

# The Concept of Independent Living

## a New Perspective in Rehabilitation

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The Concept of Independent Living - a New Perspective in Rehabilitation

### 1. Introduction

According to Gerben Dejong (1983), 1973 saw the beginning of a new era in politics for the disabled, at least in the United States. We are still becoming aware of these changes and are now searching for ways of creating a similar turning-point. Congress passed a new rehabilitation law in which Section 504 prohibits all forms of discrimination of disabled persons in all programs and activities supported by federal funds. For this reason, it was also called Civil Rights Law for the Disabled. In practice, this means that public buildings such as schools, universities, authorities etc. must be obstacle-free and equipped with facilities to guide people with sight and hearing problems. In 1990, President Bush signed the Americans with Disabilities Act (ADA for short), which gives the individual disabled person still more rights to sue when he or she feels discriminated. The accessibility of all public buildings and non-private amenities are an essential new part of the law. The law also includes public transport, telecommunications and the creation of equal opportunities in all areas of society, especially in the labour world. On the occasion of the 3rd anniversary of the signing of the ADA in July 1993, President Bill Clinton declared:

...my administration is committed to shifting disability policy away from exclusion and towards inclusion, away from dependence and towards independence, and away from paternalism and towards empowerment.

He continued on the same occasion:

...For more than 40 million people, the law is clearing barriers to full participation in American life...

(President's Committee on Employment of People with Disabilities, 1993).

This law is unthinkable without the Independent Living Movement which has successfully brought the needs and goals of disabled people into national politics. It was supported in this by many scientists from different disciplines who feel devoted to the

cause and, in their work, search for living conditions initiating and promoting the self-determination of individuals. They make it clear that they start from a new definition of politics for the disabled, one which encourages different legal regulations, promotes changes in those concerned and in society, develops new community-based services and examines the consumer orientation of all processes of assistance. It is a cross-disability movement of persons with all kinds of disabilities; the focus is on a political aim, which is to change the rehabilitation process and the social attitudes towards disabled persons. Disability-specific groups run by charity organizations, as they are really only to be found in our country, are largely unpolitical in their work; they serve to legitimize the politics of the large organizations. When politics turn to the problems of the disabled or the chronically ill, the charity organizations are heard most of all, and it is only gradually that organizations of disabled people can make themselves heard. The IL movement sees disability principally as a political and social phenomenon which is accessible to social change; it is no longer individual destiny, a cross to bear which can, if necessary, be made lighter by means of poverty laws.

The American movement was not only interested in new rights but in a change in the consciousness of rehabilitation experts, politicians, disabled people and the researchers in this field in order to develop and to supply new forms of services and of methods of assistance. A new way of thinking about disability is at stake here. In his study, *Independent Living - From Social Movement to Analytic Paradigm*, an observer of the scene, Gerben Dejong (1979), named a new paradigm showing the point of view of the disabled and possible steps to solve the problems involved. The IL paradigm sees the problem of disability not primarily in the disabled individual, but in the help structures which society offers in order to solve the problem. Or, as Rugeberg (1986, S. 49) expresses it, as a perspective of the way out of disability in the sense of handicap or isolation. Or, expressed in everyday terms, a blind person can compensate for his handicap by reducing his dependence if he has sufficient reading assistance in the way in which he needs it. In our country, too, the last two years have seen the formation of alliances transcending organizations and persons. These demanded an anti-discrimination law for our country and an addition to Article 3 of the Constitution, all following the example of American legislation. These alliances were successful in the end.

