



[EXPERIENCES FROM
PEOPLE WITH
DEAFBLINDNESS]

- a Nordic project

Getting an education and work

Birgitte Ravn Olesen and Kirsten Jansbøl

*“When I was in work
my life was a daily struggle”*

**To get an education,
to have a job,
to organize myself**

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

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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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they put into the project.

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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 the main focus is on the participation in relation to two central areas, i.e. education and work. To be integrated into a society means to a great extent participating in these fields. We will see from the informants' stories how they handle – or have handled – educational or work situations and what social resources it has contributed to compensate for their disability. Moreover, we will describe briefly the significance of organizing themselves and either using the offer of the disability organizations or involving themselves politically in these.

This booklet is closely connected with the book about “Being active”. Here, the problems concerning living with a progressive disability are in focus in a more general perspective. There are more stories about the possibilities of compensation, which contribute to making it possible for those who have become deafblind to act in the world around them.

Participation concerns a survey of the disabled

In this chapter we will first briefly give the reasons for the development of disability policy in the Nordic countries. It is the development of understanding how someone who is disabled can enter into society and the development of organizations, which take care of the special interests of the disabled that we focus on. As an extension of this, we mention FN's standard rules for "Equal Opportunities for the Disabled", where a distinction is made between function limitation and disability. A distinction, which is not made consistently in Danish and Icelandic but is integrated into this. Finally, we introduce an inquiry into possibilities and barriers in connection with the integration of the disabled into the labour market.

A historical look at policy on the disabled in the North.

The policy on the disabled in the Nordic countries has many common features and the development has proceeded on many points in parallel or with mutual inspiration. The following examination focuses on Denmark and is written on the basis of Inge Storgaard Bonfils' article "Historical path and contemporary challenges in the policy on the disabled". (Bonfils, 2003).

In the 18th century the disabled were treated as poor people and therefore was entitled to poor relief with the corresponding loss of civil rights. In the beginning of the 19th century the first private initiatives were taken to establish schools, homes, courses in crafts and domestic industry for blind, deaf and physically disabled people. The initiatives came from philanthropic associations that in addition to contributing to improve conditions for the disabled had the purpose of identifying the area as a field which the public should concern itself with. This strategy succeeded.

Later the philanthropic associations changed from being for the disabled to being member-based interest organizations of the disabled. In the first half of the 20th century a number of disability organizations were founded and in 1934 they merged together into a NGO-umbrella called the Danish Council of Organisations of Disabled People. This made it possible to create a common front and make common demands on the public.

In the Care Law of 1933 it was established that it was the State that was responsible for looking after the disabled and that they could keep their civil rights although they

were under public care. In 1960 the Revalidation Law was introduced and revalidation centers were established all over the country. The thinking behind the law was that physically disabled people should be encouraged to use their ability to work rather than live on public provision.

Between the 1960s and the 1970s criticism of the action on the disabled grew. The point of view was that the disabled should have normal living circumstances and living conditions, which could be compared with the non-disabled part of the population, arose and still applies in public practice. This understanding has since been expressed in the FN's standard rules about "Equal Opportunities for the Disabled", which the disability policy in all the Nordic countries now refers to. Here a disability is defined as a loss or a limitation of possibilities to take part in the life of society on the same footing as others. Disability is expressed in the relationship between a person with reduction of function and his surroundings and the purpose of the title is to focus on defects in the environment and in the possibilities of compensation which society makes available instead of focusing on defects in persons with reduction in function.

FN's concept of disability is described as relational because it is in the relationship between the person with reduction of function and the surrounding society that the disability occurs. Ideally the purpose is seen as compensating to such a degree that the reduction in function does not lead to limitations in development possibilities for the person who has a reduction in function. In the booklet "Being active" we go deeper into the principles behind FN's concept of disability.

FN's concept of disability constitutes a form of value framework. Within this framework specific orders and rules are established, which therefore constitute the individual disability policy content of the country. In the book "Disability policy in the North" from 1997 it is pointed out that the Nordic countries' disability policy has its strengths and individual support. Although the Nordic countries were the first to produce the formulation of the environment-related concept of disability it is still physical accessibility and other society-related conditions for the participation in society of the person with reduced function that are weakest. (NNH, 1997).

We have seen countless examples of the fact that the informants do not always find that the principles behind the FN's concept of disability survive in everyday life. Principles, legislation and lifelines are never better than the people who must administer them in

a specific situation and the economic resources, which the principles implicitly presuppose often, do not exist to a sufficient extent.

Involvement in disability organizations

At the beginning of the 20th century the blind and the deaf in the Nordic countries founded their own organizations consisting of respectively the blind and the deaf. In the rest of Europe organizations were also founded for respectively the blind and the deaf, but the central difference was that in the Nordic countries only the blind or the deaf respectively could be members of the organizations.

For many years the blind and the deaf associations looked after the deaf-blind. But during the 20th century it became clear that if the deafblind were to receive considerably improved conditions they had to found their own associations or organizations. In Norway the Association of the Norwegian Deafblind was founded in 1957. In 1989 one more association was founded in Norway, i.e. the Norwegian Usher Association which changed its name in 1997 to The National Society for The Combined Sight- and Hearing Impaired. Therefore, there are two associations in Norway, which represent the interests of the deaf-blind. In Sweden the Association of the Swedish Deafblind was founded in 1959. In Denmark this happened for the first time in 1986 with the foundation of the Danish Deafblind Association which some years ago changed its name to The Association of The Danish Deafblind Sight- and Hearing Impaired. In Iceland in 1994.

There is no doubt that the foundation of the deafblind associations has meant that the deafblind people are heard in a completely different extent than previously and so they achieve greater influence on conditions which concern the circumstances of the people with deafblindness. Moreover, the foundation of these associations has had and still has a very great significance for the deafblind who are members. This applies both in relation to the creation of identity as deafblind and in relation to giving possibilities for participation in activities together with other people who have become blind and deaf.

