

# Ireland Independent Living Movement training

Online talk, October 6, 2022 Adolf Ratzka, Ph D, founding director emeritus  
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Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent living does not describe an ideal society where everything is perfect for disabled people. It is the term for a process, for a mental attitude, for a goal.

Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation.

Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and interests, and start families of our own.

Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves - just as everybody else.

To this end we must support and learn from each other, organize ourselves and work for political changes that lead to the legal protection of our human and civil rights.

As long as we regard our disabilities as tragedies, we will be pitied.

As long as we feel ashamed of who we are, our lives will be regarded as useless.

As long as we remain silent, we will be told by others what to do

Does it make sense to talk about independence in the context of disability?  
Is not disability in most people's mind synonymous with dependence,

dependence on one's family, on the medical professions, on other people's kindness, on the taxpayers' belief that their money is spent for a good cause? Aren't most people convinced that disabled persons on account of their disability will always depend on other people, need to be protected and taken care of, since we apparently cannot take care of ourselves? But if the impairment in itself makes us helpless and dependent, how do you explain this?

In 1961, when I contracted polio and became disabled in Germany, there were no personal assistance services or accessible apartments. Therefore, I had to spend five years in a hospital. Today, with exactly the same disability, I live in Stockholm, in a barrier-free home and have paid personal assistants who help me with my daily needs and accompany me on my travels. I live with my wife who does not work as an assistant for me – she does that only in emergencies. Our daughter has moved out long time ago. My impairment has not changed since the 1960s. Society has changed. I give you another example:

*Three men, same age, same spinal cord lesion, yet so different outcomes*

With these examples I want to suggest that differences in the attitudinal and material conditions determine disabled peoples' life opportunities, how dependent or independent we can become. I am not claiming that anyone – disabled or non-disabled - can be completely independent. As human beings we all are inter-dependent on each other. My point is that persons with the exact same disabilities can have completely different lives depending on where they live. In some countries there are policies and attitudes that allow us to develop and follow our interests, get education and work, meet friends, marry and have children. In other countries, we may be confined to living in institutions, with little contact with the outside world, with no or only simple work.

We have to ask ourselves

*Is disability a medical issue or a question of political priorities? Is it the medical condition that makes you disabled or is it the politics of your country?*

Most disabled people are not helpless or dependent because of their disabilities, they are made dependent and helpless by their countries' political priorities and culture of dependency.

### *Culture of dependency: medicalization of deviations from the norm*

Our society declares people who deviate from a narrowly defined norm as sick. If you are a patient, you are to rest, stay at home and follow your doctor's orders. People have to be considerate to you. You are not expected to work or take on any responsibilities. In the medical model of disability the problem and its solutions lie within the individual, not with society. The traditional disability movement is divided into diagnostic groups and in this way confirms the medical model. For this reason, many traditional disability organizations, often competing with each other for resources for cures and treatment, have been ineffective in working for social change.

### *Culture of dependency: professionalization*

Since disabled people are seen as sick, we are assumed to need to be taken care of by doctors, nurses, physiotherapists, occupational therapists, psychologists, rehabilitation counselors, social workers, etc., whose job is to treat and train, protect and guide us through life. Due to their formal training they often believe they know our needs better than we do. The more people with disabilities believe in the authority of the helping professions, the less they will do for themselves.

### *Culture of dependency: lack of self-representation*

Until a few decades ago disability organizations commonly used to be run and controlled by persons who had no disabilities themselves. Disabled people were not considered capable of representing themselves. They were invisible in the media except in the role of helpless miserable victims. What did this lack of self-representation do to our public image and to our self-image? How credible would be a women's rights organization that is headed by men?