## 2. What is Independent Living?

Independent Living (IL) is a civil rights movement of people with disabilities. It grew in America at the end of the Sixties as a protest to clinical living conditions in institutions. It was founded by people who need quite a lot of personal assistance in everyday life. One of the most prominent representatives of this movement is Ed Roberts from Berkeley, California. The IL sees disablement primarily as a social and political problem. It follows the example of the issues and strategies of the black civil rights movement and of the feminist movement. The main issues are the articulation of one's own needs, self-determination, assistance geared to the consumer and participation in politics and administration. Adolf Ratzka (1988) expressed it more bluntly and demanded that the

politics of disability should give disabled people more power. The person with more power is the one who has financial means at his disposal and can define social situations and issues. Consequently, and in the sense of the IL philosophy, state funds should go directly to the disabled persons for which they are intended so that the latter can demand services. New structures of help and support can then emerge. This has already been put into practice for a large number of disabled persons in Sweden, Denmark and the Netherlands, where, according to the laws in force at present, disabled persons receive a personal budget according to their assistance requirements and their lifestyle. Most disabled persons profiting from these regulations come together to form cooperatives in order to support themselves via self-help in the organization and administration of assistance. This is where so-called peer counselling or peer support comes in.

## 2.1 What else does IL mean for persons with disabilities?

- They decide on their own daily schedule
- They have the competence to tell the assistant how best to help them
- They can choose how and where to live
- They can develop a private living space and lifestyle
- They have the right to friendship, love and sex
- They have the right to work and to be paid for it

IL is also a philosophy of the needs of disabled people. This makes it completely different to the traditional rehabilitation philosophy which is therapy-oriented and geared to adapting the disabled person to existing structures of working and living. Put more bluntly: A person who adapts to existing norms by means of therapy, training and other means attains the promised goal of integration. All others are put into the so-called 'final links' of the rehabilitation chain (according to the IL concept) or 'rehabilitated' (according to the language of the traditional rehabilitation concept). Jeff Bernard (1989, P. 14) clears this up by writing that "special institutions and methods of all kinds are, in contrast to what many protagonists say, not preliminary stages of integration. Only integration as such is integration; integration is therefore the negation of special institutions or methods."

## 3.0 The concept of Integration According to Nirje

Special Integration - Apartments, leisure pursuits, work and employment where they are natural and normal for other people.

Functional Integration - Fulfilment of living needs in the normal areas of the environment which are accessible to all.

Social Integration - Interpersonal, even anonymous relationships to other people.

Personal Integration - The need for relationships to other important persons develops and

changes constantly. The aim is to lead a satisfying private life, including exchange and common interests with other people.

Societal Integration - Development as a fellow citizen, the realization of the right to self-determination and to inclusion in decision-making, especially with regard to decisions concerning disabled people.

Organizational Integration - The use of general public services suitable for promoting the process of integration. When there are more specialized amenities, they should be modelled on general amenities. Nirje named the issues and components of the normalization principles in the same pragmatic way:

- Normal daily schedule
- Normal weekly schedule
- Normal annual schedule
- Normal experiences of a life-cycle
- Normal respect
- Life in a world with two sexes
- Normal standard of living
- Normal environmental conditions

These principles were published more than ten years ago, but they are still far from being a reality in most countries. On the contrary: the term "integration" conceals signs of increasing isolation.

## 4.0 Development of the Number of Homes run by Charity Organizations

The increase in the number of homes for disabled people, often celebrated as a progress in the sphere of rehabilitation, is a double-edged sword: to follow the definition of integration given by Bernard (1989) and Nirje before him, the quadrupling of the number of homes in 20 years can be seen as a continuing process of social isolation. The aim of the IL concept is independent living in an integrative setting in approximately the way in which Nirje expressed it. This is the point where science and the politically-oriented disabled people's movement meet. IL is consumer-oriented, which means that persons with disabilities are users of services like anyone else. The special needs of disabled people can be formed according to the ideas of the disabled persons themselves without being given a charitable character. The social services offered for disabled persons are geared more to the needs of the professionals than to those of the users (Bernard, 1989). This does not mean that the experts should be abolished, but we would like to see them in the role of persons offering services and answering certain needs, persons who must submit to competition with other offerers and the scrutiny of the users. This supersedes paternalistic thought and action through which disabled persons have all too often been made the victims and objects of help. IL is now also a research concept. In it, the focus of research is not primarily on the disability itself, but on living and working conditions and

the attitudes of society towards disabled persons, attitudes which often find expression in laws and practical measures. These areas are accessible to change. The disabled person should not be adapted to the external circumstances, but the circumstances to the needs of the disabled person, whereby the disabled people define their own needs and the experts act as counsellors whose role it is to facilitate certain processes.

