

Being active

To be participatory despite a progressive disability

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Publication date:
2005

Document Version
Publisher's PDF, also known as Version of record

Citation for published version (APA):
Olesen, B. R., & Jansbøl, K. (2005). *Being active: To be participatory despite a progressive disability*. Videnscentret for døvblinde.

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EXPERIENCES FROM
PEOPLE WITH
DEAFBLINDNESS

- a Nordic project

Being active

Birgitte Ravn Olesen and Kirsten Jansbøl

*“But it is not Ushers that
determines everything I do in life”*

**To be participatory
despite a progressive
disability**

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

Birgitte Ravn Olesen and Kirsten Jansbøl

Translation by Ability Top Translations



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

© The Information Center for Acquired Deafblindness 2005
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ISBN 87-990212-5-0

Many warm thanks to:

The 20 informants and their
willingness to share their experiences.

The interviewers and all the work,
they put into the project.

The Oticon Foundation, who made this
project possible by their financial support.

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This theme booklet is one of a series of six booklets resulting from “The Nordic Project on collecting the experiences of persons with acquired deafblindness with a progressive disability”. Twenty persons with acquired deafblindness from Norway, Sweden, Iceland and Denmark have annually, over a five-year period, participated in interviews about the practical, emotional and social consequences that a progressive hearing and visual disability has on such aspects as changes in the prerequisites for communication. In the booklets the project is referred to as The Nordic Project to underline, that the whole project speaks about the experiences of people with acquired deafblindness in the Nordic countries – though not Finland.

For more about the project organisation, method and theoretical basis please see theme booklet No. 1, “Theory and methods”.

About deafblindness

All the persons in this study have all become deafblindness as a consequence of Ushers syndrome, which appears as a combination of hearing loss – which can vary from moderate to total deafness – and the eye disease, retinitis pigmentosa, also known as RP, which gradually destroys the retina. Please refer to theme booklet No. 1 to learn more about Ushers syndrome, hearing loss and RP.

Persons with Ushers syndrome are either deaf and have sign language as their native language or are moderately to severely hearing impaired and have Danish, Swedish, Norwegian or Icelandic as their native language. At the same time they have an ophthalmic disease that progressively restricts their vision over a period of several years. Some become blind, but many preserve some residual vision into advanced age.

Some of the participating deafblind persons understand and define themselves as deafblind, but others understand and define themselves as deaf persons with a serious visual disorder, hearing impaired with a serious visual disorder or severely visually impaired with a serious hearing disorder.

They all have considerable difficulties in communicating, acquiring information and being independently active due to the dual sensory impairment, even though the majority

have some degree of vision and even though the participants with moderate to severe hearing impairment all speak the national language.

For the sake of clarity, this study refers to the participants as “persons with acquired deafblindness or the “deafblind”.

The titles of the theme booklets from the project are:

1. Theory and methods – Project outline, theory, methods and empirical data
2. Receiving a diagnosis – Experiences of having a disability and being diagnosed
3. Getting support – The significance of support and advice for self-sufficiency
4. Being active – To be participatory despite a progressive disability
5. Getting an education and work – Getting an education, holding a job and being organised
6. Narratives of everyday life – Narratives about living with deafblindness

Introduction

In this booklet, we will be looking a little closer at how persons with acquired deafblindness work at managing a progressive disability and what consequences they feel it has had on their lives. There is a recurring theme throughout these narratives that the diagnosis of “deafblindness” is not something that one accepts once and for all. When the interviewees have to abandon an activity, a social community or a belief about himself or herself due to loss of vision, they – and their families – must work to find new meaning in life.

Being disabled, however, is not a condition independent of the situation one finds oneself in. On the contrary, a disability becomes apparent in the relationships with other persons and in situations within which one is an active participant. The disability can become paramount and restrict participation, or it may become a fact that gives rise to certain conditions that must be taken into account. There are three factors that determine how the disability is expressed:

- The deafblind persons’ self-awareness, the situation, and one’s own potential.
- The insight/perception of those persons in the immediate vicinity of the deafblind person, the degree of consideration they take and their desire to see that communication is functional, and
- Social support, which can equalise for hearing and visual impairment.

Disabilities and participation

The UN's standard rules for "Equalization of Opportunities for persons with Disabilities" define a disability as:

The term "disability" means the loss or limitation of opportunities to take part in the life of the community on an equal level with others. It describes the encounter between the person with a disability and the environment. The purpose of this term is to emphasize the focus on the shortcomings in the environment and in many organized activities in society, for example, information, communication and education, which prevent persons with disabilities from participating on equal terms.

Thus, the definition used by the UN is relativistic. It is not the circumstances of the individual, but the circumstances surrounding the individual's relationships with other persons, that are in focus. Public policy and legislation concerning the disabled in the Nordic states are based on such concepts of relative disability. The most important concept in this is that a disability is not seen as a characteristic of the person, but rather of the situation. It is the relationship between persons and their surroundings in a given context that is characterised by the word "disability".

A person can have a functional impairment that needs to be compensated by a social initiative in order to avoid the functional impairment becoming an activity-limiting disability. In other words, the focus shifts from "limitations of the individual" to "limitations surrounding the individual".

Thus the word "disability" must be understood both relationally and in context to circumstances. This means that rather than focusing on a person's functional impairment, the focus must be on how the situation can be compensated in a manner that, ideally, can equalise the disabled person with others. Such an understanding is known as the "principle of equal treatment". This principle implies a sector responsibility principle, which means that each social sector has an obligation to ensure equalisation for those limitations that the disability involves. In addition a principle of equalisation is implied, which means that there must be the desire legislatively and economically to equalise for the functional impairment. (Clausen et al. 2004; pp. 34-37, Wiederholt, 1998.)

A large public survey of Danes' attitudes towards the disabled shows, however, that the predominant public understanding continues to be that the disability is tied to the

individual person. This means in practise that persons who do come into contact with the functionally impaired and fail to recognise they are entering into a relationship in which their actions have significance for the expression of the functional impairment, decrease that opportunity for participation. (Olsen, 2000). This has great significance for the opportunity for persons with acquired deafblindness to participate in those relationships and situations they want to be involved in. Before we turn our attention to the interviewees' experiences with participation, we will take a closer theoretic look at understanding communication and therewith what significance communication has for a person's interpretation and comprehension of one's self and their environment.

Communication is what creates our relationships and our view of our selves

It is through communication that we create the social relationships and that makes us participants in the life around us. And it is through communication that we have the possibility of understanding ourselves. We communicate in many ways: through our body language and facial expressions, by the clothes we wear, by our choice of leisure activities, by the way we speak, etc. Communication is thus much more than just words that are spoken, signed or written.

For persons with acquired deafblindness, it is not simply that it is more difficult to speak and listen to other persons. It is also more difficult to notice what one is communicating through such things as choice of clothing, and it is more difficult to interpret others' communication, when, for example, one is unable to read their facial expressions.

