

The prerequisites for de-institutionalization

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I am a researcher by training working for the Institute on Independent Living where we design and implement pilot projects in order to influence social policy towards self-determination and self-respect for persons with disabilities.

How many of you have been in prison? I spent years of my life in a place that was worse than prison. What was my crime? I had polio. After 6 months I was as healthy as I am now, but I needed, what we today call, personal assistance. So I lived in an institution, because in Germany, in the 1960's there were no personal assistance programs. My aging mother could not take me home. And what a life that would have been for her and me - tied together by mutual guilt feelings! I would have vegetated at home, unable to continue my education, unable to work, go out and meet people. It would have been physically impossible for my mother to help me with all these activities. And I would not have liked to depend on my mother - imagine, falling in love with someone and needing your mom to take you to the rendez-vous!

I had to live in a hospital also because I needed a place to live, a place without steps and with a large enough toilet. In Germany, in 1961, there were no programs for accessible housing and my family did not have the money to build a house.

I had to live in hospitals for 5 years. I was 17. Today, some 40 years later, I am still bitter about the fact that the most important years in my life were stolen from me. If I had not succeeded in emigrating to the United States in 1966, I would have been imprisoned much longer. Most likely I would have died at a young age. People in institutions, on the average, have shorter lives.

Residential institutions force you to adapt your needs to the needs of the institution. As an inmate you have to share staff with other inmates. The staff decide whose needs at any given moment are most pressing. I could not decide when to get up in the morning or when to go to bed at night - that depended on the staff. I could not even decide when I needed to go to the toilet. A criminal in prison has more freedom than I had. You become frustrated, passive and depressed. Research has shown that institutions cause hospitalism, that is declining initiative, skills, mental and physical health.

Institutions make other people think we are different. Worse, institutions make *us* think we are different and, in this way, create self-fulfilling prophecies.

In the European Union almost 1 million persons live in institutions. What a terrible waste of human life! How can we liberate our brothers and sisters?

Policies for accessible residential construction as a prerequisite for de-institutionalization

One of the main prerequisites of de-institutionalization for physically disabled people is an effective housing policy. A policy that entails non-discriminatory public works programs, non-discriminatory housing subsidies and non-discriminatory building codes.

Non-discriminatory public works programs make sure that in all new construction which is financed and undertaken by any municipal, regional or state government agency barrier-free or universal design principles are enforced. This instrument does not require legislative changes. If

the Regional Government of Tenerife, for example, were serious about accessibility in residential construction, they could start already tomorrow by including non-discrimination clauses together

with operational definitions of accessibility in their procurement contracts; no bidder would receive a contract without guaranteeing full accessibility of the finished structures.

Non-discriminatory housing subsidies mean that programs for public or social housing in the form of cash grants or below-market interest rates to builders are tied to the condition that the buildings conform to accessibility housing standards.

The third policy instrument I mentioned are building codes. No builder, whether public or private, would get a building permit without showing that the finished structure complies with the codes.

As an example for a successful policy I use the Swedish Building Code of 1977 which stipulates wheelchair access to all units in new residential buildings of three or more floors. The Code requires barrier-free passage from sidewalk via large elevators to all apartments in all new buildings. Kitchens and bathrooms must have certain minimum dimensions.

I used to live in such an apartment. When I invited foreign visitors home, they would ask, "how many disabled people live in this building?" I would answer, "I don't know. I think I am the only one, but that is not the point. All apartments are designed in a way that no one who lives here now or in the future has to move when they get disabled for any reason, that people such as I can visit friends and neighbors here, stay over night or move in."

The Swedish Building Code of 1977 was a far-sighted measure designed to enable the rapidly aging Swedish population to stay longer in ordinary housing as opposed to having to move to senior citizen homes. As a result of the Code, close to probably 10% of the total housing stock in most cities is wheelchair-accessible today. This percentage has provided people with physical disabilities with some choice in the housing market and has contributed to the phase-out of residential institutions. Almost all physically disabled people live in the community. Those who do live in senior citizen housing or nursing homes are mainly older persons. Intellectually disabled persons live today in small group homes consisting of six persons plus staff in the community. No institutions are built anymore in Sweden.

The Swedish experience shows that the additional costs due to barrier-free construction in apartment buildings are less than 1% of total costs. Most of the additional cost is due to wider hallways, larger kitchens and bathrooms - an increase in housing standards enjoyed by all.

Direct payments for personal assistance as a prerequisite for de-institutionalization

Another requirement for keeping people with disabilities out of institutions are services for assisting us in our homes with the activities of daily living. As an example I describe the Swedish Personal Assistance Allowance Act of 1994, a program which I helped to develop..

People with extensive disabilities are entitled to cash payments from the Swedish National Social Insurance Fund. Needs are expressed in the number of hours of services per week that are necessary for maintaining a "good quality of life". Assistance with personal hygiene, eating, communicating (in the case of non-verbal persons), household chores, at one's workplace, in getting around town or traveling abroad are to be covered.

The National Social Insurance Fund pays for the number of assessed hours with all direct and indirect labor costs plus administration including the costs for accompanying assistants. The monthly payments are neither means-tested nor taxable but their use has to be accounted for.

With the funds the individual assistance user can purchase services from any service provider such as local governments, private companies, user cooperatives or hire one's own assistants. Any combination of these alternatives is permitted.

I am a member of a user cooperative. I delegate all paper work to the cooperative and concentrate on recruiting, training, scheduling and supervising my staff. I have maximum control over my services, because I am the boss.

Without the money from the Social Insurance Fund I would have to rely on the municipal homehelp services, that is, workers employed by the city government would come into our home to assist me. Given the poor quality of the services I would have had great difficulties in pursuing a career, not to think of traveling and working abroad. I would have hesitated to get married, since I would have been forced to depend too much on my wife. An equal, mutually supporting relationship with freedom for both to develop would have been impossible. Also, we would not have decided to have a child, since I would not have been able to take part in the practical aspects of parenting.

Today, some 11,000 persons – Sweden has a total population of 9 million people - are entitled to the Personal Assistance Allowance. They purchase, on an average, 90 assistance hours per week. By living and working in the community our quality of life and our contributions to society are far superior to what vegetating in an institution would imply.

In the United States the White House decreed in the year 2002 that

“...segregation of qualified individuals with disabilities through institutionalization is a form of disability-based discrimination prohibited by...the Americans With Disabilities Act...”

I suggest that this congress adopts a statement that urges the European Union to pass a similar resolution declaring that

“segregation of individuals with disabilities through institutionalization is a form of disability-based discrimination that is incompatible with the spirit of the European Union, in particular with the non-exclusion articles of the Treaty of Amsterdam.”

In 1961, when I contracted polio, everybody thought I was too ill for a life in the community, that I needed constant medical attention by professionals in a hospital-like setting. Only after I moved from the hospital in Munich to a barrier-free dormitory in Los Angeles, only after I received a scholarship with money to employ fellow students as personal assistants - only then I began to realize that I could live a normal life with studies, work and a family of my own, that nothing was wrong with me, that I was a normal human being.

In 1961, my dependence on a ventilator and personal assistance was sufficient to lock me up in an institution, away from friends and family.

Today, we know that it is because of poor architecture, poor economic planning and lack of political power when people such as I are excluded from the life of the community.

In 1961, we were patients who were to be rehabilitated.

Today, we are full citizens and society is in need of rehabilitation.