

Receiving a diagnosis

Experiences of being disabled and of being diagnosed

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EXPERIENCES FROM
PEOPLE WITH
DEAFBLINDNESS

- a Nordic project

Receiving a diagnosis

Birgitte Ravn Olesen and Kirsten Jansbøl

*”I honestly had no idea
what it was”*

Experiences of being disabled and of being diagnosed

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

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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

From disbelief to terrifying certainty

In this booklet we will focus on what it is like to have a disability without knowing your diagnosis; you sense that something is not right, you always seem to be more clumsy and slower than others, and you might be seeking an explanation yet nothing is certain. Later we move into the stories from people with acquired deaf-blindness, of how they were diagnosed and how this led to shock and grief, yet for some, it was also a relief to have a clarification.

The stories demonstrate totally different reactions and actions before and after a diagnosis has been made, and it becomes clear how important it is the how you received a diagnosis of such significance as well as how old you were when it was made.

In the beginning of the booklet there is an introduction to the concepts we found relevant for the work with the topic in this booklet. It is not important to be acquainted with this terminology to benefit from the informants' stories, so if you are more interested in the stories, please go straight to page 13.

The concepts, which are introduced in the following pages relate to comprehension, coping and recognition. These terms are pivotal for understanding the very different stories about being disabled and being diagnosed that we have come across during the project. A common denominator for the three terms is the assumption that people when hit by sudden and/or inconceivable incidents try to re-establish some kind of equilibrium through their actions. This can be physiologically, socially or emotionally. The actions can be directed either towards yourself or your surroundings, and they can be of both practical and perception building nature. Dependent on how you grasp what has happened, this process can be about rediscovering a purpose in life, regaining your social roles and functions in order to handle practical chores despite the disability.

Comprehension, coping and perception building are all notions used to describe and understand how people handle the unexpected. The unexpected can be either positive or negative; winning the lottery or being diagnosed with a disability, suddenly things are not the way they were and in order to carry on, it is necessary to adjust to the new set of circumstances. An unexpected stressful incident can seem like an injury, a threat or a challenge. According to the medical sociologist, Aron Antonovsky and the American psychologist Richard Lazarus, the way we face up to a stressful incident will depend upon our earlier experiences and on our social, cultural and financial circumstances.

Comprehension

Together with the notions of “manageability” and “purpose’, comprehension forms part of Antonovsky’s theory about “Experience of Context”. For many years, Antonovsky researched how certain people overcame resistance, crisis and violent incidents without succumbing. “Experience of Context” is the result of years of research. As a result of this, he perceives an experience of life as purposeful, conceivable and manageable to be significant for how a human being reacts to stressful situations.

Antonovsky points out that a person with a strong experience of comprehension expects that the stimuli she will encounter later in life are predictable or at least that what happens by surprise can be included in a context and be explained. This means that as a starting point is the assumption that problems can be structured and understood. Even upon being diagnosed with Usher Syndrome, she manages to transform chaos into order. She might do an internet search for further information, look up people who are suffering themselves, she might try various supplements, look for a therapist or something totally different. This does not mean that being diagnosed is something acceptable or meaningful, but that the stress involved with being diagnosed becomes easier to handle. The person who has no experience with inconceivable things happening in life is more likely to remain in chaos; she will give up any attempt to understand and act in accordance with her situation and only relate to the emotional problem.

Antonovsky describes how someone who generally has some experience with the fact that life and its challenges are manageable will react differently to someone who has no experience at all. The former will react with sadness, fear, pain, anger, grief and worry if she is given a serious diagnosis, while the latter will react with anger, rage, shame, despair, abandonment and confusion.

“What distinguishes these two emotional complexes is that the first equips the person with motivation to act whereas the other one paralyzes. In the first group, emotions are focused while in the other they are scattered...it is apparent that the focused emotions are more unitable with the perception of the problems being conceivable. Moreover, it is more probable that the focused emotions will activate coping strategies, whereas the scattered emotions will lead to unconscious defense mechanisms being raised.” (Antonovsky, 1987, 152)

According to Antonovsky, having experience with incidents that are both conceivable and manageable will make it easier to gain access to the real situation or real problem with which you are faced. This notion becomes essential in the stories about having lived for years for years without understanding why you were a bit different.

Coping

In the above, Antonovsky is using the notion “coping strategies”. Richard Lazarus uses the term “coping” to describe the way in which the individual manages his/her present situation. Choosing a coping mechanism is a dynamic process that varies over time and will depend upon the individual’s view on the situation. Overall, Antonovsky distinguishes between two types of coping: the problem focused and the emotion focused.

The problem-focused coping comprises deliberate actions with a view of resolving a problem. It is used both when you believe that things can be changed and when you accept a given situation and work on your emotional reactions in order to resolve this. In brief, when you face up to the problem and act accordingly.

The emotion-focused coping is not aimed at resolving the actual problem, but rather at altering the experience of it. This can happen by insistent emphasis on the positive side of the situation or by avoiding situations that could confront you with particular problems. Finally, the emotion-focused coping occurs when the individual creates some distance to the situation – “I cannot deal with the problem right now. I am going for a ride”. The result of creating this distance might be that the individual gains control, and will be able to use the problem focused coping later.

It is important to understand that it is not about weighing the two types of coping strategies up against each other, about one being better than the other. It is more about knowing yourself and your surroundings well enough to identify which strategy that will be the best to handle the stress that you are faced with in the now

To cope with a situation means to manage it in the present. There is no concealed assumption that the chosen strategy will work long term. Coping is not an individual process, detached from the environment of the individual. On the contrary, research shows that the scope, frequency and timing of the support given all are key factors as to how the individual can cope with their situation.

