

Independent Living and Personal Assistance

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Introduction

The Independent Living Movement's origin can be traced back to California in the late 1960s - early 1970s. Students with extensive disabilities were admitted to the University of California at Berkeley where they first lived in a special wing of the University hospital. There, they received assistance in the activities of daily living from the hospital staff. But soon, they wanted to move out, into regular student housing on campus or in surrounding Berkeley. They managed to get funding for hiring fellow students who worked for them as assistants. They managed to get funding to adapt housing and make it wheelchair accessible. In order to get that far, the students with disabilities had to learn to get organized, stick together, become political, handle the media - and above all, they had to formulate their message, their ideology in their fight for self-determination and equal opportunities.

The movement started at universities but spread out into the surrounding cities as students with disabilities graduated, wanted to get jobs and have regular lives in the community. From California, Massachusetts, and Texas, the movement spread across the United States, entered Canada, and after that the United Kingdom. Berkeley, was up to the 1990s the Mecca of the movement. Many disabled people from Europe, and Asia, particularly, Japan travelled to Berkeley as often as they could, tried to stay there as long as they could, did internships there to learn as much as they could. I was one of them. Most of us returned to our home countries and started up similar initiatives, with the Center for Independent Living in Berkeley as role model.

There is a rich body of literature and research about the effects of the Independent Living approach on disabled people's lives, their health, their education, their relationships. After half a century, the term Independent Living, today, is widely used in policy documents and government programs the world over. One of our biggest achievements is the United Nations Convention on the Rights of Persons with Disabilities, a document that is permeated by the spirit and language of Independent Living.

For me, Independent Living is foremost a civil rights movement, a movement of people whose lives have been limited by thoughtlessness, ignorance, prejudice and outright oppression, a movement of people who have been robbed of opportunities to develop and benefit from their innate potential, a movement of people who, in self-help groups, have become aware of the prejudices and oppression many of us have internalized and turned against ourselves. Some of us have become their worst enemies. We all need help to become our best friends. Together, in the Independent Living Movement, we can help each other to get that far.

Independent Living Principles

Does it make sense to talk about independence in the context of disability? Is not a 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 persons with disabilities 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 a disability in itself makes us helpless and dependent, how do you explain the following facts?

In 1961, when I contracted polio and became disabled in Germany, there were no personal assistance services or wheelchair-accessible apartments. Therefore, I had to spend five years in a hospital. Today, with the same impairment, I have paid personal assistants who help me

with my daily needs and accompany me on my travels. I live in Stockholm, in a barrier-free house with my wife. Our daughter is 27 and has moved out several years ago.

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 hours on the bus to attend special schools or classes often far away from home.

In London, 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 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 people with disabilities 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. Persons with disabilities 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 our self-image? How credible would be a feminist organization 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 early childhood on that our lives are not worth anything - which is the meaning of the common term "invalid". I have often seen expressions of fear, pity, and contempt on 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 us expect very little of us, it is difficult to acquire and maintain a healthy self-confidence. Most likely we play it safe and avoid challenges for fear of failing. Without the experience of success and failures, we will not be able to learn from these experiences and grow as a person, will not realize our potential. Instead, our 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. Most residential institutions, typically, do not have apartments for couples or families. As a teenager, I spent five years in an institution. I had to go to bed at 8 pm every evening before the night shift took over. In institutions, you cannot choose the workers who are to help you - not even with the most intimate physical needs. People who need practical assistance have to accept help from female and male workers – often against their expressed will. 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 dried-up autumn leaf that is 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. 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 toward breaking the culture of dependency we demand effective anti-discrimination legislation that holds a 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, 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 is peer support sessions where we share among ourselves information, successes, and failures, insights into the mechanisms of prejudice, oppression, and self-oppression. Through peer support, 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, are united by our analysis of the causes leading to our second-class citizenship, and our approach to 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. To give you an example, the Swedish building norms of 1978 for multi-family housing construction prescribe elevators, entrances without steps, bathrooms, and kitchens that are large enough for wheelchair users. As a result, over 20 per cent of Stockholm's housing stock is barrier-free (personal estimate 2021). Also, since 1994, people who need every-day help with getting up in the morning, getting dressed and bathed, etc. can qualify for 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 (2021) purchase personal assistance services from local governments and private businesses or employ their assistants themselves.

As a result of these two reforms, there are, officially, no residential institutions in Sweden. But some 100,000 persons live in so-called group homes where they each have their own room and share the staff. These are persons with multiple disabilities including cognitive disabilities and older persons with disabilities.

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 government of Spain pays € 2,500 a month to an institution for keeping one person in the institution but pays only € 780 to an individual who needs personal assistance services for living in the community.