As the communication researcher K. E. Rosengren points out, we are in constant communication:

“We also communicate when we, as captives of our physiology, blush from shame or perspire from nervousness. We can therefore maintain that we, as people, cannot be non-communicators.” (Rosengren, 2000, p. 38)

Being able to read a situation and discern what is transpiring behind what is said has a great deal of significance for how well one can react within the situation. Thus, a hearing and visual disability becomes a communication disability. The Swedish researcher in working life, Carin Fredriksson, writes in reference to Jones, Kyle and Wood that changes in hearing strike at the heart of social interaction and thus has both emotional and social consequences. (Fredriksson, 2001, p.1)

She further refers to Noble and Hetu for the observation that a hearing disability is a matter of (biological or physiologic) change that is experienced (psychologically) by the individual in an everyday (social) interaction. Fredriksson emphasises that all three elements must be involved when trying to understand how the disability is expressed in daily life (Fredriksson, 2001, p. 12). This ambition [sic] also forms the basis for the Nordic project.

A great number of things happens when people communicate with each other:

- we give each other information
- we create meaning in that which is taking place
- we regulate the interaction
- we express and develop our relationships
- we practise social control
- we interpret ourselves and our environment in relation to the others' responses to ourselves.

This is why communication with other persons is so important. We'll now take a little closer look at two elements, namely significance of language and relationships.

Language

Words are not merely words that mean the same thing to all persons and in every situation. The language we use has a significance for how we think, how we experience events and how we communicate with each other. One may say "we don't speak the same language" about a person who, even if they share the same native tongue, is someone with whom you disagree or cannot understand. Thus we say that language is tied to experience and relationships. We can more easily understand persons with whom we are in agreement or share experiences – not only concretely, but also from a larger cultural perspective. If one comes from a family where higher education is not common, all else being equal, it is easier to speak with others who come from the same type of family, even if one has never met them before.

One common feature in all the participants' narratives about their use of contact persons and interpreters is that communication flows best when the person that they are communicating with is one they know and have had shared experiences. Thus, a common language is built between persons when they communicate. Therefore it is not possible to merely replace one interpreter with another, even if the immediate task is to translate words from one language to another.

Relationships

New research in communication indicates that when humans communicate with each other they are particularly involved in a process in which they interpret the situation, create meaning out of it and act in relation to the meaning they have created. In other words,

it is in communication with each other that we create our selves and the world around us. (Shotter, 1993; Thompson, 2003). If we treat you like a competent and interested reader, we create a different relationship than if we consider you as incompetent and uninterested. If the social worker meets a person with acquired deafblindness with an expectation that that person has plans for his or her life, she contributes to creating a different situation than if she had assumed in advance that she was forced to take care of the situation.

The context for a situation in which communication occurs sets the scene and has significance for what the other persons will understand as meaningful in what we say or do. Thus communication with others and the possibility of interpreting the situation becomes the key for how we see ourselves. Understanding the situation is really all about understanding the small nuances; if you smile when telling me I'm a fool, you tell me that the statement was tenderly meant. The smile contributes to the setting the context of the situation.

Understanding the situation is also about being able to see or sense, for example, the table manners, or the subject of conversation, of the family one is visiting. The interviewees talk in different ways about how much energy they expend in trying to interpret all that they can neither see nor hear, and they talk about how difficult it is.

The consequence is that they easily feel left out and in error. Several interviewees say that they enjoy communicating with other persons on the Internet, because their disability in the communicative situation moves into the background. The context on the Internet is less complicated (it is defined on the screen) and the interviewees experience being met more equally. This contributes to a feeling of equality.

Narratives about experiences of progression of a hearing–visual disability and its consequences

We shall now look closer at the interviewees' narratives about the significance that their progressive hearing and visual disability has for the preconditions for communication and the opportunities for participating. First, we'll look at the interviewees' own self-understanding, the preconditions for communication and how changes in these influence their relationships with other persons.

Narratives about changes in vision

Changes in eyesight are expressed at different times and in different ways. No one refers to a fixed pattern. Instead, the interviewees describe changes that happened slowly and so gradually that they are not noticeable at first. Inge, age 63 years, and who is deaf with a moderately severe visual impairment says:

“I have been seeing a little strangely the last few years. It is as if persons disappear from my field of view.”

Trygve, also 63-years old, has a moderately severe hearing impairment and a severe visual impairment, first describes his sight, as it is today and then how his visual impairment has crept in:

“The sight in my left eye has almost completely disappeared. I see very badly. I have just a little field of vision in my right eye, but with bad focus. If I see anything, it is just strange looking, but if I look at someone's face, I can't see anything in his or her head; it's gone. I can see an eye, but otherwise there is nothing else in their head. It isn't black or anything, but I see nothing... I now have a very hard time seeing what's on the PC screen and working with it... it began, I think, at the beginning of the year. It comes on slowly, this change, so when it gets to a certain point, you notice that what you used to be able to see you just don't anymore.”

Anders, 21-years old, has a moderately severe hearing and visual impairment and has the same experience that the changes just creep up slowly. He describes how he distinguishes between his own impressions of his deteriorated hearing and sight and the test results he gets:

“I recently had a hearing and eyesight test but... there were changes, of course, but not larger changes than you'd expect with such a disease. I haven't noticed any more problems in day-to-day life or anything since the last interview.”

Changed preconditions for communication

Many of the interviewees talk about how their worsening eyesight indirectly affects their hearing. Borghild, 54-years old, with a severe hearing and visual impairment expresses it thus:

“... because my eyesight has gotten worse, I can no longer really lip-read any more, and this is the way I had been able to hear for many years.”

Linda, 57-years old, with a severe hearing and visual impairment, has been very good at reading lips:

“I could sit on a train and look at others' lips and know what they were talking about. I can't do this any more ... now I need to ask a lot, especially when my husband speaks, because the pitch of his voice isn't right for me.” I don't really want to admit that my hearing is badly impaired, because I really think it is because I can't see lips any more.”

Linda is very light sensitive and feels that she can still manage to read lips fairly well during the day.

“I usually say that I hear better in daylight.”

The special aspect of combined hearing and visual disabilities is that they act together in creating serious communication problems. For example, a narrowing of the field of vision leads to common sign language taking up too much space, and for the hearing impaired a weakened eyesight means that they cannot depend on lip-reading. But, as we saw in the section about the importance of communication for maintaining relationships with others, combined hearing and visual disabilities also have consequences on the possibility to read a situation or mood. Mogens, 57-years old, was born deaf and is now functionally blind, is very aware of how his weak eyesight impacts his possibilities to communicate and its consequences for his making contact with other persons.

“The gradual change in my eyesight has been a very long process. I’ve now come to the point where I can no longer manage to recognise persons with help of eyesight. I used to be able to. I can no longer pick someone out by seeing their face. A group of persons just becomes a large grey mass. When there are many of us sitting around a table, I cannot see who is who. I cannot see and I cannot hear who is taking, and that truly makes it very hard to communicate. I miss the spontaneity and directness of communication. In my situation I am not in direct conversation with others, because – of course – much of communication between persons lies in the possibilities of eye contact.”