Recognition

The American sociologists, Corbin and Strauss have developed a theory about how people learn to live with a chronic disease. It shows how people who are diagnosed with a chronic disease have to create a completely new perspective on life and a new image of themselves. They draw attention to the fact that the required work involves repairing the interruption of the person's history and expected life perspective, and that the objective of this work is to restore control of your life and to rediscover your purpose.

Corbin and Strauss focus on the non-medical consequences of being diagnosed with a chronic disease and describe how there are aspects of experience and opinion which impact on social relations and practical conditions that are at once separated from the disease and part of it. They describe in depth an effort which consists of handling life's challenges, big and small; finding purpose in life, in spite of the disease.

Dealing with the diagnosis requires acceptance of the situation. This acceptance can be articulated by talking about yourself in a non-devaluating way about your own social identity and by emphasising activities of particular value. Acceptance is not an isolated process for the individual, to a very large extent, it will also depend on how the environment reacts. Acceptance and the conversion of values are developed as a joint effort by the disabled person and her near surroundings.

In literature, acceptance is mentioned as something that is either connected to resignation or to an altered way of thinking and reacting upon a change in one's circumstances. Resignation is linked to surrender and passivity, whereas an altered way of association is emphasising the fact that acceptance lead to new ways of reacting. As the Swedish sociologist Carin Fredriksson puts it:

"Acceptance should be seen as a re-evaluation and knowledge which have an impact on your daily life". (Fredriksson, 2001, p. 29)

In this connection it is worth mentioning that the Swedish researcher in rehabilitation, Ann-Christine Gullacksen, through interviewing people suffering from chronic diseases, has experienced that for many people "acceptance" equals coming to terms with your disability. She uses the term "acknowledge" about the phase that happens prior to acceptance. This involves having acknowledged that there are things you are unable to do without really having come to terms with your situation (Gullacksen, 1998).

In the above, we have described some theoretical concepts explaining how people find purpose and a balance in life. We will now move on to the stories told by the people with acquired deaf-blindness in this project, and how they reacted when receiving a diagnosis that also includes a progressive loss of eyesight. We will focus on the elements that were important for finding purpose and developing an identity that could incorporate the diagnosis.

Experiences of having impaired hearing and vision without knowing your diagnosis

Many informants talk about how they sensed that something was not right when they were children and how this feeling had an impact on themselves and their surroundings. 33-year-old Petter who has a medium-strong impaired hearing and vision tells us:

“The first trouble with my vision, I remember, was already as a child when we went out to make fun on New Year’s Eve – at the time I could not keep up with the others when they went to ring door bells. You had to hurry away again, and I couldn’t do this as I was night blind...I did not think about it at the time”.

In a similar way, 54 year old Borghild who suffers from a serious hearing and visual impairment, relates how she was wondering as a child:

“I have never understood why I could not catch the ball when we were playing different ball games. I have legs like a football player because I was forever bashing into things. At school I was always called clumsy...oh yes, I have done a lot of bashing in my time”.

Both Borghild and Petter felt different without knowing why. Many more have similar stories about how they were perceived as odd or clumsy and how their childhood was full of problems with being mocked, feelings of being a total outsider, and withdrawal. Having an impaired hearing and vision has for many created difficulties in developing and maintaining good social contacts during their school years. Mads will talk about this. He is 35 years old with a serious hearing impairment. As a child he went to a special school for the deaf. This is how he remembers this:

“I received very little support. They didn’t know how to communicate with me. They used big signs, but ought to have used small ones. Some were good...many knew that I didn’t see very well, but they were insecure. We weren’t such good friends. They knew that my vision was poor, yet I didn’t manage to understand this. We talked very little. Well, yes they did speak a little. It might be because they did not know how to communicate with me. The lighting and distance was bad. I got psychological problems...Due to my shyness I received very little attention. My mum and dad lived far away from there.”

Lone who is 48, is deaf and has a medium strong impaired vision. She talks about how she herself withdrew from her mates because she was unable go out with them in the evenings:

"I was out with others, but felt that there were quite a few things that I couldn't take part in and so quite naturally, I ended up staying behind at the school. I didn't go out much when it was dark without realising why. I ended up staying in while the others went out. I feel as I have lost a large part of my youth."

Lise is 48 with a medium strong impaired hearing and vision, she tells us that she did go out in the evenings, but upon reflection realises that she did take her precautions.

"I started having problems with darkness. I went out anyway, but probably only to places I knew...when I went for an evening walk it was always in the company of others...I didn't need anyone to hold onto, I could walk normally."

Lise describes how she from an early age started using compensating methods without really being conscious about it. By making sure that she went to known places or was in the company of others, she adapted to the poor eyesight and managed to follow her mates.

48 year old Marie who is deaf with a seriously impaired eyesight recalls how it felt to be mocked, although after changing schools, she also learned how meeting pals who had similar problems made it possible to exchange experiences to better understand what was actual wrong.

"The other school mates just teased me. You have a reduced peripheral vision, you can only see what is ahead of you – in fact I was not even aware of it myself. But then there was this boy in my class, I could see that we had the same problems and that the others didn't. When I moved to another specialised school for the deaf there were even more who had it, Usher, and in this way we could share our experience. From this I learned what Usher was. So, in reality it was the mates who helped me, oh yes, my mother didn't tell me enough. It was too painful for her to explain."

Marie says how significant it was for her to meet other people with similar experiences and problems like her own, and how some of what used to not make sense suddenly did.

