

## ***Personal Assistance empowers persons with disabilities and benefits the national economy***

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Persons with the exactly the 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, people with disabilities may have to live with their parents or in institutions, with little contact with the outside world, with no or only simple work. Do you remember the movie “mar adentro”? Had Ramon Sampedro, the film’s protagonist, been living in Sweden, rather than fighting for his right to kill himself, he might have been busy writing 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 State to pay people to work as his personal assistants.

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

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.

People who depend on 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 residential 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. Here, I present a policy that not only helps people to stay out of residential institutions and live normal lives - the policy I describe also promotes the national economy.

First, some general comments about how services for help with the activities for daily living can be organized. Conceptually, these services are either supply-driven or demand-driven.

A typical example for supply-driven services are residential institutions. Service providers – often local governments or private charities – have fixed budgets which imply a fixed number of staff. Since there is hardly ever enough staff for all residents, the staff must prioritize and determine whose needs are more urgent. You have to wait, you cannot make plans.

Living in residential institutions offers very limited choices: limited in geographical location, limited in the choice of your housing – if you are lucky, you have a room of your own but rarely can you live there together with your partner or your children. In an institution you have to accept help from all the staff even from people you don’t like, sometimes women cannot refuse help from men for the most intimate physical needs. The staff works inside the institution and typically cannot follow you when you leave the building and go to the university or to your work place. If you need assistance often during the day, you cannot leave the institution – you are under house arrest. In this way, the individual has to adapt his or her needs to the needs of the institution. You might recall Procrustes in the Greek mythology who

used to offer his bed to tired travelers. Those who were shorter than the bed, he would stretch with force until they fit. Those who were too long got their feet cut off. Procrustes was the first supply-driven service provider. "One size fits all" was his slogan.

Supply-driven services are often monopoly situations and typical for central planning economies. Their long-term outcome is learned lack of initiative, loss of risk-taking ability, stunted human growth, resignation and often depression.

I spent five years in an institution. That was over 50 years ago but I am still bitter about these lost years, the feeling of isolation, humiliation, lack of stimulation, the feeling of being different from the rest of mankind. I'm still bitter about the scars in my psyche I received.

In demand-driven services the user employs his or her assistants, for example, college students who need to earn money by working part-time while they study. Or users can contract a company whose employees come to you and help you with your physical needs, with household chores, such as shopping, cooking, cleaning; they follow you to your job and assist you at your workplace, for example, with going to the toilet, with meals or with carrying heavy books or whatever you need help with. If needed, your assistants can accompany you when you have things to do in town or visit friends or relatives or travel. In my own case, I would never be able to work as director of the Independent Living Institute with meetings and speaking engagements in Sweden and abroad without my eight personal assistants. My wife and my teenage daughter have their own career and their own lives.

Demand-driven services require that users have sufficient money to pay for them. This can be accomplished by direct payments where eligible persons receive funds from government. With that money recipients either buy services from service providers or employ their own personal assistants. The purchasing power enables us to become customers or employers with the ability to compare, choose and design services that best meet our current individual needs and preferences, life circumstances, family situation, aspirations and visions. Competing service providers promote service differentiation, freedom of choice and service quality. Direct payments enable us to move and live wherever we want since money follows the user and not the provider.

After my five years in an institution I received direct payments from the State which enabled me to move out and study at the university. With the payments from the State I employed fellow students to help me with whatever I needed. I still remember the feeling of freedom when I realized I could go to bed, get up in the morning whenever I wanted and could decide who would assist me with that. I also remember how tough it was when an assistant called in sick and I had no back-up. But I will never forget how proud I was when I discovered new ways to use Personal Assistance to expand my life such as, for example, go on larger trips.

The Swedish Personal Assistance Act can serve as an example of a policy for demand-driven services. Service users - not service providers - receive payments from the Social Security Fund for the purchase of personal assistance services as a legal entitlement that is independent of the state agency's financial situation, independent of recipients' and their families' income or property. Eligibility and amounts are not dependent on whether we buy services from a provider or employ assistants ourselves. The currently 16,000 recipients can purchase their services from over 1,000 competing public and private entities. Assistance need, expressed as the number of assistance hours needed, is assessed by the tax-funded Social Security Fund. Each month recipients get an amount that corresponds to the total costs of these hours including white wages, full Social Security benefits and the user's and

provider's administrative costs. Thus, private companies have an incentive because they can cover their expenses and make even profits. Users have to fully account for the funds.

The Swedish Personal Assistance Act has been in place since 1994. Before, persons with extensive disabilities had community based services in the form of municipal homehelper services or we lived in semi-institutional cluster housing facilities. There, each had his or her own apartment and shared assistants from a nearby staff apartment. By the 1980s residential institutions had been phased out in Sweden except for group homes where 4-5 persons live together in a house or large apartment with common staff. [Government studies](#) have shown that personal assistance services are superior in quality to municipal home helper services or group homes. Compared to what it would have cost to provide the same number of hours through municipal home helpers direct payments for [Personal Assistance have saved the Swedish taxpayer some €3 billion](#) – and that at considerably higher service quality.

With the help of personal assistants a number of assistance users are able to work – currently 16% of direct payments recipients. Another 24% could work, if they had more assistance hours. To these numbers we can add the family members who are free to return to their ordinary work because they do not need to help us anymore.

Personal Assistance services are labor intensive which makes them useful for stimulating domestic consumption. In Sweden where no formal training for personal assistants is required the labor market for assistants can instantly adjust to supply and demand changes. Our assistants – often immigrants, young people in transition between school and working life, freelancers and part-time workers – would often have to rely on social welfare, if they did not work for us. All their wages go to basic consumption and stimulate the economy.

The 16,000 persons who receive direct payments for Personal Assistance services together employ some 50,000 personal assistants on a full-time basis. The City of Stockholm, the nation's largest employer, also employs 50,000 persons. Thus, we assistance users constitute one of the largest employers of the country making direct payments for Personal Assistance an important labor market policy instrument. It's an inexpensive tool, since over 50% of the money which Personal Assistance users receive go straight back to the state in the form of social security contributions, income taxes and VAT taxes. Constructing and maintaining residential institutions, on the other hand, is much more capital intensive and does not benefit the national economy in such ways.

All over Europe public funds are still used for keeping people with disabilities in residential institutions – against their will in the absence of acceptable alternatives

- despite the fact that direct payments for personal assistance promote our full citizenship and are less expensive
- despite the negative effects of institutions on individual, family and society
- despite the fact that direct payments for personal assistance are better for a country's economy