A danger of splitting is specially built into deafblind associations because the members use two forms of communication, partly sign language and partly spoken language. Therefore, members cannot talk directly to each other without the presence of an interpreter. These problems constantly concern the members of associations. In Denmark this led to the association changing its name so that it became known as: The

Association of Danish Deafblind Sight and Hearing Impaired. In Norway a split in the Association of The Norwegian Deafblind took place in 1989 with the establishment of the association called The Norwegian Usher Association.

Such a split can be a drawback and it can weaken the effectiveness of the organizations. It can also create problems for the members. Three of the seven Norwegian informants mention the split as a problem several times.

The disability organizations have generally played a central role in the development of the disability policy of the Nordic countries. This can, as a result of the report on "Disability Policy in the North" create special challenges for the organizations. Because of the closely collaborate with the authorities they can experience being taken for granted in a policy, which they disagree with in principle and in practice. The organizations must in other words be able to handle a double role as a partner in dialogue and as an organ of struggle in political interests.

The report also mentions that a general tendency to economic stagnation and the decentralization policy in the Nordic countries create special challenges for the organizations. If they continue to have influence they will have an organization that can act in a decentralized way outside at the local level where disability policy is produced. This makes special demands on the organizational structure and the training of local organization members.

Factors of significance for the work situation of the disabled

An investigation of Danes with experience of reductions in function in the labour market mentions:

- That there is generally a strong motivation to work which gives independence and social contacts
- That insufficient recognition and acceptance of the disability can be a considerable barrier because the compensation arrangements, which can ensure a connection to the labour market, are not carried out.
- That the insufficient professional or social skills can create problems, a low degree of independence is seen as a special problem here
- That persons with disabilities have a low self worth which leads to a low estimate of their own work ability.

The conclusion of the investigation is that psychological factors play an essential role in relation to creating or maintaining a connection with the labour market for the disabled. (Clausen with others 2004; 24) The same conclusion is found from a Danish inquiry from 1964 where the result of a big interview investigation showed that a physical disability can be compensated to a high degree by increased self confidence. The result was used to ground the need for an increased revalidation effort (Rold-Andersen, 1964, here from Bengtsson, 2003; 47)

The above-mentioned inquiries concern all forms of disability, but the main conclusions can also be seen in The Nordic Project.

In The Nordic Project we have moreover seen a problem in the fact that many with an Usher diagnosis first come into contact with the public authorities, which can contribute to staying in the labour market via the compensating authorities when their disability has progressed so far that they themselves have given up the connection with employment, often after several years of struggle to cope with the tasks of work.

We will return to the question of work conditions. Now we will examine more closely the stories of the informants about getting an education.

Education

The stories of the informants about their experiences of difficulties in getting an education and experiences of getting an education tell us to what extent “the equal action principle” is experienced and functions in practice in a particular sector; is there sufficient compensation for the limitations, which reductions in function can lead to, within the field of education?

We will treat the question in two ways. First we will present the information that we obtained when we asked about the educational level of the informants themselves, of their siblings and of their parents. Then we will discuss the conditions for education, what the young informants of the project are experiencing is valid today.

We chose to ask about the educational level of the informants themselves as well as of their siblings and parents because we want to see whether the educational level of the informants differs from that of the parents and particularly that of their siblings. A situation in which the informants, who were all born deaf or with limited hearing in the medium to severe degree, had received a lower education than their parents and especially their siblings, will give a pointer to the fact that “the equal action principle” has not functioned in practice.

The information from the informants led to the following results.

- The educational level of the informants, parents and siblings range from no education to university education.
- Only three informants have no education and neither have their parents, while there was one sibling who had a professional education. The three are aged 50 to 65 years, one with Usher type 1 and two with Usher type 2
- Those who have become deafblind and their siblings have in general a higher educational level than their parents
- Three people who have become deafblind have siblings with a higher educational level
- Six people who have become deafblind have siblings with a lower educational level
- Ten people who have become deafblind have siblings with the same educational level as themselves.

In general we can conclude that the inborn disability has not played a role in the educational level achieved. In the meantime several mention that they chose or had to choose precisely that educational level because of their disability and the limitations that it creates. Several mentioned that they had dreamed of another education than the one that they received.

The result surprised us. Immediately, we can find two explanations for this. One is that the group of informants is not representative of the group of those who have become deafblind in general. But we have no reason to believe that this is the case. The age distribution of the project – with very few young people who have become deafblind and several people who have become deafblind with advancing age – corresponds moreover to the ordinary age distribution in the group of those who have become deafblind in the North.

The other – and we assume – more important explanation is that the moment in time for the reduction in sight was only in the case of one, perhaps two informants, seriously, already in youth. For the other informants the reduction in sight only became really serious at the employment-active age, i.e. in the 30s, 40s and 50s.

We also know that the historical basic idea behind the establishment of blind and deaf institutions in the middle of the 19th century was to give the blind and the deaf an education so that they could as far as possible feed themselves. Since the end of the 2nd World War it has been the norm in the Nordic countries to give everyone an education as a pre-condition for and necessity in a welfare society.

Here we find good explanations of why most of the informants have received the same or a higher educational level than their siblings. On the other hand, they have not experienced having the same possibilities of choice as their siblings. Some say that they chose – or were offered – an education taking their disability into account. This means that they received an education that the professionals thought would enable them to cope with their deafness or reduced hearing. That was – and remains – the situation for people with a disability.

Several informants have experienced both the ordinary schools and schools for the deaf – it appears in their stories that they felt a great relief when they came to a school with similar children and young people as them self.

We will now follow an individual young informant who has had experiences of the advanced education system.