Lack of Comprehension

The stories we hear are quite normal. The older the interviewed person with acquired deaf-blindness is, the more likely it is that we hear a story about how she herself sensed that something was wrong, yet she didn't look for neither did she gain insight into the reasons why. Antonovsky assumes that "comprehension", to understand yourself and the world around you as purposeful and cohesive is a very important prerequisite for being able to act in accordance with your own needs and desires. What Marie is talking about is exactly that comprehension. Neither she nor others like her can grasp why they cannot be like others and this leads to a lack of self-worth and withdrawal from social contact with other people. This is especially prominent in their youth during which time practice with establishing and developing social relations is of particular importance.

Anna who is 50 years old and has a medium strong impaired hearing and vision is one out of a large group of sisters and brothers of which many suffer from Usher Syndrome. Her story is slightly different:

"I remember that we were out playing hide and seek, it was dark and I couldn't see anything. As far back as to the age of seven have I lived with this condition. When we went for walks we were completely dependent upon one another. We always tried to be two together so that we could hold hands and help each other, support each other in the dark. We assumed that this was normal.

We felt quite normal. This was the way we were yet others didn't necessarily have to be like us. People are different..."

Anna and her brothers and sisters experienced not to be able to see anything in the dark as normal because the others around them felt the same. Likewise, she only had her first hearing aid when she was in the 7th grade at the school for the deaf. Anna's story demonstrates how important it is how the environment perceives your disability. She felt like everyone else and did not suffer from feeling inferior to others. Monica who is 43 years of age and deaf with a seriously impaired vision has a similar experience, not because there were others with Usher around her, but because her mother showed her respect long before it was known that she was disabled due to her vision.

"I remember this as if it was yesterday. I was three years old. I was sitting outside on the bench in the dark. I was waiting. My mother who was sitting in the light from the front door lamp expected me to get up and walk around, but I just sat there. I felt safe..

My mother called me and expected me to come to her, but it felt hard to do it in the dark. Finally my mother came to me and we walked away together.”

Had Monica’s mother told her off and demanded her to come when she was asked to, told her that she was clumsy etc., then her experience of being disabled would have been very different from the one we hear.

When you feel that something is not right...

All the informants have sensed that something was not quite right before they were diagnosed. The results of this have been varied dependent on the individual. Many, especially the older ones amongst them, have experienced feeling clumsy and as outsiders in social circles. They have not been able to understand why they were unable to be like everyone else and for some, this has involved giving up on partaking in social activities and as a result they have no experience with social communities. A few can talk about how they, despite of the incomprehension – managed to act in a way that made it possible for them to have a social life. This is true for the 3-year-old Monica who is sitting there waiting for her mother as well as for Lise who in the company of her friends just takes a few precautionary steps.

Some of the interviewed people with acquired deaf-blindness have since found out that their parents knew about their diagnosis long before they did themselves – and they experience this as a big disappointment. We will hear more about this in the following.

Shock

Unsurprisingly, a majority of the people who were diagnosed as youngsters or adults were very shocked. Many went through the feeling of being totally alone with an immensely deep loss to reflect upon. Lone tells how she was diagnosed when she was 30 years old in connection with seeing an eye specialist, when she needed reading glasses.

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

Lone then says that she later found out that her mother received the diagnosis when Lone was 18, but did not tell her. It has required and still does require a huge effort to move on. Lone tells about the time when she was first diagnosed:

“I experience that everything can be black and depressive, it is true. I have been sitting

here with no inclination to do anything at all. I am just sitting here in my flat all on my own. I understand how the situation is, yet I have no strength, but I must just fight my way through. There have been a lot of situations like this.”

For a long time, Anna herself had been trying to find information about what could be wrong. When she was 33, she contacted the doctor in the nearest big town because her vision in the dark was so bad that she even had problems seeing anything on grey and rainy days. This however did not get her anywhere. 9 years later she found another doctor who referred her to a specialist who then told her that she had Usher type II.

“I did not understand what kind of condition this was. What it meant. Then the doctor told me how it was developing with an increasingly poor vision, especially in the dark, turning night blind and that I would end up not having a good peripheral vision and that this was linked to my hearing. When the doctor told me that I was well on my way to become night blind, I was shocked. It had a very strong impact on me. I cannot live with that! ... I was in shock. I found it very difficult to understand. Would you really be able to live like that? Why did it have to be me? I have questioned if something like that could happen to me. I was thinking about all the lost years and the uncertainty I had lived with. What was this? If I had found out earlier, it is obvious that I would have done much, much more with my life. Now my vision is so bad. I no longer feel like doing anything.”

Anna is talking about this 7 years after being diagnosed, and is expressing how it still requires an effort to realise why she had to be hit by a hearing and vision disability on top of having to reach 43 before being certain about what was wrong. Anna explains how she would have chosen to do things differently if she had known earlier that she was suffering from Usher type II. It has been a loss for her not to know the diagnosis:

“I mean it could have been discovered earlier, and I could have received help earlier. It really is sad to think about. The doctor could have referred me to a specialist earlier. That is exactly why we have this system. My whole youth is lost. All the mocking and the teachers who didn't understand. It was nasty! Sometimes I am thinking that I should have written a letter to the local council to let them know about my situation and about how I have lost my childhood and my youth. They could pay for a trip around the world for me allowing me to use the rest of my vision to learn something, to have more impression and experiences. They do owe me. I could get compensation.”

Anna has not been acting in accordance with the bitterness she feels. Maybe this is due to the fact that she has managed to move on from the initial feeling of total loss of purpose. She is telling how she initially gave up but then subsequently decided to fight for a good life.

“In the beginning there were these two days but then I started to reflect, to look out of the window, reflected and started using my common sense, and thought that life must carry on in spite of poor hearing and vision. Slightly later, I came into contact with the Vision Institute and noticed all the supports and even tried some of them, and then it was as if it seemed easier...after several visits to the Vision Institute I pulled myself together and then the doctor helped me find a psychotherapist. This helped me look at the situation in a different light, at least initially. However, it is actually the work that I have had to do myself during this time that has helped me.”

