

Chapter 7

INDEPENDENT LIVING

The entire focus of the Independent Living Movement is the realization that freedom to make choices and the ability to live in the community is a basic civil right that should be extended to all people, regardless of disability.

The mission of the Connecticut State Independent Living Council is to promote choice, equal access, opportunity, and full inclusion of people with disabilities in the economic, political, social, cultural, and educational mainstream of American Society. Their vision is to see a Connecticut where all people are respected, accepted and valued, have a range of choices and are free from barriers that limit them from fully participating in society.

The birth of the independent living movement has been attributed to a group of students at University of California Berkeley with disabilities. In 1962, the first student with a severe disability was admitted to UC Berkeley. By 1969, the number of students with severe disabilities had increased to 12. The UC hospital surroundings were familiar to the new tenants, who had spent countless days and nights in custodial institutions.

A sense of unity and self-confidence developed as the residents lived in close, continuing contact with each other. As they became more aware of the degree to which control over their lives had been taken over by medical and rehabilitation professionals, the students drew on their own experience to develop a philosophy of independent living. The students believed that they did not need to change to become integrated, but rather the environment and the attitudes toward persons with disabilities needed to change. The core of these students moved on to start the Center for Independent Living (CIL) in Berkeley.

Since the founding of CIL in Berkeley, 28 other Independent Living Centers (ILC) have taken shape across California and many more in the United States, bringing this philosophy to their consumer base. There are presently 403 CILs, 330 branch offices, and 56 Statewide Independent Living Councils (SILCs).

WHAT IS INDEPENDENT LIVING?

BRINGING CONTROL TO THE CONSUMER

Independent living is about being able to exercise control over one's life. It is based on a philosophy that says:

- people with disabilities, better than anyone else, know what they want, and what services are needed to achieve their goals;
- that the problem does not lie within the individual with a disability, but rather in the community with its attitudinal and architectural barriers;
- that with adequate services and supports, a person with a disability can participate fully in all aspect of community life; and
- that these services and supports should be in the community where the individual resides or wishes, and not only in large cities or institutions.

For many social service agencies that offer support, information and referral and other services, it is sometimes easier to fall into the role of "caretaker" and controlling the situation in order to help. For some persons with disabilities, it is "easier" to let others do everything for them.

However, this way of doing things creates an unhealthy environment of dependency. As a service delivery system, independent living programs embody consumer direction, advocacy, peer support, and the removal of both physical and attitudinal barriers as the means to integration. This contrasts directly to the traditional medical model service delivery system, which defines the person's disability as a problem to be fixed and measures independence by tasks that can be performed unassisted rather than by the quality of that person's life with help and support. Independent living services are those, which promote the activities of everyday life including eating, dressing, personal hygiene, shopping, homemaking, participating in community events and recreational/social activities, housing assistance, and financial management.

WHAT ARE INDEPENDENT LIVING CENTERS? FOCUS ON EMPOWERMENT

Since the late 1970's, the federal government has been funding ILC's in the

United States, modeled after the first center at Berkeley. An ILC must be:

- *consumer-controlled*-directed, managed, and staffed predominately by people with disabilities;
- *community-based*-located within the community in which the consumers of its services reside; and
- *community-responsive* designed to address the disability-related needs of the community, and identifying service gaps and barriers, which limit the independence of people with disabilities within their community.

An ILC is non-residential; rather, it provides a locus of activity from which to promote the independent living philosophy. There are four core services provided by an ILC:

1. *Peer support* – peer counselors provide support to consumers by drawing on their own life experience with disability and negotiating the system.
2. *Information and referral* – assists individual in identifying and accessing services and supports, benefits, assistive technology, housing, personal assistance services, or any other resources to enhance independent living.
3. *Individual and systems advocacy* – assisting consumers to secure the supports and services needed to maximize their independence. Advocacy on a systems level challenges the barriers that can stigmatize and exclude people with disabilities from full community participation.
4. *Independent living skills training* – training in activities of daily living and the skills needed to make community living as full and rich as possible. Examples of skills training are management and recruitment of Personal Care Assistants (PCA's), financial management, utilizing community resources, locating housing and consumer rights and responsibilities.

With this framework, Independent Living Center staff work with and for the consumer to promote his or her independence in the community.

This differs from many social service agencies that play a caretaker or protector role to “vulnerable populations.” ILCs believe that the freedom to make

choices, including mistakes, empowers people to further their involvement in their life and community. Persons with disabilities are not clients who professionals advise what is best for them. Instead, they are consumers of services, consumers who make informed decisions on the goals they want to achieve and ILCs give them the tools to help them achieve those goals. It is consumer control based rather than a social service. Although it is a simple statement, this philosophy defines a focus that greater society often finds difficult to accept.

