

**Human rights in older age:  
Towards the elimination of ageism and age discrimination**  
United Nations Side Event September 21, 2021  
[video documentation](#)

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In my experience, people only move into residential institutions if they are forced to, for lack of acceptable alternatives in the community. Here's my story:

I became disabled at age 17, 60 years ago. Since then, I need mechanical breathing aids, like the mask you see on my face, an electric wheelchair, and help for getting up in the morning, going to the toilet, getting dressed, etc. The first 5 years I had to spend in hospitals and residential institutions. I was medically stable but my family was unable to do this work and there were no support services in the community. In 1966, I managed to get out of the institution with the help of personal assistance. I won a scholarship that included money for hiring fellow students who worked as my personal assistants. Since 1966, I have lived in the community, worked as a researcher, started a family, got involved in disability advocacy. I've had a rich and rewarding life - thanks to personal assistance. Without personal assistance, living in an institution, I would have died decades ago.

Now, at age 77, I still have a rich and rewarding life because I still have personal assistants. Since I got my disability before the age of 65 I'm eligible for direct payments for personal assistance from the Swedish Social Insurance. My payments cover the cost of 18 hrs of personal assistance/day. Had I acquired my disability after age 65, I would get now 5 hrs/day of the local government's community based services instead. 5 hrs would not be nearly enough and my wife would have to help me a large part of the day. She will be 70 soon. Imagine the pressure on my wife knowing I would be forced into an institution the day she no longer can work for me!

At age 22, personal assistance got me out of institutions. At age 77, I worry about having to move back to an institution, because a government commission recently suggested stopping direct payments for personal assistance for those over 65. I'm still the same person! My needs, interests and aspirations have not changed!

We need to open up society to all people, that means, among other things

- o to develop support services in the community for the whole life cycle, services that are based on need, not on diagnosis, on the person's preferences, not on the person's age. No one should need to become a burden on their family, should need to move into an institution!
- o to increase the supply of barrier-free housing! Nobody should need to move into an institution for lack of accessible housing in the community!
- o to phase out residential institutions where we risk neglect, abuse, and death during pandemics!