

# **Presentation on Nordic Project, Saturday 9.15 to 10.00.**

## **Presenters: Ole E. Mortensen and Birgitte Ravn Olesen**

### **Organisational framework for the project**

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- *A systematic compilation over a 5-year period of the experiences of deafblind people with a progressive impairment*
- *1999 (conception of the idea) to 2005 (birth of the project booklets)*
- *Joint venture between Denmark, Sweden, Norway, Iceland*
- *20 deafblind persons – 8 Usher type I, 12 Usher type II*
- *Interviewed six times (roughly once a year) over a five year period*
- *Interviewers: deafblind counsellors and other professionals in the field*
- *Initiated, organised, coordinated and data analysed by the Information Center for Acquired Deafblindness – primarily the former director Kirsten Jansbøl and Birgitte Ravn Olesen*
- *Nordic steering group (also with representation of the Nordic associations for deafblind people)*

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- *Overall objective: To gather insight of the consequences of a progressive hearing and sight disability and generate new knowledge for use by professionals and others involved in counseling deafblind people, their relatives and care professionals.*

### **Introduction about understandings underlying the project**

The success of the study depends on, how useful it is for people with acquired deafblindness and professionals and relatives connected to this group.

Our goal was to gather insight about the consequences a progressive hearing and sight disability can have on the deafblind person's possibilities of creating and maintaining relationships and, by extension, of participating in society.

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- *Individual perspective:*
  - *everyday life*
  - *family and friends*
  - *leisure activities*
  - *and expectations, considerations and reflections in relation to the Usher diagnosis*
- *Societal perspective:*
  - *local environment*

- *work and colleagues*
- *educational possibilities*
- *transportation and*
- *other elements which influence general possibilities of participating in social life.*

We had an individual and a societal perspective.

*The individual perspective* involves focusing on everyday life, about how small practical tasks such as shopping or repairs at home are carried out, the relationship with family and friends and leisure activities. This part also includes narratives about expectations, considerations, reflections about the Usher diagnosis and about insecurity.

*The societal perspective* involves focusing on local environment, possibilities of getting, keeping and leaving a work and relations to colleagues. What options do the deafblind persons have regarding transportation, education and getting a job?

A fundamental aspect of the project has been to focus on the deafblind person's own narratives about his or her experiences with a progressive disability.

We have also focused on which resources, both individual ones and those in their environment; contribute to create action possibilities for the individual.

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*Consequently, our project has become a narrative about how different people with Usher diagnosis live their lives, and how they need to be met in different ways by all the people that they may become dependent upon in different ways as their disability progresses.*

In book 1 we describe the theories and methods in details. Here we have chosen to focus on which knowledge we gained from the project and how we think it is possible to make it useful in different settings.

### **First: Which knowledge did we produce?**

Scientific knowledge is often thought about as knowledge from natural sciences, i.e. new information about genetics and screening as Claes Möller told us about in his excellent presentation yesterday.

In humanities we do not produce this sort of evidence based knowledge.

The results of this project must not be understood as true knowledge about what it is like to be a person with acquired deafblindness.

In collaboration with the people with acquired deafblindness who told their stories and the professionals who interviewed them, we have produced an offer of knowledge.

It is not "the true story". It is one perspective, and we hope it is an important one, but it is for you to judge that.

## About the booklets

There are six booklets from the project. One is about the theory, methods and organisation behind the project, and one contains narratives of everyday life of eight deafblind persons. The remaining four books each discuss one topic that has been in focus during the interviews and that has proven central for the deafblind participants.

Each of the booklets contain an introduction to the topic which also sketches the theoretical framework for the discussion of the topic. The main part of the booklets are based on the interviews and contain summaries and analyses of the information as well as quotes from the deafblind informants.

One of the reasons for not publishing one big report is that it should be possible for a deafblind person or a professional to give a booklet on a specific topic to someone who needs that information.

The booklets cover the following themes:

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- *Theory and methods*
- *Receiving a diagnosis*
- *Getting support*
- *Being active*
- *Getting an education and work*
- *Narratives of everyday life*

Time does not permit us to go into detail with the content of each booklet. Here we will take a closer look at one of the cases discussed in the booklet "Getting an education and work". This should give you an idea of the type and character of the knowledge that has been generated in the project.

### Getting an education and work

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*“For a person with such a serious disability as mine, in spite of principles of positive special treatment, it will be difficult to get work and so it is important to have competences which can weigh against people’s prejudices about the disabled.”*

(Signe, 19, medium-level hearing and visual impairment)

Signe is one of the deafblind informants in the project. Obviously, this is not her real name. We have taken a lot of effort in making the informants anonymous, not only by changing names but also by changing other information that would make the participants recognisable.

Signe says these words in the first interview. She is a very bright young student and both she and we feel sure that she will be able to get a degree in psychology as she wishes to.

Her parents support her and she is very good at asking for what she needs to manage to live as good as possible.

In the third interview Signe has started at university and is doing well in the study of psychology. It is a big study, which in the first year is organized on lectures for up to 100 students. Not an easy environment for a person with a dual sensory impairment.

Before start beginning of the study Signe was in contact with several consultancy offices for students with impairments. Here she presented her requirements that she had formulated after talking with hearing impaired friends about their experience of studying. Everybody did their job to make it smooth for Signe to move from one student flat to another and to organize her new study.

