Personal Assistance: True Personal Assistance vs Fake Versions

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I'm Adolf Ratzka and this is a pre-recorded video from a couple of days ago. When you see this, I will be in Helsinki at the funeral of my dear friend Kalle Könkkölä. Kalle had an incredibly rich life, among many other things he was a Member of Parliament in Finland and a giant in the international disability movement. How did he, with his extensive disability, manage to accomplished all this? He used personal assistance.

Today, I will talk about Personal Assistance, how personal assistance as a concept is being abused and corrupted, how real personal assistance differs from the fake versions we see popping up in many countries, and why we should not settle for less than the real thing.

Most of the personal assistance schemes we see today do not deserve to be called that way, because they do not enable us to have the quality of life we deserve, that is the quality of life that all non-disabled people take for granted.

Most existing personal assistance schemes limit the number of assistance hours, for example to a maximum of 40 hrs a week. How on earth did they get to that figure? How can somebody who requires personal assistance for just about everything survive on 40 hrs/week - not to speak of having an ordinary life - with family, work, and interests? If you need more assistance hours, you better have a lot of money, have rich parents or several brothers and sisters who can quit their jobs and work for you. If you don't have family members who are willing to sacrifice a life of their own, you need a place in a residential institution where they keep you alive, dry and clean. But forget your dreams of a life!

In most of the schemes that are called ”personal assistance”, the persons working for you are employed by an agency that hires, trains, and supervises workers and sends them home to you. Some of these agencies might be called Centers for Independent Living. But does that make a difference to you as user of the services when you cannot decide who is to work, when, where, with what and how? When not you but other persons make the decisions?

In these services, you share assistants with other users, must adapt your plans for the day or for the week to the needs of the other assistance users. You planned to go to the university today? Forget it. Another user of the service needs assistance for a medical appointment and somebody has decided that the appointment is more important than your lecture.

In most of these services, you never see any money. The money goes straight from the government to the service proider. We have no say about how it is used. Wages are so low that it is not clear why assistants work: for the money or because they feel pity for us.

In most personal assistance schemes where you do get the money, it is a flat amount, the same for everyone regardless of the extent of their disability. To make sure that nobody gets too much, the government gives everybody too little. We can use it for pocket money but not for buying the personal assistance services we would require for a real life.

That is roughly how the concept of personal assistance is understood in most countries today. The situation is in complete violation of the United Nations Convention on the Rights of Persons with Disabilities, the CRPD.

In Article 19 the CRPD states

”Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”, ”with choices equal to others”.
In the document General Comment No 5 on Article 19 of the CRPD, the CRPD Committee elaborates and explains the Article and defines personal assistance in this way:

”The funding of the services is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required.” This means Direct Payments, straight from government to you.

Regarding needs assessment the General Comment states
”Funding of services is based on an individual needs assessment and upon the individual life circumstances.” Thus, no flat amounts can be paid out that are the same for all users regardless of the extent of their required personal assistance.

Regarding the role of the assistance user vis a vis the service provider, the General Comment states
”The service must be controlled by the person with disability, meaning that he or she can either contract the service from a variety of providers or act as an employer.” According to the Committee, we are employers of our assistants or are customers who choose services from competing providers.

Regarding our possibilities to shape the service after our own individual requirements, the General Comment states
”Persons with disabilities have the option to custom design their own service, i.e., design the service and decide by whom, how, when, where and in what way the service is delivered and to instruct and direct service providers.” This makes it clear that the individual user, with Direct Payments can be the boss of his or her assistants, with the power to organize, custom-design and fine-tune the service.

Regarding the user’s position vis a vis the personal assistants, the General Comment states
”Personal assistance is a one-to-one relationship. Personal assistants must be recruited, trained and supervised by the person granted personal assistance.” Thus, no middlemen between service user and personal assistants.

Regarding the sharing of assistants, the General Comment states
”Sharing of personal assistants will potentially limit and hinder the self-determined and spontaneous participation in the community.”

Obviously, there is a huge gap between what the UN CRPD requires of our governments and what we are actually getting from our governments.

We need real personal assistance and not fake versions

We demand individual needs assessment
The CRPD makes it clear 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”, and what that means in terms of how many times a day we are allowed to go to the toilet or how many hours a week we may spend on studying, working or leisure activities. A personal assistance policy that conforms to the CRPD provides ”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.”

Thus, any government scheme that is not based on an individual needs assessment and on individual life circumstances, that groups us into one of several need categories or limits our assistance to a certain number of hours must be categorically rejected. Why? At best, such a scheme might give us enough assistance hours for eating, personal hygiene, getting dressed – the minimum necessary for survival according to the Medical Model of Disability. 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 use personal assistance as the most important tool to compensate our impairments, to grow and develop as human beings, to take our rightful place in family, community and society.

We demand Direct Payments,
where the money follows the user not the provider. A policy that channels funds for personal assistance to providers and not to users makes clear, symbolically and factually, that users are not the bosses; that we are objects not subjects. My assistants will not see me as the employer, as the person who has the final word. Without the purchasing power that Direct Payments give us, we users do not have the power nor the means for shaping the organization of our invidual services – making them ”personal” assistance through individualization and custom-design. Personal assistance is a wonderful tool, if honed and trimmed by you personally for just your purposes.

We demand that assistance users can recruit, train, and supervise their assistants
Without the ability to recruit and train assistants, users are given the option to choose among already employed workers. Most likely, users will have to share these 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.

These are our demands. Our demands are reasonable and justified because we demand nothing more than the same degree of choice and control over our lives that all non-disabled persons take for granted without giving it a thought.

Our demands are reasonable and justified because our governments, by signing and ratifying the United Nations Convention, have already committed themselves to fulfill them.

So what are they waiting for? And why should we accept our governments' fake versions of personal assistance when they signed the treaty and committed themselves to provide the real thing?

Let's be a bit self-critical. We have been great in playing the role of the victims, in complaining and moaning about how bad things are. But we have not been great in reminding our governments of their obligations, in making life difficult for them. We have been far too patient.

I bet that most of the Members of Parliament in your country have no idea what Article 19 of the Convention is about. How many lawyers, judges, officials in national and local governments are aware of our rights as spelled out in the Convention and General Comment No 5? Not many, I suspect. So how can we expect them to get going, to start delivering?

How many of ourselves here know Article 19, have read General Comment No 5?

We got some homework to do, we need to learn how to use CRPD, how to use the political and legal process to transform the Convention's articles into binding national legislation with tangible sanctions for non-compliance. To accomplish this, we have to increase our movement's legal expertise. We have learned to make noise in the streets to force the government listen to our needs. Now it's time to move up to the next level and move the battle into the court room.

If you want to learn more about that, join our FaceBook group Disability Rights Defenders.

Thank you for your attention