

## An Orientation to Independent Living Centers

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Most Americans take for granted opportunities they have regarding living arrangements, employment situation, means of transportation, social and recreational activities, and other aspects of everyday life.

For many Americans with disabilities, barriers in their communities take away or severely limit their choices. These barriers may be obvious, such as lack of ramped entrances for people who use wheelchairs, lack of interpreters or captioning for people with hearing impairments, lack of brail or taped copies of printed material for people who have visual impairments. Other barriers --frequently less obvious-- can be even more limiting on the part of people with disabilities to live independently, which often result from people's misunderstandings and prejudices about disabilities. These barriers result in low expectations about what people with disabilities can achieve. They not only have to deal with the effects of their disabling conditions, but they also have to deal with both kinds of barriers. Otherwise, they are likely to be limited to a life of dependency and low personal satisfaction. This need not occur.

Millions of people all over America who experience disabilities have established lives of independence. They fulfill all kinds of roles in their communities, from employers and employees to marriage partners to parents to students to athletes to politicians to taxpayers - an unlimited list. In most cases, the barriers facing them haven't been removed, but these individuals have been successful in overcoming or at least dealing with them.

### A DEFINITION OF INDEPENDENT LIVING

What is independent living? Essentially, it is living just like everyone else -- having opportunities to make decisions that affect one's life, able to pursue activities of one's own choosing -- limited only in the same ways that one's neighbors who are not disabled are limited.

Independent living should not be defined in terms of living on one's own, being employed in a job fitting one's capabilities and interests, or having an active social life. These are aspects of living independently. Independent living has to do with self-determination. It is having the right and the opportunity to pursue a course of action, and, it is having the freedom to fail -- and to learn from one's failures, just as non-disabled people do.

There are, of course, individuals that have certain mental impairments that may affect their abilities to make complicated decisions or pursue complex activities. For these individuals, independent living means having every opportunity to be as self-sufficient as possible. It isn't easy, and can be risky, but millions of people with disabilities rate higher than a life of dependency and narrow opportunities and unfulfilled expectations.

## INDEPENDENT LIVING CENTERS

Fortunately, people with disabilities don't have to do it all on their own. The purpose of this brochure is to describe a kind of service organization which is designed specifically to assist people with disabilities in achieving and maintaining independent lifestyle.

These organizations called independent living centers are extraordinary. They are run by people with disabilities who themselves have been successful in establishing independent lives. These people have both training in personal experience to know exactly what is needed to live independently, and they have a deep commitment to assisting other disabled people and becoming more independent.

## HOW INDEPENDENT LIVING CENTERS DIFFER FROM OTHER SERVICE ORGANIZATIONS

There are many different types of organizations which serve people with disabilities--State Vocational Rehabilitation agencies, group homes, rehabilitation hospitals, senior centers, home health care agencies and so forth. These organizations provide valuable services and are important links in the network of services that help people with disabilities maintain independent lifestyles.

What makes independent living centers very different from the other organizations is that centers have substantial involvement of people with disabilities making policy decisions and delivering services. Why this emphasis on control by people with disabilities? The basic idea behind independent living is that the ones who know best what services people with disabilities need in order to live independently are disabled people themselves.

## THE INDEPENDENT LIVING MOVEMENT

In the late 1960s and early 1970s, this idea led people with disabilities from around the country to take active roles on local, state, and national levels in shaping decisions on issues affecting their lives. A major part of these activities involved formation of community-based groups of people with different types of disabilities who joined together to identify barriers and gaps in service delivery. To address barriers, action plans were developed to educate the community and to influence policymakers at all levels to change regulations and to introduce barrier-removing legislation. To address gaps in services, a new method of service delivery was conceived -- one which has people with disabilities determining kinds of services essential to living independently, has people with disabilities directing the delivery of the services, and has people with disabilities actually providing these services.

The earliest center was formed in 1972 in Berkeley, CA, and followed that same year by centers in Boston and Houston. In 1978, following effective advocacy by people with disabilities and their supporters all over the country, federal legislation was passed that provided funding to establish independent living centers (Title VII of the Rehabilitation Act). Today, there are centers in virtually every state and U.S. territory.

## THE ROLE OF PEOPLE WITH DISABILITIES AND CENTERS

These centers can be easily distinguished from other service agencies by the extent of involvement of people with disabilities. Independent living centers have a majority of people with disabilities on their governing boards, and hire qualified people with disabilities to fill management and service delivery positions.

#### DISABILITY GROUPS SERVED BY CENTERS

Centers typically serve a wide variety of disability groups, including people with mobility impairments -- which may be caused by spinal cord injury, amputation, neuromuscular disease, cerebral palsy, and so forth -- as well as people who have visual impairments, hearing impairments, mental retardation, mental illness, traumatic brain injury, and many other disability groups.

The extent to which the center serves a given disability group will vary from center to center depending on the availability and quality of services from other community service organizations, the financial resources of a center; and extent to which representatives of that disability group have chosen to be involved in the center. People running independent living centers believe strongly that prior to initiating services to a disability group, efforts should be made to recruit representatives of the group to serve on the board, staff, and advisory roles. In this way, the people who are to benefit from the services have a say in designing and delivering the services.

#### HOW TO FIND INDEPENDENT LIVING CENTERS

If you are interested in locating the center nearest you, there are several approaches you might try.

Look in your local telephone directory under social services. Try both in the regular directory, the Yellow Pages, 211 Helpline in Pinellas County and United Way in Pasco County.

Contact the main office of the State Vocational Rehabilitation agency (your local public library should be able to help you obtain the address and telephone number) and request the person responsible for overseeing the agency's independent living program to provide you with information on centers in the state, or go online to [www.ncil.org](http://www.ncil.org) for more information.

You may also contact the Rehabilitation Services Administration Office of Independent Living (330 C Street, S. W., Switzer Building, Washington, D.C. 20202, 202-732-1400). Staff members will have a listing of the centers which it funds.

Or go to the Virtual CIL Website <http://www.virtualcil.net/cils/>