Personal Assistance: Key to Independent Living as illustrated by the Swedish Personal Assistance Act


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I am with the Independent Living Institute, a Sweden-based thinktank for policy formulation in the field of disability where we attempt to formulate policies that enable persons with disabilities to become more independent instead of more dependent. As part of the Independent Living Movement, the international civil rights movement of persons with disabilities, we work for the following principles:

- Disabled people are citizens
- Disabled people are experts on their needs
- Disabled people demand the same degrees of freedom of choice and self-determination that other people take for granted

The Independent Living Movement sees disabled people first and foremost as citizens. As citizens we have responsibilities. In order to be able to meet our responsibilities we enjoy rights such as the right to living in the community and the right to equal opportunities. As experts on our needs we have an obligation to take the initiative, individually and collectively, and show the way to the solutions we need. Our goal is to enjoy the same degrees of freedom of choice and self-determination, independence or inter-dependence that other people take for granted.

Our right to “living independently and being included in the community, with choices equal to others” is enshrined in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities. According to the Independent Living Movement, Article 19 requires

- support from peers and other experts depending on one’s personal resources, disability and life circumstances
- accessibility in the community including housing
- Personal Assistance for persons who depend on others for the activities of daily living

One of the preconditions for reaching the goal set forth in Article 19 is a shift of perspective within each of us from seeing ourselves as objects of care and professional intervention to being subjects of our lives. To help us reach this new perspective on our lives the Independent Living Movement has developed methods for individuals with disabilities to support each other. Through peer support we can learn from and with each other how to liberate ourselves from internalized oppression and take on more responsibility for our life, our family and society.

Another precondition for equal opportunities and choices is a barrier-free society based on Universal Design. Universal Design benefits citizens of all ages with and without disabilities. Old and disabled people can live longer at home in their familiar environment, Research shows that Universal Design in new construction need not carry much extra costs, if any, if accessibility is planned for from the very beginning. Investments in accessibility yield positive returns to society as a whole. Universal Design in residential construction offering alternatives in the community is one of the requirements for de-institutionalization - at least
for persons with physical disabilities. Building barrier-free environments requires changes in building codes as well as in enforcement and monitoring mechanisms.

Yet a barrier-free environment with barrier-free housing, a barrier-free bus at the corner and a barrier-free workplace are not enough for someone who cannot get out of bed by himself. When it comes to that kind of help persons in this group in most countries are presently dependent on family members or have to live in residential institutions – in breach of Article 19. For this group Article 19 prescribes community-based services, specifically Personal Assistance services.

Conceptually, services for assistance with the activities of daily living are either supply-driven or demand-driven.

Supply-driven services

- example: residential institutions
- service provider is under contract from municipality or charity
- fixed budget translates into fixed number of staff
- staff decides which needs have priority
- “One size fits all” principle forces users to adjust their needs to needs of institution
- users are seen and made to feel as passive helpless objects of care

Supply-driven services are often monopoly situations and typical for central planning economies

Outcomes: learned lack of initiative, stunted human growth, resignation, depression

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. In this way, the individual has to adapt his or her needs to the need 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.

I spent five years in an institution. That was over 50 years ago but I am still bitter about these lost years, the humiliation I felt, the scars in my psyche I received.

Demand-driven services

- example: direct payments for Personal Assistance
- money follows the user not the service provider
- purchasing power creates market responses
- competition promotes freedom of choice and quality
- consumers custom-design their services according to individual preferences

Demand driven services are typical for market economies where users are customers.

Outcomes: users’ geographical and social mobility incentives for users to take responsibility for their own services dignity of risk taking, ability to learn from mistakes and successes
Demand-driven services require that their users have the necessary purchasing power. This can be accomplished by direct payments where eligible persons receive funds from government. With that money recipients can enter the market and either buy services from service providers or employ their own assistants. The purchasing power enables us to become customers who can shop around, pick and choose.

After my five years in an institution I managed, with help from other persons, in particular, a far-sighted civil servant in a government authority, to receive direct payments from the State which enabled me to move to a student dormitory 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 intoxicating feeling of freedom when I first realized I could go to bed, get up in the morning when I wanted and could decide who would assist me with that. I also remember the difficult situations I found myself in when I had to fire somebody or when an assistant called in sick and I didn’t have anybody to help me go to bed because I had no back-up. But I also remember how proud I was about myself when I discovered new ways to use Personal Assistance to expand my life such as, for example, go on larger trips.

Demand-driven services, such as Personal Assistance, enable persons with extensive disabilities to have better control over their everyday life which is a precondition for taking one’s rightful place in family and society.