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*Signe made preparations for her new study in several ways:*

- *She met the study guidance department where she presented her requirements*
- *She walked around in the university district many times before the beginning of the study*
- *She asked for and was given a portable computer*
- *She ensured the reservation of a place at the front of the auditorium and the presence of an FM device*

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*Signe was also offered compensation, which she did not want:*

- *Interpreter or companion in connection with studying activities*
- *A special light next to her place in the auditorium*
- *Something else that she does not remember (at the time of the interview)*

Signe thinks indeed that the professionals that she meets are often in a hurry to find aids for her.

Everything seems to be perfect. But problems soon arise. The lectures move to other rooms without Signe seeing the note about this decision, the note on her chair saying "reservation" is often removed and some lecturers move around the room and do not want to use a microphone during their lectures.

Signe gradually gives up taking part in the lectures and in stead tries to read the curriculum by herself.

However, at the fourth interview Signe has left university.

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*"I had to give up my beloved subject. It is sad in a way, but I can always re-apply."*

There are several reasons for Signe having to make this decision. Some have to do with the choice and evaluations which Signe herself makes; some have to do with the insufficient follow up of the arrangement and practical organisation of her studies. These are some of the questions that are discussed in this booklet from the Nordic Project.

## **How can the booklets be used?**

We have reprioritised our presentation this morning after it turned out recently that we could have a workshop as well. So this is a question that we will discuss further in our workshop this afternoon, but still we want to give a few ideas as inspiration as to how we think the booklets can be put to practical use.

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1. *Use "Worth considering" in the booklets*
2. *Discuss the stories in the booklet "Narratives of everyday life"*
3. *Experiment with the "Lifestory- and Competenceoriented interview-method"*

Re 1.

One possibility could be to select one of the booklets discussing an issue that you find of particular interest and relevance.

Read it carefully and reflect on it based on your own experience – either alone or with colleagues.

To facilitate this reflection – if necessary - each booklet ends with a section entitled "Worth considering" containing thoughts and questions pointing out some of the key issues of the booklet.

Example:

In the booklet about getting support we describe how many informants experience that their consultants always think they know what is best for them. This could make consultants (and other professionals) consider their function in the meeting with deafblind people.

Are we the ones who deliver the ready made solutions and always think about how to match the problems of the deafblind person with the technical aids that are available?

In Denmark we say that if your only technical aid is a hammer, you tend to see all problems as nails.

Maybe Megan in her presentation tried to tell professionals that they very often focus on practical problems because they can suggest solutions to them.

But just as everybody else people with acquired deafblindness have many thoughts and worries that are not of a practical nature. They need somebody who wants to listen to them.

So as professionals we must ask ourselves: Can we act as midwives and counsellors whose primary function is to listen and to act as a sparring partner for thoughts and ideas – no matter if they are practical, social or psychological?

For people with acquired deafblindness it is worth considering how they can communicate in ways that puts them on top of the process and in stead of being pushed around by others.

Re 2

Another possibility is to use one of the stories in the booklet "Narratives of everyday life" as the starting point for meetings about experiences.

Yesterday we heard four very different narratives about living with Usher. It was extremely interesting to listen to their experiences.

It would be a gift for people who get an Usher diagnosis and their relatives to hear others tell how they get along.

Unfortunately, Carol, George, Nina and Beat, who we heard yesterday can not be in all networks where people with acquired deafblindness meet.

As a poor replacement you can read the booklet Narratives of Everyday Life – which are detailed accounts made by deafblind persons of their everyday life – just to find out how (other) people with acquired deafblindness manage to live good lives.

You can discuss with friends or colleagues if the narratives are trustworthy or where you find them too idealizing or too focused on problems.

It also possible to discuss:

- What does the person say about his/her life?
  - What can we recognise, what is very different from our experiences?
  - What doesn't he/she say anything about?
- and so on...

Re 3.

The interview method formed the backbone of the entire project and was developed with great deliberation. It is described in the first booklet on theory and method, and this description can be used to reflect on what it is that we are asking, and how we ask.

We know that it isn't possible to have in-depth interviews with all clients.

The consultants in the projects have put an enormous effort into the 5 years of making and analyzing one interview every year.

Nobody can do that with all their clients.

But a person with acquired deafblindness can - as everybody else - be in situation where he or she needs help to be able to talk about his or her life in order to be able to find out what to do to go on.

I think all of us know situations where we tell a good friend about a problem and while we are telling about it, we find a solution.

Just because somebody didn't interrupt or suggest anything, but only listened carefully to our thoughts.

This goes for instance for people with acquired deafblindness who

- are young and do not know what to do after primary school
- are 45 years old and have difficulties in managing their work because of their increasing impairment
- lose their mother or father because they die

One of the informants said in the last interview:

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*"I have thought a lot about what the project has meant to me. I have discovered new angles of myself. Occasionally we have had discussions and I have thought a lot about them afterwards (long pause). I have had some things confirmed when we talk together like this. I think it has been positive and instructive. You learn to see things differently.*

A social counsellor only works with problems, for example transport. We never talk about my everyday life, my routines and my network. I have never spoken about those problems either to a psychologist or to a social counsellor. They just look for a problem and then talk about it over and over again.

These are just a couple of ideas to take with you. But in order for you to make use of the booklets, you of course need to have a copy of them. Please take a set each.

They can also be downloaded from our website [www.dbcent.dk](http://www.dbcent.dk) as both Word and pdf files, if you prefer that. And we are very interested in hearing any comments you may have when reading the booklets. We thank you for your attention.