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Nordic Centre for
Welfare and Social Issues

LIFE ADJUSTMENT

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and Combined
Visual and Hearing Disability/Deafblindness
– an Internal Process over Time

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Ann-Christine Gullacksen
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PREFACE

In the last few years, quite a lot of material on acquired deafblindness has been published, ranging from projects closely linked to activity and research reports, to accounts of personal experiences of living with deafblindness. An increasing number of persons with deafblindness hold lectures during conferences, both Nordic and international conferences. This provides us with new dimensions, since it gives us a more profound understanding of deafblindness and of what life and everyday life may look like. Thanks to all persons with deafblindness, who generously share their experiences, the professional field can increase its understanding and deepen its knowledge.

Using a life adjustment model, our aim is to further systematize the experiences of developing and living with acquired deafblindness. These are individual journeys in life, but some developments and events are perceived as more or less alike by the persons we have interviewed. Our ambition is also to make this knowledge used and useful in the professional work. In this report, we address professionals who encounter persons with acquired deafblindness in their work. We also address persons with deafblindness and their relatives.

The authors of this project wish to specially THANK everyone who has participated in our focus groups, and who has shared their experiences and knowledge of living with acquired deafblindness with such generosity. A sincere THANK YOU to the project's reference group, for good collaboration through the entire work process. A final THANK YOU to Nordic Centre for Welfare and Social Issues, National Knowledge Centre for Deaf-Blind Issues, Center for the Deaf, Signo Deafblind Centre, the Foundation Signo, and the Foundation Mo Gård for financial support.

October 2011

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INTRODUCTION

The purpose of this study is to gain increased knowledge of the life adjustment process related to acquired deafblindness. We hope to be able to use this knowledge in contributing to a better match between the person's needs and the environment's support – the right support at the right time.

BACKGROUND

Developing deafblindness implies huge changes, both for the person and for everyone around, not only from the moment when the diagnosis is given. For most persons, it also signifies recurrent changes and adjustments, as vision and hearing gradually deteriorate. A combined vision and hearing disability is a huge threat to all activity and the ability to participate. It is not unusual for deafblindness to develop during the late adolescent years and the early years of adult life. There may be a feeling of uncertainty regarding the future, perhaps goals and dreams have to be re-evaluated, and many things have to be re-learned in order to cope with the demands of everyday life. Re-learning and finding new ways in accordance with the new life conditions imposed by deafblindness, constitute a great effort. The documented knowledge of what living with acquired deafblindness means, has this far been limited. However, during the last few years, an increasing number of persons living with deafblindness have started describing their life situation in different contexts. Professionals and researchers have also conducted qualitative studies highlighting personal experiences of deafblindness. Autobiographical stories are important, both to give an inside perspective of social and psychological issues, and to communicate experiences of the social support system. However, there is still a need to describe these experiences in more general terms. This study is a way of contributing to the general knowledge of social and psychological aspects of developing and living with acquired deafblindness. Knowledge that may be used both in the professional field, and in the personal comprehension of this life adjustment.

THE PROJECT GROUP

All of us who have been involved in this project have worked with persons with acquired deafblindness for several years. We have often seen a discrepancy between the person’s own experiences and understanding of the disability, and others’ aims and ambitions regarding things that ought to be done. At several occasions, we have proposed a certain kind of support or service that the person has turned down, and we may have explained this by saying ”perhaps he has not accepted his deafblindness”. Inversely, we have also supported persons by offering them the service and support that they claim to be in need of in order to be active and participate in their own life. It is a challenge to be able to offer the right support at the right time. Identifying where in the life adjustment process a person is, can provide valuable knowledge of when and what kind of support the person is willing to accept. During the development work leading up to the establishment of Region Skåne’s Deafblind Team (Göransson, 2007), we initiated a co-operation with Ann-Christine Gullacksen, a senior lecturer in Social Work at Malmö University. Gullacksen has previously tried and described a model for life adjustment in relation to persons with chronic pain (1998) and persons with hearing impairment (2002). The Skåne Project found the model relevant and useful also when working with persons with acquired deafblindness.

At The Nordic Staff Training Centre for Deafblind Services, NUD (today Nordic Centre for Welfare and Social Issues, NVC) in Denmark in 2008, the Scandinavian Network on Acquired Deafblindness, the so-called SNED-group, held a seminar about stress and coping related to acquired deafblindness, and Gullacksen was one of the speakers. After that, SNED decided to proceed and investigate the particularities of life adjustment related to acquired deafblindness. This work is a natural follow-up of the development project in Region Skåne and the seminar at NUD in 2008. The authors of the survey are:

Ann-Christine Gullacksen, Sweden
PhD in social work, working as a lecturer at Malmö University, with a background as a social welfare officer within the field of audiology in Skåne. Her thesis was a study of life adjustment in situations when life changes due to chronic illness or disability. Her continued research has been devoted to life adjustment related to deteriorated hearing, with a special focus on rehabilitation from a user perspective.