### *Culture of dependency: internalized brainwashing*

Without visible examples of positive and successful persons with a disability many of us do not see any possibilities for improvement in their situation. We get to hear from childhood on that our lives are not worth anything (Isn't that the meaning of the term "invalidos"?) I have often seen expressions of fear, pity and contempt in people's faces when they look at me. Some have told me, they would rather kill themselves than live like me

- without knowing anything about me. Being part of and growing up in our society we often internalize these attitudes and suffer from low self-esteem and self-respect. We become our own worst enemies.

### *Culture of dependency: Self-fulfilling prophecies*

When people around you expect very little of you, it is difficult to acquire and maintain a healthy self-confidence. Most likely you play it safe and avoid challenges for fear of failing. Without the experience of success and failures, you will not be able to learn from these experiences and grow as a person, will not realize your potential. Instead, your example will confirm society's prejudice that disabled people are incompetent and helpless.

### *Culture of dependency: lack of freedom of choice and self-determination*

Most disability policy seems to follow the "one size fits all" principle. Regardless of our abilities, needs or preferences we are lumped into one group, have to use services that come in one package - the same for everyone. If it does not suit you, too bad. Take it or leave it! An example: In most residential institutions, everybody who needs help has to go to bed before the night shift takes over which is quite early in the evening. People who need practical assistance have to accept help from female and male workers – often against their express will. When I choose a restaurant, I don't go by the number of stars in the "Guide Michelin" but by the number of steps at the entrance. We have to adapt our needs to solutions that other people have decided for us. With extremely limited choices and without control over your everyday life you give up making plans for tomorrow, you have no future, you go through life feeling like a leaf being blown around by the wind.

### *Culture of dependency: discrimination*

Throughout history disabled people have been facing structural discrimination, a system of tangible and intangible obstacles and sorting mechanisms that deny us equal access to life. Some mechanisms are obvious such as a largely inaccessible built environment or some countries' laws denying us, for example, the right to work as teachers or to marry. Other mechanisms are more subtle, for example, the notion that it is better for us to be segregated in special kindergartens, special schools, special housing or institutions, sheltered workshops. As a result, statistics in every country show that we, as a group, are marginalized and worse off than the

general population in terms of education, employment, income, housing, social contacts or family life.

*Breaking the culture of dependency: anti-discrimination legislation*

The Independent Living Movement demands the same degree of self-determination, freedom of choice and control over our everyday life that our non-disabled brothers and sisters, friends and neighbors take for granted.

In working towards breaking the culture of dependency we demand effective anti-discrimination legislation that holds lack of access and lack of reasonable accommodations for people with disability as unlawful and actively prosecutes violators with sanctions. One of the best examples of such legislation is the Americans with Disabilities Act of 1990 that has led to far-reaching changes in infrastructure, employment conditions and social status of disabled people in the United States.

*Breaking the culture of dependency: control over our own organizations, self-representation*

In our movement organizations are run and controlled by people with disabilities. We make sure that our demands and the solutions we propose are presented by people with disabilities who know what they are talking about from first-hand experience. In this way we demonstrate to the public, to politicians and other disabled people that people with disabilities know their own best interests and are the prime motor in the work for change.

*Breaking the culture of dependency: peer support*

Our foremost pedagogical tool are peer support sessions where we share among ourselves information, successes and failures, insights into the mechanisms of prejudice, oppression and self-oppression; where we train ourselves in taking on more responsibilities for our lives.

*Breaking the culture of dependency: de-medicalization and de-professionalization*

Our movement is not divided by medical diagnoses. Despite our different disabilities we are united by our common experience of discrimination as disabled people, our analysis of the causes leading to our second-class citizenship and our approach in bringing about social change. Rather than focusing on the medical aspects of disability we concentrate on our empowerment as citizens. Since we consider ourselves to be the best experts on our needs, we see it as our responsibility to develop, test and promote solutions to our needs. In this we need allies, members of other disenfranchised minorities, politicians and professionals who share our analysis and commitment.

