

EXPERIENCES FROM
PEOPLE WITH
DEAFBLINDNESS

- a Nordic project

Theory and methods

Birgitte Ravn Olesen and Kirsten Jansbøl

*”There can be causes to the problems,
I understand that better now”*

Main features, theories, methods and empirical fundamentals

A five-year Nordic project
focusing on the personal experiences or persons
with acquired deafblindness

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Information Center for Acquired Deafblindness 2005

The Nordic Project

Six booklets

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

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The 20 informants and their
willingness to share their experiences.

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they put into the project.

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Introduction

This booklet describes the projects objective and explains the theoretical and methodological reflections we have carried out both before and during the execution of the project. We also explain how informants were selected and how their sight and hearing status was established at the beginning and the end of the project. Finally, we have collected the most important points from the five booklets that cover the main issues in a deafblind person's life.

Aim and framework of the project

Objectives and target groups

The objectives of the project are:

- To undertake a systematic collection of own experiences of deafblind persons over a 5-year period, during which their impairment is expected to progress.
- 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.
- To build up new knowledge, that later can guide the professionals who will counsel the deafblind, their relatives and care professionals.

The aim is to let a group of deafblind persons talk about the consequences the progressive hearing and sight disability has had on their possibilities of living the life they wish. The starting point was that the narratives should permit the analysis of the changes occurring in the deafblind persons' lives, and the conditions of communication from the perspective of the individual and the society.

The individual perspective involves focusing on the narratives about daily 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 the disability, about expectations, consideration, reflections about the Usher diagnosis and about insecurity. To end, emphasis has been placed on narratives that show how individual ways of acting can strengthen or compensate the functional reduction. For example, we can observe that the use of aids such as a contact person, a white cane, hearing aids and so on, is closely related to the acceptance of the disability.

Society's perspective involves focusing on how the deafblind persons experience the fact of being met by relatives and colleagues, as well as in their local environment, together with the general possibilities of participating in social life. In this project, we have stressed the fact that being disabled is not a condition you find yourself in regardless of the context. Quite the contrary, a disability stands out when compared to other people and in situations where one is active. This means that a person's disability must always be seen in context. We have focused on narratives where the disability becomes an obstacle to family communication and to the possibilities of participating in the

local environment. Finally, we have contemplated what possibilities and limitations deafblind people experience in relation to participating in society, what options they have regarding transport, education, getting a job, and what consequences the disability has for their daily lives.

A fundamental aspect of the project has been to focus on the deafblind person's own narratives about their experiences with a progressive disability. We have decided to let the stories about the interaction between the individual and their social and physical environment take centre stage. We have also focused on which resources, both individual ones and those in their environment, contribute to create action possibilities for the individual. 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.

The projects target groups are, in the first place, professionals with direct contact with deafblindness. Secondary are other groups of support with little or no knowledge about deafblind persons or their relatives. We have issued six booklets instead of a comprehensive report because we have tried to address the need to be able to analyse individual issues in depth.

The organisation and the funding of the project

The steering group, leading the project, was:

- Heads and representatives of the national deafblindness organisations, Thord Bäckmann from Sweden, later substituted by Anna-Lena Steenson; Live Fuglesang and Elbjørg Sanne from Norway; Lilja Pohallsdorttir from Iceland; Helle Brøgger and Else Marie Jensen from Denmark.
- Representatives from the Nordic deafblindness associations, Bente Mejndor and Ole Mejndor
- The director of NUD, Anny Koppen, later substituted by Erik Thorsen
- The director of the Information Center for Acquired Deafblindness, Henrik Ottesen.
- And a working group comprised of professor Birgitte Ravn Olesen from Roskilde University and Kirsten Jansbøl, the senior consultant at the Informationcenter for

Acquired Deafblindness in Denmark (and during the first year of the project also the information manager at the Information Center, Ole E. Mortensen). They have developed the project, including the project's design, the interview guides, partial reports and booklets that have been forwarded to the Steering Group for discussion.

Deafblind consultants in the Nordic countries have participated as project contributors. They have performed interviews and written compilations, which have been sent on to the working group:

- Lilja Pohallsdottir, Iceland.
- Berit Øie, Elbjørg Sanne, Margareth Johnson, Margrete Skjæveland, Solfrid Langman and Gunilla Rönnblom, Norway.
- Anita Dath, Hannele Damm, Karin Andersson, Karin Grahn, Karin Juterod, Lisbeth Asklund, Monica Gustavsson and Ann Svensson, Sweden
- Anette Rud Jørgensen, Else Marie Jensen, Jane Seiler, Kirsten Washus, Hanne Jepsen, Ketty Skovsgård and during the first year also Elisabeth Gram and Anette Nielsen, Denmark.

The project has received economic support for the scientific work from the Oticon Foundation, while the deafblindness consultant organisations from the individual countries have worked together to interview all the informants. The Nordic Staff Training Centre for Deafblind Services (NUD) has funded an introductory seminar for the Steering Group and a midterm seminar for the interviewers. Finally, the 20 informants have dedicated time to the yearly interviews and shared their thoughts, experiences and opinions with us.

We would like to thank everybody for the contributions that made this project a reality!

Summary of the informants' narratives

In this section we summarise the main topics in each of the booklets. The order followed is coincidental and each of the booklets represents a unit in itself and can be read independently from the rest.

Booklet 2: Receiving a diagnosis

This booklet places emphasis on the deafblind persons' narratives about having a disability without being aware of the diagnosis and about coping with the RP or Usher syndrome diagnosis. The narratives show that the following factors are crucial:

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

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

Clearly, over the last 50 years, both society and the professional attitude towards how to approach a progressive disability has changed. The young deafblind persons have –with few exceptions– received the diagnosis as children or youngsters, at a point in life when they have still not defined their lives. This means that the problems with, for example, seeing in the dark or hearing what is said in a big group, are understandable. And it also means that their disability at an early age becomes a condition that they learn to relate to and can value when they contemplate the choice of an education for example. In addition, young deafblind persons have the possibility of receiving physical, psychological and social support not least from their parents as well as information about the diagnosis.

The experiences of groups of deafblind persons that are over 35 years of age are far more varied. There is a tendency towards the fact that the older the person interviewed is, the less and more incidental the information has been. We obtain a picture of unclear pieces of information and the experience that both the diagnosis and the consequences of it are discussed without taking the affected person into account. There are exceptions

though, where the deafblind persons in this group have also received the information and support they needed.

In all the cases interviewed, the informants that knew other people with Usher when they received their own diagnosis had less difficulties coping with it. Several of the informants that did not know other people with a combined hearing and sight disability say that meeting other deafblind persons on courses and at associations was important for the efforts they made towards accepting the diagnosis.

Booklet 3: Getting support

The approach in this booklet has been to focus on the deafblind persons' narratives about their experiences of the counselling and aid they have received due to their disability.

We focused on the informants' experiences of:

- Need for counselling and aid
- Desires for counselling and aid
- Experiences with counselling and aid.

The concept "action competence" appears throughout the booklet. This concept focuses on how counselling and aid contribute to develop or maintain the deafblind person's possibilities of being competent following his own goals. Action competence and the ability to cope with challenges is not something that some people have and others do not. Everybody has the potential to act in a competent manner and cope with the situations they find themselves in. Some have more experience than others, but experience is something that builds up. That means that if you have had experience in taking the initiative, it is easier to do it again next time you are faced with a problem. Likewise, if you are used to others doing things for you, then that is the attitude you have when problems arise.

The informants' narratives about practical aid to handle everyday issues and emotional support to achieve coherence and meaningfulness show how different they are as people and how diverse their needs of aid are.

We point out that we must distinguish what needs, desires and experiences the informants mention are due to their personal experience and their experience of coherence and

meaningfulness in the surrounding world. These diverse experiences are related both to their individual experiences and to the social resources they have had at their disposal.

We can observe that the degree of the informants' hearing disability is closely related to what individual experiences they have and to what social resources they come receive. Typically, many of the informants that are deaf from birth have difficulties creating and developing a social network. This means that the dependence on professional aid organisations is high and that this group manifests fewer experiences of expressing their needs and making demands.

Booklet 4: Being active

This booklet focuses on the deafblind persons' narratives on how to handle a disability that progresses and the consequences it has on their lives. The narratives show once more that the diagnosis "deafblind" is not something that you can get over in just one go. The informants describe how the vision reduction slowly progresses and that they at the same time slowly realise that there is a social environment or leisure activity which must be given up unless they can find and receive an allowance to compensate, often in the form of a contact person or interpreting aid.

There is 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 disability. 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.

A prior condition to being able to participate in family life, as well as in the local environment and society, is that there has to be sufficient possibilities of compensating the loss, often in the form of a contact person and an interpreter, or intervenor. Deafblind persons with severe hearing impairment risk becoming socially isolated and suffer from loneliness if they are not offered sufficient contact person hours and interpreting aid.