Accepting your disability can be a life long process

Anna’s story contains many different coping strategies. Initially, she describes the feeling of total loss of purpose, which cannot be changed so it disappears once and for all. For Anna and others who suffer from a progressive disability, it can be a life long process to understand and accept such a serious disability. After the initial shock has disappeared, Anna explains how she becomes aware of support aids and the psychotherapist and thus exercises “problem focused coping”. She doesn’t give in, and works in a determined way to create a new purpose and find ways that compensates her disability.

Anna is talking about how painful it was not to have known about her disability when she was younger, whereas Line who is now 35 and deaf, expresses how shocking it was for her to be diagnosed when she was 16. The context in which she received the information – at a school for the deaf by one of the employees, far away from her parents and without being prepared – this all made the situation totally unbearable for Line:

“I was told that I had Usher when I was 16. It wasn’t my parents who told me. It was one of the people from the residential ward who told me. He told me that I had Usher. I was shocked. Many of the other people who worked there got angry with him because he had told me. I can’t remember exactly what happened. I do recall meeting him there. I was in shock and I cried a lot...it was a very strong reaction... Then I had an appointment with a psychotherapist. It was all extremely serious and very sad, and I was in shock”.

The interviewer then continues to ask Line why she was so shocked, what exactly it was that the employee had told her?

“He didn’t say very much at all. He talked about vision and light. I don’t really remember much.”

Then the interviewer asks Line if her parents knew that she had Usher?

“Yes, my parents knew, but they didn’t want to tell me. They were scared of hurting me. I do remember having my eyes examined as a child, I remember this very well. I did not realise that I had a poor vision. My parents were crying a lot, but they didn’t tell me anything.”

The fact that her parents knew and were reacting on what they knew without telling Line anything about it can also have contributed to Line’s feeling of being all on her own with this new awareness. She does appreciate her parents’ attempt to protect her, yet she does feel that they let her down.

The attitude of the parents is of great importance

For most of the informants over the age of 30, it holds true that their parents didn’t tell them about the diagnosis even though they were aware of it. Conversely, the informants under 30 talk about how their parents from an early age have taken care of their disability and allowed them to grow up knowing that something was wrong in order for the diagnosis not to come as a shock later on. 17-year-old Tonje who is deaf with a medium strong hearing impairment says:

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

Tonje’s story contains three important facts about what is significant for how a progressive disability can become a circumstance of life that you can live with rather than an incident that is inconceivable, unreasonable and unfair. First of all, Tonje was diagnosed as a child and she has yet to form a biography for herself, so there is no vision for the future being destroyed. Tonje is safe and sound in the company of her mother when she is diagnosed. There is someone there who knows her and cares about her, someone with

whom she can share her thoughts, and finally Tonje knows of other people who have the same diagnosis. She has seen people with a hearing and vision disability throughout her childhood, and has seen that it is possible to live with it.

Uncertain message and a long process of acknowledgement

We have already heard, how only by accident, both Lone who actually only went to the doctor to ask for reading glasses, and Line, who spoke to an employee from the school for the deaf, experienced being diagnosed. We have also heard about Anna who went to see the doctor without getting an answer to why she was having problems. The three stories are typical. Jens, now 46 years old and deaf with a serious hearing impairment talks about a very long process of acknowledgement, which first and foremost is characterised by a lack of information about what his diagnosis is as well as about how it develops.

“When I was 7 years old, it was discovered that I had a poor vision, but they didn’t know exactly which eye condition I was suffering from. When I was 19 I was told that I had RP, yet this didn’t make me sad as I had no idea what it was. It was only when I was 27 that I was told it was a serious eye condition and at that time I became terribly sad and upset... At that point I had already sensed that RP meant something serious. I had read an article about RP in a magazine.”

Jens says that no doctor has ever told him what it means to suffer from Usher. After reading the article, he found the letter with the diagnosis, saw that it said RP and tore it up. It was too overwhelming.

He later decided to contact an eye specialist to talk to him about RP. *“But this doctor wasn’t nice, he was unfriendly. He wasn’t interested in talking at all, but I was entitled to a proper examination and treatment, oh yes, I was demanding, but he did not want to discuss anything at all... it was a very unfeeling doctor. When we had finished the doctor told the interpreter that my eyesight would deteriorate and the interpreter was feeling ill at ease talking to me about it.”*

The context is of great significance for the choice of coping strategies

According to the American psychologist Richard Lazarus, the context in which the human being is when she encounters a stressful situation is important for how she copes with it. The way in which to manage a situation is determined by time, place, the person's perception of the situation and how it develops. The perception of your own resources and goals are of importance for how you react. If we look at Jens' situation, we see that he has received information little by little: at the age of 7 he hears about an eye condition, at 19 he is diagnosed with RP, but only at 27 he decides to have certainty about what consequences the diagnosis will have for him. The fact that Jens only gets certainty about his diagnosis at the age of 27 is partly because of his environment, his family and the experts he encounters as well as his own personal choices. It is only at the age of 27 that he manages to get some insight into the situation as he unites the information from an article with the diagnosis in the letter that he has kept. His initial reaction is one of emotional coping: the letter is torn up. He is unable to cope with it. Later in the process of acknowledgement he manages to speak both to his mother and demand an examination, treatment and explanation from a doctor. Jens' description of how it requires perseverance to get to the insight that he now seems ready for, and that the doctor cannot relate to him and instead tells the interpreter what Jens' diagnosis entails, makes you think.