Signe's story about getting an education

In the five-year project we followed closely the experience of one of the young informants with education. Signe is 18 years old when we meet her for the first time. She has a hearing and sight reduction of medium severity. Signe went to the ordinary primary and lower secondary school until the 10th class, which was not always equally easy. Now she has gone home to go to the upper secondary school where there is a class for people of limited hearing. She lives in the college and has a steady lover who also has limited hearing.

Signe has chosen to take the upper secondary school over 4 years instead of the usual 3 because it takes a lot of energy to read. She is well satisfied with the decision but thinks that it is difficult to stay behind when all her friends are looking further out in life. She uses an FM device when there are more than two other pupils to be taught.

Signe gives in the first interview the impression that she is doing very well at school, she is coping well and has almost decided to read further. She would be happy to go to university where she will be able to further her interest in psychology. She also thinks that with exactly this education she will be able to support other disabled people. Moreover, she considers that the better her education is the greater are the possibilities to gain a place in the labour market:

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

In the 3rd interview Signe has finished the upper secondary school and is doing well in the study of psychology at the university. It is a big study, which in the first year is organized on lectures for up to 100 students.

Signe was before the start of the study in contact with the consultancy office of the aid centre for students of reduced function and the study guidance bodies of the upper secondary school and the university. They were involved in the move from one college to the other and the organization of study. Moreover, she has used the experience of her student friend.

Signe herself has done much to prepare herself for the beginning of the study:

- She is preparing to meet the study guidance department where she presented her requirements which she formulated after talking with friends of limited hearing about their experience of studying
- She has gone around the university district many times before the beginning of the study so that she can find the location where the lectures take place and how she can find her way around
- She looked around and was given a portable computer which she can bring to lectures
- She has ensured the reservation of a place in the auditorium, the presence of an FM device

Signe says that she has also been offered compensation, which she did not think she needed.

- Interpreter or companion in connection with studying activities
- A special light next to her place in the auditorium
- Something else that she does not remember.

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

“It is fine to find out what possibilities exist. I think that I know what is best for me. And it is not the professionals that know that. The professionals know a lot and have a lot of specialized knowledge but at the end of the day I know best myself what works in practice.”

Signe thinks in general that she receives the best advice from her friends with reduced sight or hearing. “The professionals give themselves time to listen to her, they are eager about everything and bring their own proposals for solutions

“Without doubt those that I learn most from both socially, educationally and in all ways are the others with a disability.”

Signe has therefore largely taken the initiative and is in control in relation to the arrangement of her studies. In the beginning it also looked good. The lectures take place in rooms where a tele sling is installed and Signe has a reserved place in the front

of the room. But problems soon arise. The lectures move to other rooms without Signe seeing the note about this decision, the note with “reservation” is often removed and some lecturers move around the room and do not want to use a microphone during their lectures. Signe gradually gives up taking part in the lectures and tries instead to read the material up by herself. She herself considers that school tiredness is more to blame than her disability:

“I feel that the university is right for me but I do not know whether I feel that I can cope with educating myself just now.” I went to school for many years, perhaps it is that I am suffering from school tiredness.”

At the fourth interview one year later Signe has left university behind her. She now has a temporary job while she waits to join a course in social consultancy. She has found a school that has experience of students with reduced function, which is small and therefore can be seen easily and where there are relatively few students in the classes. She is contacting the school to find out whether it is interested in a pupil like her.

Signe seems relieved to be held up in the study of psychology, but that is also connected with sorrow:

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

She sees the social advisor’s course as a good compromise. Her desire to use her education in relation to other disabled people can be kept and she still wants to take a course that brings her into close contact with other people.

Signe’s story about her educational experience shows that it is not possible to compensate to such an extent that she can take the course that she wants and, taking everything into consideration, has the ability for. There are several reasons for this. Some have to do with the choice and estimates which Signe herself undertakes, some have to do with the insufficient follow up of the arrangement of her studies.

In booklet 3 “Getting support” we introduced you to Hart’s “Ladder of participation” (Hart, 1996), which we processed in relation to this project. In the model the focus is on the involvement of the client or the professional in various phases of a process from the formulation of requirements to the evaluation of the initiative. We will now place this

model over Signe's story about her university studies to see who was active when and with what consequences.

S stands for Signe, P stands for Professional.

Areas of decision making	Definition of need	Pre-conditions and resources in the individual and in society	Choice of action/ strategy	Evaluation/ Follow up
Form of co-determination				
Client initiative Joint action	S has chosen an education, P backs up and supports the practical arrangements			
Client initiative Client action	S prepared herself thoroughly and has a great influence on defining her own needs and relevant practical arrangements		S prepares herself thoroughly by getting to know the university area	S finds out that the piece of paper which reserves a place can often not be found and so takes care to come so early to lectures that she can find a place at the front
Professional initiative Joint action	P at the previous school establishes contact with the study guidance at the university	P has general experiences which he shares with S and which lead to action on areas that S finds relevant	P sets up various compensation initiatives which S finds relevant	P organizes an evaluation of the use of microphone, reservation of a seat and information to the lecturer, but it is not followed up.
Professional information The client accepts	P indicates a social consultant's course and S recognises that this is a good possibility			
The client is not involved				If there is a follow up/ evaluation S does not hear about it. She learns only that the good advice that she experienced at the beginning is not followed up in practice in her everyday life and that this creates problems.

It is often said to be ideal to go as far up the path of involvement as possible. The best of all is if the client's initiative is followed up by joint action. Signe's story can in the meantime give a reason to make this understanding subtler. We are direct witnesses of a story of how the professionals back up a client initiative and a number of needs indicated by the client. But the story does not end happily (Signe had to give up her studies), so there are reasons to look more closely at the roles of the different actors. It can seem as if Signe's wide overview and social skills lead to the consequence that the professionals do not follow up sufficiently, either when they have to listen to Signe, when for example she does not want to use an interpreter, companion or blind secretary, or when the initiative which was arranged has to be followed up. The question that we will leave open is: Would Signe have had greater possibilities for completing her university studies if the professionals had shown more initiative and perhaps been more co-ordinated in connection with not only the start up but also the follow up of Signe's course of study?