The Independent Living Movement works for so-called Direct Payments in all countries. Direct Payments are cash payments from the State to the persons who need personal assistance services

for living in the community. Cash payments enable us to buy personal assistance services from the service providers we choose and to custom-design our personal assistance according to our 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 we need and not whether the service provider is public or private, for-profit or not-for-profit, or whether we employ our assistants ourselves.

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

In Sweden, we have had such a system of Direct Payments from the National Social Insurance Fund since 1994. With the payments, today, about 14,000 assistance users can afford to buy personal assistance services from local governments and almost one thousand private companies. In the country with a population of some 10 million inhabitants, there are altogether 70,000 personal assistants. Personal assistance has become a real market in Sweden, a market that is driven by the demand from assistance users, a market where providers compete with each other for customers on the basis of service quality, a market where we, the assistance users, have the freedom of choice.

Before 1994, the local government had the responsibility of providing community-based services of that kind. It was a supply-driven service, that is the municipality decided on a budget for these services, each year. With that budget a certain number of staff were employed who were sent home to us users. The local government decided who was to work for us - no matter whether we liked and trusted these persons or not, no matter whether they did a good job or not. They did what the municipality told them to do and not what we needed. It was a supply-driven service, the local government was the only provider. We had no choice. The quality of services was not even mentioned. As service users we had nothing to say, were forced into a passive, powerless role with no responsibilities.

Today, we get Direct Payments - that's a fantastic instrument for empowerment! As recipients of the cash payments, the government and the taxpayers believe in our ability, to make decisions in our own best interests in selecting the services that best fit our needs. 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!

A while ago, I said personal assistance revolutionizes our lives. With these services, people are able to transform themselves from powerless, helpless objects of care into subjects, into people who can make plans because they now have the means to make their plans come true. I could tell you many stories about how personal assistance can change our lives. Here, is my favorite one, it's my own story.

In 1961, at the age of 17, I contracted Polio. As a result, I have been using a ventilator, an electric wheelchair, and increasing assistance with the activities of daily living ever since. In 1966, after five years in a hospital, a scholarship enabled me to move from the hospital ward in Munich, Germany to a dormitory room at the University of California in Los Angeles.

The transition from patient to student was made possible by the scholarship that not only covered my expenses as a student but also contained direct payments for personal assistance. With that money, I hired, trained, paid, scheduled, and supervised fellow students as my assistants. I was able to pay them competitive wages, i.e. wages that they would have earned for working on campus at the libraries or cafeterias. They assisted me with everything I needed to concentrate on my studies and to enjoy life as a young adult living by myself for the first time. I had to learn to express my needs, had to learn to be the boss. That was difficult and I made many mistakes - I still make mistakes. But my mistakes have been valuable lessons.

In 1973, I moved to Sweden to work on my dissertation. Again, I hired people there as personal assistants. With their help, after completing my academic training, I worked as a researcher at the university.

Throughout the years, I must have employed hundreds of students, immigrants, and people between jobs to work for me. They not only enabled me to study and work and do my household but also to

live the way I wanted, with a rich social life, with many interests, romantic relationships, with travel for work and pleasure. With their help, I became involved in disability work nationally and internationally. I founded several organizations, traveled and lectured widely, was recruited for research positions overseas, and headed international projects.

Personal assistance was also the key for me to getting married. My wife and I were confident that - with the help of my assistants - I not only would take care of myself, independently of my wife, but could also share household chores and work around the house, on an equal basis. (That was the plan but it has not always worked out that way, I'm ashamed to admit.) My wife would not be my life-long, unpaid nurse. We wanted a relationship where we both, independently of each other, could develop and grow, pursue our interests, and have a meaningful career. For example, we both travel in our work to meetings and conferences in Sweden and abroad. When we travel together it is because we choose to so and not because I need her as an assistant. Our decision to have a child was also based on my personal assistance. My assistants would enable me to have an active part in raising and being close to my child. For instance, as a small child my daughter would go shopping with me for groceries or go fishing. My assistant would stay at a distance behind us and only interfere to prevent an accident.

The Swedish social security system pays me a monthly amount of money for which I employ eight part-time assistants to provide me with 18 hours of personal assistance a day. I can pay competitive wages. With that money, I have been able to live in the community with my extensive disability. I am a profoundly ordinary person. There is nothing special about me, I have no exceptional gifts or talents. Many, many people in my situation could have equally fulfilling lives. What is special about me is that I have had personal assistance throughout my entire adult life. That is, sad to say, very special. In countries without personal assistance services - that is, in most parts of the world - I would not have had any self-determination. With only help from my family, I would have been very limited. In a residential institution, I probably would have died decades ago.

There's a very important message that we, ourselves, and everybody else must understand and keep in mind: though we may look different from other people, walk differently, or behave differently, we still are profoundly ordinary people because, like everybody else, we need to be seen for who we are, need to be respected, need to be loved. These needs we share with everyone, these needs make us truly human. To meet these needs, we must work, live, and love in the community among our friends and family - with personal assistance.