

THE MOVEMENT FOR INDEPENDENT LIVING: A Brief History

By: Maggie Shreve, Consultant*

ATTITUDES STARTED IT ALL

A brief look at the history of how people with disabilities have been treated by various Western cultures can help us see how the movement for independent living began in this country. From nomad tribes to social change in the 1960s, people with disabilities have played various roles in their societies. What is occurring now is the horizon of a new age for people with disabilities.

The nomads considered people with disabilities useless because they could not contribute to the wealth of the tribe. Nomads left people with disabilities to die whenever the tribe moved on to a new location.

The Greeks sought rational reasons for disability. They reached such conclusions as: epilepsy was a disturbance of the mind; and people who were deaf could not learn because communication was essential to learning.

Early Christianity brought a period of sympathy and pity toward people with disabilities. Churches organized services for people with disabilities within their congregations and homes. Many Christians held superior attitudes towards people with disabilities which resulted in a general loss of autonomy. To many, disability represented impurity of some kind. This impurity could be purged through worship and forgiveness of sins, including the belief that with enough prayer and rituals the disability could be eliminated.

During the Middle Ages, Christians became fearful of people with disabilities as their attraction to supernaturalism increased. People with disabilities were ridiculed, such as court jester who was actually someone with a humped back. People with disabilities were not only ridiculed but persecuted as well. Disability became a manifestation of evil.

The Renaissance brought the initiation of medical care and treatment for people with disabilities. Education was available to people with disabilities for the first time in Western recorded history. An enlightened approach to social norms and dreams for a better future seemed to encourage active participation of people with disabilities in their respective communities.

This is not to say that people with disabilities were not often institutionalized. Periods from the Renaissance through World War II indicated that society believed people with disabilities might be educated, but usually in "special" schools, far from urban or heavily populated areas.

This institutionalization led to the ultimate in abuse during the 1930s in Hitler's Germany. People with disabilities, most notably those with mental retardation and mental illness, became the Gestapo's first guinea pigs in medical experimentation and mass execution. Before the SS began mass extermination of Jews, Gays and Lesbians and other minorities and their supporters, people with disabilities were all put to death by Hitler's concentration camp staff.

In America, the colonies' first settlers would not admit people with disabilities because they believed such individuals would require financial support. Colonists enacted settlement laws to restrict immigration of many people, including those with disabilities. This did not, of course, prohibit people with disabilities from being born in the colonies or acquiring disabilities after they were already settled here.

But by 1880, after the development of almshouses for people who were poor or in need of basic support, most states and territories had programs for people with specific types of disabilities. Most of these programs were large institutions where people who were blind, deaf mentally retarded or otherwise physically disabled were sent for treatment, education or to spend their entire lives.

The movement west, otherwise known as the American Frontier Movement, inspired a peculiarly American belief that social ills could be eradicated by local initiatives. The concept of "rugged individualism" was born in the American Frontier and still maintains a powerful hold over political debate today. In fact, the desire for independent living today carries with it the seed of many "rugged individualist" ideals. For some people with disabilities, this meant they need not be condemned because they could not earn their own living. Some community-based services began to emerge but people with disabilities were still usually segregated from society as a whole. Rural areas were the only places where people with disabilities tended to live with their families in integrated settings.

Rehabilitation services on a broad scale were introduced as a federal program following World War I. The emphasis for these first rehabilitation programs was on the veteran with a disability who was returning home to the United States. The need for training or re-training created the first federally funded program for people with disabilities -- a program now known as the federal-state vocational rehabilitation system.

During the 1940s, the blind community argued for separate services for people who were blind based upon belief that people who were blind did not need rehabilitation but education. Advocates who were blind argued that rehabilitation is based upon a "medical model" where the person who is blind needs to be treated and cured rather than educated to live with blindness. The debate over what approach to use resulted in a "split" within the vocational rehabilitation program, allowing state vocational rehabilitation agencies and agencies serving the blind to become separate entities within a state.

Not until the social change movements during the 1960s were other major services for people with disabilities seriously considered by federal legislation. Although the Social Security system provided benefits to those who had earned sufficient income over a long enough time period and had become disabled (i.e., unable to work), there was no attempt to broaden the base of services for people with disabilities beyond the vocational rehabilitation approach. For the first time in U.S. history, consumers, advocates and service professionals began an intensive examination of the human service delivery system to decide what was missing. Community-based programs for people with disabilities began growing all over the nation in an attempt to fill the gaps left by these missing services. New concepts, new technology and new attitudes were beginning to make a difference in the lives of people with disabilities.