Mogens further relates how the necessity of switching to tactile communication makes it harder to communicate with other deaf persons.

“I am losing more and more of the little residual vision I have, and this means that tactile communication has increasingly become my mode of communication... I can no longer communicate with normal signing, and I am more and more dependent on having an accomplice with me ... I feel changes in relation to the environment I’m in. It has become very hard to communicate with deaf persons. Many persons shrink away at the use of tactile signing, or they don’t. It easily results in short conversations with very little content. I only make out the keywords of what is going on around me. I notice that many pull away. It is different in the deafblind environment. It works pretty well there.”

That many are hesitant about using tactile communication can be seen in Inge’s reaction, for example, when she is asked if she can use tactile signing when the lighting is poor. Inge replies:

“No, not tactile signing; I don’t do that. Not tactile signing; I don’t want to do that. I am visually disabled, I’m not blind, you know. I can see.”

Changes in vision have many consequences

The interviewees say that changes in vision have large consequences. It impacts on their possibilities of doing everyday things such as needlework, exercising, playing the piano, and it affects their communication with other persons.

Borghild relates that her photosensitivity has become so severe that she must wear sunglasses indoors when the sun is shining. Her tunnel vision is out of focus and hazy.

It has resulted in her not getting outdoors as much, and that she easily loses her sense of locality. Her deteriorating eyesight causes many problems in daily life.

“Preparing food; because I can’t tell if the beef or meatballs are brown... I have to admit that I have become a little nervous about going out alone on the street. I don’t think people respect the white cane.”

Brian, 32-years old, with a moderately severe hearing and visual impairment and who works at a normal workplace, also mentions problems with getting about. His lateral field of vision has become limited. This means that he doesn’t notice persons approaching from the side:

“It has become harder to get about ... I haven’t walked into anyone yet, but I’m going to sooner or later ... When I leave my office and go into the corridor, I pause before I enter the corridor.”

What is worse, however, is that Brian has problems seeing his year-old son:

“My eyesight’s clearly becoming worse. My little son is everywhere now. I have now walked into him twice hard enough to knock him over.” But – as I’ve figured – he’ll just have to learn – It’s bloody awful. It is maddening. But it only lasts a few minutes, then it is over.”

Brian managed to say quite a bit there. His common sense tells him that his son must learn the necessity of looking out for his father. At the same time he is annoyed, irritated and sad about not being able to see his son. Brian thus mentions problems with walking into or stepping on persons because he cannot see them. His eyesight, however, also has effects for his direct contact with other persons.

“There were many persons at our son’s baptism, and it became so crowded in our house that I had to stop helping out. And when you greet others, you have to look them in the eye at the same time as you shake their hand, and I don’t like it. Most persons now know that I see badly. You feel that there is someone tugging your hand. It doesn’t feel like it is me who decides.”

Petter, who is 33-years old with a moderately severe hearing and visual impairment, provides another example of how communication is made more difficult in pace with the deterioration of his eyesight.

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

Petter’s progressive disability isolates him in growing degrees from the rest of the family’s communications, and it is therefore hard for him to assume the same amount of responsibility as his wife. This applies as well to the other practical duties:

“One typical problem that I am beginning to get is when I wipe off the table after we have eaten. I miss seeing a glass that’s standing there, or if a mobile telephone is lying there – or just some small things left on the table that I haven’t seen, so I knock them onto the floor. It happens all the time, because I can not see whether there is anything left on the table. I don’t see it – and it gets ruined. These are the problems I’ve begun to get.”

Petter goes on to talk about how his worsened eyesight leads to actions that irritate his wife:

“We were sitting and eating. The potatoes were off to the side of my wife’s plate. I reached over and ended up getting a hold of her plate – I myself was rather surprised by it, but my wife really became very irritated – I was sorry about it, because of course it wasn’t what I meant to do, and I’ve experienced this several times—that she gets irritated over things caused by my disability.”

It is hardly by chance that it is just Brian and Petter who speak in detail about what the changes in eyesight have meant for communication with the persons around them. They are both in a phase where their seeing impairment is progressing, with large consequences as the result. Several of the participants have learned to live with and take precautions against the many situations that Brian and Petter are just now finding a way to deal with it.

Eye operations – regaining lost territory

When eyesight deteriorates to such a degree that it has major consequences, it is not strange that eyesight-improving eye operations have a lot of significance. Three participants underwent cataract operations during the course of the study. Johan, age 52 years, and who has a moderately severe hearing and visual impairment, says:

“It has definitely led to an improvement in the quality of my life. It was about the day after the operation that I went for a walk. It was almost like getting a little of my life back again. It was an unbelievable satisfaction, suddenly there were a lot of things I wanted to do.”

Johan continues:

“Indirectly, the change meant a lot. Not only could I get around better, but I also felt more secure than before.”

Marie, who is 48-years old, deaf with a moderately severe visual impairment, also emphasises the importance of once again being able to get about by oneself in the evenings.

“It’s dark at 7 o’clock, and even though the street lighting is not that bright, I am now better able to use it. I couldn’t do this before. Even if the street lights are bad, I can follow the pavement well and see the difference between gravel and flagstones. Before, when I couldn’t see, it all looked the same wherever I went, but now I can clearly see what sort of material I’m walking on.”

To hope and believe in one’s self

As we have seen above, having a combined hearing and visual disability has serious consequences for the individual’s life. It is hard for many to recognise and accept that their hearing and vision is permanently impaired. The interviews show that recognition and acceptance for many are more a matter of a life-long process than a clear point in time when everything is suddenly understood. We see interviewees who in one moment make statements almost in denial of their situation, and in the next moment are expressing much deeper realisations. We also see interviewees, such as Anders, who express how their disability becomes a part of their life:

“It’s completely obvious that Usher affects how I look at life and how I tackle it and how I live. But it is not Usher that determines everything I do in life. It’s not that I confer with the disability and then make a choice. It’s more of a thing I try to incorporate into the rest of my life. No, I am not interested in going around and feeling disabled all the time.”

Several interviewees mention the hope that a medical or technological solution will be found in the future. Brian talks about an ophthalmologist who told him ten years ago that he had type II Ushers syndrome and at the same time expressed great optimism that within a decade a method would be found that would stop the progression of RP. It hasn’t quite gone that way, but sharing the doctor’s optimism has helped Brian in his situation. Petter also refers to the physicians’ optimism:

“They have said that I will probably retain enough eyesight that I won’t become completely blind. And as long as I can keep some eyesight I can keep my orientation, and I believe that to be very important.”

Tonje, 20-years old, and deaf with moderately severe vision impairment express some of the harshness of having a progressive hearing and visual disability:

“My eyesight is always getting in my way in my dreams.”

That Tonje doesn’t let herself be stopped by her dreams being counteracted is seen in her great effort to relearn. She points out that it is important to read as much as possible in these years:

“It is important to get a lot done before I go blind.... In the end, there will perhaps be only a few things left that I can do, and so I just have to accept it.”

Anders talks about how he believes that he has now found a way to live with his disability:

“It wasn’t easy, but I have my own theory that everyone, one way or the other, finds their own WAY. I believe that I have found my own way to tackle this, my way to live with it. But things can always change, of course.”

