National Personal Assistance Policies: what we require and how to work for it

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Most people with extensive disabilities in Europe who require assistance with the activities of daily living are dependent on their families or live in residential institutions. To improve our situation, we need to work for national personal assistance policies. What features must they contain to empower us, and how can we work for such policies?

First, what do we expect from such a policy? What can personal assistance do for our lives? There are many examples of how assistance users live with the help of their assistants. Here is my 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. 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. The 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 regularly go with me shopping 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 seven 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 despite 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.

I often get to hear that personal assistance might work for persons with physical but not cognitive impairments. In Sweden, currently 51% of the persons who receive direct payments for personal assistance - that is the majority - have cognitive impairments, such as autism and similar conditions or acquired brain damage. They might not be able to take all the decisions that are necessary for being the employer and supervisor of their assistants. But in their direct payments budget there is money to hire somebody to help them with supported decision making. Often these persons are relatives or previous assistants who the person trusts. We all can benefit from personal assistance.

From my experience with personal assistance since 1966, it is clear that a personal assistance policy that is to enable us to live with the same choices and conditions as our non-disabled brothers and sisters, friends and neighbors must meet three main conditions.

First, we must have control over our personal assistance. The best control we have when we recruit, employ, train, schedule, and supervise our assistants. The more we can adapt and fine-tune our personal assistance solution to our unique person and life circumstances, the more we learn how to handle this tool, the better will be the quality of our lives.

Second, we must control the money flow. Best for that are direct payments from the government to pay our assistants' wages, that is, money paid directly to our banking accounts. Without controlling the money, we cannot be the employer and must accept any services that the government selects for us. Without direct payments, we have no choice, are stuck with services we don't like. Also, without controlling the money, you don't have the final word in important decisions in recruiting, setting wages or dismissing employees. You will be the object, not the subject. Your assistants will have a different attitude toward you. If you are not the boss, if you cannot switch service providers you cannot enforce good service quality and you are made to feel dependent on your assistants.

Third, the Direct Payments must cover the cost of all the hours of assistance we require, must enable us to pay competitive wages. Without decent wages people working for us will come to expect our gratitude. Under these circumstances, we cannot count on prompt, competent and reliable work. With assistance that is insufficient in the number of hours and insufficient in quality, we have to rely on family and volunteers. We will be dependent, must make compromises and concessions. Planning activities or larger projects will become very difficult.

How do we work for such a personal assistance policy in our countries? How can we convince our governments, members of parliament, the media and, most importantly, the general public of our right to personal assistance?

One argument is in the area of economics. But, please, do not claim that personal assistance is cheaper than residential institutions. That might backfire. Institutions with very few staff and crowded conditions like in Third World prisons are definitely cheaper per inmate than personal assistance. Instead, we argue that with the same amount of money that institutions receive from the government for each of their residents, most residents could have better lives living in the community with personal assistance. In most countries, governments pay more for keeping us in an institution than for enabling us to live in the community. In Spain, for example, an institution received €2,400 per month for each resident while someone wanting to leave the institution could count only on €750 for personal assistance in the community. (The figures are from 2007 but their relationship is probably still the same today.) We can only speculate why owners of institutions are entitled to that preferential treatment by governments. Perhaps it's simply that they have more money than our movement, have a better lobby, and better friends in government.

Institutions are capital intensive - considerable money is tied up in land and buildings. Personal assistance is labor intensive - almost all the costs go to wages. Our assistants are low-income earners who use their wages for food and rent. This promotes the domestic demand - an excellent way for lifting a country out of a recession.

In Sweden, personal assistance has become a labor market instrument. Some 50,000 persons work as assistants or 0.5% of the country's total population. Many of my assistants would have difficulties in finding other work and would have to rely on social welfare payments from the government. Doesn't it make more sense to use direct payments for enabling us to contribute to the community, for allowing our relatives to work in their chosen field of interest, and, at the same time, for putting our assistants to work? We must make the general public understand that direct payments for personal assistance are not costs but investments - investments in people's ability to contribute to society.

The other argument for direct payments for personal assistance are health and safety issues in residential institutions and parental homes - the alternatives for assistance users. The media ever so often report about physical and sexual abuse of persons with disabilities in institutions and - to a lesser degree - in families, in particular, where parents as the sole caregivers are over-burdened and burned-out.

