

Ageing with a disability: Institutionalization or Personal Assistance?

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Some countries claim to be welfare states but have the tradition of institutionalizing older persons without family support, as soon as they cannot manage living by themselves anymore. There may be public and private community-based services designed to enable older persons to age in place, as it is called, that is, remain living in the community. But for many older persons these services are not sufficient. High staff turnover and absenteeism often confront clients with new workers who first need to learn how to assist them. Older persons with increasing requirements can experience the lack of staff continuity as unsettling. Users are typically not in the position to choose workers. In addition, assistance is limited to one's home and to the basics: help with hygiene, dressing, meal preparation, and perhaps cleaning and shopping. People who were used to deciding over their everyday life might find it hard to cope with the services, for example, when they cannot take a shower more often than twice a month.

The same countries that do not question the institutionalization of older persons have ratified the UN Convention on the Rights of Persons with Disabilities. Article 19 of the Convention enshrines the right to "living independently and being included in the community, with choices equal to others". I repeat "with choices equal to others". Article 19 and, in particular, the Convention's General Comment No 5, explain why institutionalization violates the Convention. I am sure that the majority of civil servants and administrators in Europe working with older persons are unaware of the Convention or, at best, assume the documents refer to younger persons with disabilities - as if Human Rights were limited to certain age brackets! When I turned 65, it came as a shock when I realized that the Social Services Department of the City of Stockholm consisted of two major divisions: one for citizens under 65 and one for citizens over 65. They follow different legislations, have different staff and routines, different needs assessment criteria, etc. I have had my disability since age 17 but at 65 I was, bureaucratically speaking, no longer disabled. I was just an older person.

As a result of this differential treatment by age, persons with exactly the same impairment can experience dramatic differences in their quality of life. If you get your stroke **after** the age of 65 you are forced to get by with community based services which give you few hours and poor service quality. If you get your stroke **before** age 65 you are lucky because you are eligible for the direct payments from the National Social Insurance Fund for personal assistance services as long as you need them. I was lucky, I contracted polio when I was 17.

That was in Germany in 1961. I had to spend five years in hospitals. Not because of my medical condition but for the lack of accessible housing and community-based services. Since then, I have used a ventilator, an electric wheelchair and an increasing amount of assistance by others for such activities as getting up in the morning, going to the toilet, dressing, etc.

In 1966, I was able to leave the institution and study as a regular student at the university. I had won a scholarship that included a budget for personal assistance. Since then, I earned my degrees, moved between countries, worked as a researcher, became a disability activist, lecturer and community organizer, travelled and worked in many countries, married and raised a family. I consider myself a profoundly ordinary person! There's nothing special about me! What is special about me, though, is the fact that I have had personal assistance since age 22 - throughout my adult life. And that is, sad to

say, very special. Countless other people with similar impairments could have equally rich, interesting and fulfilling lives - if they had personal assistance services.

So, what is personal assistance? Unlike community-based services or residential institutions, personal assistance services entail a one-to-one relationship between the assistant and the person. It is the user - not the staff supervisor - who decides who works as a personal assistant. It is the user who decides where the assistant works at any given time whether it be in the person's home, at work or while accompanying the person in running errands in town, visiting friends or travelling. The user decides how the assistants' working hours are to be used according to the user's preferences that may change from hour to hour and day to day.

Control over the service's organization and content gives users the means of optimizing service quality, of achieving something in their lives. Cash payments, often referred to as Direct Payments, give us most control. With Direct Payments from the State, recipients have the purchasing power to employ assistants themselves or to buy assistance services from service providers, companies, of their choice. I receive a monthly amount from the Swedish Social Insurance Fund that enables me to purchase 18 hours a day of personal assistance services. With that money, I currently employ nine part-time assistants who work for me according to a predetermined schedule. I recruit, employ, pay, train, schedule, and supervise them. I'm the boss. I'm at the top of the hierarchy and have good chances to improve my assistance services should I be dissatisfied. In an institution, I'm at the bottom of the hierarchy, have no influence over staff and service quality. That's the fundamental difference between the two solutions.

Living in an institution, I would have never been able to have such a fantastic, good life! In fact, in an institution I would have died probably decades ago. Today, at age 78, I still have a rich and fulfilling life - with the help of my assistants. A life that I would never have in an institution.

So why can't more older persons with extensive disabilities live in the community with personal assistance?

Personal assistance requires organizing and management skills that not many older persons have. That is a common counter argument. Personal assistance does require the user to be alert and organized. Younger adults can have difficulties with that too. Some of these tasks can be trained or delegated to another person, for example, bookkeeping and payroll work or scheduling one's assistants. In fact, about 50% of personal assistance users in Sweden are children and persons with cognitive or psycho-social disabilities. They can benefit from personal assistance by Supported Decision Making, that is, they have somebody whom they trust, somebody who knows their requirements and personal resources. That person can be a relative, a friend or trusted former assistant. With Supported Decision Making, the individual's mental and social resources are complemented by someone else - complemented not substituted. With such an arrangement, many persons can benefit from personal assistance - regardless of diagnosis or age.

Another argument is that people living by themselves in the community, with personal assistance, might feel lonely. But it is possible to feel lonely also living in an institution. In fact, studies show that if you were lonely before moving into an institution you are likely to be lonely also there. With personal assistance, you have somebody around to relate to. Your assistants can help you leave your house and meet family members and friends or participate in activities outside the home. Here, the issue is more of having enough assistance hours.

The danger of living by oneself with conditions, such as dementia, is a serious argument. Walking out into the streets in the middle of the night endangers one's life and health - unless you have personal assistance 24/7. In residential institutions, persons with such conditions are kept in closed wards with very restricted mobility which allows a more cost-efficient patient-staff ratio than one-to-one personal assistance. Yet, there are other costs to institutionalization as the current pandemic has shown.

Another cost to the individual, family and society is hospitalism as the result of living a restricted life in a residential institution. Here, an interesting question is if personal assistance through its required

interaction with the assistants and its decision-making has a delaying effect on the development of conditions such as dementia.

I hope, I made you interested in personal assistance as an alternative to institutionalization for older persons with disabilities without family support. There are many questions to be answered, of course: what are the total societal costs and benefits of the two alternatives, what groups in society pay for them and benefit from them, what type of changes and preparations would personal assistance for older person require, and, ultimately, which of the two alternatives meet our societies' professed values of inclusion and equality? To find the answers to these questions, I propose we start pilot projects in several countries for testing personal assistance services for older persons. I'd be very happy to be involved in such efforts. I have written articles about the subject which I can share with you.

The issue of institutionalization of older persons with disabilities vs. personal assistance for this group boils down to our notions about older persons. I grew up with prejudices against older persons, I grew up with prejudices against disabled persons. Who doesn't? I had a lot to learn to accept my disability. And I have a lot to learn to accept getting older. Non-disabled, disabled, young or old: beneath these labels, I'm still the same person! My interests and curiosity, preferences, my love for my family, my love for my life haven't changed since I turned 65. I'm sure that's how it works for all. Let's give all of us a decent chance to a rich and fulfilling life with personal assistance - all of us, including older persons!