He adds that one of the things that has helped him accept that his eyesight is deteriorating is that he has read about and seen blind persons who are doing well:

“Even if many blind persons can’t see a thing, it seems that many lead a good life, so I don’t have any extreme fear for, uh, it. But naturally, losing one’s hearing is one thing, and losing your sight is something else altogether. Losing your sense of sight is much more restrictive than losing your hearing. It is in many ways a more serious sense to lose, pure and simple.”

That, in brief, is how Anders talks about how he accepts and lives with the diagnosis he has received. Inge also talks about how she learned to live with a derived problem, tinnitus, which had previously caused her considerable embarrassment:

“... it comes and goes. It’s different, but I am trying to toughen up so that I won’t notice it as much.”

We see “toughen up” as another expression for learning to work with it, adjusting to it and trying to compensate for it.

Individual interviewees talk about how their own acceptance of worsened eyesight led to them adopting new ways to use support. It expanded their opportunities for social contact, such that it was either maintained or improved. The clearest example of this comes from Marie, who chose to use an interpreter at a family get-together and experienced that her contact with her family and friends was more relaxed, because her children did not need to take turns interpreting.

A progressive disability’s significance for self-discovery

We reviewed in the introduction to this booklet how our communication with our environment helps make us who we are. We interpret ourselves in our communication with others. Mads, who is 34-years old with a severe hearing impairment, expresses this understanding of communication very precisely when he says that he sees “self-confidence” as depending on the situation. One can have full self-confidence in one situation, in which one feels equality, but only a short while later can have low self-confidence, because one doesn’t feel oriented and feels left out. Self-confidence is not something one either has or doesn’t, but something that everyone experiences having to different degrees at different times depending on the context one finds oneself in.

We find another example with Linda, who says that it is very important to her how others see her. For example, when she can't find her way back to her shopping trolley at the supermarket, she thinks that other persons must be thinking of her as mental or drunk. This is very unsettling, because other persons' interpretations set the context for how Linda sees herself and relates to them – even when she has no direct interaction with them.

Narratives about self-confidence

In this project we asked the participants about how they view themselves and other persons with acquired deafblindness. Several express that they experience leading a good life with many opportunities despite their disability, but that they see themselves as atypical of persons with acquired deafblindness as a group. There are clearly distinctions in how the interviewees speak about persons with acquired deafblind as a group and how they talk about persons they know with a combined hearing and visual disability.

Tonje sees self-confidence as a characteristic that some have to a great degree and others to a little degree. She considers that she herself has an above average degree of self-confidence in comparison to the “acquired” deafblind as a group, and defines self-confidence as a belief and will to accomplish something. Low self-confidence, on the contrary, is synonymous with being afraid.

For Hilda, who is 44-years old, with a moderately severe hearing and visual impairment, confidence is reflected in how one dares make demands on one's surroundings. She sees a connection between how demanding one is and how much one wants, and feels that the deafblind are getting better at making demands in comparison to 10 years ago, when she began entering the world of deafblindness.

Johan has a third definition of what self-confidence is. He emphasises that self-confidence is something one develops by taking responsibility for one's own life and by finding possibilities in the situations one encounters.

For all three interviewees, their own views of what self-confidence is and how it comes about has a significance for their view of themselves and the demands they put on themselves. Tonje has high demands on herself for being able to manage things, preferably by herself. She is afraid of being weak and not being able to do the same things as her seeing friends.

In her definition of self-confidence, Hilda focuses on daring to make demands on others. Hilde is good at that herself. She spends a lot of energy finding out which opportunities and rights she has and to insist on them. Self-confidence in this connection becomes something that can be achieved, rather than whether one has it, and what one and others can do in respect to altering the situation.

Johan's definition contrasts sharply with Hilde's. He sees self-confidence as something one develops in situations, where one faces up to challenges that one manages to handle satisfactorily. Johan's definition is tied up with his own experiences, in which he has been good at assuming responsibility for the situations he has had to face.

If we look at the understanding of the importance of communication, as we did at the beginning of this booklet, there is no doubt that the understanding of self-confidence represented by Johan provides the greatest possibility for being participatory in everyday relationships with other persons.

There are two themes that recur in comparing the concepts of self-esteem and self-confidence. The one presupposes that self-confidence is needed to make demands on oneself and others, while, conversely, being able to make demands and experiencing success also leads to self-confidence. It is thus a matter of positive and negative feedback loops. The other theme takes up the importance of being in contact with others with the same disability.

Many of the interviewees who are in contact with others with hearing and visual problems mention this contact as very important for their self-confidence. Here they meet similarly minded who understand them and recognise their communication problems. Some mention the importance even back in their school days of meeting others with similar disability as meaningful for the self-confidence they have today.

On the other hand, one individual narrates that it may seriously cause a sense of inferiority when he meets other deaf persons who don't pay attention to him. Finally, there is one individual who himself has a hearing/seeing partner who believes that the cause of the "acquired" deafblinds' possible isolation can be blamed on their deficient interest in making contact with other persons who don't have the same disability. He determinedly chooses not to have contact with other persons with acquired deafblindness.

We have now heard the interviewees narratives about how hearing and visual changes manifest themselves and what consequences they experience in their daily life and the possibilities for communicating with others. Having concluded this individual focus, we shall now examine in more detail the interviewees' narratives on the possibilities for participating with other persons and the community around them.

Relations with other persons – a question of insight and will

In this section we will focus on the interviewees' narratives about how they manage to participate in relationships with the persons around them.

Here, the interviewees relate about their experiences with how others view and think about them and the problems involved in entering into conversations. It is an issue of being a part of the social relationships within the community and remaining oriented in society.

Experiences with others' views of those with acquired deafblindness

When the interviewees were asked how they manage communicating with signing, tactile signing or lipreading, several mention how they feel that others see them. Lone, age 48 years and who is deaf with a moderately severe visual impairment talks about how she feels that others consider her:

"... And it tears at me; I have felt that other persons see me as a little stupid, because I can not see, or not see completely normally. So, they conclude that I am a bit thick, but of course I am not. I have thoughts and feelings like everyone else. But I can notice their attitudes, and it's harsh."

She mentions as an example a visit to a restaurant where the lighting was dim. She had trouble seeing what was being said, and thus had to ask others to repeat what they said. Her need for repetition is understood as if she cannot understand what is taking place.

Some of the interviewees have experience with how important it is that the persons they are together with know something about their disability and its consequences.

Tonje has had problems with acknowledging her visual disability and has therefore often fought to keep it hidden. But she has reached the realisation that openness is a precondition for being able to communicate properly with others:

"It can be embarrassing meeting new deaf persons. I had met with a friend, he was speaking with me, but it was so hard to understand what he was saying because it was so dark. He was wondering why I kept misunderstanding what he was saying; so he thought it over and asked me if I had seeing problems. I said no, but he later discovered

it nonetheless, so I had to tell him that I didn't dare say it the first time. The first meeting was a pure fiasco, I misunderstood so many things."