## 5.0 Four large areas of influence for rehabilitation measures:

1. Disablement/injury as a personal factor.
2. Environmental conditions such as the accessibility of the man-made environment and of transport systems and workplaces, the systems and organizational forms of community-based assistance and different forms of living.
3. The attitudes of society towards persons with disabilities.
4. The attitudes of disabled persons toward themselves.

The IL concept pays great attention to the fields of environment and attitudes in order to create new structures of help and assistance geared to the needs of disabled persons. They also take into account the principles of normality and participation. This can help to avoid institutionalized isolation. It on no account excludes medical measures which start with the disability and help to reduce it. The important thing is to consider the needs of disabled people with regard to quality of life and lifestyle. Comparison: Rehabilitation Concept - Independent Living Concept (according to Dejong, 1982)

	<b>Rehabilitation Concept</b>	<b>Independent Living Concept</b>
What is the Problem?	The disabled person is a deficitary being whose ability to play social roles is restricted.	The disabled person is dependent on experts, rehabilitation centers and factors such as environmental and other political conditions.
Where is the Problem Situated?	In the disabled person himself.	In the environment, the rehabilitation process and in social and political circumstances.
How is the Problem Solved?	By the expert procedure of doctors and other specialists. The disabled person is cared for by certain organizations.	By self-help, peer counselling, self-organization of assistance, the reduction of psychological, social and other barriers, consumer control.
What is the Social Role of the Disabled	Patient, client.	Consumer.

Person?		
Who is Competent?	Experts.	Consumer.
What is the Desired Result?	Psycho-physical independence. Reduction of the "disability". Profession or institutionalization.	A self-determined life, possibly a profession, the ability to organize and to accept assistance. Assistance structures close to the consumer.

## 6.0 Self-determination versus Determination by Others

Self-determination primarily concerns the shaping of leisure time and the fulfilment of elementary needs. Disabled persons are often denied this right when they require a considerable amount of care and assistance in everyday life. For medical and social reasons, official doctors and social authorities consider institutionalized care necessary when a large amount of care and assistance are required, unless relatives agree to care for the disabled person in their own household. Care in nursing homes, institutions and old people's homes is regulated from the outside, and the inmates must constantly submit and adapt to these structures and rules in the fulfilment of their physical needs, intimate or otherwise; their life is thus almost completely determined by others. In addition, there is no privacy in the sense of an apartment of one's own in which the disabled person is his or her own boss. He or she is accommodated and given a bed. Ernst Klee (1980) says of people in institutions with home structures that "their right to free development of the personality is restricted resolutely". The concept of Independent Living considers the problem of care and assistance not as being localized primarily within the individual, but in the solutions and the assistance offered by rehabilitation. The latter continue to judge the disability according to medical aspects and can only imagine care models based on hospital methods. Up to now, if you had enough money, you could avoid moving into a home and could finance the necessary assistance in the surroundings of your choice. The Federal Republic of Germany pays approx. 6.000 DM per month for each place in a home for the severely disabled. If this money were given to the disabled people themselves, they could finance the necessary care and assistance in the surroundings of their choice. The experience of the VIF in Munich and of other community-based assistance services shows that the authorities oppose change here. They are used to paying the money to charitable care institutions, which consider themselves as being beneficial to severely disabled people. Standard care charges mean standard helplessness. Disabled people are denied the right to live according to the "Independent Living" concept; up to now, individuals were able to regain this right only after considerable conflict with the authorities involved, and often only after going to court.