Lise's story is slightly different. She had her first hearing aid when she was 12, but didn't use it until the age of 30. She learned how to mouth read when she was a child and she managed with that. She discovered that there was something wrong with her vision only when she got migraines in her 30's.

"No, I didn't have problems with my vision...it only arrived in connection with heavy migraines for which I received medication, but it didn't help. I was then referred to a neurologist, and he might have pointed towards something in that direction, but I wasn't told anything and I wasn't allowed to read my file. I was then sent to the Eye Department. I was often there, every month for a year until I was told to become a member of the Association for the Blind."

You weren't diagnosed, just asked to become a member of the Association for the Blind?

“Yes, I frequently went for check-ups and they examined my eyes and gave me eye drops. They might have told me without me realising it. I can’t remember and of course...I am not very good at asking, but I do think that the doctor ought to have informed me. He did not say anything about it, just that I should become a member of the Association for the Blind...for sure; I was wondering what on earth I was supposed to do there. I didn’t feel that I ... I tried to forget, did not want to face it, I couldn’t, not at the point. I was wondering what was wrong with me... I was all by myself ... so I walked and walked, thinking and thinking, I was actually walking around all day and the next, I am not sure how much time passed before I told anyone about it, I do not recall.”

When information is not being heard...

Lise does realise that someone might have tried to tell her about her diagnosis, but that she was not listening maybe because she was not ready to handle the facts. It can be regarded as emotional coping to push information away that you cannot handle. Although Lise didn’t quite understand the reason why, she did become a member of the Association for the Blind and was offered a course targeted at people with vision disabilities. The course provided information about people with hearing and vision problems and she was asked if she had Usher.

“I don’t know, I said. I haven’t got a clue. Then they asked if they could examine me and I had to sign some papers ...it was then at that time I was told that I had type II. They told me in a letter.

Did you receive the letter about having Usher type II by post?

“Yes I did.”

How did you feel about that?

“To be honest, I didn’t actually know what it was...”

Lise is telling us this in her third interview in which she also says that after receiving the letter, she didn’t receive any further information about what an Usher diagnosis entails. She has, however, found something:

"Then I saw the word "progressive" which made me dread what it could be. I then found out from one of my neighbours what it means – that it will develop slowly ... yes, this is what I was told and I thought it sounded unpleasant!"

In the fourth interview, Lise is saying that she has managed to speak to a doctor who has given her information about Usher Syndrome. For 18 years, Lise has been aware that something was wrong, but did not receive any information, either because the experts were disinclined to do so, or because she was unable to hear what they had to say. Lise has been in a process where both emotional focused coping – pushing the problems away, rejecting to ask for information – and problem focused coping – becoming a member of the Association for the Blind and asking people she trusts – have been used.

Corbin and Strauss describe the acceptance of ones diagnosis as an never-ending endeavour. This has been true for many of the informants in this project. In her final interview, Tonje is explaining how the interviews for this project have contributed to her work on accepting a progressive vision disability. She has always suffered from the hearing disability, while the vision disability is something that keeps surprising and disturbing her.

Has it been hard to talk about your vision?

"Yes, it has been hard at times, I have been sitting here thinking that is was difficult and have sunk deeper into my seat, but it has also been good for me because I have had to practice being honest. I used to cry when speaking about my vision problems however, during the time we have been talking, I have become better at saying it. As a child there were teachers, and when they said I had problems with my eyesight, I would immediately break into tears. During our conversations, I could feel the pain inside when talking about my vision problems. This has not been the case today, however ...after some time it has stopped hurting ... maybe it is because I understand myself better now, it is hard to say ...It has been a good practice for saying yes I have problems with my vision, and so what ...I will answer honestly when asked ...yet 3 years ago I might have denied it. Talking with you has been a good way to discover things step by step ... Then it is as if it has moved something in me, also my confidence, and possibly my acceptance. I feel more confident saying ...yes, I have vision problems."

Tonje is saying how important it is to talk about her vision, what she expects from it and how she can live with it. She also explains that it is not an easy conversation to have neither one that can be had once and for all. On the contrary, it is very difficult, yet it slowly becomes easier as you meet people with whom you dare to talk despite it being so hard.

Accepting a progressive disability

The way people with acquired deaf-blindness talk about their work on accepting a progressive disability vary greatly. Lone states that she doesn't know the contents of the Usher diagnosis:

“Forgetful ... it is really bad ... I am starting to wonder if it follows ... I think it can follow with the condition ... I am not quite sure, but I imagine so.”

The more extensive you imagine your disability to be, the bigger the threat to your life it becomes. This is why a lack of knowledge can lead to an inability to accept the diagnosis.

It is less clear why Inge whose vision is seriously impaired has problems accepting her diagnosis. Nonetheless, it is a fact that she, being 63 and deaf, has various different ways of describing her diagnosis.

“I was born deaf and at the age of 7 I started having problems with one eye. Later on, I also started having problems with my balance due to trouble with one of my feet. In 1966 I saw an eye specialist who told me that I had something with my field of vision. But it was not RP, it wasn't. It was very tough and I was so shocked and I didn't even want to think about it. It was something with my field of vision, I forgot what it is called ... but it wasn't RP. I also had a cataract operation. On the left eye in 1995, and in 1996 on the right eye.”

In the fourth interview, two years later, Inge tells us that she has RP and how she feels that she can live with it, while in the sixth interview, she expresses doubt and talks about the fact that she might have a mild degree of Usher. Inge's acceptance of her disability seems to be closely connected with what her life situation looks like. When the disability is manageable and doesn't seem to be too limiting, then the diagnosis is acceptable while it becomes totally different during the times when the vision disability is progressing.