The Swedish Personal Assistance Act : An example of a demand-driven policy

- legal entitlement, independent of the funding agency’s budget
- users’ assistance need expressed in number of hrs /week
- needs assessment decisions can be appealed in administrative courts
- money follows the user not the provider
- eligibility independent of user’s or family’s income or property
- payments’ amount only depend on user’s needs of assistance
- payments’ amount do not depend on service provider
- all costs are covered incl market wages, social insurance fees, administration
- recipients fully accountable for how funds are spent
- recipients free to buy services from any provider or to employ their own assistants

Currently 16,000 persons receive cash benefits for Personal Assistance (Sweden’s total population is 9.5 million). Nearly 1,000 private and public entities offer Personal Assistance services.

The Swedish Personal Assistance Act can serve as an example of a policy for demand-driven services. Assistance needs in terms of the number assistance hours needed are assessed by case managers at the tax-funded Social Security Fund. Each month recipients get an amount that corresponds to the costs of these hours. Budgets are not dependent on the financial situation of the state nor on recipients’ and their families’ income or property nor on whether one buys services from a provider or employs one’s assistants. Users pay white wages at going market rates for this type of work. Use of funds has to be fully accounted for. Our budget also contains funds for the provider’s administrative costs. Thus, private companies have an incentive because they can cover their expenses and make even profits.

Some outcomes of the Swedish Personal Assistance Act of 1994

- tremendous improvement in quality of life for assistance users and their families
- greater visibility of persons with extensive disabilities in public
- less need for services such as home helper, respite care, special transportation, etc
- better quality of life at lower costs than municipal home helper services
• better quality of life at same costs compared to group homes
• € 3 billion savings to taxpayer compared to municipal home helper services

The Personal Assistance Act has been in place since 1994. Government commissions and researchers point to unquestionable and significant improvements in the recipients’ quality of life in comparison to what they had before. Before 1994 our group 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. 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. In addition, as official government reports and independent researchers show, Personal Assistance users consume less healthcare, special transportation and other local government services.

Before generalizing these results a word of caution is in order. There is an inflation of the use of the term “Personal Assistance”. In Bulgaria, for example, the government called it “Personal Assistance” when a few disabled persons received assistance from relatives who had to have been unemployed for at least three years. In Romania residential institutions were being phased out with the help of “personal assistants” - foster families received small amounts for caring for an orphaned child with a disability. Obviously, with such programs the outcomes reported above will not be achieved. Therefore the following definition is offered:

Personal Assistance

• enables the user to decide who is to work, with which tasks, where, when and how
• is not tied to any particular form of housing or location
• is not limited to a particular category of persons who can work as assistants
• pays white market wages to assistants
• covers all costs including provider’s administration

Obviously, persons with cognitive and psychiatric disabilities might need compensatory help from others, for example, relatives, guardians or other trusted persons, in making the relevant decisions and in monitoring service quality.

An important outcome of direct payments for Personal Assistance services is their impact on the Swedish national economy.

• 16% of assistance users work with the help of assistants - an additional 24% could work if they had more assistance hours
• important labor market policy instrument with over 50,000 FTE assistants
• vulnerable persons in the labor market work as assistants: immigrants, youth in transition from school to working life, freelancers and part-timers
• over 50% of costs go back to State as taxes and social insurance contributions
• wages are spent on basic domestic consumption

With the help of personal assistants a number of assistance users themselves are able to work – currently 16% of all 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.

Presently, some 16,000 persons receive direct payments for Personal Assistance services. This group together employs some 50,000 personal assistants on a FTE basis. The City of Stockholm, the nation's largest employer, employs the same number. Thus, assistance users collectively constitute one of the largest employers of the country making direct payments for Personal Assistance an important labor market policy instrument - an inexpensive one at that, since over 50% of the direct payments which Personal Assistance users receive go straight back to the state in the form of social security contributions, income and VAT taxes. Our assistants – often immigrants, young people in transition between school and working life, free lancers and part-time workers – would often have to rely on social welfare, if they did not work for us. Their wages go mainly to basic consumption thereby stimulating the domestic demand. Constructing and maintaining residential institutions, on the other hand, is much more capital intensive and does not nearly benefit the national economy in such ways.

Many citizens are outraged that European Union tax money is used for incarcerating people with disabilities in residential institutions - and that today, when we know the detrimental effects of institutionalization on the individual, the family and society; when we have long experience with other solutions like the one I just described, solutions that promote our citizenship.

Numerous studies show that community based solutions do not only offer better quality of life but also cost less than residential institutions. Although I am an economist by training, I am not in favor of this line of argumentation: human rights are not for sale.

But the argument can be turned around: at each level of expenditure direct payments for Personal Assistance services deliver better quality than residential institutions. With the same resources we can achieve much better outcomes through Personal Assistance services than with residential institutions.

There are no excuses.

Further reading:

Westberg, Kenneth et al. 2010  Personal Assistance in Sweden
www.independentliving.org/docs1/personal-assistance-sweden.html

Ratzka, Adolf (ed). 2004  Model National Personal Assistance Policy
www.independentliving.org/docs6/ratzka200410a.html

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