Signe's experience is not unique

We had four young people in the project, apart from Signe there were three other informants who had experiences of so-called integrated education, i.e. education in ordinary educational institutions. Two of them left during the project.

Mikkel is 19 years old at the start of the project and has a hearing and sight reduction of medium severity. He is just beginning to study law and tells us about the start of his time at university:

"We were more than a hundred persons in the group. When I stood up – it was very difficult – but I said that I see and hear badly and so if someone wonders why I behave a little strangely it is because I have difficulty in hearing and seeing and so he can come and ask me. If I had not given that information things would have gone badly. It is better to make things clear from the start. I felt that as soon as I had said that everything became much easier. I can indeed give the environment a chance. So, I did not have to use more energy experiencing strange looks. It is clear that they do that anyway."

Later Mikkel says:

"You always feel on the outside, that is nothing new. I have felt that for a very long time – I am always different from the multitude and so I always feel on the outside."

He is in a considerably worse position than Signe as regards to the support at the beginning of his studies. Although he asked early for aids such as a special light and a portable computer he did not manage to get these things before the end of the first semester. Mikkel also gave up his studies after one year.

Gry is 21 years old, she is deaf and has a medium reduction in sight. Gry works as a teaching assistant and would like to be educated as far as possible so that she can become as qualified as possible for her work. But she says:

“I do not want to educate myself just now. I am tired of it... but there were many problems before when I went to a hearing school. The teachers thought that they knew what was best for me but they did not know. The two years at school became so tiring and I still feel it inside myself... I do not want to be in contact with them, nor with the pupils, none of them”

Gry’s previous experiences frightened her and in the light of Signe’s and Mikkel’s experience it is clear that there will have to be a goal-oriented effort if Gry is not to experience a failure on the day that she begins an educational course.

Finally there is Anton who is 17 years old and goes to a school for the deaf where we meet him. He is deaf and has a reduction in sight of medium severity and is making plans for his future. Anton would like to build bridges. He wants to become an engineer. Apparently there is no-one who examines together with him what is involved in becoming an engineer or perhaps support him in finding other ways to find work in the field that fascinates him. Instead he lives with his a dream that no one seems to take particularly seriously.

Briefly, the stories indicate that changes must take place in the guidance system for young people who already have serious sight problems in youth if they are to have a chance of completing a desired educational course. It is largely left to themselves to have an insight into how much their reduction in function and the existing compensation possibilities make their desires realistic. They must also deal by themselves with informing themselves about their studies and obtaining relevant aids and taking the initiative in evaluation and follow-ups. The result is shown below.

Who has the task of supporting young people with a combined hearing and sight disability in the choice of education and employment? And what professional qualifications have these professionals both for educational guidance and guidance in relation to a hearing and sight disability and for following up the educational course.

Labour market

“For every person it is important to receive recognition in several fields and working life is a very important part of life in today’s society. “

So says Anders who is 21 years old with a hearing and sight reduction of medium severity who expects to make an active contribution to the labour market after the end of his education.

Ottar who is 46 years old with a hearing reduction of medium severity and a serious sight reduction says:

“I do not think that I know a single deafblind person who works until the age of 65. He is stopped earlier.”

Both statements are central to the experiences, which the informants talk about in relation to the labour market. On one hand it is very essential to have work to feel a part of society, on the other hand it is so tiring that many stop in their 50s.

We will now look more closely at the experiences of being active in the labour market and here too focus on what possibilities the informants find that there are for participating in society.

First a brief report on the informants in the Nordic project’s connection to the labor market: Two of the 20 informants are in education and therefore have not yet had a chance to be connected to the labour market. Of the others, 18 have been in the labour market, but for one 34-year old only in a long-term practice initiative. Two of the women, both without education, left the labor market when they got married and had children. All the others have been in the labour market for 10-25 years. Seven are still in work but one is classified as long-term sick. They are 32-48 years old and they all have an education, from professional to longer-term.

Two of the informants who are now pensioners have worked in the project period at finding or creating jobs in special conditions. They did not succeed. One of them decided after a work testing course that she no longer wishes to look for work, while the

other continues to try and at all interviews he returns to the situation in which he finds support in being integrated into the work market in special conditions for less money.

It is worth mentioning that 6 out of 10 deaf people are in work, while only three out of 10 people of reduced hearing are in work, of these one ceased work during the project, while another is undergoing training.

The eight informants who are in work or have been in work until very recently were employed in the following categories:

- Work in relation to others with a sight or hearing disability (4 informants)
- Work in an ordinary work place (4 informants)
- Work independently short time in a new professional area that follows from a progressive disability (1 informant)
- Work in a protected workplace (1 informant).

For each category there are some problems in relation to participation, which we will now examine more closely.

Work in relation to others with sight and/or hearing disability

Some informants have a job that is connected directly with their double qualification as both having become deafblind and professionally qualified within the specific field.

Ottar worked previously for 17 years as an electronic mechanic in the same company. Now he is working in schools and associations for the disabled. He is employed full-time in ordinary conditions of pay and he thinks a lot of his work:

“I must next thank the disability for the fact that I have this job which I have today and which I am doing very well in.”

He emphasizes the aspect of the work that he likes, that his efforts are significant for other disabled people. In the position that he occupies, he can help others to move on with their lives. Ottar has over time had his work arranged for him, and so it becomes his need; not too many journeys and transport, willingly granted days of work at home etc.