There is ample scientific evidence that institutionalization, through lack of stimulation, exclusion from family, friends, class mates, and isolation, leads to hospitalism, that is, retarded development and loss of social skills. I lived five years in such a place, from age 17 to 22. It took me nearly a decade to recover from the damages of this most horrible period in my life.

The current Corona pandemic provides further evidence of the dangers of institutionalization. So far, a higher percentage of older persons have died in institutions than in the community. It would not surprise me if this were also true for younger persons with disabilities.

A third argument are our Human Rights. The European Union, as a whole, and all its member states have signed and ratified the United Nations Convention on the Rights of Persons with Disabilities. According to Article 19 of the CRPD, we have the right to living independently and being included in the community, at conditions equal to others. The General Comment Nr 5 in its operational definitions makes it very clear that residential institutions must be phased out and replaced by personal assistance services.

Sure, we shouldn't need to enumerate these economic, health and safety, and legal arguments to convince people of our right to personal assistance. In a decent society, all citizens have equal opportunities for living in the community in safety, health, and enjoyment of their innate potential. But, as we know all too well, we don't live in decent societies. We have to make them decent first!

I suggest the following strategies for working for a decent society.

More accessible housing

Our societies have to become more accessible. To replace residential institutions with personal assistance services, we must have more accessible housing in the community. Otherwise, many persons with disabilities - even if they had personal assistance - would still be forced into institutions. We need Universal Design in housing. For that, building codes for new construction and government grants for housing adaptation of existing buildings must be in place.

Coalition building

In line with the CRPD General Comment Nr 5, residential institutions are to be phased out by redirecting resources from institutions into direct payments for personal assistance. For our movement to succeed in this, our base has to become much wider. As Founding Chairperson of the European Network on Independent Living, I'm proud about our organization and its achievements. But we have to get better at coalition building, particularly at the national level.

In many European countries, the disability movement is still divided into organizations **for** and **of** persons with disabilities. Some of the "for" organizations run residential institutions and cannot be counted on as allies in working for de-institutionalization through personal assistance. On top of that, European organizations are mostly oriented along medical diagnoses. Thus, we find countries where one organization, for example the Muscular Dystrophy Organization, works for personal assistance but not the Spinal Cord Injury Association or any of the other organizations of the country. As if people with Cerebral Palsy, rheumatism, autism, sight impairment, Downs Syndrome, etc. would never need personal assistance! Would not our fight for personal assistance be more successful, if more organizations, more people were pushing the issue?

National organizations for Personal Assistance

I suggest we start ad-hoc one-issue organizations in our countries - national organizations for personal assistance. Anybody who wants to support or work for the goal is highly welcome regardless of their medical diagnosis or affiliation with other organizations.

Coalitions with the organizations of retired and older persons

Having worked for personal assistance for the last 40 years, I realize that we make a big mistake when we do not build coalitions around personal assistance with the organizations of retired and older persons. If our movement could get these often large, rich and influential organizations to support our cause, lawmakers would pay more attention to our demands. How can we get these organizations on board?

Let us join organizations of retired and older persons

One of the ways is that those of us who are old enough join them and try to climb up in their ranks. We need these organizations to understand that their members being old are prone to become disabled sooner or later, with some probability of needing assistance by others with the activities of daily living.

In many countries, the type of support services we may receive depends on our age: if we need assistance with the activities of daily living before the age of 65, for example, we are considered disabled and may be eligible for community-based services if there are any. If we cannot manage on our own after age 65, we are just old. Different municipal departments, budgets, staff and legislation may apply, and if we are lucky, we are offered a room in an old age home. Older persons with disabilities often face harsher conditions than their younger counterparts. But human rights are not restricted to certain age brackets. They apply to us all. Let us combine our forces and work for our right to live in the community with personal assistance regardless of age. Otherwise, the younger ones in our movement will be in for a bad surprise when they turn 65.

Our motto: We are profoundly ordinary people

We must double our efforts in making everybody - most importantly ourselves - understand: we may look, walk, or behave different but we 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 the help of personal assistance.