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Independent Living for people with disabilities: from patient to citizen and customer

Abstract
[Excerpt] 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.

Keywords
disability, independence, Independent Living, human rights

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The Independent Living Institute is a policy development center specializing in consumer-driven policies for disabled peoples' self-determination, self-respect and dignity.

The Independent Living Institute is a policy development center specializing in consumer-driven policies for disabled peoples' freedom of choice, self-determination, self-respect and dignity. Our ultimate goal is to promote disabled people's personal and political power. Towards this end we provide information, training materials and develop solutions for services for persons with extensive disabilities in Sweden and internationally. We are experts in designing and implementing direct payment schemes for personal assistance, mainstream taxi and assistive technology.

We are a not-for-profit private foundation run and controlled by persons with disabilities. With roots in the Swedish and international Independent Living movement the Institute is a duly Swedish registered not-for-profit foundation. The majority of our employees has a disability.

We run a virtual library and interactive services for persons with extensive disabilities. We are experts in designing and implementing direct payment schemes for personal assistance services, mainstream taxi and assistive technology.

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 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.

Independent Living for people with disabilities: from patient to citizen and customer

Keynote at the conference in Barcelona 22 October 2007 organized by the Catalan Party Convergéncia i Unió in commemoration of the 25th anniversary of The Spanish Law for Persons with Disabilities of 1982

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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 disability 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 with wife and daughter, and have paid personal assistants who help me with my daily needs and accompany me on my travels.

Before 1973, no wheelchair user in the United States could use public transportation busses. Today, it is almost impossible to find a bus in the US which is not accessible to wheelchair users.

In the US most children with Downs Syndrome are integrated in regular public schools. In Sweden, pupils with Downs Syndrome instead of going to the neighborhood school with their non-disabled brothers and sisters have to spend ours on the bus to attend special schools or classes often far away from home.

In London, all taxi cabs are accessible for wheelchair users by law. In Zurich, Switzerland none of the taxis are accessible and you need to book a ride with the special transport system several weeks in advance.

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. Do you remember the movie "mar adentro" ("The Sea Inside")? Had Ramon Sampedro, the protagonist, been living in Sweden, he would have had more options than wanting to die. Instead of spending his energies on fighting for his right to kill himself, he might have been busy writing, traveling, and raising a family. In Spain, Sampedro, without any state support for personal assistance, was made dependent on his brother's family whom he no longer wanted to burden. In Sweden, Sampedro would have received money from the social insurance system to pay people to work as his personal assistants.

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 dew 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 a feminist organization headed by men be?

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 early childhood on that our lives are not worth anything (Isn't that the meaning of the common term "invalidos"?) or at least not worth as much as other peoples' lives (as indicated by the more common term "minusvalidos"). 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! The public health care system in Stockholm provides only two models of ventilators, none of which can be used on airplanes. One is too big, the other one uses Lithium batteries which are prohibited on planes. In most 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

How can we liberate ourselves from this culture of dependence? Independent Living is the name of the international civil rights movement of disabled people. In Spain the movement calls itself Foro de Vida Independiente. 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 lead 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 10 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. 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 some

14,000 people purchase personal assistance services from local governments and private businesses or employ their assistants themselves.

As a result of these two reforms there are no residential institutions left in Sweden (with the exception of 5,000 persons with multiple disabilities including cognitive disabilities who live in so-called group homes where each person has his or her own room). In other countries, the largest resistance against de-institutionalization comes from charity organization that own institutions.

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.

Breaking the culture of dependency: demand-driven instead of supply-driven services

In Sweden, we have had such a system of cash payments since 1994. There is now a market consisting of about 14,000 assistance users, 300 local governments and some 450 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 using service quality as a weapon.

Before the reform, the local government's budget determined how many hours of assistance were to be allocated among how many assistance users. Users had no choice as to which persons would work for them, when, with what tasks and how. It was a supply driven service, the local government was the only provider and quality of services was not even mentioned. Service users were forced into a passive, powerless role with no responsibilities.

Today, recipients of the cash payments are entrusted to make decisions in their own best interests in selecting the services that best fit their needs. Persons with cognitive or

psychiatric disabilities are supported in their consumer role by relatives or friends. In fact, a large assistance user cooperative consists exclusively of persons with multiple disabilities including learning disabilities. They run and control the organization and direct their personal assistants with the help of their legal representatives. 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!

Breaking the culture of dependency: de-regulation promotes competition and quality

In most countries, assistance with the tasks of daily living cannot be called a “market”, since the number of sellers of services is restricted to a regional monopolist or oligopolists and consumers are not free to choose. The numbers of assistance hours a given provider produces is determined by the budget and not by the customers who prefer one provider over another on the basis of service quality. No matter how poor the quality, providers will be assured that all assistance hours produced within the budget are used up - assistance users simply have no choice.

A similar situation existed earlier in Europe’s telephone market. Regional or national monopolies effectively blocked technological changes, productivity gains or quality improvements. The accelerating innovations for telephony users within the last decade are not due to technological advances but to the European Commission’s de-regulation of the telephony market. Without the abolition of national monopolies consumers would not have been free to choose among a multitude of new service providers who compete for customers by employing the latest technology for better quality services at lower prices.

I would like the Commission and national governments to also de-regulate services for persons with disabilities. Tax money spent on today’s monopoly or oligopoly providers for assistive technology or assistance would yield far greater efficiency and user satisfaction, if it was paid out in the form of cash payments to users. Only then we would have a demand driven market with its advantages.

A democratic society is based on the principle of citizens’ freedom of choice as voters. A modern interpretation of democracy would extend this freedom of choice from the voting process to the market of goods and services. In most areas of life our society trusts in its citizens’ ability to make decisions in their own best interest. It is time that disabled people too are recognized as full citizens with full freedom of choice not only on election day but also as customers in the market place.