Lone who is 48 years old, deaf and with a reduction of sight of medium severity, works as a teacher in text treatment for the deaf 3 whole days a week in ordinary payment

conditions. She teaches 4 persons at a time and passes around among them most of the time and explains while they sit at the computer. She has problems seeing the screens against the light and thinks that the new edb program has fewer signs. Lone is very alone in her teaching and misses more contact with colleagues. Transport to and from work is by train and takes approximately an hour. The three days with full working time mean that Lone will go to the school and back in the rush hour. She says that she is always very tired when she gets home. Lone would like to work less but the workplace insists that she must work 50% and it has not been possible to distribute the burden of work more evenly over the days of the week.

Monica is 43 years old, deaf and with a serious reduction in sight, works as an accountant at the Association For the Deaf. She works three days a week from 9-13 and is very glad about that. In the meantime some structural changes mean that she is uncertain whether she can keep the job.

Finally, Tonje who is 20 years old, deaf and with a reduction in sight of medium severity, works as a teaching assistant at a childrens home for the deaf. Contact with the workplace was established via Tonje's deafblindadviser, but Tonje remarked in the conversation that her reduction in sight will not create problems in relation to the job. She wants to ensure for herself the best possibilities to get the job. Since then she has been able to go back to the manager because she can see that she needs some special consideration to be taken. For example, she is allowed to come late and go early in the winter time because she can only use public transport when there is enough light for her to find her way.

The only common denominator between Ottar, Lone, Monica and Tonje is that their work is directed towards others with sight and/or hearing disability. The very different conditions which Ottar and Lone have are particularly noticeable. When Ottar succeeds in organizing a working life which takes account of the special conditions which are connected to his situation, Lone must struggle with a number of situations which make her working conditions particularly difficult. Tonje can risk getting into the same situation if she does not persuade the workplace of her special needs and find that they are taken into account. Work related to other disabled people is therefore no guarantee that there is special provision in the workplace for specific needs.

Work in an ordinary workplace

Brian, who is 32 years old and has a hearing and sound reduction of medium severity

works full-time in ordinary conditions of payment as an engineer. He is afraid of being a bother because of his disability. He experienced recently an example of what this can mean. He had problems for a long time with his computer screen, which changed colour and flickered. He assumed that it was his sight that reacted differently from usual and therefore did not notice it. Only when a systems expert happened to see his screen and remarked that the screen was not right, did he ask for a new one.

Brian does not use special aids in his work. In fact, the Job requires that he himself can drive out to customers, but when his driving license was withdrawn, the manager made a work arrangement, which means that Brian always has a colleague who can drive a car with him when he is out. In the period of the project Brian applies for a job as a middle manager. He does not get it and thinks that it has something to do with his disability.

Martin, who is deaf and has a very serious reduction in sight, works full-time at a big company. He has been there for 23 years. He finds the work itself trivial but thinks that there are no other possibilities. He has never accepted an offer of further education that could widen the field of work. The work consists of accepting orders for goods and noting the remaining stocks. He carries out this process with a powerful magnifying glass when the material must be found and a magnifying screen (reading television/CCTV) when the remaining stocks must be noted. Moreover, he has a computer and a text telephone. Martin cannot communicate with the other employees in the workplace because they do not know sign language. This implies almost total isolation in the workplace. Only in the period of the project does he have a vibrator installed which can alert him in the event of fire.

Martin takes a bus from work. He has several times asked for a taxi both ways because the bus journey is very tiring.

Mogens who is 57 years old is deaf like Martin said and has a very serious reduction in sight. He works part-time as a furniture upholsterer and is supported in the workplace by an interpreter/guide and a guide dog. He has good contact with the manager and is glad for the work. He goes to and from work by bus where his guide dog is his only support.

Finally, we chose to invite Johan who is 52 years old and has a hearing and sight reduction of medium severity and belongs to the group that was active in the labour market until a few years ago.

Johan worked full-time in a post office in ordinary conditions of pay for 23 years until his sight became so bad that he had to stop. He managed to function as a manager for a number of years. His recognition that it was not possible to remain in the job came slowly both to him and to the management, and he chose to leave in connection with some considerable restructuring. After he stopped working at the post office Johan took another educational course (see the next category), which has given him new work possibilities.

Again, the situation and the conditions are very different for the four informants. Brian copes without special consideration, but struggles to make the (very ordinary) demand to work because he is doubtful how far his need is acceptable. It does not seem that there is in the organization a formulated appointment policy, in which it has been expressed for example how flexible it is desired that the workplace will be.

Johan has - like Brian - functioned in ordinary conditions as an official and then as a manager. Johan's story about work gives no insight into how far a compensating initiative could have secured for him several years in the labour market. He mentions only that the last year was a daily struggle.

Mogens and Martin are both, as admitted, deaf and with very serious reductions in sight and they both work in ordinary workplaces, after all they come from the same country. But, this is where the similarities stop. Their work situation is highly influenced by the support, which they receive - or do not receive. While Mogens with support from an interpreter/guide and a guide dog has a working day characterized by professional pride and an experience of belonging to the workplace, Martin is isolated and describes his work as characterized by routine without the possibility of development. Here therefore there is a clear example of what significance compensating efforts have for how far the person of restricted function can participate in society.

Work as a self-employed person on short term basis

Johan has, since he stopped working at the post office, taken an educational course as an alternative handler. He has had his own practice for several years in which the customer base was satisfactory, until his sight became much worse. He thinks that this can be partially explained by the fact that there is a lot of competition for orders, partly that potential customers may have seen him with a guide dog and therefore considered that his sight is too bad. He has now - after a successful operation for cataract - made

contact with the municipal caseworker with a view to getting a job in special conditions. Johan would like to work 2-3 days per week and could imagine himself being connected to a company or department (for example the municipal home helps) where he could treat health problems through alternative handling and advice. He has not yet received a reply to his application.

Johan communicates without problems with the outside world by telephone and can also follow ordinary conversation if not too many people talk at the same time. He arranges transport for himself to known places and feels, after the operation for cataract, secure enough to take the bus because he can see the number and the text.