## 7.0 Control over the Environment and one's own Body

Independent Living also means control over one's environment, and one's own apartment is usually the place over which most people exercise control and can decide for themselves with whom they maintain contact and with which intensity. One's apartment is also the place in which one fulfils one intimate sexual needs. All human beings naturally accept a variety of services from others and, equally naturally, pay for them. We can learn to find it just as natural that care and personal or mobility assistance should be paid for by the user. Disabled persons often require more assistance than their able-bodied counterparts, but this does not give us the right to see this assistance as an especially charitable gesture of the public and expect gratitude for it. Independent Living also means the possibility and the ability to make as many decisions as possible for oneself. This freedom of decision to look for alternatives is still denied to many disabled people by an excessively powerful rehabilitational bureaucracy with its public servants and social workers. An essential element of self-determined living is the option to choose one's own lifestyle by obtaining information and counselling and by examining the available resources. This also means taking risks and exchanging the known and accustomed for the unknown and unusual. Taking risks is necessary for the growth and development of the individual; I. Zola has pointed this out in many publications. The same goes for whole societies; their structures and institutions become rigid. My personal experience has been that, when persons with disabilities are constantly being cared for and have maximum external security and are to a large degree determined by others, their own initiative, self-responsibility and competence for social activity decreases.

### 7.1 Personal Assistance as the Key to a Self-determined Life

According to Adolf Ratzka (1986), personal assistance is one of the keys to a self-determined lifestyle. Assistance for disabled persons is not basically different to the assistance which all people accept in order to develop and maintain their own personal lifestyle. These are a variety of services of the everyday kind, and we don't think twice about when and where to recruit the services of hairdressers, auto mechanics, tailors and many others: all these are forms of assistance. For disabled people, personal assistance is a possibility to compensate, via the help of others, for everyday things which are difficult or impossible to do on their own. The decision as to which tasks should be delegated, and to which extent, lies in the competence of the person requiring the assistance. Ideally, the disabled person should function as an employer, with all rights and duties which this entails. The word "personal" is used to make clear that the assistance must be geared to the needs of the user and to his view of life. The focus here is not on supplying care and assistance prescribed by experts. We often use words such as care, nursing and "looking after someone". These words frequently mean that those concerned are not capable of looking after themselves and are unable to make decisions concerning everyday life and make plans for their lives. Of course there are disabled and able-bodied people who are

for certain reasons not capable of looking after themselves and making decisions to fit the situation in hand. "Disablement" is often equated with helplessness and the inability to make decisions. This results in the removal of responsibility, which leads to the acquired helplessness described above.

## 8.0 The Role of Society for Independent Living

The discussions on European level have shown that certain legal requirements are necessary for a more self-determined life for disabled people. In Germany, France, Belgium and, I am sure, many countries in the Mediterranean area, people with various disabilities are being institutionalized and put into nursing homes which are paid standard charges by the social insurance authorities and which in return promise to supply all-round care. This means that people are accommodated in rooms with several beds and have no privacy; also, nursing conforms to a staff plan and the day is structured accordingly. These systems function almost everywhere, give the charities a profit and try to combine all-round nursing with the rational use of funds. The result for those concerned is passivity, repetitive routine and a general loss of everyday self-determination and responsibility for their own lives. Most European societies must change their way of thinking and find new horizons for social work in general and rehabilitation policy in particular. What we need is not nursing or assistance conforming to a medical model of disability and which focuses on the defective body instead of social conditions which can be changed. What is necessary is the creation, as far as possible, of an environment without barriers. One example of this is Sweden, where rented apartments without barriers have been built since the late 70s. A flat of one's own is a first necessity for self-determined living. A further necessity is the introduction of a personal budget for the payment of the necessary assistance. The Arhus scheme in Denmark according to S 48.4 of the social security act sets an example for Europe and allows independent living for a large number of severely disabled people. Integrated education should be put into practice and not seen as the remote goal of special rehabilitation measures. Disabled people must have a say in all decision processes and solutions concerning them. This means that there must be no all-round nursing by charity organizations which, in many countries, have the power to define our needs and to supply us with solutions which take away our self-determination and profit from our situation.

## 9.0 The Role of the Individual

I would not be so arrogant as to try to say which role the individual person should play in the process of self-determined living. Instead I would like to suggest that we talk to each other about what self-determined living means for each of us. This is the only way for each person to find a way suited to his personality and to his needs.



