

What is an expert by experience?

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The concept of “expert by experience” in healthcare is somebody who has active experience with illness, handicaps and/or mental health problems and who has gained specific expertise in living with this illness, handicap and/or mental health problem and also with socio-cultural and institutional contexts where the illness, handicap or mental health problem gets significance. To become an expert by experience it is demanded that one reflects about ones own experiences and shares experiences with others who have same kind of experiences. It is demanded that the experts test their own experiences to a variety of other experiences in different situations and of other persons.

What kind of experiences do we mean?

Experiences may f.e. deal with:

- Characteristics of the illness, handicap or mental distress, the impact on the body and the identity, coping with these characteristics.
- Autonomy and independent living in everyday situations. Disability management.
- Realities and feelings of being included and excluded.
- Living in a world where your being way of being human is not the norm
- active participation in society
- getting healthcare, using healthcare systems, asking for support
- being in a crisis and being dependent in that situation on professionals

How is this expertise gained?

An expert by experience has gained expertise and knowledge by

- reflecting on these experiences and analysing them
- sharing them with others
- testing them with others

How can this expertise be used?

In the years long process of emancipations of people with (chronic) illnesses, handicaps and mental health problems all kind of functions, (paid and unpaid) jobs and even specific professions have been developed which are fulfilled by experts by experience. A few ones are: patients’ advocates, facilitator selfhelp, support to people who get direct funding, trainer of professionals, researcher from the perspective of users, manager of a user organization, copywriter for patient information, etc.

In all these functions and jobs there are a number of expectations, demands or competences of the experts by experience. Sometimes these competences are explicated in advertisements. It is dependent on the specific function and the specific goal of the organization which competences are relevant. We distinguish between general and specific competences.

General competences

I Am able to speak about my own experiences and listen to those of others.

I know about experiences of various other people with (chronic) illness, handicaps or mental health problems.

I am able to answer the question what it means to have an illness, handicap or mental health problem in all kind of situations like how does it feel like to be disabled.

I am able to reflect on my experiences with disabilities and share these reflections in a respectful and equal way.

I have learned to live with my illness, handicap or mental health problem and given it the right place in my life.

I can deal with the emotions which experiences can cause.

I can distinguish between personal and social problems.

I am able to recognize the general features of my own and others experiences.

I can identify the specific and individual differences in comparison with what is generally experienced.

I have a general consciousness about processes of inclusion vs exclusion, empowerment vs disempowerment, solidarity vs struggle.

Specific competences

I can use experiential knowledge to reflect and comment on the work of professionals, researchers, politicians, managers, teachers, etc.

I can make analyses of change processes in terms gains and losses and in terms of chances and obstacles.

I can make the difference between the impact of expertise by experience in certain situations and the impact of this expertise on my own story and my own use of my experience.

I know about patients rights and human rights.

I have didactic capacities to transfer the expertise by experience or experiential knowledge to others, whether these are users and professionals.

I am able to present experiences to the public

I am able to initiate, support, implement and/or evaluate social changes.