Johan's high level of initiative is specific and goal directed. He is still finding new ways and knows the surrounding society so well that he can manoeuvre in it. But in his experience he cannot get the backup that he needs. Johan is looking for a high level of coordinated effort for people with a double disability as regards to their admission to the labour market.

Work in a protected workplace

Robert is 48 years old and has a reduction in hearing and sight of medium severity. He worked as a mechanic for 15 years until his field of vision became too restricted. He lives in a sparsely populated area and therefore has only been able to get new work at a protected workshop where the other employees are of restricted development or mentally ill. It was in the beginning far from satisfactory because Robert felt insecure with the other employees who have unmotivated sounds and movements. After a while he made good contact with the personnel which made him much more satisfied with the work situation.

Robert's work situation is characterized by the fact that there is no obvious supply of work in his near environment. He was very glad for the work as a mechanic and the social relations that he had in the job.

Work gives identity and the possibility of participation

For informants in work the job is an essential part of their identity. The informants who stopped working all say that they experienced it as a big loss and several had serious mental breakdowns in this connection.

At the same time several give the impression that they saw no other possibility than to give up because they felt that it was unacceptable to function at a “lower” level because of the reduction in sight. Ottar says:

“It is a bit insulting to work as a disabled with a payment subsidy etc. and the help round about makes you feel dependent on others.”

He refers specifically to the fact that he was not considered as having full working capacity in spite of his big work effort. Others give the impression that they could not compromise with having another role in the workplace as their sight worsened. One informant functioned for many years as a middle manager. She struggled to cope with the task in spite of the progress of her sight reduction and is giving up because she can no longer live up to her own ambitions and demands in the job. Therefore it is not necessarily the workplace that does not want to keep the person who has become deaf-blind, it can also be him or her that gives up.

The working conditions of the informants are very different. It seems that it can be relevant to talk about good and bad circles in relation to working life. Some people experience one or another degree of acceptance of their person - in spite of the disability. This experience means that they expressed their needs, the needs are respected and they receive increased respect. Ottar and Mogens are in this situation.

Others feel that there is no basic respect for the individual in the workplace. They have perhaps never drawn attention to their special situation and so no one knows that they have special needs or they simply do not express what needs to be taken into account. It is possible to function in such a situation for many years. Brian could risk having a working life characterized by uncertainty and stress because he finds to some extent that he must hide his disability.

Other bad circles can occur if they try to express their needs but find that they are not recognized, as Lone finds, or simply give up expressing what they want because their experience of not being understood is so frequent. A situation that Martin will perhaps confirm with a nod of his head.

The last condition in relation to the work situation will be briefly mentioned, i.e. the experience of the informants of having a double disability. One woman describes very

precisely what a double disability can mean. She worked for ten years in the archives of a big company. She found that she was put in the archives because she was deaf. At one time the company employed one more deaf person. Then she found that the other employees thought that the other deaf person was far better while she could not keep up because of her double disability. Again it becomes clear how important it is that the workplace should make clear the degree of flexibility and its manifestation in practice and that the employee can, in spite of his disability, express his needs so that they can be taken into account.

Three informants have been connected by their work to others with the same or a similar disability (paid work for the association or teaching). In the meantime it does not seem that such an arrangement ensures conditions that take account of the special disability of the informant, which Lone's situation witnesses to.

Lone's situation is also a good example of the fact that having a job is so tiring that the person cannot take part in activities or build up social contacts outside working time. This helps to make the loss of the workplace more serious.

We will close this chapter with a story about Annika's working life because from this we get an indication of the problems that many informants have talked about.

Annika's working life

Annika is now 44 years old. She has a hearing and sight reduction of medium severity. She lives alone and now receives a pension. She went to the ordinary primary and lower secondary school and completed her schooling with a two-year secretarial course. Before that she had obtained work for some years as a home help. Annika was employed at the local town hall where she gained experience in different areas. After three years she was offered a position in a newly established aid office. Here she created her own job:

"It was not long before I could not do without it."

Annika soon found out that work in normal conditions was too hard. She worked gradually 10 hours a day to achieve what she previously could have done within the normal working hours:

"I slaved away and worked the seat of my trousers off to achieve what I had to."

Annika was offered a pension but held onto the job on short time. This meant a lower rate of pay which was a problem because in the meantime she had been separated. This situation functioned for 9 years but ended by being too great a burden:

“One day I went to one of the officials. I was the secretary for two people, and that was actually the most distant of them. So I said to her:” I can hardly bear this any longer. I am going to pieces inside. I felt as if I was torn apart inside. I am now forced to have some help.”

Annika gave up her secretarial job which were both a relief and a lack. She got instead a less tiring part-time unpaid job at the Deafblind Administration. This work suited her well because she could maintain social contacts and had something significant to concern herself with. After two years in this position the arrangement was terminated and Annika changed completely to a position as a pensioner.

The days can be long and Annika tries to fill them with free time activities and courses but must also admit that she often sleeps a lot of the day away, watches TV and needs energy to deal with housework at home.

Annika’s story witnesses that there is a long way to go before it is possible to compensate for a disability so that the person of restricted function can keep his work. The move from being employed in normal conditions to being employed with pension payment takes place relatively pain free but after that there is no constant follow-up in relation to how Annika’s disability is progressing. Only when Annika is on the edge of a breakdown is the matter taken up and the result is that Annika leaves the labour market.

At first this is not considered as a disaster because there is a possibility to keep an identity as a productive person by voluntary work for the Deafblind Administration. There is therefore a constant social offer, which can compensate for Annika’s reduction in function and her story witnesses that this compensating arrangement is very important for her sense of herself and everyday life.

Economic savings mean in the meantime that this situation is terminated and Annika is now, at just 44 years old, transferred to an existence as a pensioner.

Involvement in organizations for the deaf, the blind and the deafblind

Many informants are involved in activities connected with organizations for deaf, blind or deafblind people. Some have paid work in the association administration.

