Independent living is a concept occupational therapists have long valued. In fact, we have directed our service delivery to support the individual's rights and to help the mentally and physically disabled individual to develop the skills to function as an independent person in work, leisure, and maintenance activities. Perhaps we were the first profession to direct our services toward this goal, certainly one of the strongest with this as its primary goal.

Why is it then that the independent living movement initiated by the Rehabilitation Act of 1973 and defined in law by the amendment 95-602 in 1978 does not identify occupational therapy as a primary service or even mandate that independent living centers use occupational therapy in the planning of service delivery? In fact, the reason independent living centers were established was that the law extended the concept of vocational rehabilitation, which defined work as the sole criterion of adjustment, to include development of improved social skills, use of leisure time, acquisition of personal skills leading to expanded personal independence, and made them legitimate goals of the rehabilitation process (1, p 10).

Independent living by definition supports the concept of choice of independent decisions for the nation's disabled individuals. It does not limit its focus to the living situation but combines rehabilitation, physical modification of the environment, and the client’s rights. The combination of these three aspects are important for these individuals so that they can be in control of themselves in relation to necessary services and living alternatives (1, pp 1-8). This truly defines the process of rehabilitation.

The Current State of the Art
Advances in medical treatment have prolonged the survival of persons with a severe disability. Now they have lives to live and new problems to face. With the advance of medical services we have also seen the changes in the health care delivery system with cost becoming the controlling factor in determining length of stay. The idea that a person who has had a stroke becomes completely capable of functioning as an independent individual in 26 days is erroneous. The type of long-term care we saw before 1965 no longer exists. Even rehabilitation facilities and extended care facilities are limited in their rehabilitation stays. Essentially this has meant that occupational therapists, in order to provide the services an individual needs to obtain a status of independent living, must link services and develop a network that will be supportive of the long process to independence.

A startling statistic that raised consciousness for me came from our State Vocational Rehabilitation Agency—35,607 referrals were made to Vocational Rehabilitation in the state of Missouri in 1979, only 7,187 of those persons were put into the job market (2). What happened? Perhaps these people did not have the social, prevocational, and basic life skills to proceed through the process. As therapists we must find the answer—I think we can help change this statistic.

I see the current delivery system as a big circle with disintegrated sections. We see the acute rehabilitation process initially, and then there is a void before vocational rehabilitation and, eventually, independent living takes over in the rehabilitation process. Certainly, each of these services is a closed system with each component accepting responsibility only for its own goal, not focusing on individuals and their needs for independent status.

Society certainly is not open to the needs of the disabled individual. Stigma exists for most disabled persons and generally represents the most salient and frustrating problem to be overcome. Without the negative community attitudes, disabled individuals and their families and the rehabilitation professions could deal with the medical limitations. With these negative community attitudes, all must deal with hosts of other problems that severely restrict the disabled individual and often contribute to severe problems of personal, social, and vocational adjustment (3). To be thrust into a rather hostile society without adequate preparation or introduction to the realities of living, a disabled individual can experience psychological and emotional problems that compound the difficulty (4). I think it is also critical for us to examine our own attitudes since we play such a critical role in helping newly disabled individuals to internalize their self worth.

The July/August/September
1980 issue of The Journal of Rehabilitation reports the research study conducted by Krantz in 1971. It formed the baseline for independent living education and justified the development of new professionals in the rehabilitation field. It pointed out that occupational therapists were among those surveyed for the data. Basically, each person was asked whether certain skills are critical to job functions and independent living, and the additional skills that are critical to independent living alone. These professionals then were asked whether they provided training in these skills. A serious gap was found in the services available for the disabled individuals and thus, independent living specialists were conceived. This is a quote directly from the article, “the goal of independent living specialists should be to aid the individual with a disability with the knowledge and skills necessary to achieve individual objectives in the personal, social and community aspects of living.” The authors feel that extensive training is needed for new professionals and paraprofessionals. They hope that the independent living techniques and concepts will eventually be used at the same level where they are perceived as important, and they believe that the specific needs of disabled individuals will be better met by having the services available provided by independent living specialists (5).

Certainly it is too late for occupational therapists to retain the sole leadership role in this movement, but we must contribute to its growth. We must support its concepts and retain a co-leadership role in the entire movement. We are the service that can make the transition from the hospital or the rehabilitation facility to the vocational experience. We can network with independent living centers and we can provide services to independent living centers. In occupational therapy we do not have the manpower to provide these services to all of the nation’s population who need it. I do believe that we can have a very significant role in making independent living a reality for our nation’s disabled. Occupational therapy must join with other rehabilitation professionals and disabled consumers in networking to develop a continuance of care that allows and supports an individual in reaching the maximum potential for independent living.

We represent a dynamic force in supporting a disabled individual’s work toward obtaining the ultimate potential for independent living. During the acute hospitalization and rehabilitation phases of service, the occupational therapist provides the necessary treatment and encourages individuals to develop the skills for control of themselves and their environment. We must also prevent the secondary effects of trauma, disease, or illness that might ultimately interfere with reaching independence. Following the acute rehabilitation phase, the patient’s contact with occupational therapists in rehabilitation centers, community health centers, halfway houses, daycare programs, home health services, and independent living centers must have an expanded focus. The focus of service at this level must be to help individuals to develop the skills for vocational preparation, to help individuals to integrate into the nondisabled community (including their families); to help them acquire skills that lead to personal independence and to encourage them to engage in leisure-time activities. During this phase the occupational therapist will be integrating occupational therapy services with vocational rehabilitation and, where available, with consumers and independent living centers.

We must provide the linkage for these individuals so that they receive the necessary services. We must form planning groups with independent living councils and vocational rehabilitation to establish a formal network so that each person who has the desire to do so can function as an independent person. In this entire process I see a critical role for occupational therapy, and I see no need for us to vie for a position or compete with physical therapy in service delivery. There is much to do in providing a comprehensive service. If we are doing our part — developing the skills for living — and if physical therapists are doing their part — developing the strong musculoskeletal system to support function — together we will have accomplished the first step in rehabilitation and made it possible for the individual to begin a developmental process toward independent living.

We also cannot forget our great responsibility to work toward changing social attitudes so that we will ultimately produce a barrier-free environment for the disabled. We also have the professional responsibility to educate students on the concepts of independent living and provide them with experiences that will allow them to make a career choice and carry on the concepts presented in an educational program.

Finally, there are some research questions that occupational therapists must begin to answer. We do not, as a profession, have a standardized assessment tool that functions in any capacity as a predictor of success in independent living. Recently, in writing a grant, I had to go to tools outside occupational therapy to measure functions that I, as an occupational therapist, wanted to measure. We have work to do. Let us make our commitments to education, to research, to service delivery, and, most of all, to the concept of independent living. We, as well as society, will benefit from our commitment.

REFERENCES

2. State of Missouri Vocational Rehabilitation Annual Report, 1979
3. English R: Correlates of stigma toward physically disabled persons, Rehabil Res Practice Rev 2, 1-17, 1971