Booklet 5: Getting an education and work

This booklet focuses on the deafblind person's narratives about getting an education and a job. Precisely these two issues are so important in the Western world, that access to

them is decisive when it comes to feeling as part of society.

Through the informants' specific narratives about their experiences with the education system and the job market, it is possible to see how social resources in practice create options for or hinder participation. Nearly all informants have received some form of education, although it may not have been the one they desired, and all except for one have been on the job market, ranging from a few years to many years – except the younger informants who are still studying.

Younger informants find that getting an education is a lonely and demanding affair. Problems arise at several levels, but there is a basic lack of guidance regarding to what extent their functional reduction and the existing compensatory options make their wishes a realistic possibility. They lack help to inform the training centre of the need for relevant aids, which are known and ready at the beginning of the course, and they also lack coordination and monitoring, that can offer them support throughout. In general, the informant group has achieved a level of education as high as or higher than their siblings.

A thought-provoking fact is that 6 out of 10 deaf persons have a job, compared to only 3 out of 10 people with a hearing impairment. The informants that were on the job market had very different experiences. Regardless of whether they have a normal job or a job where there is awareness about disabilities, some experience that they are paid attention and taken into account, while others feel that they have to adapt as well as they can or are otherwise not welcome.

The main reason for leaving a job is in most cases that the informant him or herself does not consider that he or she is able to live up to his or her own demands and ideals as the vision reduction worsens. In some cases, we have observed that trying to cope with the job is so demanding that there is almost no energy left over to handle the housework or social activities. This makes the situation even worse when it comes to having to give up the job.

Participation is about individual possibilities in everyday life, but it also involves the possibilities of contributing to the disability agenda. The Nordic deafblind organisations are very important for the deafblind person's possibilities of being participative, both as the spokesperson for a group of citizens, that otherwise could easily be overseen, as in the role of the organiser of social meetings for people with hearing and vision reduction and their relatives.

Booklet 6: Narratives of everyday life

The 20 deafblind persons that were interviewed for the project were asked what desires they had for the project. Many of them wanted to know how other people with deafblindness lived their lives. They wanted to know how physical, psychological and social barriers in everyday life could be overcome in different ways. This led us to choose 8 "ideal types", which do not correspond to any of the informants, but that draw on traits from several informants that have been gathered into a joint description of an "ideal type" person. In this way, eight deafblind persons' daily lives and thoughts are worked with.

Choice of informants

Criteria for the selection and choosing procedure

When you elaborate a quality project, which intends to reach conclusions about ways of acting, understanding and experience, that can be extrapolated to the group of deafblind persons as a whole, based on in-depth interviews with a smaller group, it is fundamental to make sure that the interviewees represent the different typical life situations. This has been our intention when choosing our subjects, and we have taken into account the following:

Distribution of the vision and hearing status

We decided that all informants at the beginning of the project should be in a situation where it could be expected that their hearing and/or vision reduction would worsen. In the section on Usher, you will find more information about hearing and vision status.

Distribution of spoken and sign language

12 spoken language users and 8 sign language users participated in the project. 4 informants used tactile communication increasingly.

Age distribution

We decided to focus on young and adult deafblind persons. The youngest informant was 17 years old at the start of the project; the oldest was 63.

Marital status

The project was comprised of: 10 women and 10 men of which: 11 were married/living with their partner, 2 had boyfriends/girlfriends, three were divorced, 1 was a widow, 3 were single and 14 have children. They all live in their own home.

Geographical distribution

The project includes deafblind persons from all of the Nordic countries. Norway has 7 informants, Sweden 6, Iceland 1 and Denmark 6. We have also taken into account the distribution between the city and the countryside, and have worked with the following categories: city (9 informants), town (7 informants) and countryside (4 informants).

Choosing procedure

Deafblindness consultants in the participating countries were asked to point out 3-4 of

their clients whose vision and/or hearing they expected to worsen. The names along with some basic information were sent to the countries' head of deafblindness consultants who then sent them on to the working group. From among the almost 60 possibilities, the working group chose a sample as described above. The heads then sent a letter (the same letter in all countries) to the selected deafblind persons inviting them to participate in the project. A few rejected the offer, in which case another person in an equivalent situation was chosen. Before launching the project, the working group had written a short article on the project, had it translated to Swedish and Norwegian, and asked the directors of deafblindness associations in Sweden, Norway and Denmark to publish it in the associations' journals under their name.

After the initial interview, our assessment was that the informants worked out to be exceptionally active from the social point of view, with many resources and articulate. We considered two possible reasons. One was that the deafblindness consultants, when choosing the informants for the project, had focused on the most articulate, the other possibility was that the informants at the first interview needed to show themselves as "well-functioning" according to society's rules and values. Social psychologist Goffmann uses the concept "face" for the impression we wish to give strangers of ourselves. (Goffmann E. 1959)

During the elaboration of the project we were convinced that the latter possibility was the valid one. At every interview more problems were brought up and analysed in depth.

Replacements during the project

Informants

During the project 3 informants, 1 deaf person and 2 hearing impaired persons decided to abandon the project. Two of these were among the youngest informants, so we found two new young informants that participated from the second interview on.

Interviewers

Seven interviewers resigned as deafblindness consultants during the project period. We managed to obtain funding for four of them to continue in the project, while three informants received new interviewers, specifically their new deafblindness consultant.

Usher - a definition and the distribution of informants according to their hearing and vision status

Deafblindness is a disability that involves great complications when it comes to communication, access to information and finding one's way and coping with the surroundings. The Nordic definition put forward by Nordisk Nämnd för Handicappfrågor in 1980, reads as follows:

“A person is deafblind when he or she has a severe degree of combined visual and auditory impairment. Some deafblind people are totally deaf and blind, while others have residual hearing and residual vision. The combination of sensory impairment results in an inverse reduction of the chances of using the possible residual hearing and vision. This means that deafblind people cannot automatically utilize services for deaf people or for people with visual or hearing impairments. Thus deafblindness entails extreme difficulties with regard to education, training, working life, family and social life, as well as hinders access to information and participation in cultural activities...Deafblindness must therefore be regarded as a separate disability which requires special methods of communication and special methods for coping with the functions of everyday life.”

Deafblind persons are divided into two groups: those with congenital deafblindness and those with acquired deafblindness

The congenital deafblindness group includes both those that are born with a severe degree of combined hearing and sight disability and those that have become severely hearing and sight disabled during the first 18 months of age, before speech development.

The acquired deafblindness group is by far the largest. It is estimated that there are at least 25 deafblind persons per 100,000 citizens, of which at least 88% have acquired deafblindness. All people with acquired deafblindness share the fact that they have become deafblind as older children, youngsters, adults or elderly, after they had learnt a language, either spoken language or sign language. The group with acquired deafblindness is very heterogeneous, but can be divided into three main groups depending on the moment the sensory reduction occurred:

1. Primarily deaf/hearing impaired: People that are born deaf or hearing impaired and later become blind or severely sight impaired.
2. Primarily blind/weak sighted: People that are born blind or severely weak sighted, and later become deaf or severely hearing impaired.

3. Primarily seeing and hearing: People that are born with normal sight and hearing and that later become deaf/severely hearing impaired and blind/severely weak sighted.

Age-related sight and hearing reduction is the main cause of deafblindness when it comes to figures. Recent research shows that age-dependent deafblindness is far more widespread than what was thought before.

Amongst teenagers and young deafblind persons, Usher Syndrome is the main sole cause of deafblindness. In addition, people become deafblind due to hereditary disorders, diseases such as meningitis, and accidents.

Usher Syndrome

All deafblind participants in this study suffer from Usher Syndrome (syndrome is the name for a disorder/disease that affects several organs at once). Usher Syndrome can be a congenital disease that manifests itself as a combination of hearing loss – that can range from moderate hearing reduction to complete deafness – and the eye disease Retinitis Pigmentosa (RP), that gradually destroys the retina. RP is described below. Hearing loss is neurosensory, which means that it is caused by a change in a part of the inner ear called cochlea. Hearing is the final result of a process where the sound waves hit the ear and are received as electrical signals by the cells in the cochlea, which are then sent, via the auditory nerve, on to the brain that perceives the sound. In the case of a neurosensory hearing loss this process is hindered, which implies that the sound waves that hit the ear are not perceived by the brain, or only partly.

Taking into account the studies of the progression of the disease and the genetic research, Usher Syndrome has been divided up into three types: Usher I, Usher II and Usher III, mainly depending upon the nature of the hearing loss and the person's sense of balance.

People with Usher Syndrome type I are born deaf, and therefore usually grow up with sign language as their first language. This situation may change as more and more deaf infants undergo a cochlear implant operation. However, this issue is not relevant to the Nordic Project. People with Usher I often suffer from visual disorders as children due to RP, typically in the form of nightblindness and incipient reduction of the visual field.