Trygve has had his experience with how important it is to show other persons how one wants to be taken into account:

"When I was at the chemist with my sister, I asked her if there was a chair. She grabbed me violently from behind and simply spun me around. Of course there were a lot of persons there, and so I felt humiliated. When we came out, I told her how it felt and she understood it well. Later, when we had come home, I taught her, because she wasn't used to leading persons with impaired sight. First I did it like she had. Then I did it properly, showed how she should hold my elbow and lead me to a chair. When we reached the chair, I asked her to stretch her arm so that she had the chance to notice where the chair was. One can speak a little carefully about it. Many persons really want to do a good deed. Naturally, you can not instruct them all, and some can never learn it, even some who work at the hospital have a hard time learning it."

Many interviewees mention the importance of persons in the local surroundings knowing about their disability. Marie has experienced how an interview with her about her disability in a local newspaper lead to positive expressions from neighbours and others locally.

Talking about one's disability can thus be meaningful, but Marie has done more than that. Soft, indoor lighting is a problem that virtually all of the interviewees mention. Should they ask for lots of electric light when the others who are present prefer to sit together in the glimmer of candlelight? Marie talks about how she arranged parties according to her needs, and where there was enough lighting. Conversely, she recognises that activities cannot always take place on her premises, but she then takes care to have an interpreter along so that she can function given the conditions that others set.

Some of the interviewees mention how they sometimes deal with others' surprise when their disability is not so clearly obvious. It can happen when they begin to use a white cane, or when they get on a bus and have a card permitting them to bring an attendant along. This can cause them to stop using the cane or the card. Monica, 43-years old, deaf, with a severe visual impairment, talks about the reaction after a family reunion to which she and her cognitively disabled brother chose to arrive by taxi.

“My cousin called and said that the family was upset that we rode in a taxi at the taxpayer’s expense. It was just like “Well! Just look at how well off the disabled are. We have to pay out of our own pocket if we want to take a cab.”

Lack of understanding can cause a lot of grief. Monica feels that communication with her family is awkward, and when she hears about their indignation she gives up maintaining contact. This has led to Monica’s almost complete isolation outside of her workplace.

Engaging in conversations

We have already mentioned how a progressive hearing and visual disability affects communication with others. Problems with interacting within larger groups are particularly mentioned. In such cases, they have difficulty following the conversation, and the interviewees carefully consider how much special attention is reasonable to expect others to pay them.

Johan relates that he almost never interrupts to ask someone to repeat something. Instead he hears what he can and then asks his wife what they were talking about once they get home.

Two other interviewees mention something similar, namely that they do not think it reasonable that others generally must take special consideration, so they reason that only whenever there is something that is especially interesting or important to them, they ask for the pace of the conversation to be slowed down.

Ottar, who is 46-years old, with a moderately severe hearing impairment and a severe visual impairment, mentions what it is like to sit in the company canteen with his work mates and must ask them to repeat something they say:

“It is something I don’t worry about. As old as I am, it’s not important that I hear everything said. I am resigned. I used to try to keep up during the coffee break, but you give up eventually; you lack the energy to keep asking. You just don’t care. If I can’t hear what was said, I don’t worry about it. If it’s not in a meeting, then it’s all the same to me. But if it is a meeting, then that’s different. Then I ask.”

Others choose to avoid getting into situations where it is difficult to communicate. Robert, who is 48 with a moderately severe hearing and visual impairment, tells how

he decided not to go to a birthday celebration, because his wife could not attend and he didn't have anyone else to accompany him. Similarly, he has quit walking past the workshop where he used to work and greet his old work mates.

Finally, we have Marie, who used to have her children interpret for her, but decided to use a professional interpreter for a large family reunion. She says this about that:

"I got a lot out of that, and my family was so impressed. About having an interpreter there: we have always had to write to each other, and now we could just talk via the interpreter, or as earlier when the kids had to interpret; but they didn't have to this time and we were able to communicate via the interpreter. It was nice to be able to keep up, even with the speeches that were made. Finally, the interpreter said 'It's 11 o'clock now, and I have to be getting home'. I really wanted to keep talking some more, but there was nothing I could do about it."

Many interviewees mention that they prefer not to participate in large gatherings and thus send their apologies to family reunions or large get-togethers such as the deaf association. The need to have an interpreter or contact person available becomes pretty clear. We will return to this in the next section.

Participation via close relationships

Several mention that friends and family are the most important cause of their experiencing participation. It can be anything from the friend who tells the news about other friends, to the grandchildren who pay a visit and tell you that there is a new note in the stairwell.

Others talk about how important it is when – for example – neighbours come by and say hello, and one individual mentioned that she sometimes invites the janitor for coffee and asks him to talk about what the other residents in the property are doing.

Lise, who is 48-years old with a moderately severe hearing and visual impairment, mentions a particular strategy to staying oriented. When she comes to a new place, she asks someone to tell her what is in the room she is entering, where the furniture is etc. In this way she finds it easier to stay oriented and to concentrate on the persons who are there.

Anders mentions that he cannot participate on equal footing with the other occupants. For example, he does not participate in his block's clean-up days, because he "knows he would just stumble over the shovels and rakes".

Linda also mentions that her disability limits her participation. She used to frequently go and swim near her summer house. She doesn't do this any more, because she finds it discomforting that she can't see who is on the beach and thus can't greet them. She waits instead and goes with her husband. Finally, Hilde talks about how hard it is to go shopping, for example. She gets bruises because she bumps into things, but on the other hand feels it is good to maintain contact with the local shops.

Participation in community and society

It is possible to participate in many ways in addition to the neighborhood and society in general, and many express that they feel themselves as participants in life around them, even if some wish that they could be more involved. One important medium for greater involvement is assistance in the form of interpreters and contact persons. We will return to this in the next section.

Participating in the community

Being active in the community, which begins in and around one's home, requires considerable effort. All of the interviewees who moved during the project mention how their residence had to be adapted to their needs. Lise, who has moved in with a man in his house, struggles to have a permanent place for things, light-coloured walls and stronger lighting in the house. Monica and Anna have both moved into newly build housing complexes where they have had to contact the tenants' association in order get better lighting on the front walkway and at the entrance to their flats.

Several interviewees point out that the possibilities for compensatory transport is very important for their opportunities to participate. Taking a bus and then transferring to a train requires that all of their senses be at a heightened state of alertness in order to understand what is happening. Moving about in public space requires deep concentration, which means that even minor shopping errands can be fatiguing. When in addition to that, bus stops are moved and ambulances are flying (which one is not able to hear), the problems can become truly serious. In other words, several interviewees describe how negotiating such daily events require planning, energy and willpower. Some can mobilise what is needed, but at other times they refrain from leisure activities or meetings and visits to friends, because getting there is too exhausting.

One example of the concrete consequences, which changes in the legislation can have for the individual's experience of being able to participate, comes from Norway. During the time that the project was under way, new rules were established that stipulated that the interpreter could not act as a chauffeur for the client. This means that some informants would have to use both a contact person and an interpreter, should they need to visit, say, a physician. Several mention this as a big problem, because then there will be fewer contact-person hours available for using in more leisure-time activities.

