

Independent Living: Ideology and Movement Suggested Definition

Adolf D. Ratzka, Ph.D.
Stockholm Group for Independent Living (STIL), Sweden
World Institute on Disability, Berkeley, California, USA

Draft August 1987

Independent Living is the name of the international civil rights movement of people with disabilities that works against discrimination and for more personal and political power for people with disabilities.

The movement consists of people of all ages and all types of disabilities. With origins dating back to the 1960's it has derived much of its philosophy from the American civil rights movements of blacks and women and is now represented in a growing number of countries such as the US, Canada, United Kingdom, South Africa, Japan, West Germany, France, and Sweden. The movement consists of an informal network of local organizations which work as political pressure groups for equal opportunities and provide such services as advocacy, counselling, personal assistance and housing referral. In some countries national coalitions of Independent Living initiatives exist that have gained wide political recognition.

The philosophy of the Independent Living Movement or Disability Rights Movement, as it is also referred to, is based on the principles of self-determination, self-help and consumer control.

Anti-Discrimination

Statistics show that in all countries disabled people as a group are worse off than the rest of the population in terms of education, jobs, income, housing, social and political opportunities. For this reason the Independent Living Movement is working for anti-discrimination legislation and for services which guarantee us equal opportunities.

The Medical Model

One of the reasons for the discrimination disabled people are exposed to is that deviants are often declared sick. This medical model of disability assigns us the helpless and passive patient role in which we are considered dependent upon the care of others, unable to work, exempt from normal duties, leading worthless lives, as evidenced by the still common term "invalid" (Latin for "worthless").

In the traditional rehabilitation process the problem is seen within the individual who is to be normalized and integrated by experts. Who defines "normal"? Integration at whose terms? Instead, the Independent Living Movement demands self-determination.

Disability is not a medical problem but a problem of unequal power. We are an underprivileged political minority whose second class citizenship standing can only be improved through political power and far-reaching systemic changes.

De-Institutionalization

With the justification that we are sick and unable to care for ourselves many of us are confined in institutions, deprived of the most basic decisions and opportunities which other people take for granted. They suffer loss of social skills, self-confidence and stunted human growth. The Independent Living Movement has amply demonstrated that nobody, regardless of type and extent of disability, needs to waste his life in an institution, if provided with the appropriate services in the community.

Institutions need not consist of brick and mortar. The Independent Living Movement has shown that many of the services presently provided in the community carry institutional vestiges in that they deprive us of the freedom of choice, prevent us from taking responsibility and keep us in paternalistic dependency.

Control over Our Services

Today many services such as special housing and personal assistance are designed for the needs of the service provider and not the needs of the consumers. As a result, consumers are forced to use uniform, general solutions which cannot meet their individual, differing needs. Such services deny our uniqueness as human beings and deprive us of choices.

The Independent Living Movement demands the same range of options and the same degree of control over our lives that our non-disabled peers enjoy. To this end people with disabilities need services that are designed in such a way as to maximize control by the individual consumer. Choice is the key to independent living. Nobody else can make that choice for us. We are the experts on our lives.

Control over Our Organizations

Traditional disability organizations are organized along diagnostic lines, for each medical condition a separate organization, thereby emphasizing the sick role and focusing on what divides us instead of concentrating on our common agenda. Seeing disability as a medical problem instead of a political problem traditional disability organizations are often run by non-disabled experts both in elected and staff positions.

The Independent Living Movement claims that our organizations can work more effectively towards the goal of full participation and equality when disabled people themselves are in control. Disabled people are the best experts on their needs. We need to demonstrate to the public and to ourselves that we are fully capable of taking our cause in our own hands. Given the high unemployment among disabled people we need the work and training opportunities in our organizations ourselves.

Peer Counselling

Since people with disabilities are part of their respective communities, many of us have internalized society's prejudices against disability. The Independent Living Movement recognizes that our political emancipation must go hand in hand with liberating ourselves from internalized oppression, self-contempt, and low self-confidence. For this purpose the movement has developed its own pedagogy, peer counselling.

Peer counselling means to share the fruits of one's experience. In peer counselling courses and support sessions individuals with disabilities learn from each other the practical and social skills needed for a self-directed life in the community. The living example of a person in the same situation with which one can identify oneself is a more powerful intervention than the advice of the best rehabilitation expert.

Peer counselling provides appropriate role models, helps to increase self-reliance and encourages to take charge of one's life. No longer are we helpless victims dependent upon other people's charitable attitude. Regardless of type and extent of disability, we all can learn to take more responsibility for ourselves. The Independent Living Movement empowers the individual with the tools to bring about these changes in one's life.