A prominent trait of Usher Syndrome type I, which distinguishes it from Usher type II and in part from Usher type III, is the associated balance problem due to impaired

vestibular function. This means that the balance organ in the inner ear does not work normally. In a child with Usher I therefore, motor development may be delayed and he may first learn to walk at an age of between 18–24 months and later on may take longer to learn how to ride a bicycle, for example. Normally the balance system functions aided by the interaction between vision, the inner ear's balance organ and the proprioceptive system, that is composed of the impulses from the soles of the feet, joints, muscles, back and back of the neck. People with Usher Syndrome type I therefore become highly dependent on the proprioceptive system as eyesight worsens.

People with Usher Syndrome type II are born with hearing impairment ranging from mild to severe. Residual hearing is often enhanced with a hearing aid, and therefore the child grows up with speech as the first language. As Usher Syndrome type II does normally not entail reduced vestibular function, persons with Usher Syndrome type II do not have balance problems as those with Usher I. The reduction in hearing is symmetrical, that means that auditory examination gives the same results for both ears. People with Usher II hear low tones best, while high tones sounds are difficult to hear or often cannot be heard at all. Hearing loss stays relatively stable throughout life. However, people with Usher II, as everybody else, can suffer from age-related hearing reduction, which leads to additional hearing loss. In the Nordic Project, several informants say they perceive that their hearing is worsening, although this is not detected by hearing tests. The perception of worsened hearing is considered by the informants as being related to weaker eyesight, which makes it harder for them to lip-read as a support for hearing.

People with Usher Syndrome type III can be hard to distinguish from people with Usher II, as both appear in a similar fashion. The group with Usher III is made up of people that are born with about normal hearing and then suffer from gradual, increasing hearing loss and develop RP. Often, the hearing loss advances in steps, which means that there are stable periods amongst the worsening of the hearing. Usher III can lead to deafness already in early adulthood.

Retinitis Pigmentosa

All three types of Usher Syndrome present Retinitis Pigmentosa, RP. RP is an umbrella term for a series of different but related progressive eye diseases that gradually destroy the retina. RP can end in total blindness, but it is thought that when associated with Usher Syndrome it often appears in a milder version than otherwise. Only very few people with Usher Syndrome go totally blind.

A series of diverse symptoms are related to RP, but RP progresses in a much individualised manner. Therefore, not everybody that has Usher Syndrome will necessarily present all the following symptoms.

The typical symptoms of RP are:

- Night- and darkblindness: This is usually the first perceptible symptom of RP. The person has difficulties finding his or her way around in the dark and often walks into things when in badly lit surroundings.
- Reduction of the field of vision: It starts with blind spots in the peripheral vision (the outer part of the field of vision) that gradually spread and result in a very limited field of vision called tunnel sight. The effect is equivalent to looking through a tube or binoculars (except for the fact that objects are not enlarged). When the field of vision is reduced to approx. 10 degrees (which means that the field of vision is so small that it is filled by a person's face at a distance of a metre) central vision is still usually retained for decades.
- Reduced vision: The central part of the field of vision (visus or sharp vision) that is used for example for reading and other detailed tasks worsens.
- Light sensitivity: Many people with RP are blinded by bright light. For example, the reflection from snow, sunlight, bright artificial light or the reflection from walls, boards, tabletops, etc.
- Adaptation problems: The eye has greater difficulties when trying to adapt to changes in lighting that occur for example when going from a badly lit room to a brightly lit one or vice-versa. Adaptation to different lighting conditions takes longer, maybe several minutes.
- Contrast vision: Many people have problems distinguishing between small contrasts, e.g. between light grey and white. A white plate on a light grey table may therefore be difficult to see.
- Colour vision: RP may affect colour vision, for example, it becomes more difficult to distinguish pastel colours.

- Cataracts: Many people with RP develop eye complications such as cataracts, an opacity within the lens of the eye that blurs vision. In the Usher syndrome group of ages comprised between 20 and 30, about 20 % have cataracts. In the age group of over 50, about 75% have cataracts. Nowadays it is completely normal to have cataracts operations and results are usually good.

The symptoms above may appear at different stages of the disease. RP usually develops symmetrically, that is, it affects both eyes in the same manner, except if there are additional problems such as cataracts, for example. For the moment, there is no treatment for either RP or Usher Syndrome.

RP is seldom detected in the course of an ordinary eye examination, where the strength of the central vision is tested. Central vision is usually unaffected until a late stage of RP; many cases are not diagnosed with Usher Syndrome until late in life, and often it is due to other symptoms.

Loss of communication

As the two most important communication senses, hearing and sight, weaken (in the case of deaf persons, hearing is already absent at birth) persons with Usher Syndrome gradually have greater and greater difficulties communicating in the usual fashion.

People with Usher I who uses sign language will with time have difficulties communicating in the usual way, as the interlocutor must sign within the reduced field of vision. The person speaking must not be too close to the person with tunnel vision either, as the field of vision will be so small that it cannot embrace both the speaker's hands and his face, where a considerable amount of the sign language is articulated. In the case of group conversation, it can be very difficult for a person with tunnel vision to move the field of vision quickly enough to see who is talking, and therefore risks being left out of the conversation.

The symptoms above, which may accompany RP, may also give rise to difficulties reading sign language. Deficient contrast vision may also be a problem if the speaker is wearing light-coloured clothes, as it is more difficult to distinguish the hands from the pale clothes. Light sensitivity may be a problem if the speaker is standing with his back to a window because the light may be blinding and therefore impede vision of the speaker's hands and face.

People with Usher II usually make the most of both hearing and lip-reading. When eyesight problems arise, it becomes more difficult to cope among hearing people as lip-reading becomes a lot more complicated. It quickly becomes difficult to spot a new speaker, for example when sitting around a table. If you do not have time to see the person who said something, you do not know who to ask to repeat the utterance either. Light sensitivity, as in the case of Usher I, may also be a problem as it may be blinding and hinder lip-reading.

Informant's diagnosis and hearing and sight status

All informants participating in the project have been diagnosed Usher Syndrome. Eight were diagnosed with Usher Syndrome type I, that is, born deaf with RP, and twelve with Usher Syndrome type II, born with impaired hearing and mild to severe degree of RP.

In the Nordic Project it is the eyedisease RP that is the progressive factor. When a person's eyesight is examined, for example to assess whether he or she is entitled to an early retirement pension, there are two fundamental aspects that are the basis for the assessment: the person's sharp vision or visus and the field of vision. To have reduced vision of eg. 6/60 denotes that a normal seeing person can see from a distance of 60 metres what the affected person needs to be 6 metres away to be able to see. In the case of the field of vision, a person is considered socially blind if the field of vision has shrunk to 10 degrees. This means that the person suffers from tunnel vision.

Therefore, people with RP suffer from serious sight problems on two different fronts. On one hand they have a reduced field of vision, and on the other worsened sharp vision within the field. In an attempt to quantify the informants' combined symptoms of reduced vision, we have tried to draw up some tables where sharp vision or visus appears in the vertical columns and reduction of the field of vision in the horizontal ones. The groups have been numbered 0 to VIII, where group 0 represents the mildest vision problems, that is, normal visus and a field of vision of more than 20 degrees, and group VIII, the most severe ones, with visus of 1/60 or less and a field of vision of 1 degree or less.

Distribution in groups according to the sight criteria visus and field of vision:

	$>20^\circ$	$\leq 20^\circ$	$\leq 10^\circ$	$\leq 5^\circ$	$\leq 1^\circ$
6/6	0	I	II	III	IV
6/18	I	II	III	IV	V
6/24	II	III	IV	V	VI
6/60	III	IV	V	VI	VII
1/60	IV	V	VI	VII	VIII

After completing the table with the field of vision and the sharp vision, the 20 informants were distributed in the following manner at the beginning of the project:

- Group 0: 2 informants
- Group I: 1 informant
- Group II: 2 informants
- Group III: 5 informants
- Group IV: 3 informants
- Group V: 3 informants
- Group VI: 3 informants
- Group VII: 1 informant
- Group VIII: none

The persons in groups 2 to 8 are, by definition, socially blind, while the ones in groups 0 and 1 are, by definition, weak-sighted.

If we compare the grouping above with the hearing reduction, the distribution at the start of the project was the following:

Group	Medium hearing reduction	Svær hearing reduction	Deaf
0	1	0	1
I	0	0	1
II	1	1	0
III	3	1	1
IV	1	0	2
V	3	0	0
VI	0	1	2
VII	0	0	1
I alt	9	3	8

Informant's hearing and sight status at the end of the project

Five years can be a short period when it comes to perceiving changes in the eyesight and hearing regarding people with Usher Syndrome. In this project the following occurred:

Three suffered a measurable worsening of their hearing, though not important enough to go from a medium hearing reduction to a severe one or to deafness. However, these categories are very rough.

Nine informants stated that their eyesight had worsened and gave specific examples of tasks they could no longer perform in everyday life. Seven informants showed a vision deterioration that was measurable.