One other country has changed its legislation about assisting with the transport needs. Inge has felt the consequences and reports having to withdraw from local societies, because it was too hard to get to meetings, while Ottar is upset about having lost the contracted and known chauffeur that he used to ride with.

Several interviewees describe their strategies for navigating the public space. Tonje talks about how she can still visit her friends despite her bad eyesight. She can take the train to the station where they live and asks them only to come get her at the station. Ottar discusses the fine arrangements he experiences when he needs to fly as part of his job.

“I am picked up by a chauffeur who drives me to the airport where he follows me to the entrance. I walk by myself towards the counter, where one of the staff from the airline company comes out. She follows me to the plane so that I can get to my seat before the other passengers board. I am given the safety procedures in braille, but of course I can’t read them. The stewardess comes with coffee and she has been taught to touch my shoulder when contacting me. When I deplane, I wait until all the others have gone, and again someone comes in and follows me out to the buss and then makes sure that a taxi is called at the terminal.”

Leisure-time activities – an important factor in daily life

Participation in the local community also involves how one is included in activities together with other persons. The interviewees have many different leisure-time interests, and in that way do not differ from the rest of the population in the Nordic countries. They use their time for friends, family, exercise, walking, swimming, skiing, skating, going on holiday, cleaning up, washing, shopping, baking, making jam, knitting, sewing, home renovation, going to the cinema, throwing darts, playing bingo, investigating genealogy, being politically active in disability issues, participating in deafblind organisations or residential associations, reading the papers, listening to the radio, using a computer, etc.

We can see clear differences in the level of activity of those interviewees who hold jobs and those who have all of their time at their own disposal. In most cases, the interviewees who have jobs experience their jobs as so demanding that they do not have the energy for anything else. Besides working, there is of course cleaning, laundry, shopping, etc. Lone describes:

“Sometimes I notice that I can’t be together with very many others ... I get tired when there are many people, because of all that with my eyesight. I would rather do things I can relax with; I read a little, read my e-mail, watch TV in the evening. I’d really like going for a walk in the woods on Sundays, but I don’t have the energy. I have to save my energy for the next workday ... it is not enjoyable to take a stroll alone. I think it is difficult to go to the cinema alone, and –for example – when I read in the paper about an excursion together with hearing persons, I feel disadvantaged because of my eyesight problems, so I don’t go along.”

Lone further explains that she used to have some friends, but she gradually lost contact with them. She has experienced that her bad eyesight has made her hard to be with. The three single, job-holding deaf persons who have become deafblind seem to have no friends. They expend all their energy at work and on practical chores in the home, so that their leisure activities are limited to reading with the help of technology. In addition, two of them participate in annual meetings for the deaf and deafblind.

The deaf persons with acquired deafblindness who live with a partner are more active, even those who have work. This may perhaps be attributed to the social and psychological support they get in daily life providing them the resources to overcome more obstacles. At least two of the interviewees have sole responsibility for the housework, so being two to share the housework is not all that matters. A common characteristic is how everyday tasks take a long time and require considerable concentration. Even simple tasks like cooking food or cleaning up can be completely exhausting. Linda describes:

“I don’t have enough time, because everything takes such time. Like cooking: to read the recipe, to find the ingredients and the utensils I’m going to use and so on.”

The interviewees’ narratives about how demanding commonplace household activities are make it relevant to consider if equalisation in such things as home help can provide the motivation to develop or maintain social relationships.

The single deafblind persons with impaired hearing are all outside of the job market. This leads to more time for leisure activities. For example, Borghild swims once a week and goes to relaxation class twice weekly. In addition, she has a female friend, in whose garden she enjoys. She takes walks in the countryside and likes going out to eat with friends. Generally, Borghild is very frequently together with hearing and seeing persons

at their houses or hers or outside. In addition, she manages all of the practical household tasks at home.

Some of the hearing impaired persons with acquired deafblindness are also active in local societies. This include the chairman and vice-chairman in the deafblind associations centrally or locally, or in the ERFA-Groups. Anna, who is 50-years old with a moderately severe hearing and visual impairment, says the following about working in ERFA Groups:

“I like the work. I feel that it is important and useful, and that I do something for other persons in the same situation as myself. It is very important to me. I am also working for my own cause. I get to talk about my experiences and get to say what I mean about things.”

The interviewees with acquired deafblindness with a moderate hearing impairment and who live with a partner can generally be characterised as very active. Here we find those who point out who important it is for them to remain physically active.

Johan says that before he received a contact person, he could be envious when he met joggers:

“It was like a stab in the heart: I’d think, ‘that could have been me’. It made me sad, not depressed, just sad. Now that I have a contact person I feel that I still can manage some things. I get in a good mood, good-natured and my health is sound.”

Johan now jogs with his contact person. This works by jogging two to three meters behind the contact person who is wearing special, brightly coloured clothing. Linda has not found a similar solution. In the last five years she has given up piano, skating and riding, but she still frequently goes out with friends, a group of hikers and with her husband.

“My biggest fear is to end up sitting still. The most important thing for me is movement.”

Generally, there is a difference in the level of the activity between the deaf and hearing impaired, where the latter group has more interaction with others. The deaf interviewees

who are single, particularly, are characterised by having a sparse social network. It is easier for the hearing-impaired deafblind to find activities they enjoy when they leave the job market. They can speak the national language, which expands their opportunities, but the deafblind always need interpreters in order to be together.

Participating in society at large

Many name TV, radio and computers as very important sources of information about what is going on in the community and that being able to follow what is happening, internationally, nationally and locally is very important. It is difficult to keep up to date in what is taking place in society. Linda explains:

“I read the newspaper in the morning, which steals a lot of time, so I only read the headlines and when there are recipes or something on health and medical issues. It takes time to read the newspaper. I sit by the window; daylight is the best.”

Marin, who is 44-years old, deaf and functionally blind, explains that she has mainly given up her favourite media and now keeps herself informed with e-mail, the Internet—including the newspapers’ web pages and teletext, but it is becoming steadily harder.

“I used to read the paper, but then my eyesight became worse, so I gave it up. But I miss reading the paper, I kept myself informed by reading the paper, so I miss it... football and sports... I now use the Internet, but there are so many photos. I’m not interested in them, so I skip them. I am only interested in the text. I read through the headlines, picking those I want to read, print them out and then I read them on the CCTV. It’s a troublesome procedure that takes up a lot of time.”

Anders and Brian, who both have relatively good vision, say that they don’t think they pick up as much information as others, but they are generally satisfied with the level of information they get when out looking for information. Mogens expresses that his weak eyesight makes it hard to stay oriented, but he is always finding new ways.

“I also have an electronic dictionary. It’s brilliant. It was very hard before to find info with large bulky books, which had to be placed under the CCTV.”

