widening doorways, expanding seating areas, and installing ramps or lifts. This also includes community-wide efforts to install ramps on curbs and provide access to both public and private buildings.

With respect to personal barriers, there are several possible solutions. Rehabilitation counselors, psychologists, social workers, and other professional human service providers may help a client analyze and overcome these barriers. Peer counselors may share information, serve as role models, and provide support. Family members and friends may give encouragement and support. Finally, a client's self-determination, self-control, in addition to simply the passage of time, may be instrumental in the resolution of personal barriers. On a broader scale, positive attitudes and expectations of the general public, and positive portrayals of spinal cord-injured persons by the mass media, would be helpful.

Economic barriers may be not only the most difficult to overcome but also the most important, because they may affect solutions to the other two types of barriers. Obviously, spinal cord-injured people who are independently wealthy or whose families have substantial means are not as likely to be bound by economic barriers as are others. However, the vast majority of people who are disabled must depend on private or public insurance, private or public aid, and their own abilities to work and earn money. Independence costs more for spinal cord-injured people than for nondisabled people because in addition to normal expenses (e.g., housing, transportation, food, clothing, and routine medical care), they have expenses for adaptive equipment, medical supplies, and attendant care. The economic barriers to independence for spinal cord-injured people are frequently complicated by the fact that to be independent, most people need a job, but to have a job, one must be reasonably independent.

Examples of solutions to overcoming economic barriers include housing subsidies to help pay for housing, vocational rehabilitation agency grants or subsidies to help pay for educational or work-related expenses, welfare or human service agency subsidies to help pay for attendant care expenses, and work income or Social Security Disability Insurance payments to cover the balance of other expenses. More general solutions would include a nationalized health insurance program, a nationwide attendant care or home health care program, or a nationwide system for purchase and distribution of equipment and devices for disabled people.

Role of Independent Living Programs

Of the many organizations and programs set up to provide support for severely disabled people living in the community, one new type of program seems to be comparatively successful at facilitating independence by people with spinal cord injuries. This is the independent living program, which is defined as:

A community-based program which has substantial consumer involvement, provides directly or coordinates indirectly through referral those services necessary to assist severely disabled individuals to increase self-determination and to minimize unnecessary dependence on others. Services that an independent living program must provide or coordinate through referral are housing, attendant care, readers and/or interpreters; and information about goods and services relevant to independent living. Other services that are either provided or coordinated by independent living programs include transportation provision or registry, peer counseling, advocacy or political action, independent living skills training, equipment maintenance and repair, and social-recreational services. Note that custodial care facilities and primary medical care facilities are specifically excluded from the definition of an independent living program (1).
because they usually serve a cross-disability population, and they often organize their services around a peer support model, as opposed to one of professional intervention or treatment. Perhaps most important of all, they often provide a broad range of services, including housing referral, attendant care referral, information about goods and services provided by other agencies, peer counseling, transportation, equipment repair, independent living skills training, and advocacy (3). Independent living programs tend to focus on solving problems caused by the environment and the person’s interaction with the environment as opposed to the usual approach in rehabilitation of focusing on problems associated with the individual and his or her specific disabling condition.

Since the independent living movement began in the early 1970s, nearly 200 independent living programs have been established. Programs are now located in every state, and together they are annually serving more than 20,000 severely disabled people, many of whom have spinal cord injuries. According to the Registry of Independent Living Programs maintained by the Independent Living Research Utilization (ILRU) project in Houston, more than 90% of these programs serve people with spinal cord injuries (4). As a matter of fact, most of the early leaders in the independent living movement were people with spinal cord injuries, and today many programs are managed by people with such injuries.

A particular type of independent living program, the transitional program, is defined as follows:

An independent living program that facilitates the movement of severely disabled people from comparatively dependent living situations to comparatively independent living situations. The primary service provided by these programs is skill training in such areas as attendant management, financial management, consumer affairs, mobility, educational-vocational opportunities, medical needs, living arrangements, social skills, time management, functional skills, sexuality and so forth. Additional services may be provided. Transitional programs are usually goal-oriented and/or time-linked (1).