If we compare informants' hearing and sight status at the beginning of the project and at the end, we obtain the following table:

Nine informants with medium hearing reduction are distributed in the following manner:

Vision group	Project start	Project end
Gruppe 0	1	0
Gruppe I	0	0
Gruppe II	1	2
Gruppe III	3	1
Gruppe IV	1	4
Gruppe V	3	1
Gruppe VI	0	1
Gruppe VII	0	0
Gruppe VIII	0	0

One individual in Group 5 did not want to send his updated medical report, but his eyesight had improved, as the result of a cataracts operation, while one person in Group 4 did not want to give updated information on his eyesight either. In this case, we considered, basing ourselves on the descriptions the informant gave, that it had worsened substantially and so the informant would be placed in Group 5 or 6.

Three informants with severe hearing reduction are distributed in the following fashion:

Vision group	Project start	Project end
Gruppe 0	0	0
Gruppe I	0	0
Gruppe II	1	1
Gruppe III	1	1
Gruppe IV	0	0
Gruppe V	0	0
Gruppe VI	1	0
Gruppe VII	0	1
Gruppe VIII	0	0

Eight informants are deaf and are placed in the following groups:

Vision group	Project start	Project end
Gruppe 0	1	1
Gruppe I	1	1
Gruppe II	0	0
Gruppe III	1	1
Gruppe IV	2	3
Gruppe V	0	0
Gruppe VI	2	0
Gruppe VII	1	1
Gruppe VIII	0	1

The eyesight reports above show that even over a short period of five years, many informants have undergone relatively big changes in their eyesight, which is probably common to persons with Usher Syndrome. However, it must be taken into account that eye doctors use different methods. In order to have precise results, this project should have used just one optician to perform the measurements at the beginning and end of the project. In this case, to observe trends and hear the informants' descriptions of the consequences was more important than obtaining precise eyesight measurements.

Read more about this issue in the booklets "Participating" and "Receiving a diagnosis"

Guarantee of anonymity

The project has been reported to the Norwegian Scientific Ethics Committee, and their guidelines have been followed. We have discussed during the project how the anonymity of the individual could be preserved. This is an important issue in the project; it is the people with hearing and vision reduction themselves that come forward with their own formulations that you can relate to and maybe identify with. On the other hand, we have a great responsibility towards the individual informant, to assure that he is not recognisable nor feels revealed.

We have tried to assure anonymity by changing the informants' names, jobs and so on. Particularly sensitive experiences are referred to as "one informant says" and in a few cases we have decided to let an informant appear under yet another name, different to the one used throughout.

The project follows the guidelines established by the Norwegian Social Science Data Services, NSD. We have also decided not to write quotations or descriptions we would not like to see written about ourselves.

It must be mentioned that we have asked the members of the Steering Group whether they could recognise the informants from the material they had received. It has been the case just once, and it led to further efforts at concealment.

Finally, we have adapted some technical terms to Danish. In the Norwegian, Swedish and English versions, national terminology has been used. For example, deafblind persons according to Norwegian, Swedish and Danish legislation are entitled to a contact person, a paid assistant for x hours a week. This person has to act as the eyes and ears of the deafblind person. In Norway and Denmark, this person is called a contact person, but in Sweden the term personal assistant or companion is used. In the thematic booklets the national terms are applied, despite the fact that some of them may be a bit vague.

In Norway and Sweden, interpreting aid includes the possibility of a companion for the deafblind person. In Denmark, the deafblind person must use the contact person hours for accompaniment, as Danish intervenors must only interpret. Once again, to ensure the anonymity of informants, the word intervenor is used, instead of using intervenor + companion or otherwise.

In both Sweden and Denmark and partly in Norway, deafblind associations try to start up activities at local level so that deafblind persons have the possibility of meeting other deafblind people once a month for example. In Denmark we call this "experience groups", in Sweden, local association. Once again national terminology is used.

Phenomenological research methodology

The project is built upon the following hypothesis that is the basis for the choice of theory and method:

- Based on “past experiences” – the informants’ subjective construction of themselves and their relationship to the surrounding world
- Based on the specific daily life – how do the informants through the description of their everyday life, past events and desires for the future create meaningfulness?
- Based on the idea that the objective of the research is not to find the “essence” but to label the descriptions of the phenomena related to acquiring, having and living with a progressive disability – specific theories are not included in the labelling process

The first bullet point refers to the supposition that it is never possible to decouple a declaration during an interview from the interviewees’ everyday situation, which is touched upon. If such a direct relationship were not presumed, one would suppose that informants could talk in an “objective” manner about themselves, their acts, their motivation, their attitudes and feelings. The description of reality is never identical to reality, but the expression of a concrete adaptation in a concrete context. (Sørensen, 1988)

In other words, we express an interpretation of our surroundings and ourselves when we express our opinions, experiences and events. Declarations are made in a specific situation and have an intention. The fact that the narrative occurs within the interaction between the informant and the interviewer is fundamental. The informant will probably emphasise other aspects if she tells a friend than if she tells the optician or if she tells the person she is in love with. In the same manner, we must accept that what the informant tells is an expression of her considerations and experiences at that moment. Events occurring in the future may change the interpretation of what has already taken place. The informants’ way of describing themselves and their situation enters in a (individual and social) story with a past and a future. That means, that it is context-bound and conditioned by the immediate surrounding and the socially dominant values.

The second bullet point refers to the fact that we have made a great effort to get deep insight in the individuals’ everyday lives and the considerations and interpretations of

these. We have mainly enquired about specific events instead of general experiences (see below under research methodology). We have valued the informants' narratives, basing ourselves on the idea that people construct themselves through the narratives they develop in relationship to others. This means that the deafblind person that tells the interviewer (maybe via the intervenor) about what happened and how she reacted when she received the diagnosis and how she has handled the worsening situation, at the same time is presenting a specific narrative about herself – a narrative that can be placed within greater cultural stories about health, success, quality of life, etc. (Goffmann, 1959)

The third bullet point is related to the understanding of the aim of the research, to present an offer of knowledge instead of presenting truths about a given issue. We do not consider that we have the "true" or "definitive" narratives. Narratives have to be seen within the context that was true for the informants when they spoke. Other people involved (for example the opticians or teachers that are mentioned in several narratives) may have other stories about the events, but here we only focus on how the informants construct their understanding of themselves and their lives through the narratives about living with a progressive disability.

In this project, we have strived to describe the deafblind persons' communication conditions in a period in which their disability worsened. The descriptions that have arisen from the six interviews that have been carried out in total with each informant have been analysed in relation to different theoretical perspectives that have contributed to the discussion of the described phenomena.

The most important points are summarised here:

Sense of coherence

Under the concept "Sense of Coherence" the Israeli sociologist Aron Antonovsky designates the factor he considers most relevant to how a person reacts towards stress factors. Antonovsky throughout his lifetime has researched why some people overcome adversity, crises and violent situations without surrendering while others give up. Research shows that the fact the person senses the situation as meaningful, comprehensible and manageable is decisive. To have a Sense of Coherence implies that one experiences what is happening to themselves and their surroundings as "comprehensible", "manageable" and "meaningful".

Antonovsky points out that a person with a strong experience of comprehensibility expects the stimuli she is going to come across in the future being foreseeable, or at least, those that come as a surprise can be placed within a coherent framework and explained. This means that her starting point is the supposition that problems can be structured and understood. Even when she receives an Usher diagnosis, for example, she tries to change chaos into order. She may try to find additional information on Internet, to meet other people with the same diagnosis, maybe she will try out different kinds of aids, see a psychologist or anything else.

By this we do not mean that receiving such a diagnosis is experienced as something acceptable nor meaningful. She will probably react with despair, fear, pain, anger, guilt, sorrow and worry, but the stress factor itself, the fact of receiving the diagnosis, will be manageable. The person that has not experienced that events in life are comprehensible will probably sink into the chaos. She will react with fear, anger, shame, doubt, neglect, and confusion and she will give up before any attempt at trying to understand or handle the situation is made and only dedicate herself to her emotional chaos.

“What separates these two emotional complexes is that the first one equips the person with the motivation to handle the situation, while the other one is paralysing. In the first group, feelings are focused, while in the second they are diffuse... obviously focused feelings are more compatible with the feeling that the problems are comprehensible. Focused feelings are also more likely to activate coping strategies, while diffuse feelings trigger unconscious defence mechanisms.” (Antonovsky, 1987, 152)

We will turn back to the coping strategies Antonovsky mentions later, but first we will present the research carried out by American sociologists Corbin and Strauss on how people who receive a chronic diagnosis work to create a new life perspective and a new picture of themselves.

Working with creating meaningfulness

Corbin and Strauss state that it is hard work to repair the damage done to the individual's present and expected life story that occurs, for example, when receiving an Usher diagnosis. The aim of this work is to regain control over one's life and have a sense of meaningfulness.

