Personal Assistance as Prerequisite for De-institutionalization

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I am the founder and now retired director of the Independent Living Institute, a Sweden-based think-tank for policy formulation in the field of disability. We work for policies that enable persons with disabilities to become more independent. Our work is based on these principles:

- Disabled people are first and foremost citizens, not patients
- 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

As citizens we have responsibilities. To meet our responsibilities, we must live in the community, must have equal opportunities. As experts on our needs, we must take the initiative, individually and collectively, must show the way to the solutions we require. 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, the CRPD.

To have “choices equal to others in the community” we need an accessible society based on Universal Design. Universal Design in housing enables people of all ages to live at home in their familiar environment, among friends and family. Accessibility in new construction does not cost more, if it is planned from the very beginning, as research shows. Accessibility in all new residential construction plus state subsidies for the adaptation of the existing housing stock are necessary for creating alternatives to residential institutions. This requires builders, planners, and politicians to think. It requires changes in building codes, enforcement and monitoring mechanisms.

An accessible society with accessible housing, an accessible bus at the corner and an accessible workplace are not enough for those of us who cannot get out of bed by themselves. When it comes to that kind of help, persons in this group, still depend on family members or have to live in residential institutions – in violation of the CRPD Article 19 that demands community-based services, specifically, Personal Assistance services.

Accessibility in housing and personal assistance are required to get people out of institutions and to help them avoid getting there in the first place. A de-institutionalization strategy requires the involvement of the building sector. Since this sector is not represented here today I focus on personal assistance.

22 EU countries offer “personal assistance” today. But, there is an inflation of the term “personal assistance”. In Bulgaria, the government called it “personal assistance” when a few unemployed persons received wages for helping disabled family members. In Romania, they call it “personal assistance” when foster families receive small amounts for caring for an orphaned child with a disability. In Malta, personal assistance means you are entitled to one foreign guest worker from the Philippines who works 6 days a week around the clock for a wage that no European person would accept. There is a lot of fake personal assistance around. So what do we mean by true personal assistance?

True 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 including social security benefits
- 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.

What are the differences between true and fake personal assistance?

True personal assistance systems use individual needs assessments. Fake personal assistance uses assessment categories with a few flat rates of money or assistance hours that depend on our medical condition and not on what we want to accomplish in our lives.

The CRPD clearly states that quantity and quality of personal assistance services cannot depend on a country's financial priorities. Or on the population's notion about the quality of life we ”deserve”. How many times a day do we “deserve” go to the toilet? How many assistance hours a week may we spend on studying, working or leisure activities? According to the CRPD, personal assistance must provide ”all necessary means to enable users to exercise choice and control over their lives, to support living and inclusion in the community, with choices equal to others.”

Any personal assistance scheme that groups us into several need categories or limits our assistance to a certain number of hours is fake personal assistance. At best, such a scheme might give us enough assistance hours for eating, personal hygiene, getting dressed – the survival minimum. Such a policy may keep us alive, but will not give us a life! It cannot give us enough assistance hours to have ”choices equal to others”. It will not enable us to compensate our impairments, to grow and develop as human beings, to take our rightful place in family, community and society.

True personal assistance schemes use Direct Payments

In true personal assistance, the money follows the user not the service provider. Channeling funds for personal assistance to providers and not to users makes assistance users to objects not subjects. My assistants will not see me as the boss, who makes the final decision. Without the purchasing power that Direct Payments give us, we users do not have the means for shaping our individual services – making them ”personal” assistance through individualization and custom-design.

In true personal assistance the service users can recruit, train, and supervise their assistants

In many fake personal assistance schemes, users have to share their assistants with other clients of the service provider with all the problems, limitations and frustrations that sharing entails. What can I expect from an assistant who works for half a dozen clients? Will he or she remember my intricate way of pulling up my pants that I've developed over the years to prevent pressure sores? Or, how to change the program in my ventilator? My tricks and techniques may not be applicable to other clients and vice versa. To assume that a generic training program will enable assistants to work for any assistance user is naive. It reveals ignorance of what personal assistance is about because it assumes that all assistance users are alike, have the same bodies, requirements, personal resources, tastes and preferences, aspirations and dreams - in short, it negates our uniqueness as human beings. That assumption is de-humanizing.

What quality of life can true personal assistance help us achieve?

I answer this question best by telling you the story of how my entire adult life has been based on personal assistance.

In 1961, at age 17, I contracted polio in Germany and ended up in a hospital ward for persons who were medically stable but required mechanical breathing aids. We received physical therapy and assistive devices, and could have left had there been alternatives for us in the community in the form of accessible housing and assistance with the activities of daily living such as getting up in the morning, getting dressed, etc. We had no future, the hospital ward was a warehousing facility for us.

After five years, at the age of 22, and after finishing highschool in the hospital with private tutors, I managed to leave the hospital in Munich and move into a regular student dormitory at the University of California in Los Angeles with my electric wheelchair, my ventilator and my considerable need of assistance with the activities of daily living. I didn't know anybody in the new country, none of my family could come along. I am still grateful to my mother for letting me go, for never trying to hold me back. She must have believed in my ability to learn how to take care of myself. And I proved her right!