It has proven to be exceptionally effective in helping spinal cord-injured individuals acquire the information and skills they need to successfully establish an independent life-style following rehabilitation. Transitional programs provide instruction in areas of mobility, medical self-care, financial management, attendant care, housing, sexuality, and social skills among others. More important, these programs encourage individuals to make decisions for themselves and to be responsible for their own lives. Examples of transitional independent living programs that are effectively serving spinal cord-injured individuals are being operated by several regional spinal cord injury centers, including the Institute for Rehabilitation and Research, Rancho de Los Amigos, and Craig Rehabilitation Institute.

For people with spinal cord injuries, independent living programs may provide the kind of community-based support services necessary to expand the range of living options beyond those traditionally available in most communities. These people have already demonstrated that, given appropriate support services, they can live comparatively independently in the community outside of their parents’ homes, nursing homes, and other institutions.

Role of the Occupational Therapist

In 1981, the American Occupational Therapy Association adopted an official position paper that emphasizes the congruences between principles and practices of occupational therapy and the field of independent living. The discussion here is intended to provide more specific ideas on how therapists might operationalize these general concepts in specific ways to help disabled people live independently (5).

The role of occupational therapists in the independent living stage of the rehabilitation process can be similar in some respects to their role during earlier phases of medical rehabilitation. Important therapist functions in both phases include teaching clients adaptive techniques, helping them acquire and learn to use equipment, and providing consultation on physical modifications of home or work environments. These approaches may be useful in all of the major occupational domains of the person’s life, including work, leisure activities, and self-care. Beyond the functions of occupational therapists that are most evident in earlier phases of medical rehabilitation, there are several additional ways in which they can be helpful to clients at the independent living stage of their rehabilitation. These are examined in terms of the distinctions established above between personal, environmental, and economic barriers to independence that severely physically disabled people face.

In helping clients deal with personal barriers to independent living, it is extremely important that we recognize the definition of independence that is fundamental to the independent living movement.
Heumann (6), in a classic monograph in the literature of the independent living movement, succinctly stated the following definition. "To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent upon a 'normal' body" (p 1). This definition of independence as a "mind process" leads to considerable expansion of the therapist's potential role beyond the focus on physical skills which are usually key priorities during medical rehabilitation.

The implications of the independent living philosophy to the practice of occupational therapy dictates that the therapist's principal role be one of support in helping the client learn to solve problems related to his or her interaction with the environment as opposed to directing therapeutic activities designed to restore certain of the client's abilities. This is not to say that restorative activities are not important but that there is sometimes far too much emphasis placed on changing the person as opposed to helping the person adapt to the circumstances and change the environment.

The theoretical literature and professional training of occupational therapists equips them well to teach clients specific skills of self-direction. These skills include creative problem solving, crisis management, sequential planning, communicating effectively, identifying resources, setting priorities, comparing choices, making commitments, assessing risks, and making decisions (7). Such skills are usually taught by working through hypothetical examples. However, several years of experience in the New Options Transitional Living Project at the Institute for Rehabilitation and Research in Houston indicates that these skills are often more effectively taught through experiential learning on field trips or through other activities in actual community settings (8).

Occupational therapists possess a theoretical framework, which may enable them to help clients analyze their life-styles in terms of the relationship between activities and roles and to understand how what they do shapes who they are. The concepts of occupational behavior theory are useful a) in considering how activity competencies are combined into social roles for a given client, and b) in helping the client recognize that loss of specific competencies need not mean that he or she must withdraw from associated roles if substitute activity competencies can be acquired. For example, this approach can help a client realize that he can be a good father, although he personally does not show his child how to play baseball, or a good husband, although he does not mow the lawn or make home repairs. This point may seem self-evident, but experience with a large number of independently living clients indicates that they often feel they must give up present or future roles because they lack specific activity competencies usually associated with the role.

Because occupational therapists have a background in activity analysis and because they are aware of the importance of "doing" for a sense of competence and control, they can often provide counseling about role issues in much more concrete terms than can counselors with other backgrounds. The appeal to many handicapped people of a practical and concrete approach to life planning is demonstrated by the great popularity of peer counseling in consumer-run independent living programs. Thus, to help overcome the personal barriers to independence, occupational therapists can play important roles as teachers of skills of self-direction and as counselors or advisers who help clients analyze their life-styles in terms of concrete activity patterns.