The work that is linked to coping with having a chronic illness is threefold, and we will give examples of each case taken from the daily life of a deafblind person:

- **Illness related**, where the handling of the symptoms and crisis prevention and management belongs. Specifically it refers to remembering your eye drops or having spare batteries on you for the hearing aid.
- **Biographical**, where defining and maintaining one's identity belongs. It is a matter of including the illness in one's biography, to make it part of your continuing life, to accept it and the limits it sets and, in the light of all this, create a new understanding of yourself. Specifically it refers to developing one's identity when you have to give up your job, have to change your priorities when it comes to activities depending on your resources and have to prepare yourself of being dependent on other people's help.
- **Related to everyday life**, where shopping, cooking, cleaning, raising children, recreation and other everyday activities belong.

Corbin and Strauss therefore focus on the non-medical consequences of getting and living with a chronic diagnosis. They describe how there are experiences and opinion aspects that affect social relationships and practical situations that are both separated from the illness and at the same time part of it. The most important message is that it is crucial for a person that receives a chronic diagnosis to work on both the illness related and the biographical and everyday life related areas. In the interviews with the informants, we take a closer look at how the deafblind persons in this project manage this work.

The main point Corbin and Strauss make is that the process can be described as work that has to be carried out to be able to handle the illness or disability. Adaptation does not only have to be the illness but to the whole way of understanding life, and the work not only has to be carried out by the person that has the illness but also by the people surrounding that person.

By this, they put forward an important interpretation of what communication with the milieu means, which we shall come back to.

Coping

Antonovsky employed the concept "coping" which is often traced back to Richard Lazarus. His concept of coping is characterised by focusing on what the individual does to handle the present situation. Lazarus, who focuses on cognitive comprehension as meaningful to how people can act, considers that the main point is that the individual

acts upon her interpretation of a context. This means the individual's acts must always be seen in relation to what experiences she has from similar situations and within which framework she acts.

The choice of a coping strategy happens within a dynamic process that varies with time and in relation to the changing demands and differing assessment of the situation. "Coping" therefore occurs in the interaction between the individual and the milieu. Carin Fredriksson uses the concept of coping, among others, in her doctoral thesis "Learning to live with a progressive hearing reduction- a perspective" She writes:

"Coping" is contextual and process-orientated. Coping with a situation is related to the time, place, the individual's perception of the situation and how it develops. In this process the perception of one's own resources, aims and the motivations are important to how the individual reacts. The individual's perception of the relevance of the action becomes important. The cognitive assessment, an active interplay between the individual and the milieu, is crucial in the cognitive "coping-theory". (Fredriksson, 2001, 16)

Literature about coping strategies places emphasis on the idea that coping must always be considered procedural. Coping with a situation is not something that one does once and for all. Quite the contrary, it is a process where a strategy in a given situation can later lead to another strategy becoming relevant. Although a person first uses an emotionally oriented coping strategy and, for example, refuses to talk about her eyesight problems, she may later, when she feels more confident, substitute this strategy for a problem-focused strategy, where she talks about her sight problems and the consideration she needs others to show her.

Coping with a situation means managing to bear it for the moment. It is not a foregone conclusion that the chosen strategy will also work in the long run. Coping is not an individual process separated from others surrounding the individual. To the contrary, studies show that the scope, frequency and timing of the support that is given are decisive when it comes to how the individual copes with the situation. (Antonovsky, 1984, 36)

"Coping" can both be about how you mentally prepare yourself for the changes in your life and how to manage to live with it and how, from a practical viewpoint, you face a situation when, for example, you cannot see where the pavement ends and the road starts. The last type of coping mentioned can also be illustrated as a compensating method.

The Swedish researcher Carina Fredriksson writes that compensation is a planned way of acting in relation to a specific, observable or subjective defect that the action carried out may diminish or compensate for. (Fredriksson, 2001, 18).

Health and action competence

Asger Schnack, professor of Health Pedagogy, using a broad definition of health has worked on how to enhance people's possibilities of being competent in the fulfilment of their objectives.

The idea is that a person's self-esteem is strengthened when they realise that they can use their understanding of the world to influence and direct their own situation. Action competence is characterised by personal competences on three levels:

- Concrete actions, which are expressed as skills and performances
 - Knowledge, which is expressed through the potential for reflection and knowledge
 - Self- and opinion level, which involves potentials related to identity
- (Jensen, 2002)

The primary objective of the professional that has to give support or counsel a deafblind person must be to strengthen the deafblind person's action competences, his or her experiences, and the resources to be able to act in a planned manner using his or her own situation and needs as the starting point.

Schnack states that action competence is a training ideal. This means that you cannot say that some have and others lack action competence. Action competence is more an objective for everyone, which some people have more developed than others depending on the area. The degree of action competence is to a great extent determined by the individual's experience of being able to influence his situation and being able to do something to change it. (Schnack, 1998)

This means that everybody has action competence and that everybody has the potential to develop their action competences and therefore that their performance is the visible tip of the iceberg, while the potential lies underneath and can be mobilised and developed. (Jensen, 2002)

Some people experience that their opinions and acts mean something. They can act in a planned manner to meet their needs, while others have experienced that initiatives are

carried out without taking them into account. If the latter type of experiences is what one has had, it is necessary to develop experiences by acting in a planned manner according to personal needs and to start at a small scale. Several researchers have indicated that giving responsibility to people that do not have experience acting competently to achieve their own objectives can contribute to failure and defeat. (Thomsen, 2000, Hansen & Sørensen, 2000)

Communication

We indicated above that Corbin and Strauss state that working towards finding a new meaning is not only carried out by the person that has received the diagnosis but also by the people surrounding that person. The relationships between people are therefore significant to how we manage challenges in our everyday lives.

Through communication we create social relationships that make us participate in the life around us. And it is through communication that we get the chance to understand ourselves. We communicate in many ways, through our body language and gestures, through the clothes we wear, the leisure activities we carry out, the way we talk, etc. Therefore communication is far more than the words we pronounce or write.

As a deafblind person, not only is it more difficult to speak and listen to other people, it is also more complicated to realise what we convey, for example, by the way we dress and communicate, and it is more difficult to interpret others people's communication if, for example, you cannot read their gestures.

To be able to interpret situations and find out what is going on behind the spoken word it is crucial to react adequately to the situation. Therefore, a hearing and sight disability becomes a communication disability. When people communicate with each other, many things happen:

- we convey information to each other
- we find the meaning of what is going on
- we control interaction
- we express and develop our relationship
- we exert social control
- we interpret ourselves and our milieu according to the other person's responses

This is why communication with other people is so important. Two main elements of communication are language and relationships.

Words are not just words that mean the same to everybody in every situation. The language we use is relevant to how we think, how we learn and how we communicate with each other. It can be said that "we do not speak the same language" about a person that, despite having the same mother tongue, you do not agree with or do not understand. Therefore, we say that language is linked to experiences and relationships. It is easier to understand a person you agree with or that you share experiences with; not only specific ones but also in a wider cultural perspective. If you come from a family without a literary education, you will always find it easier to speak with others that come from the same type of family despite never having met them before.

A recurrent trait in informants' narratives about their use of the contact person and intervenor shows that communication works best when they talk to a person they know and with whom they share experiences. A common language is built up between people when they communicate. Therefore, you cannot just switch one intervenor for another, although apparently, it is only a matter of translating words from one language to another.

Recent communication research indicates that when people communicate with each other, they become involved in a process where they interpret the situation, create meaning and act according to the meaning they have created. In other words, it is through communication with each other that we create our selves and the world around us. (Shotter, 1993, Thompson, 2003)

The context of a communicative situation sets the scene and is relevant to what the other person will perceive as meaningful of what we say or do. Therefore, communication with others and the possibility to interpret the situation we are in is crucial to how we see ourselves. Understanding a situation means understanding the small nuances; if you are smiling when you tell me I'm stupid, I know that it is said with affection. The smile is part of the context of the situation. Understanding the situation is also about seeing or sensing, for example, how a family you visit behaves at the table or the conversation topics they have. Informants report in different ways how much energy they use on trying to interpret everything they can see and hear, and many narratives reflect how difficult it is.

We have now explained some of the project's theoretical sources of inspiration. The hypotheses that introduced this chapter have led the development of the project, while

the above-mentioned theorists have contributed to challenging and shedding light upon the narratives the informants have offered.

Now we are going to have a closer look at the methodological basis for The Nordic Project.

Methodology and experimental design

Phenomenological method

The phenomenological method implies that the informants' experiences are at the centre stage. The Danish researcher Steinar Kvale writes:

"A phenomenological perspective includes focus on the world we live in, openness towards the interviewees' experiences, prioritisation of precise descriptions, readiness of understanding and the search for invariable, fundamental meanings in the descriptions" (Kvale, 1994)

Consequently, phenomenologically oriented research is particularly suited to gathering insight into people's experiences and the interpretation of the world they live in. The aim is not to quantify *what* is experienced but to see *how* the individual informants' experience and interpret their lives.