The transition from the hospital ward to the student dormitory was made possible by my personal assistants. They got me up in the morning, helped me with bathing, toileting, and dressing. They did the shopping, cooking, cleaning and other household work. They helped me with my ventilator, carried my books. As my personal assistants, I hired, trained, paid and supervised fellow students who needed the income. I paid them with my scholarship from the German State that also covered my other expenses.

In the hospital, I had been a patient (according to the word's Latin root ”one who waits and suffers”), at the bottom of the hierarchy. I was forced to adapt every detail in my life including toilet visits to the requirements of the hospital ward. In the dormitory, as the employer of my assistants, I was at the top of the hierarchy and was expected to direct them. At age 22 and - more importantly – after five years of hospitalization it was at first difficult for me to become aware of my needs, not to speak of expressing and getting them realized. I had no role models or training by peers, friends in the same situation, and made many mistakes.

After seven years of study and work at the university in the US, I moved to Sweden on a research grant. In Stockholm, I hired, trained and supervised personal assistants with money from my grant. They did everything I needed to concentrate on my research. They drove me to work, assisted me at my workplace, accompanied me when I went out.

After finishing my Ph.D., I stayed in Sweden, worked as a researcher at the university, got involved in disability politics, introduced the Independent Living movement and the concept of personal assistance to Sweden by taking the initiative to the Stockholm Cooperative for Independent Living (STIL), the first European personal assistance user cooperative. I was the founding chairperson of the European Network on Independent Living, spent an academic year as guest professor at the University of Costa Rica, and founded the Independent Living Institute in 1993 whose director I was until 2017 when I turned it over to my successor after we had grown to a staff of 18 persons. Since the 1980s, I have traveled, lectured and worked in many parts of the world. All this was made possible by my personal assistants.

In my first relationship – in California - my girlfriend helped me with everything I needed. She worked as my only assistant. We lived together, were inexperienced and very much in love. She was always there, every day, every week, every month. I found that very convenient and after a year the relationship ended. In my following relationships, I tried to be smarter and insisted that my assistants work for me as much as possible and my girlfriends as little as possible. Forty years ago, I met my wife and after a few years we got married. We took this decision after much deliberation. We had met many couples where one of them - often the wife – was the sole caregiver of the other, where both lived in extreme mutual dependence, where none could take a step without the other, were tied together like Siamese twins. My wife was familiar with my system of personal assistance. We both wanted to live together but also needed to feel free in a relationship where we, independently from each other, could develop and grow as human beings. We knew this was possible with personal assistance. With the help of my assistants I would continue to take care of myself. With the help of my assistants, I would do my part of the household chores. Sharing household responsibilities equally among partners is the cultural norm in Sweden. Well, that was our vision and it hasn't always worked out that way.

My wife and I travel in our work and on vacations. She frequently visits her large family in Germany, attends international conferences or works abroad. I too get invitations to lecture or work abroad. She often travels by herself and I want to be able to do likewise with the help of my personal assistants. When we travel together, it is because we choose to do so and not because I need somebody to accompany me as my assistant.

Our decision to have a child was also based on personal assistance. At that time, Sweden had just passed a law entitling people in my situation to Direct Payments from the central government for personal assistance. Personal assistance would allow me to have an active part in raising and being close to my child. Sharing the responsibilities for children is also the cultural norm in Sweden. I would do my share of the physical work in child raising with the help of my personal assistants. I took our daughter Katharina to the kindergarten in the morning, my wife picked her up after work. I also wanted to be alone with my daughter and do things together – only she and I. So every Saturday, Katharina and I did the grocery shopping, visited museums, went fishing. I instructed my assistants to stay behind us and only interfere when I'd ask them or to step in to prevent an accident.

Without my personal assistants I would have had to depend on the local government's community based services that are plagued by very high staff turnover, where the user has no say in what work is to be done, where the staff cannot work outside our home. Most likely, the community based services would have assisted me with my physical personal requirements only, would not have enabled me to share responsibilities for the household, not to speak of sharing the work and responsibility for our child. My wife would have been busy with child, household, and probably even me. She would have been unable to work in her profession. There would not have been much left of an equal relationship.

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. Despite my extensive disability – need for mechanical breathing aids and an electric wheelchair since 1961 - I have been able to live and be included in the community, to study or work throughout my adult life, to emigrate twice to another country, to lecture and work abroad, to have a social life with friends and romantic relationships, to marry and raise a child. I am very satisfied with my life. I am proud of what I have achieved, of what has become of me. I cannot imagine that my life without the disability would have been very much different. It has been – and still is – a full, rich and exciting life.

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 similarly fulfilling lives. What is special about me is the fact that I have had personal assistance throughout my adult life. That is, sad to say, very special. In countries without true personal assistance services – that is, in most parts of the world - I would not have had so much self-determination and such a good life. With only help from my family, I would have been very limited. In a residential institution, I probably would have died decades ago.