

The Nordic Project – from information to knowledge

The Nordic Project has generated a great deal of information on deafblind people's own experiences of different aspects of life. But now we face the next challenge: How do we go about making sure that the information in the project is converted to knowledge and put to practical use by professionals and deafblind people?

In this workshop we will discuss this issue.

We will continue working on the booklet on education and work, which was also presented this morning at our plenary session.

But first just a few words about the topics discussed in the other booklets.

Receiving a diagnosis

This booklet focuses on the deafblind persons' experiences with having an impairment without being aware of the diagnosis and about coping with the RP or Usher syndrome diagnosis.

All informants could tell about problems in their childhood or youth that were due to the vision problems of Usher, but without anyone realising it at that point:

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"I did follow the others out at night, but felt that there were quite a few things that I couldn't take part in and so quite naturally, I ended up staying behind at the school. So I didn't go out much when it was

dark without realising why. I ended up staying in while the others went out. I feel I have lost a large part of my youth.”

(48 years old, deaf, moderate vision impairment)

The concept “comprehensibility” appears again in this booklet. If you comprehend - understand – what is going on inside yourself and around you, everyday activities and changes become easier to handle. It will not necessarily be easy, but possible.

The following factors were found to be crucial for the person's ability to cope:

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- At what point in life you receive the diagnosis
- Under what circumstances does it come
- What support you receive to move forward

An important step towards coping is getting the right information and support when the diagnosis is made. One person says:

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“It was awful, I did not get any support, it was dreadful, ...I was in the centre of town waiting for the bus, the weather was bad and I was all on my own. I arrived home all on my own and I thought it was awful. It was horrible.”

A completely different situation was this:

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“My parents and I felt there were problems with my eyesight when I was 7 or 8 years old so they took me to an eye specialist. There are people in my family who are deaf-blind and my mother had lots of information about Usher, which she passed on to me.”

(17-year-old deaf girl with a medium severe vision impairment)

This quote actually highlights three important factors for the optimal way of receiving the diagnosis:

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- The diagnosis is given early at a point where the girl still hasn't defined her life. This means that the impairment at an early age becomes a condition that she can understand and learn to relate to in the different aspects of her life
- The diagnosis is given in a secure environment and there is plenty of information to be given to the girl when she needs it – both directly after and in the time and year to follow, because her mother can provide this information.
- There are other persons with Usher in the family. We saw that the informants who knew others who had Usher had less difficulties coping with their own diagnosis. And several of the informants that did not know other people with a dual sensory impairment say that meeting other deafblind persons on courses and at associations was important for their own efforts towards accepting the diagnosis.

As for the system to find out that there is a problem and what is it early on, one person told that she went to see one doctor at the age of 33 after many years of increasing vision problems. That didn't get her anywhere. Nine years later she found another doctor who referred her to a specialist who could tell her – at the age of 43 – that she had Usher type II.

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"I mean it could have been discovered earlier, and I could have received help earlier. It really is sad to think about. The doctor could have referred me to a specialist earlier. That is exactly why we have

this system. My whole youth is lost. All the mocking and the teachers who didn't understand."

Getting support

A 52-year-old informant is asked the question if he has ever been given advice that he could not use, and answers:

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"Yes, I have, as regards aids. As late as last Friday, when I was at the eye clinic where the eye specialist said that if I thought it was too difficult to read, I could obtain a CCTV. So I said stop, I can read well today. Upgrading to bigger aids is not for me. I think you must be careful with that; there is not a problem with technology today, but it must occur in line with your need."

(Johan, 52, medium-level hearing and visual Impairment)

It sounds as if Johan do not experience receiving information about a possibility that he can express an opinion on. Instead he experiences the professional taking over and defining his needs, and thereby the offer of aids becomes overwhelming.

In the first interview, Johan tells about not wanting a guide dog. He has many good reasons; not to be depended of a dog, he can have walks with his wife, he don't want to walk that much and so on. In a later interview, he has got a guide dog and says:

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"I see it as an advantage to get a guide dog early to develop the cooperation and be able to feel safe when you go out, particularly when it's dark. I can now go out and go on walks, go down to the sea, I can go to places where I haven't been able to go for the last few years. This is the way I've chosen to solve my limitation

problems and to get out again. My wife can steadily cultivate her interests and I avoid having to ask her.”