Through in-depth, focused interviews, we have tried to discover how the informant experiences his situation, other people's reactions, possibilities and limitations, etc. In some situations, the informants say things that sound completely wrong to the others present. This places a huge demand on the interviewer, as it is the deafblind person's experiences that have to be focused upon and not what the spouse or the interviewer considers facts. The informant may say, for example, that he has spent two years claiming to get his computer properly installed and nothing has been done about it. Here the interviewer (which in this case is also the informant's deafblindness consultant, see below about the selection of interviewers) makes a note about the fact that something has been done, as a computer expert has visited the informant on several occasions, but unfortunately it has been to no avail. Therefore, both parts are right. Something has been done – the consultant has done his job and made sure that something has been done about the problem and nothing has happened – the informant's problem has not been resolved.

The interviewer may ask further questions about what surprises her. An example is an informant in her early fifties that after many years as a housewife now wants to train as a beautician. The interviewer wonders how the informant can wish to be a beautician with her limited eyesight. Instead of asking directly, the informant asks in-depth questions about the notion the informant has of the job. The informant's answers to the questions

leads to her start to reconsider her own possibilities of becoming a beautician.

In these circumstances, where the interviewer really can find respect and understanding for the informant and show it in the interview situation, the relationship can really develop in such a way that both the interviewer and the informant learn a lot about themselves in the interview situation. The interviewer is not just a person that holds the microphone. It is demanding to keep track of the many statements and be sure that you have heard right. A good example of how to check whether a sensitive issue has been correctly understood could be:

Have I understood correctly that as your parents are no longer around, your husband has become more important than he was before? Or have I misunderstood you on that point?

In the interview guides which were sent out as guidelines for each interview we recommend that it is important to focus on individual, concrete events and experiences. The descriptions have to be as detailed as possible. Another way of interviewing is to practise distinguishing between acts, feelings and explanations.

- Acts explain what is going on
- Feelings refer to what it does to you
- Explanations refer to why it happens.

Example:

Informant: When I go shopping, I sometimes knock something down.

Act: Then what do you do?

Informant: I try to pick it up.

Feelings: How do you feel in that situation?

Informant: I think it is embarrassing.

Explanation: Why do you happen to knock things down?

Informant: I can't see if they have placed things differently.

Feelings: How do you feel when you realise they have changed the layout since the last time?

Informant: I feel insecure.

Act: Then what do you do?

Informant: I'm especially careful and sometimes go to the cashier and ask for help.

Feelings: How do you feel about asking for help?

And so on.

Experimental design

The project can be seen as an action research project in the sense that the initiative to start the project came from the Videnscentret for DøvBlindBlevne i Danmark, that sensed the need among consultants in this field. In addition, the steering group and the consultants involved have participated actively in the shaping and/or execution of the project. Their assessment of their own contribution is described in the next section.

The structure can be summarised as follows:

- The working group draws up guidelines and condenses interpretations on the basis of theoretical and methodological experience and insight into the field of deafblindness.
- The consultant/interviewer summarises the interviews.
- The informants talk about their own experiences, desires and evaluations answering to open questions and are asked about their intentions for the project.

As for the experimental design in itself:

- On the basis of a preliminary theoretical and methodological framework the working group carries out a pilot study where an interview is performed with an informant. The experience from the pilot study is used to write a project description with the guidelines for the project. A phenomenologically inspired framework and experimental design is presented.
- The working group prepares a summary for the consultants that are going to act as interviewers. The summary lays out the demands that will be placed on the interviewers and is the basis for a seminar that is held in each country before the start of the project. At the seminar, the interviewers learn how to use the interview method in practice.
- The working group tries to steer the empirical work by supervising and holding a midway seminar for interviewers, in which the differences between the talks consultants usually have with the deafblind persons and the requirements of the interview are highlighted. Every consultant receives before every interview an exhaustive interview guide and guidelines for the report. It has also been important to underline that we need to grasp the informant's individual situation precisely. Therefore, there has to be time to go into depth about their special conditions.

- The consultants are responsible for performing the interviews, possibly with the aid of an intervenor. The interview is transcribed and the consultant writes a summary for the report using the report guidelines. Reports are typically 15-25 pages long, and are sent on to the working group.
- Every year the working group writes a summary (1-3 pages) of each informant's statements and the consultants' comments as reflected in the report. The focus is placed on the answers to the questions that were crucial in that year's interview. If the report is incomplete, the interviewer is asked to go into depth about those parts in the next interview.
- On the grounds of the summaries, the working group writes a partial report every year, in which we have tried to present a provisional interpretation of the trends observed in the materials. The aim is to have an overview over all the material in order to clarify the focus of future interviews and structure the subsequent analysis.
- The analysis of each subject is led by a review of the partial reports and summaries (and in some cases of the reports), in which relevant data are located and noted down. To keep track of the enormous amount of data (aprox. 200 pages of reports) we drew up a list of issues that appeared as important in the interviews. Subsequently all reports were read through again and notes were made every time an informant had spoken about one of the issues. Examples of issues are "Education", "Useful Counselling", "Useless Counselling", "Self-esteem", "Consideration towards Others", etc.
- The list with what each informant has said about a specific issue gives an overview, which makes it possible to develop relevant secondary issues and categories. In this way it is possible to see how widespread an event or an experience expressed in the materials are. When writing the booklets that make up The Nordic Project we were able to focus on an issue and go directly to the reports in which it was touched upon.
- To a great extent, we have made a horizontal reading of the reports. This means that we have compared different information given about specific issues. However, we also wanted more complete visions: everyday life, thoughts, feelings, experiences and opinions of the individual informants. For this reason, we have decided to draw

up a list of ideal types, which are not directly characteristic of individual informants, but that bring together aspects from several of them. In this way it is possible to show how diverse deafblind persons are and how different lives they live.

The interviewers' significance and the significance for interviewers

Throughout the project the interviewers have played a fundamental role. They have put in an enormous amount of effort and contributed in an invaluable manner. To reflect the work load involved, it must be said that the working group originally thought that an interview would take about 1-1.5 hours. Nearly all interviewers reported that the interviews took at least 2, and in the case of a few individuals, up to 8 hours, including breaks, to perform the interview. Consequently, it has been very demanding for both consultants and informants to carry out the interviews. At the same time, it points to the communication barriers that must be overcome. As on each occasion the interview guides were prepared for an expected duration of 1 hour for a person with normal eyesight and hearing. The interviews were recorded on tape and then transcribed. The interviewer then produced a report based on the transcription, which led to a yearly report of about 15-25 pages.

The interviewers have been responsible for establishing and maintaining contact with the informants. Their professional insight and experience communicating with deafblind persons make them particularly suited to perform these interviews. On the other hand, they lack experience with scientific empirical production. To compensate for this, as we mentioned above, we wrote very detailed guidelines and checked how they were being followed, and also met the interviewers at the beginning and midway through the project. Doubtlessly, once in a while it has been a big challenge to let others "see your cards". We are thankful for the trust the interviewers have displayed and we have done everything possible to live up to that trust.

One of the things the interviewers have been trained in is to clearly distinguish between summarising, quoting and assessing what has been said in the interview. This is further explained in the section "Critical review of the methodology".

Several interviewers have finished off their reports with reflections over their own practise based on their experiences with the interviews. One of them writes in her report of the 1st interview:

"I have learned incredibly much about nuances in the deafblind persons' situation in their everyday lives. Tiny, tiny details, which I think, will help me a lot to collect information as realistic as possible about deafblind persons. It is important to find small details in everyday life, which affect most people like, for example, requests for a companion. If the information is too general it is too far from reality and what is easy to understand."

After the second interview, she goes into further depths:

"I consider that the interviews have contributed to the development of a slightly different methodology to manage "practical tasks". Interpretation is now more important. I spend more time preparing the work and the information both for the deafblind person and for the officials the deafblind person has contacts with. It avoids a lot of insecurity as both the deafblind person and the professionals are aware of the conditions before the meeting."

Another interviewer reflects on her informant's narrative about having gone to a deafblindness reunion and despairing on meeting so many severely sight and hearing disabled persons.

"As persons working with deafblind people, maybe we don't always think about the fact that in their everyday lives they do not meet that many disabled people. Is it right or wrong to get them together at special meetings? We professionals often say that it's good they meet each other. But do we consider that it could come as a shock to meet others with severe problems? How do we handle this? We are good at informing about the medical reality, but do we speak about how they experience it? There was obviously no-one at the seminar my informant went to with whom he could talk about his experiences and his concern about his future."

There are many examples like the one above. When reporting on the seventh interview we asked the interviewers to reflect upon the significance the yearly interviews had had for them (apart from the heavy workload). A series of thought-inducing answers were obtained:

One of the interviewers summed up what she had learnt from the project in a series of points:

- I have learnt to ask in a correct and direct manner.
- I have learnt to be humble towards my interviewee. He has a lot of knowledge which I have to get hold of.

