

Build back better: phase in personal assistance for all ages, phase out residential institutions of all sizes, for all ages!

United Nations Side Event September 21, 2021

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Next month, it will be 60 years that I am disabled, that I use mechanical breathing aids - like the mask you see on my face, that I move around in an electric wheelchair, that I need help to get up in the morning, go to the toilet, get dressed. The first 5 years after contracting polio, I spent in hospitals and residential institutions in Germany. I was medically stable but there were no support services in the community, and my small family could not do this work. In 1966, I managed to get out of the institution with the help of personal assistance. I won a scholarship to study in California. The scholarship included a budget for hiring fellow students who worked as my personal assistants. Since then, I have lived in the community, earned a Ph.D., moved to Sweden, worked in research at the university, met my wife, started a family, got involved in disability policy, became an activist, founded several national and international organizations, and so forth. I've had, and still have, a rich, interesting and rewarding life - due to personal assistance. Personal assistance has been the foundation on which I built my life. Without personal assistance, I would have died already decades before the pandemic.

I consider myself a profoundly ordinary person. I have no special talents. What is special about me, though, is that I have had personal assistance all my adult life. That is, sadly, very, very special. Millions of people, the world over, could have similarly rich and rewarding lives, could realize their inborn potential, if they had personal assistance, that is, direct payments from the government for buying assistance services from the service provider of their choice, or, better yet, for hiring, training, and supervising their personal assistants themselves. That degree of control is required for optimizing the quality of assistance, the quality of one's life.

Is this a solution for everyone who needs help with the activities of daily living? How about persons with psycho-social and cognitive impairments, autism, dementia? With Supported Decision Making from relatives, friends or trusted former assistants, many in this group could manage a life in the community without being a burden on their families. In Sweden, almost half of the recipients of direct payments for personal assistance belong to these groups or are children. Yet, no person with dementia, to my knowledge, has personal assistance in Sweden. You are **not** eligible for personal assistance if you acquire your impairment after age 65, and in most cases, Dementia is diagnosed after 65.

In many countries, the alternatives for persons who require extensive assistance are the family or an institution. Relying on the family is a ticking time bomb. Sooner or later they will get too old and feeble to work for you. Without a family, we hopefully find a place in an institution. These facilities have different names, such care home, group home or other euphemisms that are to distract from the fact that they are institutions. In the language of the CRPD, they are "particular living arrangements", that violate the Convention. Whether for two or two thousand inhabitants, as long as housing and services are bundled together and offered in the same location, as long as the staff is shared by the inmates, and you have no control over who is to work for you, when, where, with what tasks, and how - you live in an institution. In General Comment No 5. on Article 19 of the Convention, you find the definition and the reasoning. Sharing the staff by all has caused the many deaths in institutions in Sweden and other countries, during the pandemic.

At age 22, personal assistance got me out of the institution. At age 77, I worry about having to move back into an institution. My needs, interests and aspirations are the same, but a new government might take away the legal entitlement to direct payments for personal assistance for my age group. The institutionalization of older citizens is still widely accepted. Human rights are still restricted to certain age groups.

The lessons from the pandemic:

- Develop support services in the community for the whole life cycle, services that are based on need, not on diagnosis, not on age - such that all who need the services, including older persons like myself, can live in the community, and do not become a burden on their families, do not have to move to institutions!
- Radically increase the supply of barrier-free housing! Nobody should need to move into an institution for lack of accessible housing in the community!
- Phase out residential institutions where we are at risk for neglect, abuse, and pandemics!
- I'd love to use my experience to contribute to this work.