(Johan, 52, medium-level hearing and visual Impairment)

Johan shows in these quotes an ambivalence which is seen in many interviews.

The ambiguity in relation to aids can be seen as ambivalence in relation to taking charge of ones situation.

Refusal of practical support can be a matter of lack of acceptance of own impairment.

At the same time, refusal means that it is confirmed to you that you have many limitations.

If you had experience of for example using a guide dog and thereby found that many things were possible in spite of your impairment, this could possibly lead to greater acceptance.

For some, the ambiguity is expressed slightly differently. They say that they would like to be informed so they can make up their own minds, but do not want to use assistance associations until it is absolutely necessary.

This may for example be because they feel that the use of aids also comes at a price.

There must be a reasonable relation between the endeavor that must be made to acquaint you with new aids, and the benefits of using the new aid. Each aid creates dependency: a guide dog must be looked after, also when you are going on holiday, a hearing aid has to be adjusted, and a wire loop cuts you off from other sounds in the room. Wanting to manage without aids can be a matter of wanting to manage on your own as universally as possible in life.

It is a great challenge for the professional to meet acquired deaf-blind people who have an ambivalent relation to their impairment in a way that shows them respect and increases their possibilities of acting competently in relation to their goals.

Being active

This booklet focuses on the consequences that the impairment has on taking part and being active in in one's family life, in leisure activities and in society as such. Often full participation here requires the help from the outside, often in the form of a contact person, guide/interpreter, intervenor.

Many factors play a role in the opportunity to take equal part. Obviously, the vision status (and hearing status for the persons with Usher type II) is very important here. If vision (and hearing) deteriorates, the same does the possibility of taking full part in the life and world around you.

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"I don't have trouble hearing my children when I am alone with one of them. But when the kids are talking between themselves – I might just as well forget all about trying to keep up. It is getting harder and harder to step in or mediate when the kids start quarrelling."

(33 years old, moderate hearing and visual impairment)

In this case, the vision and hearing impairment restricts the father from taking full part in the family life.

Because it is so strenuous to have an impairment like deafblindness, we see a clear difference in the level of activity of those informants who hold jobs and those who have all of their time at their own disposal

when it comes to taking part in social life, In most cases, the informants who have jobs experience their jobs as so demanding that they do not have the energy for anything else. Besides working, there is of course cleaning, laundry, shopping, etc.

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"Sometimes I notice that I can't be together with very many others ... I get tired when there are many people, because of all that with my eyesight. I would rather do things I can relax with; I read a little, read my e-mail, watch TV in the evening. I'd really like going for a walk in the woods on Sundays, but I don't have the energy. I have to save my energy for the next workday."

(48 years old, deaf, moderate vision impairment)

There were three single deaf persons who were holding jobs in the project, and they all seem to have no friends. They expend all their energy at work and on practical chores in the home, so that their leisure activities are limited to reading with the help of technology. However, two of them do participate in annual meetings for the deaf and deafblind.

Also family gatherings can provide so big obstacles that deafblind persons might want to excuse themselves and not participate. However, one of the deaf informants tried bringing an interpreter for a large family reunion.

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"I got a lot out of that, and my family was so impressed... We have always had to write to each other, and now we could just talk via the interpreter. Earlier, the kids might also interpret, but they didn't have to this time and we were able to communicate via the interpreter. It was nice to be able to keep up, even with the speeches that were made. Finally, the interpreter said 'It's 11 o'clock now, and I have to be getting home'. I really wanted to keep talking some more, but

there was nothing I could do about it.”

Interestingly, On this topic we saw a great difference between the life the informants live and how they see themselves and their situation. It is worth mentioning that many informants say that they consider that they lead a good life with many possibilities – despite their impairment. At the same time, they see themselves as atypical for the group of deafblind persons. They consider that other deafblind persons cope worse than they do.

GROUP WORK

Group 1 discussed the following question:

The participants demonstrate great creativity when looking for ways to be able to participate. The many ideas for coping with challenges in daily life must be shared between them – what is the best way to accomplish this?

Group 2 discussed the following question:

How could the professionals' advice to a greater extent be based on the deafblind person own experience of her situation?

Group 3 discussed the following question:

How can it be explained that the majority of the deaf deafblind people in this project are in work, while this is not the case for the deafblind with a hearing impairment?