The distinctive feature about the above stories is that they are all told by people with acquired deaf-blindness over 40 (except Tonje). The imprecise information, the feeling of both diagnosis and its consequences being discussed over their heads and the experience with receiving such an important diagnosis by post without follow-up, is interesting. The people, whose stories we have heard, have lived for many years with various physical and psychological problems, which have been impossible to understand, and therefore also hard to relate to in a constructive way.

In the following, we will learn more about how the interviewed people with acquired deafblindness have managed being diagnosed with Usher.

Coping

“Little by little, the word DEAFBLIND dawned on me. And then, I really felt how dreadful it was. Then I wished I was dead ... I was so depressed and negative. I drank for two days. I did not give a damn about anything. I was drinking to calm myself down. I didn't care about anything or anyone. ... How can you survive without being able to see or hear?”

Anna is telling us how she reacted when she realised what the diagnosis meant. Anna reveals how she initially uses an emotion focused coping, she doesn't give a damn about anything, gets drunk and isolates herself. Most informants will recognise this initial reaction. Borghild is telling us about her reaction to the diagnosis:

“I was feeling really awful when I was told what RP is, and that there is nothing you can do about it. It was very hard for me to accept in the beginning. And I still don't want to accept it ... when the sun comes out then everything is milky white for me.

Were you offered any expert help?

“Yes, but I have spoken to my family and a few friends. They are the ones I have spoken to. I have of course been offered seeing a psychotherapist and to take part in a group. But I am not very good at opening up either. I think things seem ok here.”

Borghild's initial reaction is also one of not being able to or wanting to accept. Moreover, she claims that she still cannot accept it, but does then say that she has used her family and friends to talk to, as she does not see herself as someone who easily opens up to

strangers. She finishes with concluding that she actually has been able to speak to a stranger during this project, which could mean that Borghild is getting closer to accepting her situation.

Robert who is now 48 with a medium strong hearing and vision impairment says that at the age of 35 it was discovered that he was socially blind, and united with the hearing impairment with which he was born, had to be declared deaf-blind:

“When they told me that I was deaf-blind, everything looked black. I went for a long walk and only had dark thoughts. I was despairing about what was happening to me. I was newly married and we were expecting a baby. My wife was in hospital to give birth to our child. I wanted to wait until after she had given birth to tell her about my deaf-blindness. But my sister-in-law went to see her at the hospital and told her about it without my knowledge. I thought this was a disgrace. And my wife told me off for talking to my brother about it and not to her ... Later I talked to the mobility instructor and for three months I was taught various things about being blind. I was taught in ADL, mobility and also received psychological help.”

Robert’s story is a good example of problem-focused coping. He chose not to tell his wife initially as she was under stress about having to give birth. This choice could be considered as a procrastination of the confrontation (emotion focused coping), whilst also being a careful decision, putting the consideration to his wife first. Later Robert decides to take classes and get psychological help in order to learn how to live life being deaf-blind.

Certainty about the diagnosis gives peace

It is however not everyone who recollect the diagnosis as being a shock. Mogens who is 57, deaf with a serious vision impairment have three paternal cousins who have become deaf-blind. He started having significant problems with his eyesight in his twenties, was diagnosed when he was 35, and his response to whether it was good to be diagnosed is:

“Yes absolutely. There are more courses and meetings in the contact club, trips and get-togethers. I met other people in a similar situation there. To begin with, I thought there were an overweight of older people there, but is changed over time. Still more young people become part of the environment.”

Linda who is 57 with a serious hearing and vision impairment has a similar positive experience:

"A colleague of mine watched a TV programme in which a doctor was talking about Retinitis Pigmentosa. My colleague thought I should contact him as he had said that anyone who had the symptoms he was talking about should get in touch. And so this is what I did. Both my hearing and vision was tested. It was very good and practical to be diagnosed. This allows you to tell people as it is."

The reason for Linda's positive experience with being diagnosed might have to do with the fact that for a long time she had felt there was something wrong. At the age of 30, she was involved in a car accident, which happened because she had not seen the car coming from her right side. This caused her a great deal of worry, as Linda was unable to understand why she hadn't seen the car. Due to this, she booked an appointment with her doctor, yet he made no diagnosis at that time.

To be diagnosed with Usher is for most people linked with a loss of purpose, but can however also be a relief, an explanation, an opening to new opportunities as former experiences of feeling different are clarified and support aids become visible and accessible. Anders who is 21 with a medium strong hearing and vision impairment, had his hearing impairment discovered when he was 7 years old, and from his teens he can recall him and his mother jesting about the fact that not only didn't he hear very well, his vision was also quite poor. He talks about the process of being suspicious through diagnose to progressing in life:

"At that time, I remember feeling that it became very tiring, that I was not performing as well in front of my computer screen as I used to do, but that there could be something wrong with my eyes, no, that I didn't believe. There might, however, have been a small suspicion at the back of my mind."

Anders' problems with his eyesight were discovered during a routine check-up in the 10th grade. He was referred to an eye specialist who thought that it could be RP. To be certain about the diagnosis, the doctor referred him to another specialist. Before the second specialist saw Anders he says:

"I didn't think about it that much. However, there was a state of quiet seriousness between my mother and me. My father was away at the time (he is a sales man), so I guess it wasn't discussed that much."

The specialist examined him and told him that he had Usher Syndrome. He also informed him that this condition could lead to blindness over time, but that the development largely depends on the individual.

"It didn't become clear to me until we arrived home after an hours drive, then I started thinking a little. I suppose that I initially went into a state of shock. The first thing I did when I came home was to get in front of the computer to look up the words RP and Usher. This is my way of dealing with things like this ... the word blindness ... but I had a hearing impairment, and at that point I could relate to being deaf, knew that there were several degrees of hearing impairment ... I understood very quickly that blindness doesn't equal black blind, without any light at all."

