

Keynote speech: Celebration of the tenth anniversary of personal assistance. Sapporo Center for Independent Living

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Dear friends and fellow assistance users,

As persons with extensive disabilities our way to a life with interests and hobbies, challenging and meaningful work, relationships and families of our own is personal assistance. The better our individual solution of personal assistance is organized, the better will be our self-determination, life satisfaction, and self-respect.

In my experience, the most important conditions for improving our individual personal assistance solution are

- individual control over your assistance

You, as assistance user, are in charge. That requires direct payments from the government directly to you - not through intermediaries whether they are another government agency, a private charity or a center for Independent Living. In the eyes of your assistants, you can only be the boss if you are the one who decides who is to be hired as assistant, who trains your assistants, schedules, supervises and pays them. In this way, you are the subject, not the object.

- sufficient personal assistance hours

You have sufficient hours of assistance each day - not only to keep yourself fed, warm, and clean. We are not interested in survival but in a life, a life with the quality that your non-disabled brothers and sisters, friends and neighbors take for granted. The more functions we take on in our families, the community, and in society, and the more work and interests we have, the more assistance hours we require. Remember, to fulfill our obligations to family and society you and I require the full implementation of our right to personal assistance as enshrined in Article 19 of the UN CRPD and as elaborated in the CRPD General Comment No. 5.

As we know, the need of personal assistance alone doesn't make you automatically a good boss of your assistants. Everybody needs training and support with these functions. Some of us have cognitive impairments and, in addition, will need Supportive Decision Making (SDM) in these functions. To provide training and support including SDM is a typical task for a Center for Independent Living.

I have had personal assistance since 1966 when I was 22 years old. Since then, with personal assistance, I have had - and still have at age 77 - a very good life with studies, work, interests, friends, and a family of my own. Hiring, training, and supervising hundreds of personal assistants has not been easy for me. I made - and still make - mistakes. But from our mistakes we learn more than from our successes.

I learned to have several part-time assistants employed. In this way, you reduce your dependence on any one of them. They work for me according to a schedule that I, together with them, make four times a year. Presently, eight assistants work for me whom I have recruited and trained myself. When one of them is prevented from working he/she has to inform me as soon as possible so I can find a substitute among my other seven assistants.

I learned to make a difference between assistants and friends. From friends and volunteers, you cannot expect and demand punctual, reliable work at your conditions. You have to make concessions and compromises. You often have to adapt your needs to their needs. In this way, it will be difficult to live your life according to your plans and aspirations.

To treat your assistants as employees and not as your friends is difficult, in particular, if you - deep down - feel emotionally dependent on your assistants. Many of us who have been living with their families as caregivers or in institutions are prone to want as few assistants as possible. Try to avoid this, if you can. Using one or a couple of assistants might work for a short while but in the longer run - especially if you require considerable personal assistance every day - it is destructive, in my

experience. Without noticing, you run the risk of becoming dependent on them, make increasingly more concessions, and allow them to run your life.

I learned - and am still learning- to treat my assistants with respect, openness, and patience, especially during the training period. Explain your requirements, over and over again, elaborate why certain routines are very important for you and have to be carried out in a particular way. Give your assistants constant feedback about how they are performing their tasks. It is important that the positive feedback far exceeds the negative feedback. If an assistant does something in the way you like, acknowledge that with a positive comment as often as you manage. If you are not satisfied with something, gently explain how the task can be carried out better - but avoid words such as "bad" or "wrong". Remember, if you are grouchy and ill-tempered, you stress the assistant. Under stress, most people perform and learn worse. So, if your assistant does not seem to understand or remember what you said, ask yourself whether you could be the cause. In that case, you are in a position to solve the problem by improving your interplay with the assistant.

Having good assistants whom I trained that way greatly influences my life, allows me to concentrate on my family, and enables me to do things I want to do. There is hardly an adventure you cannot do together with an assistant in whom you invested time and energy for training, somebody you trust and rely on.

I love to travel. Nowadays, I need a lot of personal assistance and assistive equipment such as my heavy power chair, my light-weight mobile hoist to transfer me from wheelchair to bed, my ventilator with hose and mask assembly incl. spares for everything, etc. My packing list for a weeklong trip contains over hundred items. Before I take somebody along on a trip as my only assistant, he or she has to be good at the daily routine at home, and, in addition, has to have accompanied and assisted me on a trip before when another assistant was in charge. I try to explain and train with the assistant, over and over, what has to be done at every point during the journey.

My trusted assistant Peter has been working for me for over a decade. He is a musician, bass guitarist for a Swedish Heavy Metal Rock band. But he cannot live on that and finds it perfect to work part-time as my personal assistant on the side. He wears his blond bleached hair in a long ponytail, dresses only in black, and displays lots of skull and bones tattoos on his arms. With his band, he often travels to countries in other parts of the world. A few years ago, I had a job in Taipei and gave a workshop on personal assistance in a huge auditorium before an audience of some 500 persons with disabilities, service providers, and government officials. As usual, I started my presentation by introducing my accompanying assistant, explained Peter's work situation, and mentioned the name of his band *Crash Diet*. After the morning part of the workshop, everybody stayed for lunch in the same hall. All of a sudden, like an explosion, there came a deafening crescendo from the stage, like an airplane at take-off. I looked up and saw on the big screen a bunch of long-haired blond guys with guitars galloping around like horses. As I found out later, a Heavy Metal lover among the workshop organizers had googled for the website of *Crash Diet* and downloaded their music video onto the hall's sound and video system.

After that lunch, Peter was surrounded by dozens of new fans - more fans than I was able to attract!

In case, you got interested in rock musicians as personal assistants, here's the link to one of *Crash Diet*'s music videos <https://www.youtube.com/watch?v=HuEEJq587H8>

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