THE IMPACT OF OTHER SOCIAL MOVEMENTS

Five other social movements of the 1960s and 70s contributed to the evolving movement for independent living for people with disabilities. These were:

- Civil rights movement
- Consumerism
- Self-help
- De-medicalization
- De-institutionalization

According to Gerben DeJong in his paper, "The Movement for Independent Living: Origins, Ideology and Implications for Disability Research," these five social movements created the necessary atmosphere for the current activities of both the disability rights movement and the development of centers for independent living. Centers still emphasize the primary principles of these other five movements in their services and advocacy approach.

Starting with the Center for Independent Living (CIL) in Berkeley, California in the late 1960s, disability rights and independent living concepts merged into one operational organization. Essentially, individuals with disabilities joined together to protest their exclusion from society's mainstream and to demand more humane, non-medical attention from the nation's service delivery system. By 1972, there

were at least five states where CILs similar to the Berkeley model had been established. These new organizations, run by people with disabilities for people with disabilities, were trying to respond to a rising demand from the disabled community for control over their own services.

Much of this demand sounded like the **civil rights movement** led by African-Americans during the 1950s and 1960s. People with disabilities pointed out that -- just like other minorities -- they were being denied access to basic services and opportunities such as employment, housing, transportation, education and the like. Like Rosa Parks, people with disabilities want and need to be able to ride the bus. The only difference is that Rosa Parks as an African-American woman was not permitted to sit in the front of the bus while people with disabilities just want to get on the bus.

Consumerism, a movement led by well-known national figures such as Ralph Nader, contributed another element to the growing disability rights and independent living movement. People with disabilities were, for the first time, stressing their role as consumers first and "patients" last. In other words, individuals with disabilities wanted the right to educate themselves and decide for themselves what services and products they wished to purchase (even if a third party was paying for the service or product). As "clients" or "patients," people with disabilities were rarely given any autonomy or power over the services and products they would use.

Self-help is nothing new in the United States, but organized self-help programs are relatively new. The original non-professional, self-help program which is best known in the U.S. is Alcoholics Anonymous. Having a severe disability may not be exactly the same as having a

problem with alcohol, but a strong parallel remains. Leaders of the disability rights and independent living movement believe that only persons with disabilities know best how to serve others who have the same or similar disabilities. The concept of "peer" counseling and self-help groups are the most common methods for addressing this parallel.

De-medicalization and **de-institutionalization** share certain common characteristics. De-medicalization for people with disabilities means

removing the involvement of medical professionals from the daily lives of individuals with disabilities. People with disabilities are not "sick." They are disabled and not dependent upon medical professionals for every day needs. The perfect example of a "de-medicalized" service for persons with severe mobility disabilities is that of "personal assistance." Personal assistance is a consumer-directed service whereby the person with the disability recruits, hires, trains, manages and fires his or her own personal assistants. When consumers with disabilities are allowed to buy the services they need for daily survival from whomever they choose, they have "de-medicalized" the service. Unfortunately, the vast majority of services provided to people with disabilities are still rooted in the "medical model," regardless of the individual's needs and desires.

De-institutionalization, which began in response to large mental health facilities for those who are mentally ill or mentally retarded, follows the principles of de-medicalization. Most institutions are staffed by medical personnel, even if residents are not ill. Since many such individuals are only disabled by some permanent type of condition, placement in institutions is inappropriate and are by far more costly than providing those same residents with the support services they need to live in their chosen communities. The disability rights and independent living movement is working towards the development of those other non-medical and community-based services which would assist institutionalized persons to move back to their home towns or areas.

The disability rights and independent living movement is a compilation of all five social movements as they pertain to and are defined by people who have disabilities.

INDEPENDENT LIVING AND TRADITIONAL REHABILITATION

Since most traditional rehabilitation programs are built upon the "medical model" of service delivery, the disability rights and independent living movement promotes a completely different approach to service delivery. Independent living as a movement is quite unique compared to existing programs and facilities serving people with disabilities. Centers for independent living across the nation are working toward changing their communities rather than "fixing" the person with a disability. CILs were originally defined by the first CIL in Berkeley and now are commonly referred to as consumer-controlled, community-based, non-residential not-for-profit organizations providing both individualized services and systems advice.

Referring again to Gerben DeJong, traditional rehabilitation and independent living programs see the problems associated with disability from two different (almost opposite) perspectives. DeJong has put these differences into a chart which is re-printed below.