Computer technology must be named in this connection as a central factor applying to opportunities for participation. This applies to short communications or retrieving

concrete info such as train timetables. It applies to e-mail, chat sites and lonely-hearts ads on the net. It applies to ordering goods and communication with caseworkers. And it applies to information about the community via newspapers' websites or websites with more specific information within a special sphere of interest. Several interviewees talk about the significance of how the Internet allows them to communicate without seeming different than the other parties involved.

Feeling participatory in society is also about experiencing that one has choices and will be taken seriously as citizens. Options can include training and career choices, which we will return to in booklet no. 4 "Getting an education and work"; but also include smaller choices such as using interpreter services or transportation options that makes a large difference.

Equalisation – social resources

In this section, we will focus on how various social initiatives can make it possible to compensate (equalise) for a progressive hearing and visual disability, and we shall hear narratives about how apparently small administrative changes can have great significance for the individual's opportunities to participate in the life around them.

Interpreter and contact person – important actors for participation

The interviewees' statements show agreement that progressive visual difficulties lead to steadily more massive communication problems and hence, in continuation, problems arise with initiating and maintaining social contacts.

The difference between a contact person and an interpreter.

Let us first clarify the difference between an interpreter and a contact person. Monica presents a clear picture of the difference.

"I have noticed that there is a difference between using a contact person and an interpreter such as when I go shopping. If I use a contact person, she can pick different things up and show them, and the staff in the shop understands that I am deafblind and I have an assistant. They also retrieve things to show me. If I use an interpreter, it doesn't work quite right. The interpreter is neutral and she translates, and the staff in the shop may be a little uncertain about what they should do and are too busy to assist. I can feel a little stressed out when I use an interpreter. This doesn't happen when I have a contact person with me, so it is really an important difference.

In other words, a contact person function as both one's eyes and ears, and as someone with whom one can have a dialogue with, while an interpreter only translates. The talented contact person backs up the initiatives of the deafblind person and supports her in reaching her own goals.

Many interviewees express the opinion that their contact person is their most essential contact with the outer world. It is the contact person who makes it possible to participate in leisure activities, go to courses or even merely go shopping or pay the bills. One important requirement of a contact person is that she should be neutral. Monica adds:

"I feel that my contact person is super talented, because she is neutral. She doesn't try to influence me or steer me in any way. If I want to have help, she helps, but she doesn't

try to steer. I previously had a contact person who used to work for someone with an developmental impairment, and she wanted to steer me.

Marie also discusses a good relationship with her contact person.

“I am very happy with my contact person. I feel secure, and she tells me a lot of what is going on. She can listen to a little bit of radio and talk about what is happening. It’s exciting and we have a very good time together. She knows everything about social regulations and the local government. It is so nice. I am very happy with her. She leads me to different events, and when I have to go to the doctor, she helps me by interpreting.

Some interviewees feel that the contact person-system has too many rules. They lack the possibility to do something spontaneous and they feel that daily life is regulated when the contact person is arriving. Hilde tells that she easily becomes friends with her contact person and increasingly takes her contact person’s schedule into account, and what her needs are. Perhaps the criticism must be seen in relation to many of the interviewees’ experience of their contact person as something between an employee and friend. It is easy for the boundary to become fuzzy, which can contribute to frustration for both parties.

All things considered, it has to be stated that the regulations governing contact persons are decisive for many. Several interviewees mention the number of contracted hours for a contact person as determining the opportunity to participate in society for a person with acquired deafblindness. Ottar says that there are many communities one is excluded from if you don’t have enough contact-person hours, and relates the example that he naturally has to prioritise shopping over a football match, even if the latter is one way of participating. Johan has reduced the priority on his organisational activity, because there are other things that are more important to use his contact person hours on. Finally, Mads says, that he would go out more in the evenings if he could have an interpreter along.

Interpreter assistance is crucial for participation

The interpreter issue is central for the deaf interviewees, even if their eyesight is good, while the hearing interviewees first have a use for interpreters when their possibility for using lipreading and other ways of staying oriented cannot be supported by their residual hearing.

The deaf interviewees feel that a general lack of interpreter funding leads to isolation and misunderstandings. One talks about, for example, what it is like when she has to correspond with a doctor or when she is at a medical examination; and another discusses how he stays home away from gatherings, because he can't get an interpreter and feels very left out if he attends without one.

The isolation is felt in many ways: For example, Martin says:

"It's a long time since I have been to the deaf association. I cannot go there alone any more. I am basically home every evening. It is hard to get an interpreter in the evening and weekends. They want time off. They want to work daytime. My contact person seldom comes to the deaf association, because he has variable working hours in his other job."

Mads has tried to solve his problems by himself using his laptop computer. He also uses a writing interpreter when he goes to lectures at the local youth organisation, but has now come to prefer his computer.

"I have the laptop with me, and I feel that I have better contact with the other youth, but I feel it is impersonal to write, so it is not as good as sign language. It is easier to make contact with others using the computer than using the writing interpreter. It is a nice feeling. The computer is good, but I am lonely. I used to be active and went to football matches. I now have to watch it on TV. I do not have the same possibilities to choose any more."

It's another example that there can be some compensation along the way, but a massive amount of support is needed if a young person with acquired deafblindness is not to sit alone and isolated in front of the television.

One deaf interviewee talks about how a revision of the country's interpreter regulations means that he can no longer initiate contact with an interpreter, but has to call a centre, which in turn assigns an interpreter. This causes him problems because not every interpreter is aware of the problems the deafblind have, and it is exhausting to meet new ones and make them aware of their situation. Finally, there is the issue of "chemistry". With some persons everything goes smoothly, with others it is more difficult. Again, it is worth pointing out that the greater the communication disability, the more important

it is that the equalisation measures are correctly designed, so that they can contribute to actual participation. The interviewee who uses energy to instruct the interpreter does not get the full return from the arrangement for which he had wanted interpretation assistance.

In one of the other countries during the study period, a national research project has been carried out making interpretation available in all situations in which the deaf blind person felt a need. One interviewee who participated in this arrangement relates that she previously had turned down a cataract operation when she could not cope with it. She has now had an interpreter accompanying her for the last two hospital visits, in which she once again was provided information about the possibility of getting a cataract operation. With the support of a professional interpreter, the interviewee felt that she could make a decision regarding the operation based on a firm foundation, whereupon she decided to have it done. The professional interpreter helped the interviewee to become a participant in her own situation.

A few deaf persons almost never use an interpreter. Lone says that she does not use an interpreter, because she has a need to feel herself free and independent of others. She manages, therefore, with lip reading and spoken language. The interviewer says that she has heard another deafblind person say that she feels freer when she used an interpreter and an escort. To this Lone replies:

“Have you heard that? Well, it is, but completely the opposite from what I believe. What you are saying sounds so positive, perhaps I should try it some time.”

Perhaps what we are seeing here is an example of information that may be significant for Lone’s future. She receives – without any form of pressure – an introduction into another’s experience of using interpreters than the one she imagines. It can set thoughts in motion and perhaps permit Lone to consider using an interpreter, when a opportunity offers itself in the future.

Interpreters and language

The interviewees’ narratives about the use of interpreters are almost exclusively about whether they are available and whether one knows them.

