

Se och hör mig

Personer med förvärvad dövblindhets erfarenheter av delaktighet,
rehabilitering och medborgerligt liv.

AKADEMISK AVHANDLING

Som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet, kommer att offentligen försvaras i hörsal Arvid Carlsson, Academicum, Medicinaregatan 3, Göteborg

Fredagen den 27 januari 2017, kl 13.00

av

Ann-Britt Johansson

Institutionen för neurovetenskap och fysiologi, sektionen för klinisk neurovetenskap Sahlgrenska akademien vid Göteborgs universitet,
Sverige

Fakultetsopponent:

Gunn Engelsrud, seksjon for kroppsøving og pedagogikk, Norges
Idrettshøgskole, Oslo, Norge

**SAHLGRENKA AKADEMIN
INSTITUTIONEN FÖR NEUROVETENSKAP OCH
FYSIOLOGI**



Abstract

Title: See and Listen to Me - People with Acquired Deaf Blindness Experiences of Participation, Rehabilitation and Citizenship.

Author: Ann-Britt Johansson, Department of Clinical Neuroscience, Institute of Neuroscience and Physiology, The Sahlgrenska Academy at University of Gothenburg, Sweden

Language: Swedish, summary in English

Introduction and objective: There are very few research studies about the experiences of living with deaf blindness. The objective of this dissertation is to capture the experiences of people with acquired deafblindness regarding their participation, rehabilitation and civic life in order to develop a deeper knowledge and understand how it is to live with deafblindness. The research questions relevant to this study are based on a life-world phenomenological research approach and builds on an openness towards phenomena to be studied: What does the concept of "participation" mean for people with acquired deafblindness? What are the conditions required for people with acquired deafblindness to experience participation in their lives? How do people with acquired deafblindness experience their own living conditions? How do they live with an acquired visual and hearing impairment, deafblindness? How do people with acquired deafblindness experience their rehabilitation? What ideas do they have about their experiences? What conditions are necessary for people with acquired deafblindness to exercise their citizenship and their civil privileges?

Method: Eight people with acquired deaf blindness have participated in this qualitative study, which has a life world phenomenological approach. The participants have been interviewed a number of times and were observed in a participant observation. The interviews have been transcribed, analysed and interpreted with a hermeneutic method.

Results: The study identifies three major areas of life that are strongly connected to participation. These are work, family and social life and efforts from society. All of the participants have experiences in their rehabilitation that relate to the theory of "the Lived body" and the concept of horizon and the intentional arc. The whole person in his life-world is not often the focus of interaction. The impairment tends to be the focus. To be able to live in society as full citizen requires special services to enable people with deaf blindness to participate and take advantage of their civil rights and citizenship.

Conclusion: The study provides evidence that special services from society to people with acquired deaf blindness enable them to participate more fully in daily life. These services are not always available and this can lead to frustration and social isolation. The participants emphasized also a lack of response towards people with deaf blindness, which also exists among professionals. This lack of response and bias towards emphasizing disability is often found in society.

The study also uncovered a lack of knowledge about the importance of addressing the special needs of people with acquired deaf blindness, and the need for changing attitudes towards people with deaf blindness.

Keywords: deafblind, adult, acquired, participation, rehabilitation, citizenship, lifeworld, phenomenological, hermeneutic, the lived body, horizon, intentional arc

ISBN: 978-91-628-9975-2 (PRINT)

ISBN: 978-91-628-9976-9 (PDF)

<http://hdl.handle.net/2077/48663>