Anders printed out the information he had found about the syndrome, reflected upon it for a while before telling his mother about what he had read. He didn't find it difficult to speak with her about it, she had, after all, been with him to all the various check-ups over the years.

"We always had a very close relationship and I guess it became even closer from that moment."

Anders tells us that he was depressed immediately after being diagnosed and that it was hard for both him and his family. It was a heavy and difficult autumn that year. But since then, he has learned that a vision disability can be manageable too. An important element in Anders' story is his experience of understanding and support from his family, and from his mother especially. He has not felt alone with an unmanageable future. This and the fact that Anders already knows that a hearing disability is manageable makes it possible for him to adapt to the vision disability.

Experiences of being disabled and of being diagnosed

It is clear that society's and the experts' attitude to when and how you inform someone about a progressive disability has changed over the last 50 years. The young people with acquired deaf-blindness have all – with one exception – been diagnosed when they were still children or youngsters, at a time when they had yet to create a biography for themselves. As a result, it becomes easier to understand the problems related to seeing when it is dark and hearing what is being said in a large group of people. It also means that their disability becomes a condition that they learn to relate to and bear in mind when choosing their education for instance. Moreover, it seems as if the young people with acquired deaf-blindness have had the opportunity to have physical, psychological and social support, not least from their parents around the time of the diagnosis.

If we look at the group of people with acquired deaf-blindness over the age of 35, the spectrum of their experiences is far wider. The tendency seems to be that the older the interviewed person with acquired deaf-blindness is the less sufficient and the more sporadic the information has been. You get the impression that both diagnosis and discussions of the consequences were made over their heads. Yet there are exceptions within this group with some people feeling that they have received the information and support they needed.

Among the young people with acquired deaf-blindness there is only one person, amongst the older group there are more, who talk about how their parents knew about their disability. One person discloses how he could sense that his parents were worried although he didn't realise why. The group of people with acquired deaf-blindness who later discovered that their parent knew about their disability describes the lack of inclusion as a disappointment. A disappointment they would depict as a "misunderstood concern".

For all the interviewed people with acquired deaf-blindness it holds true that those who already knew others with Usher syndrome, found it easier to relate to the diagnosis. Several of the informants who didn't know anyone tells how meeting other people with acquired deaf-blindness on courses and other places have had significance for their work with accepting the diagnosis.

During the analysis of the stories about being diagnosed, we have paid attention to whether there is difference between when people with acquired deaf-blindness under Usher type I (deaf) and type II (hearing impairment of medium to strong degree) were diagnosed.

It is clear that all deaf children, except one, have been to an eye specialist in their childhood because they or their surroundings found that they had vision problems. Still, only a few of them were diagnosed with Usher Syndrome when they were children. If and when they have been diagnosed with RP is not clear, but all except one were between the age of 21 and 35 when they were diagnosed with Usher. The general trend is that the parents have known of the RP diagnosis, perhaps Usher Syndrome, whilst the children were still at the school for the deaf. One person is a total exception as she in the 4th interview only at the age of 65 acknowledges that she has Usher Syndrome type 1 (her vision difficulties were discovered at the age of 7). And then there is someone who only at the age of 27 realises that he suffers from an eye disease.

Three of the hearing impaired persons have already at an age of 14, 16 and 22 respectively been diagnosed with RP and Usher syndrome. The rest were diagnosed in their late thirties and forties, with the majority in their forties.

Worth considering

In this topical booklet, we have had a close look at the experiences that deaf-blind people have of being diagnosed and the various coping strategies they use to live with and accept a progressive disability. To draw one single conclusion is difficult, however, there are some significant trends in what the people with acquired deaf-blindness say which will be looked at more closely at the end, and which present a range of questions to the experts who are working within this field.

Comprehension and early knowledge about your disability

Comprehension is a very essential concept. With reference to Antonovsky who in his research has revealed the significance of having experience with things happening in life that are comprehensive or predictable, we have heard the people with acquired deaf-blindness talk about their experience of knowing and not knowing their diagnosis. The conclusion is that if you are aware of your diagnosis then you are able to understand and structure events and problems, if you don't, then you have the feeling that the world around you is tumbling down without you being able to prevent it happening.

In other words: When you understand when and how you are getting difficulties (e.g. with seeing anything in the dark) then you can work on finding practical solutions. You are able to let other people know what is happening and you are (perhaps first and foremost) able to accept yourself as a person who are unable to see in the dark or hear what is being said in a large group of people rather than being critical and doubtful about your own clumsiness or lack of prospect of hearing anything in certain situations.

It seems that the sooner you realise why you have particular problems, the quicker the process of acknowledgement can start. This is a process towards acceptance of the disability and its effects.

This indicates that attention to children and young people who suffer from a hearing and or vision disability is of vital importance.

- Who needs to be informed to make this happen?
- What information is relevant to which groups?
- Who should compose and provide the information to the groups above?

In this connection, it is also important to consider how the child or the young person can get the relevant information to an extent and with a complexity that is adapted to age and level of acknowledgement.

Useful information about one's own disability

Yet, information is not something you get once and for all and many adults have experienced having too little, too poor or no information at all about their disability and its potential effects. It might be that part of the experience with insufficient or no information is linked to the fact that many experienced being diagnosed in an inadequate way; people talked over their heads, they read something in the newspaper, they accidentally heard about it.