By charter, at least 51 percent of employees at Independent Living Centers have disabilities, as does 51 percent of the center's board of directors. Center employees also represent all types of disabilities from those with cognitive disabilities to mobility impairments to people who are visually or hearing impaired to persons with learning disabilities. These factors underscore the importance of consumer control in the Independent Living Centers.

The center vests power and authority in individuals with disabilities and is designed by and for the local disability community.

It is important to note that ILCs do not operate any type of residential facilities. ILCs are not assisted living or skilled nursing facilities, a common misconception. Instead, independent living advocates direct their efforts toward the goal of freeing people with disabilities from institutional living while educating the community on accessibility issues. With the proper support system from the community, people with disabilities can live where they choose and pursue their dreams just as any other individual does.

Toward this mission, ILCs provide peer counseling, information and referral, independent living skills training, individual advocacy for a particular individual and systems advocacy for the community. Individual centers may provide more services, including:

- Children and youth services,
- Community mobility training including using public transit
- Personal assistance service
- Assistive Technology outreach coordination
- Transportation services
- Vocational services

- Any other services that promote independent living

Independent Living Centers realize that persons with disabilities do not need “to be taken care of” but rather need to be empowered to make their own choices and manage their own lives. In other words, ILC staffs do not “manage caseloads” or “follow up” to other agencies on referrals. The consumer has an active role in the services he or she receives, constantly giving feedback, and expressing concern with goals and expectations. By presenting education and supports even those persons with disabilities who have not been traditionally thought to have the ability to make their own choices, are allowed to participate and direct their own decisions.

For many persons with disabilities, control has always been unavailable because of agencies “taking care of their needs.” However, when one is empowered to live his or her own life, the ILCs believe the role of empowerment is key to the independence of a person with a disability. The consumer can be more active, independent, and may be able to be a vocal and productive member of society.

CT STATE INDEPENDENT LIVING COUNCIL

In accordance with Federal Statute, the Governor of Connecticut appoints each member of our twenty-three member statewide council. The Council is charged by the United States Congress to advance the principles and philosophy of Independent Living for all citizens with disabilities. Federal Statute requires that at least fifty-one percent of the Council’s membership be comprised of persons with a disability. The Council, which is funded by both state and federal resources, collaborates with five Centers, located in the communities of Hartford, Naugatuck, Norwich, Stratford, and West Haven. A primary responsibility of the Council is to develop and administer a three-year strategic plan known as the State Plan for Independent Living (SPIL). The “SPIL” details Council’s plans, advocating, and financially supporting independent living initiatives for individuals with disabilities.

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respected, accepted and valued, have a range of choices and are free from barriers that limit them from fully participating in society.

The **CT Department of Social Services** provides comprehensive independent living services through contracts with CT's five community based ILC's. These centers offer the following related services:

- Peer support
- Information and referral
- Individual and systems advocacy
- Independent living skills training, including management and recruitment of personal attendants, financial management, utilizing community resources, consumer rights and responsibilities

The Department of Rehabilitation in Connecticut provides assistance to the ILCs.

Organizational structure - PA 11-44 created the Bureau of Rehabilitative Services, bringing together the programs that were formerly known as the Department of Social Services' Bureau of Rehabilitation Services, the Board of Education, and Services for the Blind, the Commission on the Deaf and Hearing Impaired, the Workers' Rehabilitation Program and the Driver Training Program for People with Disabilities. Based on recent legislative changes, the Bureau is recognized as the Department of Rehabilitation Services (DORS) effective July 1, 2012.

The new Bureau creates the opportunity to better align existing resources and will improve services to Connecticut citizens with disabilities. The agency will continue to provide, without interruption, high quality services to support individuals with disabilities to work competitively and live independently.

CONNECTICUT ILCs INCLUDE

Disability Resource Center of Fairfield County
203-378-6977
www.drcfc.org
Email: info@drcfc.org
80 Ferry Boulevard
Stratford, CT 06615

Center for Disability Rights

203-934-7077

www.centerfordisabilityrights.org

Email: cdr7077@aol.com

764A Campbell Avenue

West Haven, CT 06516

Independence Unlimited

<http://independenceunlimited.org/contact.html>

860-523-5021

Email: indunl@aol.com

151 New Park Avenue, Suite D

Hartford, CT 06106

Disabilities Network of Eastern Connecticut

860-823-1898

www.disability-dnec.org

Email: dnec@snet.net

238 West Town Street

Norwich, CT 06360

Independence Northwest

<http://independencenorthwest.org/>

info@independencenorthwest.org

203-729-3299

1183 New Haven Road, Suite 200

Naugatuck, CT 06770

Connecticut Association of Centers for Independent Living (CACIL),

The Executive Directors for each of these ILCs form the Connecticut Association of Centers for Independent Living (CACIL)

151 New Park Avenue - Box 18

Hartford, CT 06106,

860-656-0430, or 800-261-3769