Involvement in organizations takes place at different levels. There are among the informants people who are and have been active in management work, others take part in communication work as information officers or in a theatre group while most take part in activities organized by associations for the deaf, blind and deafblind.

Management work

Anna who is 50 years old with a hearing and sight reduction of medium severity was for a number of years the vice president of the management of a deafblind association. She says:

“I like the work. It is important and useful that I am doing something for others in the same situation as myself. It is very good for me. I am also working for my own sake. I can talk about my experiences and can say what I think about things and matters.”

In this way she expresses a general experience among those who are active in management work. They experience both doing something for others and for themselves and receiving something from participating. For Robert, who lives very isolated, work at the management of the deafblind association means that he gets a chance to meet others in the same situation. They see each other rarely but after they learned how to use e-mail contact can be maintained between meetings.

Some informants participated earlier in the work of the association but gave it up. Trygve who is 63 years old with a hearing reduction of medium severity and a serious reduction in sight gave up participating in the management of a blind association, gave up because he was tired of argy bargy:

“They talk only about themselves. Everybody seems to talk about him or herself. It became too much. So I think that it is better to be at home at leisure and talk to myself. So I get the answer that I want.”

Others talk about gossip and unfriendliness as the reason why they do not come to the local deafblind association and finally a deaf informant says that he experiences a hierarchy in the deafblind associations:

“Those who sit at the top of the association have restricted hearing and do not experience the same problems. There is a big difference between the deaf and those of restricted hearing. People of restricted hearing remain dominant, they are only good at talking. We the deaf cannot make progress with our wishes and needs. We are completely overruled – the others only talk and talk.”

Finally someone says that he thinks the active people in the organization remain a kind of professional deafblind people:

“The people who have something to do with the association are people for whom the association takes up so much of their lives that they know little else.”

During the project period he joined in the political selection at the deafblind association because he was asked directly whether he wishes to make a contribution there. He says that he would be happy to contribute if someone thinks that he has skills which can be used but he does not want just to sit and talk.

Three of the seven Norwegian informants express in different ways that they find it sad that there are two deafblind organizations. One of them expresses it like this:

“I could indeed wish that there were more and better contact inside the deafblind world. So that younger and older people with Usher would have better contact. We have much in common and could contribute much to each other. There is much suspicion and hostility today and it rubs off on new members who join that world.”

The informant also says that he thinks that several younger deafblind people find it threatening to see how the reduction in sight progresses. At the same time she thinks that many young people could enjoy meeting older deafblind people and see that it is possible to live an active and involved life in spite of a progressive reduction in sight.

Communication work

Several informants take part in different forms of communication work. They go out

and talk about Usher and the everyday life of the deafblind in different connections. This can be at educational institutions and on courses for other disabled people. Some also take part as teachers on courses for shorter or longer duration.

Finally some function as assistants in arrangements in the association or as group leaders in experience groups.

Some informants say that because of their association work other deafblind people come to them both to get information about specific rights and to discuss more private matters use them. Ottar says:

“In the deafblind association you can get good advice about what rights you have. Often it is easier to talk to someone with the same disability than to an employee of the social administration.”

Lone confirms that it can be good to talk to others in the same situation:

“I made contact with the deafblind association when I found out that I had that diagnosis. I think that I drew strength from having contact with others with Usher. It is difficult to talk to persons who have not experienced themselves what they want to say and get a diagnosis”

Activities of the association

Almost all the informants participate in activities organized by deaf, blind or deafblind associations.

The activities extend from holidays and courses via weekly leisure activities such as riding and swimming to experience and conversation groups. The informants who live in areas where there are activities which they can participate in express great satisfaction with them. The activities contribute to creating content in everyday life and many find new friends in situations similar to their own.

Borghild who is 54 years old with a serious reduction in hearing and sight talks about the special arrangements in the deafblind association:

“It is something completely different from being together with normally sighted people. It is clear that a lot of good results occurs when everyone is together in the same boat.”

The more thinly populated the area is where the informant lives the more he is welcomed to the organization and the activities which now exist in the neighborhood. For some this means that the local deaf association is the only possibility to meet other users of sign language. But when the visual disability progresses it becomes difficult to stay. A younger deaf informant who struggles a lot with loneliness says:

“I feel alone in the deaf association. There is too little attention to signing and when the deaf do not take notice of me I feel inferior.”

It is characteristic that it is the 5 people with the weakest social network, which do not - or do to a very limited extent - use the offer from deaf, blind or deafblind associations. They say that they feel outside if they do not take part with an interpreter or contact person or that they cannot get started.

A single younger informant who is still in work says that he does not want to make contact with the deafblind association and its activities. He finds that his situation is different partly because he is younger than the average, partly because he still has both sight and hearing intact. At the same time he needs to know others in a situation that is similar to his. He noticed this when he met someone in the same position on a course arranged by the Blind Association.

Organization means participation in several ways

It is clear that the deafblind associations have a great significance for the deafblind to be able to participate. They have significance as a sounding board for a group of citizens who can otherwise be easily overlooked and have significance as a social gathering point for people with hearing or sight reduction and their relatives.

Being organized in an interest organization can be seen as an expression of collective participation. Here there are people who themselves have problems with hearing and sight reduction in their lives and who undertake to draw attention to what social contributions exist if participation in society is to be a possibility in spite of reductions in function of different kinds. They can on the basis of their own experiences or the experiences of others formulate demands in the arena of disability policy and can support the individual in formulating his own demands in specific situations. Both parts contribute to creating attention around the deafblind.

In the meantime an equally important function is to organize activities for the deafblind. Almost all informants have participated or are participating in activities of the associations and express great satisfaction in and profit from meeting others with experience similar to their own.

