

Views on everyday life among adults with spina bifida: an exploration through photovoice

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The **aim** of this study was to actively integrate expertise of persons living with spina bifida, used to explore conditions embedded in everyday life.

Photovoice
- a community-based participatory research approach
- engages people as experts in their own life through dialogue and photography.

A group of five persons met once a week for eight weeks together with facilitators. Each week the group formulated a theme, based on which the members took pictures

An exhibition was created to share results with community and stakeholders. Themes for exhibition:

Meaningful everyday life

Accessibility is a right

The struggle in everyday life

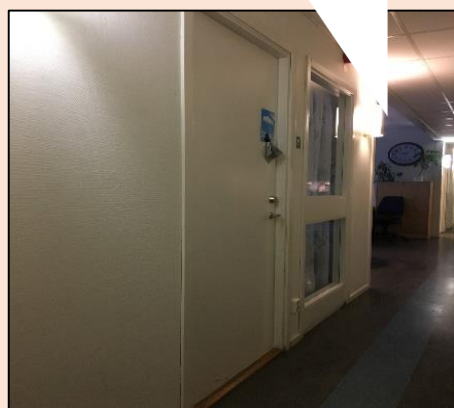
Communication



The exhibition opened on the World Spina Bifida Hydrocephalus Day and has been touring for one year. It has been shown in ten separate locations, included a library, university college, university and rehabilitation centers in Sweden and Norway.

...it looks very much like that at work, several persons go to meetings... many who work there often end up sitting for several hours without anything to do. It's like, no one really cares that you should have something meaningful to do

An overarching theme that characterized experiences among the group was, **An adaptation for us, but it works for no one.** Conceptually, the findings were strongly imbued with the following aspects **accessibility to work, social accessibility, and accessibility to influence.** Despite efforts to improve accessibility, members in this project illustrated gaps between policy intentions and citizen actualities. Visually and metaphorically central experiences to the project were depicted by broken elevators, unsafe transportations, closed doors, and lack of real opportunities to be involved. This project illustrates that persons with Spina bifida can actively engage in, and share experiences, relevant to the design of inclusive communities.



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