### *Breaking the culture of dependency: de-institutionalization*

People who depend on practical help by other persons for such tasks as dressing, eating or personal hygiene often live with their parents. When the parents are getting too old, their children have to move to institutions. There, they live as invisible citizens, confined to segregated and restricted lives, far off the mainstream of society. One of the Independent Living Movement's priorities is to liberate our brothers and sisters from institutions by working for community based solutions.

To phase out residential institutions we need barrier-free housing and personal assistance services in the community. The Swedish building norms of 1978 for residential construction prescribe elevators, entrances without steps, bathrooms and kitchens that are large enough for wheelchair users. As a result, well over 20 per cent of Stockholm's housing stock is barrier-free. Also, since 1994 people who need every-day help with getting up in the morning, getting dressed and bathed, etc., receive a monthly sum from the National Social Insurance Fund for the purpose of buying personal assistance services. I'll describe this in some detail.

As a result of these two reforms there are no residential institutions left in Sweden. The exception are some 50,000 persons with multiple disabilities including cognitive disabilities who live in so-called group homes where each person has his or her own room and older persons who live in different types of homes for older persons.

### *Breaking the culture of dependency: cash payments instead of services in kind*

Most countries pay more money for keeping someone in an institution than for enabling that person to live in the community. For example, the recent Spanish Ley de la dependencia pays € 2,500 a month to an institution per person but only € 780 to an individual for contracting personal assistance services in the community. Could one explanation be that charities running institutions can afford to spend more money than their inmates for lobbying?

The Independent Living Movement aims to replace state support in the form of services in kind by state support in the form of cash payments. In such a solution, cash payments enable users to buy services in the market from the providers of their choice and to custom-design their personal assistance according to their individual needs and personal preferences (that is the reason why call them “personal” assistance services). Payments are based on needs in terms of the number of assistance hours and not on the type of service provider that delivers the services. Thus, the same amount of money per hour of service is paid to the recipients of the cash payments regardless of whether their service provider is public or private, for profit or not for profit, whether recipients join personal assistance cooperatives or employ their assistants themselves.

In Sweden, we have had such a system of cash payments since 1994. The payments are not income taxable, do not require co-funding, are to cover 100 per cent of the costs of personal assistance and are paid regardless of the person’s or the family’s income or property. With that money we can purchase personal assistance services from local governments and private businesses or employ our assistants ourselves.

There is now a market consisting of about 18,000 assistance users and some 800 private entities that provide services, with altogether 70,000 personal assistants. The market is driven by the demand from assistance users. Providers compete with each other for customers on the basis of service quality.

Before 1994, community-based services were provided by the local government’s budget. Their clients had no choice as to which persons would work for them, when, with what tasks and how. The local government was the only provider and quality of services was not even mentioned. Clients were forced into a passive, powerless role with no responsibilities.

After 1994, recipients of the cash payments are entrusted to make decisions in their own best interests in selecting the services that best fit their needs or employ, train, and supervise our own personal assistants. Persons with cognitive or psychiatric disabilities are supported in their consumer role by relatives or friends. Before the reform, we used to be called “the weakest of the weak”. Now we are customers and employers. It’s been a real revolution!

I was tempted to stop here. But history never stops. What we achieved in the past may not be around tomorrow. Since 2008, it has become increasingly difficult in Sweden to qualify for cash payments for the purchase of personal assistance services. Some 80% of new applications for the payments are turned down, and you need a specialized lawyer to help you appeal the decision. The law that regulates personal assistance has not changed that much. What has changed is the interpretation of the law in the courts. As more and more people with disabilities are discovering this beautiful service, as they apply for more and more hours of services per week, as personal assistance users enjoy life and live longer due to the service, the total costs of personal assistance have gone up over the years. Politicians are doing their best to stop that development.

The message I want you to take home

is we can never relax and become complacent.

We need to be vigilant all the time, as individuals and as a collective.

It is not enough to know your rights, to know the CRPD and the General Comment No 5 on Article 19. We need to learn how to use the law as a tool for claiming our rights - in court, if necessary.