	Rehabilitation Paradigm	Independent Living Paradigm
Definition of problem	physical or mental impairment; lack of vocational skill	dependence upon professionals and others
Locus of problem	in the individual	in the environment; in the medical and rehabilitation process
Solution to the problem	professional intervention; treatment	barrier removal; advocacy; self-help; consumer control over services
Social role	individual is a "patient" or "client"	individual is a "consumer" of services
Who controls	professional	Consumer
Desired outcomes	maximum self-care; gainful employment	independent through control over acceptable options for every day living

The rehabilitation paradigm defines the problem with disability as the actual physical or mental impairment whereas independent living defines the problem as the dependence upon professionals and others. Under the rehabilitation paradigm, the person in control of service is the person with a disability, i.e., the consumer. In the rehabilitation model, the desired outcome of service delivery is maximum physical or mental functioning (or, as in vocational rehabilitation, gainful employment). Desired outcomes in independent living are tied to having control over one's daily life. Control does not necessarily mean having the physical or mental capacity to do everyday tasks for one's self. For some disability groups, complete control may not be possible, but the independent living movement continues to work toward complete consumer control wherever and whenever possible.

These philosophical differences may be hard to realize when thinking about services and programs in your local area. Obviously, every community needs the rehabilitation paradigm for the provision of adequate medical-based services. But, more importantly, each community needs

an equal amount of service and attention from services and advocacy stemming from the independent living paradigm. Currently, 99% of all public dollars go into the rehabilitation paradigm while less than 1% goes into independent living.

Picture if you can, a town where every curb has a curb cut and ramp - - where children with disabilities are fully integrated into all schools and all grades with non-disabled children -- where there are no institutions or "state schools" but many scattered small group homes for those with disabilities so severe that they are not capable of controlling their every day lives -- where buses are equipped to pick up any type of passenger, including those who use wheelchairs or have other mobility impairments -- where closed or open captioning is available on every TV station and for every program -- where in-home services are available at any time and for any person, regardless of type of disability or level of income.

Such a picture is possible. Based upon historical developments such as those cited above, upon the numerous federal, state and local laws currently in place and those to come, and upon the pure energy, dedication and drive of people with disabilities in this country, a new vision of the United States is becoming a reality. Now, with the passage of the Americans with Disabilities Act of 1990, we have full recognition of the harm done by discriminating against people with disabilities and a federal law which will assist the movement in creating the picture. A picture of equal opportunity and access for all. A picture shared by people involved in both the traditional rehabilitation system and the newer, younger disability rights and independent living movement.

Some material about the history of the role of people with disabilities in various societies was drawn from an unpublished paper titled "Attitudes Toward the Disabled: An Historical Perspective," by J.K. Hannah and M.L. Jones (1982) at the Research and Training Center on Independent Living at the University of Kansas. Their work used information from Frank Bowe in his book, Handicapping America.

FEDERAL LAWS SUPPORTING INDEPENDENT LIVING MOVEMENT

1968 Architectural Barriers Act (designed to eliminate architectural barriers in all federally owned or leased buildings)

1970 Urban Mass Transit Act (required that all new purchases of mass transit vehicles be life equipped; APTA sought and won a court injunction barring implementation of the proposed regulations)

1973 Rehabilitation Act (Section 504 and related non-discrimination provisions in programs receiving federal funds)

1975 Developmental Disabilities Bill of Rights Act (Protection & Advocacy or P&A agencies in each state established)

1975 P.L. 94-142, Education of All Handicapped Children Act (written to require a free, appropriate public education for children with disabilities in the least restrictive environment; mainstreaming children with disabilities into regular classrooms)

1978 Rehabilitation Act Amendments (Title VII, Comprehensive Services for Independent Living, was created; Part B funded creation and operation of "centers")

1983 Rehabilitation Act Amendments (mandated that each state operate a Client Assistance Project or CAP; Title VII Part A funded by services for IL clients - a concept parallel to the basic VR program)

1985 Mental Illness Bill of Rights Act (Expanded P&As to cover mental illness)

1986 Rehabilitation Act Amendments (advocates fought for and won "consumer control" for Title VII Part B center boards; supported work programs created and funded)

1988 Air Carrier Access Act (designed to provide for equal access on private airlines)

1988 Civil Rights Restoration Act (clarified that any organization or corporation receiving federal funds may not discriminate in any of their programs)

1988 Fair Housing Act Amendments (prohibits discrimination against people with disabilities in housing and creates universal design in new construction provisions)

1990 Americans with Disabilities Act (creates broad civil rights protections for people with disabilities modeled after the Civil Rights Act of 1964 and Section 504 of the Rehabilitation Act of 1973)

* Maggie Shreve is a consultant to ILCs. This paper was written under a federal grant for an ILC Training Module, around 1982.