The coping strategies of Lazarus, in which he distinguishes between problem focused and emotion focused coping can help understand what it means not to have received a sufficient amount of information. It could be that the person with acquired deaf-blindness have received information at a time and in a context that made it impossible to relate to it in a problem focused way. It can be impossible to really listen to certain facts when you are very scared, angry or grieving. All your strength is being used to handle all the strong emotions. Conversely, there are other situations where the person with acquired deaf-blindness faces things in a problem focused way, and needs the information related to the situation and the problems that seemed to be of most importance in the present. It is in situations like this that a certain number of people with acquired deaf-blindness thinks that the whole support system is too rigid, and only focuses on its own agendas.

It requires a lot to provide the information that the people with acquired deaf-blindness feel they need rather than focusing on your own subject matter and the knowledge you have derived from this. Even if the adult with acquired deaf-blindness gained insight in their disability as a child or an adult, she will continually find herself in situations where she needs new information or have information repeated, as she will listen to it differently due to the new situation she is in.

Relevant information is linked to the actual situation a person is in. When you for instance have just received a very serious diagnosis, then your ability to listen and understand becomes very limited. In a similar way, it is possible to have heard about the possibilities of learning Braille when you were young and had a relatively good vision, but you forget it the day it becomes relevant for you to consider. It is in fact possible that several of the

people with acquired deaf-blindness in the project who claim that they have received no information actually have been situations where someone has said something about their diagnosis or given them a leaflet about Usher. However, in this connection it is totally irrelevant if someone has made an attempt at saying anything. If the person with acquired deaf-blindness believes that she has not received any information then it is because she hasn't been given the information at a time and in a way she was ready to receive it. In other words, the relevant part is not what the eye specialist, the teacher at the school for the blind or the deaf-blind consultant have said, it is what the person with acquired deaf-blindness has heard.

- How can you make sure that the expert has a level of knowledge, experience and insight that will allow them to see, hear and relate to what requirement for information the individual person with acquired deaf-blindness has?
- How can you make sure that the expert can fulfil the request himself or herself or will know where to send the person with acquired deaf-blindness to get the answers to their questions?
- How can you manage written material to a wide audience with large individual differences?
- How can you provide information in a form and format that responds to what the individual can cope with?
- How can you ensure follow-ups, was the person with acquired deaf-blindness able to use the information she received?

Coping and the importance of social contacts

To have met or even know others with a similar disability is of great significance for the process of acknowledging and coping with your own situation. The young person who knows others with Usher Syndrome will be in a better position to choose a problem focused coping strategy where the search for solutions is in focus. Conversely, a person who hasn't met anyone is more likely to compare herself to people who are not diagnosed, and as a result she is more prone to choosing emotion focused strategies, which is characterised by rejection or surrender.

Several of the young informants mention their parents as their most important sparring partners when they had to learn how to manage their situation in their childhood. One person can also talk about how it has influenced him, that he could sense from his parents that something was wrong without realising that the grief and worry was about him.

- How can the expert support the parents to allow them to support their child with a disability and the effects the disability has for the child as well as for the family?
- How can the experts help parents to become aware of the potential effects of their child's disability in a way that allows them to talk to the child about these?
- Which group of experts should hold the main responsibility for the contact to the parents?
- What kind of material will the parents be able to use when talking to their child about the disability and the effects of it?

Summary

In this booklet, focus is on the stories from people with acquired deaf-blindness, on being disabled without having a diagnosis, and on being diagnosed with RP or Usher Syndrome.

It is clear from the stories that it is of great importance

- what stage in life the diagnose is made
- under which circumstances it happens
- which type of support is given for carrying on

The concept “comprehension” recurs throughout the booklet. If you understand what it is that is happening to and around you, it becomes easier to understand and cope with everyday events and changes to your vision.

A young woman with acquired deaf-blindness tells how being diagnosed with a progressive disability becomes part of your life rather than an incredible, unreasonable and unjust phenomenon. Her story contains some reasons:

- the diagnose is made while she is still a child so there is no broken illusions about the future
- the diagnose is made in a safe environment in the presence of a person who knows and loves her
- the diagnose is not totally alien as she already knows people who have a hearing and vision disability, and has therefore seen that it is possible to live with it

It is evident that the attitude of both society and experts to when and how one acquaints oneself with a progressive disability has changed over the last 50 years. Young people with acquired deaf-blindness have – with one exception – been diagnosed when they were still children or youngsters prior to creating a biography for themselves. This means that it becomes easier to understand the difficulties with seeing in darkness or hearing what is being said in a larger group, for instance. And it means that their disability quickly develops into a condition they learn to take into account when considering their choice of education etc. Moreover, it seems as if young people with acquired deaf-blindness have had the opportunity to get the physical, psychological and social support they need, not least from their parents around the time of the diagnosis.

The group of people with acquired deaf-blindness over 35 has far more diverse experiences. It seems that the older the interviewed person with acquired deaf-blindness is, the more insignificant and sporadic the information provided. You get the impression that both diagnosis and discussions of its effects were made over their heads. Yet there are exceptions within this group with some people feeling that they have received the information and the support they needed.

For all the interviewed people with acquired deaf-blindness, it holds true that those who already knew others with Usher syndrome found it easier to relate to the diagnosis. Several of the informants who did not know anyone talks about how meeting other people with acquired deaf-blindness on courses and other places have had significance for their work on accepting the diagnosis.

During the analysis of the stories about being diagnosed, we have paid attention to whether there is a difference between when people with acquired deaf-blindness under Usher type I (deaf) and type II (hearing impairment of medium to strong degree) were diagnosed. Generally, parents of deaf children have known of the diagnosis RP, possibly Usher syndrome, while the children were still at a school for the deaf. Three of the hearing impaired have children already at an age of 14, 16 and 22 respectively been diagnosed with RP and Usher syndrome. The rest were diagnosed in their late thirties and forties, with the majority being in their forties.

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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