Lena Göransson, Sweden
Head of National Knowledge Centre for Deaf-Blind Issues. Wrote the book *Deafblindness in a Life Perspective – Strategies and Methods for Support*, and

a report on the evaluation of 44 projects related to deafblindness *Från projekt till delaktighet – Utvärdering av 44 projekt relaterade till funktionsnedsättningen dövblindhet*. For several years, she has been responsible for developing and building up both The Deaf Team and the Deafblind Team in Region Skåne.

Gunilla Henningsen Rönnblom, Norway
Works as a counsellor for persons with deafblindness, giving advice and guidance to persons with acquired deafblindness, their families, and professionals that they encounter. Member of the national interdisciplinary team on diagnosis and identification of deafblindness *Nasjonalt tverrfaglig team for diagnostisering og identifisering av døvblindhet*, and employed at Signo Deafblind Centre in Andebu. Has previously worked with projects focused on work related rehabilitation for persons with deafblindness.

Anny Koppen, Norway
Works as a counsellor for persons with deafblindness, giving advice and guidance to persons with acquired deafblindness, their families and professionals that they encounter. Employed by the regional centre for the deafblind *Regionsenter for døvblinde, Statped Vest* in Bergen, and was previously the director for The Nordic Staff Training Centre for Deafblind Services (NUD).

Anette Rud Jørgensen, Denmark
Works as a counsellor for persons with deafblindness at Center for the Deaf, Odense, counselling adults with acquired deafblindness, their families, and professionals who have contact with this group. Involved in agency and project work, and has been responsible for, amongst other things, a three-year project for persons with acquired deafblindness and work related issues, resulting in a report on meaningful activities *Meningsfuld beskæftigelse for døvblindblevne*. She is also a member of an interdisciplinary team for the deafblind *Det tværfaglige udrednings-og rehabiliteringsteam for døvblinde.*

THE TERM DEAFBLINDNESS

When we use the term deafblindness in this report, we use it as a generic term for an acquired combined visual and hearing disability, according to the Nordic definition of deafblindness. The term *deafblindness* has been discussed from several perspectives in this report, both with the reference group and in the focus groups. The word deafblindness often holds a strongly negative meaning for the person, and it is not rare for problems to occur when someone tries to explain its meaning to others. Hence, it is important how, and in what contexts, the term is used. In the chapter *Central Topics Related to Life Adjustment,* we will return with a more thorough description of the informants' thoughts and experiences of the term deafblindness.

THE OUTLINE OF THE REPORT

In the *Introduction*, we present the project's background, how it started, what we wanted to know more about, and what we wished to achieve. This is followed by the chapter *Definition and Description* of Deafblindness with a closer description of acquired deafblindness. In the chapter *An Overview of Current Knowledge*, we will go through some of the studies, lectures, and papers that have inspired us and that we have used as a background and a framework for understanding. This chapter also includes the background for and presentation of Gullacksen's model for *Life Adjustment*, which has been a framework of interpretation in our research. In the chapter *A Presentation of the Project,* we describe our method as well as the participants in the project. After that, we give a presentation of the *Results* of our study in two steps. First, we describe the process of life adjustment related to acquired deafblindness, as shown in our survey. Next, using our material as a starting point, we highlight some *Central Topics Related to Life adjustment.* We finish off with some *Final Reflections* on the results and usefulness of the project.

The quotes in the report have been translated between Norwegian, Danish, and Swedish, and are partly reformulated. Therefore, the quotes cannot be traced to any of the countries. We have also altered the personal information that may have been found in the quotes. The participants in the focus groups are therefore completely anonymous in the text.

DEFINITION AND DESCRIPTION OF DEAFBLINDNESS

THE NORDIC DEFINITION OF DEAFBLINDNESS

Since 1980, the Nordic countries have had a common definition of deafblindness. This definition has been revised, resulting in a new definition in 2007. The Nordic definition is as follows:

Deafblindness is a disctinct disability.
Deafblindness is a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree, that society is required to facilitate specific services, environmental alterations and/or technology.

These comments are a clarification to the definition of deafblindness:

1. Vision and hearing are central in getting information. Therefore a decrease in the function of these two senses that carry information from distance, increases the need to use senses that are confined to information within reach (tactile, kinaesthetic, haptic, smell and taste), as well as leaning on memory and deduction.

