

Deafblind People and Self-identity

- new findings based on interviews in Denmark and New York

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How do people with acquired deafblindness describe or think of themselves? What does it mean to call oneself deafblind and not, for instance, Deaf with a vision problem or hard of hearing with retinitis pigmentosa. The list of diagnoses is long – and so is the list of terms that can be used by people to describe themselves. So, who chooses to use the term “deafblind” to self-identify and describe themselves?

The Information Center for Acquired Deafblindness, Denmark and Ilene Miner from New York City, USA, set out to find answers to these questions. Ilene Miner is a Clinical Social Worker and was until recently the Director of Mental Health Services at the League for the Hard of Hearing in New York. Today, the answers are at hand, and the paper **“Deafblind people and self-identity”** is now available.

Views on disability and services available make the difference

We wondered if the process of self-identification as a deafblind person is similar or different in communities that have differing views of disability issues and differing kinds of services and access. Rather than focusing on a person’s functional impairment, the focus in Denmark may be on how the situation can be compensated in a manner that, ideally, can equalize the person with others. In practice, this philosophy results in laws that result in a variety of services being provided, many of which are virtually unknown in the US, as Ilene Miner states in the paper.

We decided to make a comparative study and to interview deafblind people in Denmark and in New York, US, letting the two places represent communities that have widely differing approaches to the provision of routine services to people with disabilities.

In all 27 deafblind people were interviewed – 14 in Denmark and 13 in the US: 16 women and 11 men. In the Danish cohort there were 7 sign language users, 3 of whom use tactile sign language. In the American cohort there were also 7 sign language users, 5 of whom use tactile sign language. All interviews were conducted by Ilene Miner, and in sessions of 1-1.5 hours the interviewees were asked about their lives and living circumstances, their experiences, and their issues about identity and self-identification.

Yes, I am deafblind!

The interviews show that 11 of the 14 Danish interviewees self-identify as deafblind. They experience that being deafblind is their identity. This is the case for both sign language and spoken language users. A few call themselves culturally Deaf, either simultaneously with their deafblind identity or secondary to it. However, in the cohort from New York with 13 American deafblind interviewees, only two experience having a deafblind identity.

There is no doubt that experiencing and developing a self-identity as deafblind is very closely connected to:

- the rights given by law
- the services available
- the possibility of access to a community where there are other deafblind people

All of the Danish interviewees who self-identify as deafblind are active in FDDB (The Danish Association of the DeafBlind), they participate in FDDB events and activities, where they meet other deafblind people. Similarly, the two people in the US cohort who self-identify as deafblind both have access to a context of other deafblind people.

The paper “Deafblind people and self-identity” contains many examples and stories from the lives, experiences, and psychological processes of the deafblind interviewees. For instance, they talk about their reactions upon diagnoses and the psychological implications of becoming deafblind “all of a sudden”. It also explores what it takes to find a new identity or to reconstruct an old one.

Contact

You can download the report “Deafblind people and self-identity” from the English section of our website at www.dbcent.dk.

Here you may also download or order a copy of another of our publications, “The Nordic Project – experiences from deafblind people”, in which 20 deafblind people in Denmark, Sweden, Norway and Iceland were interviewed once a year over a five year period.