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

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https://youtu.be/YsPNcEuuocU

Most people with extensive disabilities who require assistance with the activities of daily living are dependent on their families or live in residential institutions. To improve our situation, to live in the community at conditions equal to our non-disabled brothers and sisters, friends and neighbors we need to work for a national personal assistance policy. What does such a policy have to look like, what features must it contain? Should such a policy be based on the results of the present CAVI pilot projects?

People who know little about personal assistance assume that our assistants mainly make sure that we don't freeze, don't starve, don't smell.

That may be all we need to survive. But we are not interested in survival - we want to have a life! To have a life means to grow up in our family, play and hang out with the kids of the neighborhood, get an education and develop our mind, work in interesting jobs, contribute to society. Like all humans we want to make friends, fall in love, start a family. Like all humans we need to feel that we make a difference. We can achieve all this - despite our disabilities - we can have rich and full lives with true personal assistance.

True personal assistance meets the following conditions:

The first condition is that we users are in charge of our personal assistance. We are in charge 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 unique personal circumstances, and the better we learn how to use this tool, the higher will be the degree of our self-determination and the quality of our life. That's what makes personal assistance "personal".

Yet, in the Portuguese pilot projects users are not in charge: they cannot recruit, employ, train, schedule and supervise their assistants. Somebody else is doing this. Assistants receive 50 hours of generalized training. Most likely, much of this training consists of telling our assistants the medical implications of different disabilities - what's "wrong" with us, what we cannot do and what we should do by ourselves. I don't want somebody else tell my assistants what they should do for me and how they should do it. Somebody who's never seen me and doesn't know anything about my life, my person, my assistive technology, my family, my work and interests! We are the best experts on our needs. If anybody needs training it is us, the users! Because we need to learn how to train and supervise our assistants.

We often get to hear that personal assistance might work for persons with physical but not cognitive or psychosocial impairments. In Sweden, currently 51% of the persons who receive direct payments for personal assistance have autism and similar impairments or acquired brain damage. They might not be able to take all the decisions that employers and supervisors must take. But their direct payments budget contains money for hiring someone for supported decision making. That can be a relative or a former assistant whom the person trusts. In Sweden, a number of assistance provider companies and user cooperatives specialize in clients who need supported decision making. The Independent Living movement has been developing solutions for supported decision making from its beginning to make sure that we all can benefit from personal assistance.

The second condition: the user controls the money flow. We control the money through direct payments, that is, money from the government goes directly to the users who then have the means to recruit, employ, train, schedule, and supervise their assistants. The money must follow the user not the service provider. In this way, there are no middlemen who pocket a percentage of the government money and rob us of the control over our services. Here, we meet the biggest resistance in countries were disabled people are over-protected, and considered unable to make decisions in their own best interest. Service providers will do their best to spread such an image of us to defend their *raison d'être* and to defend their income.

In your pilot projects, assistance users do not control the money. Can they switch easily from one service provider to another, if they are not satisfied? Do they make the final decisions about hiring, setting wages, or firing assistants? When we don't manage the money, we can't be the employer and must accept any service provider that the government selects for us. We will be the object, not the subject. Our assistants will have a different attitude toward us. If you are not the boss, if you cannot switch service providers you cannot enforce good service quality, have to accept what you get, are made to feel dependent on your assistants.

The third condition requires that the direct payments cover the costs of all the hours of assistance we require and enable us to pay our assistants competitive wages. Without decent wages, people working for us will expect our gratitude. Under these circumstances, we cannot count on prompt, competent and reliable work. Without sufficient assistance hours, without sufficient service quality, we will have to rely on family and volunteers, be dependent, make compromises and concessions. We will have little self-determination.

In your pilot projects, assistance users get a maximum of 40 hours/week of assistance, fewer than 6 hours/day. How are people expected to live who need more? In my case, for example, I need at least 18 hours/day. How would I manage in Portugal? Obviously, people in my situation must rely on relatives, friends and volunteers. They would not "live independently and be included in the community" as the Convention on the Rights of Persons with Disabilities stipulates. My wife and I aspire the same independence or interdependence from each other that other Swedish couples enjoy. She wants to leave the house, go to work, travel abroad by herself just as I do. We do travel together - when we both want to and not because I need her to come with me as my assistant. With the Portuguese pilot projects, my wife would be forced to be my Siamese twin, my life-long unpaid assistant. That's a terrible strain on a relationship!

The fourth condition is that eligible persons must receive personal assistance regardless of age. Personal assistance is listed in the Convention as a human right. Human rights are not restricted to certain ages. But your pilot projects restrict personal assistance to users older than 16 years. Yet children and their families would benefit tremendously from personal assistance. Parents and siblings would be relieved from being on duty all the time, could get more time for themselves. They could carry on with their lives, continue their jobs or education, go out without a bad conscience. I met parents of small children with multiple disabilities who were at the brink of psychosis for lack of sleep. They got their life back after their children had personal assistants.

For the child with a disability, personal assistance is the way to gradually become more independent from the family - just like any other child. With personal assistance, a child can learn do things by itself, hang out with friends. With personal assistants, a child can take over responsibilities for the family's household chores, go to school. Doing things without mom or dad is essential for personal growth. Naturally, when the child is very young the parents need to make sure that the assistants apply the same pedagogic principles as the parents. But as the child grows older, the assistant should be seen not as the prolonged arm of the parents but as somebody who enables their child to discover and participate in the world around it - on its own terms.

The fifth condition is that users do not have to share their personal assistants with other users. In institutions, everyone has to share workers with other inmates. That's what all institutions have in common. That's the reason why most of us try to stay away from them. Sharing assistants turns our homes into mobile institutions and drastically reduces our self-determination.

The pilot projects together employ 570 personal assistants who work for altogether 833 users. 570 assistants for 833 users. So, quite a few users are forced to share assistants, cannot choose who is to help them in the shower, in the toilet, who will open their mail, listen to their phone calls, witness their family quarrels. This is humiliating, and has nothing to do with "living independently and being included in the community".

In summary, the pilot projects do not meet these five conditions. This is not what the Independent Living movement and the CRPD mean by "personal assistance". Your solution does not comply with UN CRPD Article 19 as defined in General Comment No 5. Your pilot projects do not give users the means to control and optimize the quality of their services and, thus, the quality of their lives. It does not give taxpayers the best value for their money. With the same money, a much better system could have been designed, a solution that liberates persons with disabilities from dependence on their family, that empowers them to live with self-determination in the community.

This does not come as a surprise. Most CAVIs were formed by organizations for people with specific medical impairments, such as Cerebral Palsy, neuromuscular or other impairments. These organizations are typically run by persons without disabilities. For them disability is a medical issue - not a social and human rights issue. They may be experts on medical interventions and rehabilitation. But how much do they know about what it takes to “live independently and be included in the community”?

Also, a number of the organizations that run the pilot projects have been managing residential institutions for decades. What do they know about enabling persons to live in the community? They probably organized their so-called personal assistance services as much as possible in the same way as their institutions. With the same organizational culture, same hierarchical structure, perhaps even with the same staff.

Sure, the pilot projects might offer a quality of life that may be slightly better than that in residential institutions. But residential institutions are not our criterion of comparison! Our comparison is the quality of life that non-disabled people take for granted.

Two years ago, at the kick-off event of the project in Lisbon in June 2018, I made the very same points when I defined what true personal assistance is about. I’m sorry to say that your pilot projects have nothing to do with **true** personal assistance, they are **fake** personal assistance. I do hope the Portuguese future national personal assistance policy will **not** be based on these pilot projects.

Thank you.

I kept my presentation short to give us more time for questions and answers.