2. The need for specific alterations regarding environment and services depends on

- the time of onset in relation to communicative development and language acquisition;
- the degree of the hearing and vision disability, whether it is combined with other disabilities and whether it is stable or progressive.

3. A person with deafblindness may be more disabled in one activity and less disabled in another activity. Therefore each activity and participation in it needs to be assessed separately. Variation in functioning within each activity and participation in it may also be caused by environmental conditions and by internal personal factors.

4. Deafblindness causes varying needs for co-creating* alterations in all activities and especially in

- all kinds of information;
- social interaction and communication;
- orientation and moving around freely;
- activities of daily life and effort demanding near-activities including reading and writing.

5. An interdisciplinary approach including specific know-how related to deafblindness is needed in service delivery and environmental alterations.

The Nordic definition is based on functional consequences of deafblindness. The life situation as a whole, including both activities and the possibility to participate, is gravely affected by the combined disability. Accordingly, a person is not required to be complete deaf and blind to be defined as a person with deafblindness, most have residual vision and/or hearing. A more detailed description and an in-depth definition are given in *Vägledning om förvärvad dövblindhet* (2010), which is intended as a complement to the definition.

When affected by a combined visual and hearing disablility/deafblindness, i.e. when both senses carrying information from distances are affected, it also becomes more difficult to compensate for the two impairments. With a hearing impairment it is possible to compensate for this to a certain extent, by using vision to read the environment. And inversely, a person with a visual impairment relies on the hearing in different situations. Persons with various degrees of deafblindness lack this ability to compensate. It is primarily the senses carrying information within reach: smell, taste and the tactile sense, that support or replace the failing distant senses to a varying extent. The tactile sense becomes important for persons with deafblindness. Therefore, deafblindness may be regarded as a distinct disability, in which the consequences are far more extensive than the sum of its different parts. It generates a need for thorough changes in daily life and life in general.

** Co-creating means that the person with deafblindness and the environment are equally involved. The responsibility for this to occur lies on society.*

DIFFERENT CAUSES OF ACQUIRED DEAFBLINDNESS

Persons with deafblindness constitute a very heterogenous group, especially when it comes to ways of communicating and the time of onset. Persons with deafblindness use different methods to communicate with others and to obtain information. The methods can be very individual. However, it is possible to divide persons with acquired deafblindness into three groups, depending on the time of onset of the visual and/or hearing impairment:

1. Persons who are born with a hearing impairment or deafness, and who later on develop a severe visual impairment or blindness.

2. Persons who are born with a visual impairment or blindness, and who later on develop a severe hearing impairment or deafness.

3. Persons who are born with normal hearing and vision, and who later on develop both visual and hearing impairments.

Group three mainly consists of older people with age related causes for the visual and hearing impairments. Deafblindness can also develop as a result of an illness, accidents or syndromes. Among younger persons with acquired deafblindness, *Usher syndrome* is the most common reason for the disability. It is a hereditary condition that appears as a combination of a hearing impairment that can vary from being a moderate hearing impairment to complete deafness, and the progressive eye condition retinitis pigmentosa (RP), which destroys the retina of the eye and leads to a gradual reduction of the field of vision as well as reduced night vision.

The time of onset of deafblindness may be of significance for how the person deals with the visual and hearing disability and copes with different situations in daily life. It is crucial if the onset takes place during adult life, when identity is already developed, or during the early adolescent years. The experiences and the strategies that a person develops also depend on which of the senses is affected first, and on the degree of the visual and hearing impairments.

CONSEQUENCES OF ACQUIRED DEAFBLINDNESS

Living with deafblindness has far-reaching consequences for the affected person and others around him or her. It leads to difficulties in communicating with others, getting access to information, and being independent in orientation and mobility. Losing vision and hearing also leads to various consequences of psychological and social nature, such as feeling sorrow and anxiety, having existential reflections, and experiencing identity crises. All of this affects the person's possibility to maintain activities and to be involved in society as well as in life in general.

Communication

When vision and hearing deteriorate, it inevitably affects social interaction and inter-human communication. In the interaction with other people, we use vision, for example to read facial expressions and body language, and eye contact is important for turn taking in conversations. We use hearing to perceive both what is being said and how it is said, but also surrounding sounds. Put together, this gives content, comprehension and meaning to the conversation. Persons with a visual impairment compensate by using their hearing, and focus on tone of voice, strength of voice, and rate of speech. Persons with a hearing impairment compensate by reading other persons' body language and facial expressions. This opportunity for compensating is more difficult or is totally default for a person with deafblindness. Therefore, it is hard for persons with deafblindness to take initiative to participate in social contexts, if the proper adjustments are not made.