That an interpreter must be available to make it possible to participate on one’s own premises is self-evident. We can note, however, that the interviewees are a long way from

finding it possible to always have an interpreter at their disposal – even for important meetings with doctors or caseworkers.

We wrote in the introductory theory section: That interpretation is not merely about translating words. It is an issue of understanding what the words represent for those saying them. The expression in Danish is “It is just fine”. The expression can mean both “OK, I don’t want to discuss this any more” and “That’s brilliant, I’m happy about it”. The meaning depends on the circumstances, intonation and gestures. The better one knows a person, the easier it will be to capture nuances and communicate the other person’s meaning behind the words. Thus the significance of having a known interpreter at one’s disposal has a greater significance the worse the preconditions for communication become.

Several interviewees feel that not being able to choose among known interpreters is a problem, and some centres assigns them one who may not know their particular situation. Using a known interpreter allows one to develop signs of support, which can help one better understand the context of the conversation the interpretation is a part of, and thus increase the preconditions for communication. In other words, the support signals can provide a degree of compensation for difficulties caused when impaired vision means that aspects of the nonverbal communication are missed.

Participation is about the individual, persons in the environment and the possibilities for equalisation

This booklet began with details about three factors that are significant in determining how the individual expresses a progressive disability.

- The deafblind persons' self-awareness, his or her situation, and one's own potential.
- The insight of those persons in the immediate vicinity of the person with acquired deafblindness, their degree of consideration and their desire to see that communication is functional.
- Societal measures which can equalise for hearing and visual impairment.

We then heard the interviewees' narratives about how they experienced these three factors. We have heard the interviewee's descriptions of how the progression was experienced in daily life, how the visual impairment slowly progressed and how one day it is no longer possible to see the piano keys. Similarly, changes in the preconditions for communication take place at the same rate that the visual impairment progresses. Suddenly, one hears worse, because one can no longer depend on lip reading.

We have also heard how equalisation in the form of contact persons and interpreters have been decisive in being able to participate both in the local community and in the larger society. It is especially the deaf persons among those with acquired deafblindness who are socially isolated and have problems with loneliness when they are not offered good opportunities for contact persons and interpreters.

Compensation in the form of transport support and performing household tasks are offered on widely differing conditions – even within a single country. It is generally expected that those with acquired deafblindness can take care of their own household tasks, which – accordingly – they do. The interviewees' many statements about how demanding these tasks are, especially for those who also have employment, make it relevant to consider whether there are grounds for increasing the degree of equalisation.

Relationships with other persons may be divided into two broad categories:

- These are: relationships with persons one does not know well, such as other bus passengers or other persons attending a meeting; persons one has never met before.

Here several interviewees talk about how they experience being looked at as odd. This is very unsettling and several interviewees talk about how they try to avoid getting themselves into such situations.

- When it comes to persons one knows well, such as family and work mates, the problem is different. This deals with having to constantly assess the degree to which one can demand that other persons be accommodating. Most have given up trying to follow conversations with several participants. Some have the possibility of having the conversation summarised later, but many withdraw from social gatherings, because it is worse to feel alone among other persons gathered together, than to feel alone back home.

Leisure-time activities are important for nearly everyone, especially for those who do not hold jobs. These activities span a broad spectrum and demonstrate that whenever there is a will, there is often a way. The interviewees who do not have leisure-time activities become easily isolated. Once again, it is primarily the deaf persons among those with acquired deafblindness who often are unable to participate in activities for the hearing. It must be mentioned in this connection that the greater the population density in an area where those with acquired deafblindness live, the greater the selection of possible activities. All else being equal, the risk for becoming isolated is greater in less densely populated areas.

Finally, it must be pointed out that there are other forms of compensation than resources for interpreters and contact persons, of course. These forms of equalisation are described in booklet no. 3 “Getting support”.

Worth considering

- It is important for persons with acquired deafblindness to be given permanent interaction with a limited number of interpreters, because this leads to the development and assistance of the communication. Is this problem being paid enough consideration by the interpreters' administrators?
- The interviewees demonstrate great creativity when looking for ways to be able to participate. The many ideas for handling challenges, both large and small, in daily life must be shared – what is the best way to accomplish this?
- There is a connection between where the deafblind live and which possibilities they find for encountering equalising and participating in activities, when taking functional impairment into account. The larger the city, the greater the opportunities – how can this be taken into account in the plans those with acquired deafblindness make for their own lives in both the long and short run?

Summary

This booklet has focused on how persons with acquired deafblindness work at managing a progressive disability and which consequences they feel it has had on their lives. There is a recurring theme throughout these narratives that the diagnosis of “deafblindness” is not something that one accepts once and for all. The interviewees describe how, accompanying the progression of their visual impairment, they have slowly had to acknowledge that there are social contexts or leisure-time activities that they must abandon when they cannot acquire authorisation to equalisation, often in the form of a contact person or interpreter assistance.

We have emphasised in this project that to be disabled is not a condition that one is independent of the context one finds oneself in. On the contrary, a disability becomes apparent in the relationships with other persons and in situations within which one is an active participant. The disability can come to dominate one’s self-image and one’s view of the opportunities and limitations determining one’s development. But the disability can also become a condition that one must relate to actively. There are three factors that determine how the disability is expressed:

- The deafblind persons’ self awareness, his or her situation, and one’s own potential.
- The insight of those persons in the immediate vicinity and their desire to see that the communication is functional.
- Societal measures which can equalise for hearing and visual impairment.

There are large differences in how the interviewees experience themselves and their situation. What is remarkable is that many interviewees say that they have a good life with many opportunities despite their disability. At the same time, they see themselves as being atypical of persons with acquired deafblindness as a whole. They assume that other persons with acquired deafblindness manage things less successfully than themselves.

The interviewees talk about two types of relationships with other persons:

- These are relationships with persons one does not know, such as other bus passengers or other persons attending a meeting; persons one has never met before. In this regard, several interviewees how they feel when others see them as being strange. This is very unpleasant and affects their self-esteem. On the other hand, several interviewees name the Internet as providing fantastic possibilities to meet other

persons on an equal footing. No one sees their disability there, and thus they feel that they have been met with equally.

- With respect to those one knows well, such as family and work mates, the issue is how to deal with having to constantly assess the degree to which one can expect or demand that other persons to be accommodating. Most have given up trying to follow conversations with several participants. Some have the possibility of having the conversation summarised later, but many withdraw from social gatherings, because it is worse to feel alone among other persons gathered together, than to feel alone back home.

This means that equalisation in the form of contact persons and interpreters have been decisive in being able to participate both in the local community and in the larger society. It is especially the deaf persons among those with acquired deafblindness who become socially isolated and have problems with loneliness when they are not offered good opportunities for contact persons and interpreters.

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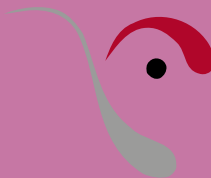
EXPERIENCES FROM PEOPLE WITH DEAFBLINDNESS

- 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