- I have learnt that it does not hurt to ask, even though the questions may seem very direct.
- I have received a lot of knowledge – both visible and silent.
- I have learnt to work in a different way, to do my homework well and organise my work”.

Many interviewers feel this learning experience from having participated in the project. One mentions focusing on a forward-looking and constructive perspective:

“... one specific thing which I have become much more aware of is the prominent coping strategies of the individuals. When I visit someone at home, I can always find something to “praise” the individual for in their way of coping with life”

Another adds that now she better understands that solutions must be thought of in relation to the individual’s perception of his needs:

“The project has given me deeper insight into the living conditions of disabled persons, but also the conviction that it is important to work towards finding solutions that are based on the individual’s needs. The few contact possibilities and having to elucidate the conversation require time.”

When you focus more on differences, as the following interviewer did, it becomes especially relevant to use the individual’s perception of his needs as a starting point:

“I have also learnt that problems vary from one person to the next regardless of whether their sight and hearing status is the same on paper...in contact with other deafblind persons I make good use of all the strategies for coping with everyday life you have taught me. He sees the possibilities, not the problems.”

Finally, several mention that they have been convinced that a good job requires resources in the form of knowledge and time:

“The project has strengthened my prior perception, namely that those that have to carry out rehabilitation with deafblind persons need to work in crosscutting teams...there is a need for knowledge and cooperation both at the state and local level”

Another writes:

"I can only recommend that the interview method that is used in the project is transposed to everyday use...You just have to leave plenty of time for the first visit"

The informants' significance and the significance for informants

There is little doubt that it has been difficult for the interviewers to prepare, perform and report on the yearly interviews. However, there is no doubt either that the informants that were willing to talk about their lives and thoughts have shown both courage and willpower. It is very demanding to have to reflect about yourself and your life. Especially when it is to a person and in a context you know more or less well. This project would not have existed without the deafblind persons that volunteered and that held out to the end despite that fact that some of them sometimes said that they would like to skip an interview when life was particularly difficult at the time of the interview.

In the last interview, the informants were also asked what The Nordic Project had meant to them. Several mentioned that they had found it demanding to participate and that once in a while were tired of having to meet the interviewers. About the same number said that they would miss the yearly interviews and in the case of a few informants the interviewer and the informant have agreed to maintain some kind of contact or other in the future. We have decided to let just one informant's statements express what we sense that a number of informants have expressed in different ways:

"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. That is how you tackle a problem, but we never discuss aspects related to the problem. There can be causes to these problems, I understand that better now."

Later in the interview, the informant continues:

"I think that we have to open more doors; there are many things you don't think about normally. Sigurd (a psychologist) and I tried to explore exits and he opened many interesting doors, he did. But you and I have opened many more doors. I think it has been positive, but it would have been nice to continue for the rest of my life. It's a shame it's over...The interviews have been far apart, and that annoyed me. But it's fortunate that they were not more frequent as it would have been more difficult to end them. They have given me so much. Our discussions have been so meaningful...I think that you know more about me than my own husband."

In interview No.5 we asked informants to talk about what they wanted to highlight in The Nordic Project and what they considered especially important that others gain insight into.

The answers have pointed in many directions and have been significant in the preparation of the booklets, as they prove that there is a special interest among those who know where their problems lie. The answers to the question about what informants' want insight into appear below:

- Other deafblind persons' lives and ways of handling everyday problems

Especially a group of younger deafblind persons, who have not had contact with others with the same disability, would want to have insight into others' lifestyles. They want to know about how others cope with family life, possibly with a hearing/seeing spouse and children, they want to know about others' contact with society and find out about their childhood and teenager experiences. Have they felt left out, and if they have, did they feel it was due to their disability?

- Other deafblind persons personal experiences and handling of crises

Some want to know how others feel when they meet people who are not sight and/or hearing disabled.

A younger informant experiences that some disabled persons have great self-confidence and dare to do all sorts of things, while others don't dare to do anything. She inquires about the relevance of education to how disabled persons fare as adults.

One mentions specifically that she would like to know how other people with physical disabilities cope with a progressive disability, which will lead to different crises in life as the illness advances.

As to the question about what informants consider that others have to know, the answers were:

The importance of having a job

Several mention that there is not enough emphasis on the importance of holding a job. They would like to focus on how a job can contribute to creating an identity and social contacts as well as what is needed to keep a deafblind person on the job market.

The deafblind as resourceful people

Four of the most resourceful informants stress that the project has to show the deafblind persons are also resourceful persons. One mentions that he wants to break free from the "sick person" idea. Another says that he would like to see deafblind persons described as people with resources, interests and experiences, and a third states that he would like to focus on what deafblind persons can do, instead of what they can't.

Practical information about how to communicate with a deafblind person

Several mention that they often come across indecision, that it is frequently ignorance that other people do not show appropriate consideration.

The family must not only be better informed, but must also be supported and be aware of their special role as parents, spouse or children of a disabled person.

In deaf persons circles there could be more information about the specific requirements there are to communicate with a deafblind person.

Professionals need to be aware of the specific problems associated to having a dual disability, which could lead, for example, to special consideration when assigning intervenors.

Subjects for the interviews

The individual interviews have had the following subjects (the interview and reporting guides can be requested from the Videnscentret for Døvblindblevne in Denmark):

1st interview: General introduction:

The family and other social networks, leisure activities, access to news and information, education, work, past history, the specific situation of the disabled person, resources.

2nd interview: In-depth study of social relationships

Who makes up the social network, what significance do the different actors in

the informants' lives have, what is relevant to how relationships are started and maintained?

3rd interview: Education and work with focus on real exercise of functions

What education do the informants, his/her siblings and parents have? Has the informant received the desired education? Does the informant have a job related to his/her training and how is it handled? How are transport, shopping and other everyday activities coped with?

4th interview: Experiences with counselling and support

What does the informant expect from counselling and support? What experience does he have and how does he value it? Does he participate in the support he receives?

5th interview: Focus on the special issues the Steering group wanted to highlight in the project

Isolation /loneliness

Self-esteem/self-confidence

Consideration towards one's own needs versus others needs

Participation versus feeling left out

6th interview: Focus on the project's methodology

What has occurred in the last five years? What significance have the various interviews had for the informant and the consultants?

There have been two issues that have appeared in all the interviews. The aim of one of them was to give the informant the possibility to express what was important "there and now". On each occasion the question "What are you most busy with at the moment?" was asked. The other issue was to highlight the resources the interviewer could see that the informant had.

The project has worked on the basis of the supposition that all people have strong points – they can be eloquent, open, extroverted, have a strong will, have close social relations, an education, etc.

The interviewers have been asked to round off the interview by talking about the resources they have seen in the informants and asked why he/she values the fact of having precisely these resources, for example.

- You receive visits nearly daily, what is it that makes so many people pass by to see you despite having busy lives?
- You have had a hard time with your divorce and your mother's death. Even so, you have the strength to insist on doing your own shopping so that you get out once in a while. Where do you get your strength?
- You seem to be a very pensive person who is good at expressing experiences. Why do you have this ability?

Using this type of questions the informants are invited to reflect on their own strengths and possibilities

Critical review of the methodology

In this section, we explain how the framework and conditions established for the data production of the project can be significant to the narratives that are the basis of this project. We will reflect upon the statements the 20 informants have made, which we consider can be extrapolated to a larger group of deafblind persons.

It is not a matter of arguing to what extent the picture of deafblind persons' living conditions that is described is actually true. We are aware that the narratives are the product of the way we have designed the project. In other words, the narratives are the result of the joint effort of the working group, the consultants and the informants. It is a constructive process where the questions that are asked, the way they are asked, the person that asks the questions and the person who answers are all relevant to what is said.

The quality criterion for the project is therefore not whether it is true or not but whether it draws a credible picture. We have strived to describe the insight we have gained via the many reports with as many nuances and perspectives as possible. Therefore, we consider it to be a credible picture of deafblind persons' living conditions over a five-year period.

Even so, we consider it necessary to point out some of the conditions that have marked the construction of the data in The Nordic Project.

Relationship between interviewers and informants

In most cases, the interviewer was a deafblindness consultant who already knew the informant. At the beginning of the project, there already existed a relationship and throughout the project the deafblindness consultant continued in that role. It is possible that due to this there may be relationships the informant could not talk about. It can also have influenced to what extent and how criticism is expressed. We chose this format because we considered that the informants would feel safer speaking about themselves and their lives to a person they had already established contact with and therefore had experience and confidence communicating with them.

In some cases, an informant found it difficult to speak about personal issues. An informant's eyesight improved halfway through the project due to an operation, and she was worried that talking about it in the project could mean losing compensation.

