

Ageing and Disability: Concepts and values for the future

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Introduction.

From epidemiological research (Miettinen, 1991) we can learn that the human race in the Western part of the world shows a strong tendency to live longer. The same tendencies can be observed for people with a disability. (Hogg, 1997)

In the light of human diversity, having more older people in our communities should be seen as an enrichment of our world. Beside of the positive message we have to keep in mind that older people and older people with a disability are groups to be seen under high risk of discrimination (Janicky, Mc Callion et al, s d)

From my own work and research with older persons with disabilities I've learned a lot about this high risk of discrimination for this group. This discrimination can have many faces like: poverty (material well-being); poor access to medical services (physical well-being); shrinking social networks (interpersonal relationships); less participation (inclusion); not being involved in important decisions (self determination); living with stressful situations (emotional well-being); declining independence (personal development) and a higher risk on abuse (rights).

Values.

To make sure that we don't think that we can work in a kind of technical vacuum, I'm suggesting four deeply rooted values as the fundamentals for our work. The strongest statement we can make is not to discuss these four fundamentals. They have to be seen as the assumptions that serve as a compass for our work.

1. everybody wants to **belong**
2. all human beings want to share and try to contribute to the communities they belong
Generosity is a fundamental human longing.
3. people want to live a life with a health balance between independence and **interdependence**
4. to learn new things, to refine skills, to keep hold of certain abilities, ... are central tendencies connected with human nature. (**mastery**)

From our point of view those four values can offer a bridge to the human rights framework that can be used in policy making, research and practice concerning successful positive ageing and inclusive communities. We try to make this human rights framework concrete via a holistic set of concepts. These concepts can help us to form a dam/dike to support ageing people (with a disability) in responding to the risks mentioned in the introduction of my lecture.

Economic security

Positive self perception

Ageing friendly communities

Engagement in activities

Accessibility

Adaptation

Care for a life long health

Advocacy

Involvement of family members

Training of support staff

Empowerment

Technical support tools

Decision making

Choices

The right to retire

Communication

Mobility

From abstract words to concrete action. Can these concepts make a difference for the life of William and Laura?

William and Laura are in their sixties and they live in a village near the big town. They share a house, and get support from a supported living service. They both worked for several years, William visited an activity centre and Laura worked in a kitchen of a hospital. Till last year they lived together with Agnes who passed away. They like each other and present themselves as 'big friends'.

1. They both suffer from a lot of health problems (William has serious back problems with a consequence of restricted mobility – Laura has communication and mobility problems due to a stroke) → we need to make sure that they get access to the necessary medical treatment
→ we have to make sure that their physical impairments do not isolate them (e.g. a volunteer is driving them once a week to a big shopping mall)
2. Laura has emotional problems. Her care givers are worried (is it a beginning dementia??) → Laura has to be seen by a specialised team to make sure that a 'differential diagnosis' is organised
3. For William and Laura the question 'where to live?' becomes a central one. Now they live in their own house with support → the question is if William and Laura live a happy life in this house with this package of support (enough activities? – enough social contacts? – enough safety and security in the house/out in the streets - ...?)
→ one of the alternatives could be a transfer to a local institution for older people. While considering this alternative the following elements seem to be crucial:
 - the involvement of William and Laura while preparing this eventuality
 - while considering this at first sight interesting alternative we should take in mind all the things we have learned from research about institutional care (Hatton and Emerson, 1996)
 - the clear statement of William and Laura that they want to stay together if they have to move (they are not officially married)
 - the involvement of both families:
 - William's sister is living in the same community and William likes to live close to her. She visits and phones him regularly
 - Laura's sister-in-law is very worried about the financial consequences of certain alternatives. She is convinced that this will lead to extra costs
 - The way the team members of the service of supported living are interpreting their job. Do they feel secure to go on giving support to William and Laura in this situation?

Living in a period between the 'Montreal Declaration on Intellectual Disabilities' and the 'International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities' it's very useful to gather in Graz to make sure that we take care of the concepts and values that will guide the field of 'ageing and disability'

Literature

- Hatton, C, Emerson, E. (1996) Residential Provision for People with Learning Disabilities: a Research Review Hester Adrian Research Centre: the University of Manchester
- Hogg, J (1997) Intellectual disability and ageing: ecological perspectives from recent research *Journal of Intellectual Disability Research*, vol 41, 2, 136-143
- Janicky, M, Mc Callion, P, Force, L, Dalton, J *Dementia Care for Adults with Intellectual Disabilities (s d)* <https://www.iuc.edu/orgs/rttcamr/DementiaCareofAdults%20withID.pdf>
- Miettinen, O (1991). Epidemiological research on ageing: an orientation *International Journal of Epidemiology*, vol 20, 2-7.