

# New research paints a merciless picture of life as a deaf-blind person

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Credit: University of Gothenburg

It is like being in a dirty glass jar, unable to reach out and with acquaintances passing by without saying hello. New research from the Sahlgrenska Academy paints a merciless picture of life with acquired deaf-blindness.

"These are people like you and me. They have a family, they have

children, they have lived a normal life and suddenly they are hit by this disease and everything is upended," says Ann-Britt Johansson, a researcher within the field of neuroscience and physiology.

Her thesis "See and hear me" is based on interviews with eight people, three women and five men, over a period of four years.

Several of them have Usher syndrome or a similar course of the disease with impaired hearing or deafness from birth accompanied by progressive problems with vision in their 30s.

One of the persons interviewed worked half-time, seven of eight stood outside the [labor market](#).

## **Removed from the labor market**

"Everyone referred to this; the fact that they were not allowed to continue working even though they wanted to. They had had factory and office jobs that they were forced to leave and they regarded being removed from this important life arena as a major problem," says Ann-Britt Johansson.

"Sweden is a prosperous country. We have ratified the UN Declaration of Human Rights and the Right to Work. There are societal efforts within healthcare, at job centers etc, but they do not work. Everyone complains about the treatment they receive; there is great ignorance and a shortage of skills in the system for this group," she continues.

Ann-Britt Johansson is a senior adviser for a national resource center for the deaf-blind in Drammen and has worked with the group for many years. Her qualitative interview study confirms what she herself has observed of difficulties the deaf-blind have in obtaining societal efforts, i.e. escort services, interpreter assistance etc., in order to function in

daily life.

"You have to constantly check that communication is working both ways. Confirm this by asking them to retell what has been said otherwise there will be a great deal of misunderstanding. Those who are born with a severe hearing impairment have sign language as their mother tongue, which makes it all the more difficult.

## **Socially shocked**

There is also a lack of participation in social life, something that many of those interviewed in the thesis testify to.

"It's like being in a dirty glass jar. Only contours and a lot of mumbles."  
(Emma, 42, about why she avoids parties these days.)

"It feels as if I am limited. I have so much inside me that I can't use."  
(Oliver, 62, about the difficulties in establishing contact with people.)

"It feels so unpleasant when someone walks passed and doesn't say hello." (Samuel, 70, about how old acquaintances react to his new medical condition.)

"It's obvious that there will be problems if you encounter a person with whom you do not know how to communicate, even if there is a deaf-blind interpreter present. Nevertheless, we must change our attitudes towards people that we are very uncertain about," says Ann-Britt Johansson.

Provided by University of Gothenburg

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