There was also the risk that the informant would not want to criticise professionals in the deafblindness field in order not to inform the interviewer's colleagues. However, in our view this has not been the case in general.

Changes due to recurrent interviews

It is well known in the world of research that when you measure a phenomenon, you are affecting it at the same time. This fact is particularly valid in the case of sociological studies such as this one. The mere fact of being chosen according to some specific characteristics means that the informant starts to see himself in a different light. The interview situation poses questions that lead to reflection, new thoughts or ways of seeing things, which can change the way of acting afterwards. Both interviewers and informants have repeatedly mentioned that they have got a lot out of the yearly interviews, because they led to thoughts and new relationships in their lives. Compared to the theoretical perspective on which The Nordic Project bases itself, these reflections can be seen as a kind of task to manage the understanding of themselves and develop their own handling competences. Therefore, the interviews themselves could be significant for the collective development of the informants' life situation. In other words, maybe some situations in their lives would be different if they had not participated in the yearly, in-depth conversations/interviews about their lives. We shall mention two examples, which indicate this tendency.

In the first interview 3 out of 20 informants said they had received an Usher diagnosis, but considered that the diagnosis was incorrect. Two of these informants abandoned the project after the first interview. We suppose that one reason for the withdrawal was that their insecurity towards the diagnosis and/or the lack of acceptance of their own disability was overwhelming. Maybe it was too demanding to have to reflect over their situation.

The other example is of a young man who is weak-sighted and severely hearing impaired. In the first interview, the impression that he gave was that he would hardly admit to having problems. The interviewer wrote in the report that she found it difficult to get the informant to go into depths about his life and that she felt that maybe everything would not be as easy as it had seemed. In this case the informant and the interviewer did not know each other at the start of the project. However, through the yearly interviews the relationship became so strong that they agreed to maintain the yearly conversation. The young man said at his last interview:

"Although I have known others for longer, you know me best from the inside as a person, my thoughts, my plans. Others know me better from the outside, in this sense I feel safer with you. At first it was difficult because I did not know you and had to sit and talk to you and give you my flesh and blood...Now it's easier...It has been so difficult to talk about my bad eyesight, but it has been good for me because I needed to practise being honest...When we sat speaking together, it hurt me when I spoke about my sight problems... but after our talks I have got better at saying it... Gradually it has started hurting less. I find that strange, but maybe it's because I understand myself better now, it's hard to say."

Interpreting and translation problems

The interviews were carried out with interpreters/intervenors, except for the few cases in which the interviewer knew sign language and performed the interviews alone. In the cases of hearing informants, solely the interviewer performed the interviews. In a few cases, the interviewer recorded the interview on video and then had it translated by an interpreter. All the other interviews were voice interpreted and transcribed from a tape recorder.

The presence of one or more interpreters or intervenors may affect what the informant wishes to talk about. On several occasions it was observed that the informant refer directly to earlier situations where the same intervenor had interpreted for them. For example, one mentioned that the intervenor had been there when she received her Usher diagnosis and had therefore seen her in a very painful situation. Several mention a more generally the issue of to what extent they trust the interpreters' professional secrecy.

Relevance of the chosen approach

It is important to reflect upon what situations, relationships and problems we have captured with the chosen methodology, and which we have overseen. In other words: have we captured the main problems deafblind persons face? We have strived to do so. At the beginning of the project we drew up the text above based upon the hypothesis about what situations are relevant to people's living conditions and how they could be elicited from specific people. These guidelines have been developed and shaped from one interview to the next, because the many statements gave us continuous insight into crucial problems that needed to be analysed.

Reporting is an interpreting job

There have been several links in the chain of the project. The interviewers have not only signed the interviews, but also elaborated upon them before sending them on to the project leaders. We have therefore chosen to use the experiences and the perceptions of the participating deafblindness consultants (otherwise designated as interviewers) in an active manner instead of considering them a methodological source of errors. In the report guidelines, deafblindness consultants are asked to distinguish between summaries, quotations and assessments. An example of a report would be the following:

What do not appear in italics are the deafblindness consultant's summaries and reflections, while the text in italics is quoted from the informant. In The Nordic Project we have only used direct quotations from the informants.

"Marie's mobile lies next to her and she uses it often to send messages and not less frequently (approx. twice a week) to text her two grown-up children. If they have to say a bit more, the fax is used. The textphone is used for example to get an appointment for the doctor's and once in a while to communicate with acquaintances. The textphone is not popular in the family:

"Since I got the mobile I have had more contact with my children. We can of course write to each other on the textphone or call via the mediation centre, but my children hate it. It is so slow that it can be difficult to contact. It is easier with the mobile, so I actually have more contact with my children with the mobile telephone ..."

Marie also complains about the waiting time and considers that there is not enough staff at the mediation centre and therefore the service is bad.

Comment: "Marie's choice of language and gestures indicate clearly that the text messages are perfectly suited to contact with her young, grown-up children. I actually think that many young people would highly value that their parents (for example the undersigned) adopted this form of communication, as Marie does in this case, where she meets her children on equal footing."

As can be seen in this extract from a report, the deafblindness consultant distinguished clearly between summary, direct quotation and comments/own reflections. In many reports the interview quotations make up between half and a third of the report, so that despite the summaries it has been necessary to make the material manageable as there have been so many pages of interview quotations. The working group has used all these narratives when trying to appreciate the informants' situation or make assessments about a given issue.

Final words

We have now explained the framework of The Nordic Project and some of the participants' experiences of taking part in it. What we have left is the series, which the booklet you have in your hands is part of. In relation to the series, we, the Steering Group of the project and the Informationcenter for Acquired Deafblindness have had to make a series of choices

We decided not to write a single, comprehensive report but instead to present the insight we have gained in a series of booklets, each with their own focus. We hope this will make the project more accessible and therefore more useful for professionals, deafblind persons and their relatives.

We also decided to take the common Nordic part of the problem seriously and assure translation to both Norwegian and Swedish. Hopefully, this will enable deafblind persons in these countries to read it. In addition, we have decided to offer the project simultaneously in Norwegian, Swedish and English, which in part has meant that we have continuously had to send booklets to be translated as they were completed. It is exceptional for a research and development project to be translated and printed before the whole product has been completed. We consider, however, that we have had a sufficient overview of the whole project and the finished project would only have had minimal changes.

The advantage is that now we can present the project at the same time in the countries that have contributed and in that way show our gratitude for the invaluable effort that has been made by many people in Iceland, Norway, Sweden and Denmark.

Summary

The objective of The Nordic Project is:

- To undertake a systematic compilation of the own experiences of deafblind people over a 5-year period,
- To gather insight of the consequences of a progressive hearing and sight disability
- To build up new knowledge, which later can guide the professionals that have to counsel the deafblind, their relatives and care professionals.

This booklet sets out the theoretical and methodological aspects we reflected upon both before and during the execution of the project. Our starting point was the informants' subjective construction of themselves and of their relationship to the outside world. That means that we have focused on concrete lives and the reflections of the informants. The aim was to categorise the descriptions of the aspects related to getting, having and living with a progressive disability. We have based our work on specific theories that have shed light upon the narratives that have emerged.

The Nordic Project has been constructed around six interviews carried out by deafblind consultants and others working in the field of deafblindness. The informants were interviewed over a 5-year period about their daily lives, with special emphasis on how changes were experienced, as well as the resources directed at coping with these.

Interview No 1 focused on a general introduction to the informant's life

Interview No 2 focused on social relations

Interview No 3 focused on education and work

Interview No 4 focused on experiences related to counselling and aid

Interview No 5 focused on issues the informants wished to express in the project

Interview No 6 focused on the projects method

Every interview has laid the basis for a report that has been produced by the project leader in yearly reports.

This booklet also explains the choice of informants and their sight and hearing status, and offers a critical review of the meaningfulness of the chosen method. Finally, there is a summary of the main points from the five booklets that, together with this one, make up The Nordic Project.

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EXPERIENCES FROM PEOPLE WITH DEAFBLINDNESS

- a Nordic project

The Nordic Project is a joint cooperation between the Nordic countries. 20 people with acquired deafblindness from Norway, Sweden, Iceland and Denmark have every year over a 5-year period, participated in interviews about the practical, emotional and social consequences of having a progressive hearing and visual disability.

The result is 6 booklets covering different subjects and containing very personal narratives and experiences of life, which gives the professional world a possibility of discovering or re-discovering the people, that the professional work is pointed at. The booklets talk about what is good – and what does not work. About being in the centre of a rehabilitation process or about the feeling of loosing control over ones own life, and where the strengths and weaknesses lie.

The booklets can be used as a source of inspiration for adapting or developing the work and the services offered people with deafblindness. The 6 booklets can create a deeper understanding of the individual perspective and the necessity of maintaining a focus on each individual person. Finally, the booklets can be seen as a historical cut in time, a documentation of the lives of 20 people.



Information Center for Acquired Deafblindness