Participation in education, work and organizational commitment

The stories of the informants about their experiences in the primary and lower secondary school are often characterized by suffering. It was difficult for people of restricted hearing who were considered as a bit stupid and clumsy in the primary and lower secondary school to feel anything but on the outside. But also for the deaf who found at the deaf school that many conversations went over their heads and that others found it troublesome to involve them.

When we considered the educational level of the informants and their siblings we can see that their congenital disability did not mean that they received a lower education. On the other hand several remark that their choice of education was characterized by their disability and the limitations that it creates. Some say that they had dreamed of another education than the one that they got.

The stories about getting an education indicate that - in spite of a big effort from both the young people themselves and from the compensation institutions of society - it is particularly difficult. The problems occur at several levels but most fundamentally guidance is lacking on how much their reduction in function and the existing compensation possibilities make their desires realistic. They lack support to inform them about studies, to receive relevant aid and to take the initiative for evaluation and follow up.

The informants who are in the labour market have very different experiences. It is remarkable that 6 out of 10 deaf people are in work while only 3 out of 10 people of restricted hearing are in work, of whom one stopped work during the project and one other is in education.

We find it equally remarkable that the conditions in which deafblind people work have nothing to do with whether he or she has work in relation to others with sight and/or hearing disability or has a job in an ordinary workplace. An assumption that workplaces in relation to others with sight and/or hearing disability takes particular notice of how it can pay attention and compensate for the reduction in function, is not proven by the stories.

In both types of workplace some find that they are listened to and attention is paid to them while others find that they must adapt themselves as best they can and otherwise they are not welcome.

For informants in work the job is an essential part of their identity. The informants who have stopped work all say that they found it to be a big loss and several had serious nervous breakdowns in that connection. At the same time several give the impression that they cannot see another possibility than to stop because they did not feel that they could live up to their own desires and ideals when the reduction in sight progressed.

Finally we can see in the case of some informants in work that it is clear that the job is so tiring that they struggle to cope with the housework and have nothing left for any form of social activities. This makes them extremely vulnerable on the day when they must give up the connection with employment.

Some of the informants are active in organizations and almost all take part in activities for the deaf, blind or deafblind. The commitment extends from actual management work via information work to participation in travel and leisure activities. In general there is satisfaction with what is offered on the part of the informants who live in the areas where it exists.

Worth thinking about

There is a close connection between where the deafblind people live and what possibilities he/she has to find education or work conditions which can take account of the reduction in function. The bigger the village community the greater the possibilities.

Involvement in organizational work is giving both for the individual himself and for the group of deafblind people. Important experience is exchanged and converted into political demands to improve possibilities for participation.

Young people with a combined hearing and sight disability need support in connection with a choice of education and employment. What professional has professional qualifications for both educational guidance and guidance in relation to the hearing and the sight disability and to follow up the educational initiative?

For deafblind people in work the work effort is often so tiring that there is nothing left for any form of social activities. This creates vulnerability when they give up work. Could compensating arrangements for example a home help for parts of the housework ensure that there was something left over for social activities so that there was something to build on on the day when the job had to be given up?

How can it be explained that the majority of the deaf deafblind people are in work while that is not the case for the deafblind of reduced hearing?

How can we ensure the establishment of a connected initiative with action plans and evaluation procedures in collaboration between the deafblind and the professionals?

How can we ensure that workplaces that employ people with deafness and blindness have sufficient knowledge of what attention they can pay and what compensation possibilities exist?

Summary

In this book the main focus is placed on stories of the deafblind about getting an education and having work. Precisely these two fields are so central in the Western World that access to them has a decisive significance for the possibility of feeling like a participant in society. It is through the specific stories of the informants about their experiences in the education system and in the labour market that it becomes possible to see how the social resources create in practice a possibility for participation or hinder participation.

Stories by the informants about getting an education witness to the fact that there are many struggles to be fought. In general the informants achieved the same or a higher educational level than their siblings. The congenital disability therefore had no decisive influence on the educational level achieved but for some the disability was limiting for the choice of education.

The young informants show again that the work involved in getting an education is a solitary and tiring business. The problems occur at several levels but very fundamentally guidance is lacking about how far their reduction in function and the existing compensation possibilities make their desires realistic. They lack support for information about studies, they lack relevant aids, which are known and ready at the beginning of study and they lack a coordinated and a following up authority that can support them on the way.

The informants who are in the labour market have very different experiences. It is thought provoking that 6 out of 10 deaf people are in work while only 3 out of 10 people of reduced hearing are in work.

The 9 informants who are in work have different types of jobs. 4 have work in relation to others with hearing and/or sight disability, 4 have work at an ordinary workplace and one works in a protected workshop.

We can see from the stories by the informants about their working life that the conditions under which the deafblind work have nothing to do directly with whether he or she has work in relation to others with sight and/or hearing disability or has a job in an ordinary workplace. In other words no particular attention is paid to workplaces where there are others with sight and/or hearing disability. At both types of workplaces some find that

they are listened to and attention is paid to them while others find that they must adapt themselves as best as they can or otherwise they are not welcome.

The main reason for stopping work is most often that the informant himself does not feel that he can live up to his own desires and ideals when the reduction in sight progresses. We can see in the case of some informants in work that it is so tiring to do the job that they struggle to do the housework and have nothing left for any form of social activities. This makes them extremely vulnerable on the day when they must give up the connection with employment.

Finally we considered the stories of the informants about organizing themselves. Participation concerns individual possibilities in everyday life but it also concerns possibilities for contributing to setting the agenda of disability policy. The Nordic deafblind associations have great significance for the possibility of the deafblind to participate both in the role of sounding board for a group of citizens who can otherwise be easily overlooked and in the role of organizer of social gathering points for people with hearing and sight reduction and their relatives.

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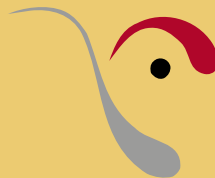
EXPERIENCES FROM PEOPLE WITH DEAFBLINDNESS

- 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