

Personal Assistance and the Crisis: Now is the time to promote Direct Payments for Personal Assistance

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Already before the current crisis people with disabilities fared worse than the general population as measured by most social indicators such as income, employment, housing etc. But now the gap is widening as recent official statistics, for example in Sweden, show.

Those of us who need assistance with the activities of daily living such as getting up in the morning, with personal hygiene or getting dressed, etc. feel the austerity cuts most. In Belgium, for example, the waiting list of persons who have applied for personal assistance budgets has now increased to 50,000 which implies five to ten years waiting. In the Netherlands, by 2014 some 117,000 people are expected to lose their personal assistance budgets. In the United Kingdom, there are plans to shut down the Independent Living Fund in 2015. In Sweden, harsher needs assessment has led to an accelerating number of people who lose their direct payments for personal assistance. We could go on and on with such statistics showing the devastating effects of the austerity measures on persons with disabilities and, in particular, on people who need personal assistance. But I believe it is more useful for us today to talk about what we can do to fight back.

Earlier this month, a colloquium in Brussels convened by the Office of the High Commissioner on Human Rights addressed the use of the European Union's structural funds, such as the European Social Fund, for constructing new and renovating old residential institutions. This violates Article 19 of the UN Convention on the Rights of Persons with Disabilities that assures our right to "living independently and being included in the community with choices equal to others" and requires, among other conditions, access to Personal Assistance services for those who need them. At the meeting in Brussels the director of the European Association of Service Providers for Disabled People stated that smaller service providers, especially providers of community based services, are hit harder by the crisis than residential institutions. As an explanation he suggested the lobbying power of the charities running institutions. In fact, the crisis seems to lead to increasing investments in institutionalization. According to legal experts at the event, national governments and the Commission can be taken to court for this violation of the UN Convention. Thus, holding our governments accountable for using tax funds in accordance with the Convention should be high up on our national organizations' agenda.

Compared to the standard set by Article 19 – living independently in the community with choices equal to others - most of the people who depend on other persons for everyday practical help have always been in some state of crisis: in most countries, this group either depends on family members, typically the parents, or they are warehoused in institutions. The independent Living movement, from its very beginning, has been addressing this permanent crisis by promoting direct payments for Personal Assistance services. There are

no reasons to stop that effort because of the current economic crisis. On the contrary, there are several good reasons to double our efforts. In the following I attempt to show why.

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

Supply-driven services

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.

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 humiliation I felt, the scars in my psyche I received.

Demand-driven services

Another way to organize services consists of letting market forces respond to the demand for services which requires service users who 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 personal assistants. The purchasing power enables us to become customers who can shop around, pick and choose and in this way customize services according to our current needs and preferences. Competing service providers promote service differentiation, freedom of choice and service quality. Recipients of direct payments can move and relocate within the country since money follows the user and not the provider. Thus, users experience greater geographical and social mobility. Also, service users have an incentive to invest time and effort in shopping around, negotiating and organizing since they now have the means to directly improve service quality themselves. While freedom of choice requires informed customers and entails risk-taking, users can easily change providers, learn from their mistakes and successes.

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 a 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 an assistant called in sick and I had no back-up. But I will never forget 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.

Supply-driven services might insure our survival. But only demand-driven services, such as Personal Assistance, enable persons with extensive disabilities to have more control over their

everyday life which is a precondition for taking one's rightful place in family and society and living up to UN CRPD Article 19.

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

The Swedish Personal Assistance Act can serve as an example of a policy for demand-driven services. Recipients - not service providers - receive direct payments from the Social Security Fund (Försäkringskassan) for the purchase of personal assistance services as a legal entitlement that is independent on the state agency's financial situation. Assistance need in terms of the number of assistance hours needed is 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 recipients' and their families' income or property nor on whether one buys services from a provider or employs one's assistants. The currently 16,000 recipients can purchase their services from the provider of their choice - presently over 1,000 competing public and private entities offer services - or employ their assistants themselves. Users pay white wages at going market rates for this type of work with full Social Security benefits and coverage of unsocial hours. Use of funds has to be fully accounted for by the user. Budgets contain funds for the provider's and user'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

The Swedish Personal Assistance Act (LASS) 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 perceived 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. In addition, as official government reports and independent researchers show, Personal Assistance users consume less healthcare, special transportation, in-home support services, respite care 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 calls it “Personal Assistance” when disabled persons receive assistance from relatives who have to have been unemployed for at least three years. In Romania, residential institutions are being phased out with the help of “personal assistants” - foster families receive 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, children and 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.

The impact of direct payments for Personal Assistance services on the Swedish economy

In a government report (Socialförsäkringsrapport 2011:18 p. 53) 24.1% of the assistance users interviewed responded that they required personal assistance to be able to work. To these numbers we can add the family members who before had to stay home to assist their relatives but are free to return to their ordinary work because personal assistants have taken over their tasks.

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. Their wages go mainly to nondurable goods and services such as food, housing, transportation, education, entertainment, etc. thereby stimulating the domestic demand. Constructing and maintaining residential institutions, on the other hand, is much more capital intensive and does not benefit the national economy in such ways.

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 which makes assistance users collectively one of the largest employers of the country and qualifies direct payments for Personal Assistance as 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 for their assistants, their assistants' personal income tax and VAT on their assistants' expenditures.

Now is the best time to promote direct payments for personal assistance services

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. This practice is still rampant today

- despite existing solutions, like the one just described, that promote our citizenship and benefit the economy
- despite the known detrimental effects of institutions on individuals, the family and society
- despite the fact that residential institutions in the vast majority of cases cost more than direct payments for personal assistance
- despite the UN Convention that prohibits member states to invest in residential institutions

We do not have to feel as helpless victims of the crisis, we can fight back. We have the arguments, we have the legal tools: member states that do not use their resources towards promoting Article 19 of the Convention can be taken to court. Our governments might not have known what they committed themselves to when ratifying the Convention. But we and our organizations have to know what they signed and how we can use the Convention for our work.

Crisis or not - there is never an excuse for wasting human lives.

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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