Occupational therapists can also help clients deal with environmental barriers to independence. Traditionally, therapists have helped people deal with such barriers in their immediate home or work surroundings by recommending space modifications, rearrangement of furnishings, the use of ramps or curb-cuts, and the use of adaptive tools and equipment that can compensate for inconvenient features of environmental design. The independent living movement challenges occupational therapists to think of the environment much more broadly, at the level of the neighborhood or perhaps the community. At this level, the environment can be thought of as an array of opportunities and resources accessible to the individual, but they must be within the mobility sphere of the individual. Using an environmental frame of reference, a therapist might help a spinal cord-injured person choose an apartment in a neighborhood that has a grocery store, bank, pharmacy, recreational facilities, and opportunities for social interaction within range of an electric wheelchair. The therapist might also help the person analyze the decision to move to a new community that offers more job options, better support services, or a milder climate.

Occupational therapists can also act as advocates for changes in the environment. For example, they might join and become active in an organization whose purpose is to assure accessible transportation for disabled people, or they might de-
velop a new attendant training and referral program for the community.

Economic barriers to independence often seem to be outside the realm of the occupational therapist because they arise from basic family circumstances and from public policy and formal benefit systems established by the government or large organizations (e.g., insurance companies). However, at the level of the individual, therapists can help disabled people learn to use the support services and benefit programs available to facilitate independence. Also, by using reimbursement-oriented terminology (9), therapists can help clients develop maximum available benefits coverage and assistance. For example, occupational therapists may write prescriptions for needed equipment giving carefully detailed justification of its therapeutic benefits; this will substantially increase the probability of insurance sponsorship of the purchase. Therapists can also teach clients to use informal helping networks and assistance exchanges, which can minimize the need for direct financial expenditures. An in-kind exchange might be, for example, a relationship between a physically disabled person and an individual with mental retardation or an emotional disability in which physical attendant services provided by the mentally impaired person are exchanged for help with self-direction provided by the physically disabled person.

On a broader level, occupational therapists can become knowledgeable about public policy issues that affect economic barriers to the independence of disabled people. They can make positive contributions to improve opportunities for the disabled population by becoming involved in organizations such as local, state, or national consumer coalitions, independent living programs, or Governors’ Committees for Employment of the Handicapped.

Summary

Occupational therapists typically possess knowledge and skills that equip them well for helping clients in the independent living stage of the rehabilitation process. With their holistic perspective of the individual within an environment, with a view that emphasizes effective functioning in broad domains of work, play, and self-care occupations, and with their preponderant emphasis on activities and “doing” rather than cognitive or intellectual approaches, occupational therapists can provide a form of assistance that is practical and concrete. They can help clients change their lives in clearly visible ways. As professionals who typically practice creative problem solving using common sense and everyday objects rather than highly specialized medical or therapeutic equipment, occupational therapists can help clients learn to overcome barriers and develop solutions to problems that are workable within a community context of everyday life. Finally, because of their background of study and involvement in psychiatric practice, occupational therapists have the broad theoretical framework necessary to consider independence as a mind process that emphasizes self-direction and choices. By applying the independent living philosophy to the practice of occupational therapy and by appropriately expanding the scope of their knowledge and skills, occupational therapists may serve as vital allies to disabled people seeking the goals of independence.

ACKNOWLEDGMENTS

L. Frieden and J. A. Cole, formerly research director and project director, respectively, of the New Options transitional living project at the Institute for Rehabilitation and Research (TIRR), acknowledge the many meaningful ideas and experiences that were shared with them by former New Options staff members and participants and which contributed to the substance of this article. This project was supported in part by a grant to Baylor College of Medicine and TIRR (RT-4) from the Department of Education, National Institute for Handicapped Research (No. G008300044). For further information related to independent living, write ILRU, PO Box 20095, Houston, TX 77225. ILRU is a national center for information, training, and technical assistance for independent living. Its goal is to improve the spread and use of results of research programs and demonstration projects in the area of independent living.

REFERENCES