How communication is affected by deafblindness varies depending on whether sign language or spoken language is the first language. Most persons with acquired deafblindness have their own culture's spoken language as their first language, and have grown up in a community where most people are hearing. Another group has sign language as their first language and have grown up in the deaf culture. The deaf community describes deaf culture as a life pattern dependent on the visual language, childhood conditions, history, and traditions. The fundamental factor in this culture is the social community and the free and unobstructed communication, the feeling of belonging, and common identity (Göransson & Malmström, 2002).

Information

It is hard for persons with deafblindness to get access to all the information that reaches sighted and hearing persons every day, information that is taken for granted. This concerns all the information we receive through TV, radio, and newspapers, not to mention the information we acquire from listening to other people’s conversations. Both auditive and visual information becomes difficult to attain. Information provides important knowledge and is a prerequisite for participating in different contexts, on the same terms as others. It also forms the basis for decision making, concerning both small and big issues. As previously mentioned, deafblindness limits the social relationships, which further contributes to the reduced access to information. The fewer social situations a person participates in, the smaller the chances are to be able to take part of current discussions in society.

Orientation and Mobility

Persons with a primary visual impairment/blindness rely, to a large extent, on their hearing for orientation and mobility. So when their hearing deteriorates, they lose an important ability to compensate. Persons with primarily a hearing impairment/deafness, and who are experiencing vision loss, lack that ability to compensate. Persons with deafblindness, to a varying extent, become dependent on support, such as transport services, personal guides or a personal assistant, in order to get around safely. Many experience a loss of independence and freedom as the physical dependence on others increases.

Progression

Acquired deafblindness is often caused by a progressive state, which means that hearing and/or vision deteriorate gradually. This creates anxiety and insecurity about the future, and repeated adjustments are necessary, a process that takes time and energy. Once you are used to or can handle the situation, vision and/or hearing deteriorates, and you are once again forced to find new strategies to cope with everyday life, and life in general. This creates insecurity and a psychological strain for the person’s life, with experiences of stress and energy loss as a consequence.

In order to meet these specific consequences of the functional disability deafblindness, an interdisciplinary view and special knowledge, when it comes to service and adjustments, are required. This is stated in the Nordic definition of deafblindness, and becomes evident in different ways in the following chapter.

AN OVERVIEW OF CURRENT KNOWLEDGE

LIVING WITH ACQUIRED DEAFBLINDNESS

In recent years, persons with their own experiences of deafblindness have more frequently contributed by shedding some light on social as well as psychosocial consequences of living with deafblindness. How does one manage to lead an active life despite severe visual and hearing impairments? These personal stories relay important knowledge and are necessary in order to make it possible for professionals to offer adequate support. Research results from different areas of knowledge are necessary for a comprehensive understanding of how a person's life situation is affected. Already, there is available extensive and advanced biomedical research of the causes and prognosis for deafblindness. However, research on social and psychosocial issues has not yet reached that far. This kind of research often requires a qualitative research method, thus making people with personal experiences important sources of knowledge. The results of these two research areas are joined together in a bio-psychosocial perspective, which is a prerequisite in order to understand the complex situation that may arise when having acquired visual and hearing impairments. In this overview of current knowledge, we will shed light not only upon research and development projects, but also on personal experiences concerning the psychosocial issues.

The health effects of living with deafblindness may be considered from several angles. Today, health is classified from a bio-psychosocial perspective and is therefore a multidimensional term including physical and psychological conditions, as well as social conditions. This is established in the WHO's International Classification of Functioning, Disability and Health – ICF (the National Board of Health and Welfare, 2003). *Participation* constitutes a crucial element of a good life according to this classification concerning how different factors influence health. Participation is defined as a person's involvement in a situation. A combined decrease of vision and hearing has severe consequences for a person's social life. The risks are isolation, loneliness, and social exclusion, which in turn jeopardize the psychological health. Therefore, deafblindness is a severe threat to a person's ability to participate (Göransson, 2007; Möller, 2008; and others).

In her thesis *Impact on participation and service for persons with deafblindness* (2008), Kerstin Möller states that participation restrictions for persons with deafblindness are found both in the surrounding physical environment and in the social relationships with other people. Möller's research results show, that sometimes social support services can constitute a restriction for participation, even though the purpose is quite the opposite. Specific support service can be completely lacking, or sometimes it is existing but not satisfactory, i.e. there may be a lack of an overall view and co-operation between different parties as well as insufficient knowledge of how a combined visual and hearing disability affects activity and participation. It is important to understand how deafblindness affects the possibilities to participate in different ways, in order to improve the support service.

In a research programme on deafblindness at Örebro University in Sweden, Moa Wahlqvist (2011) studies physical and psychological health amongst persons with Usher syndrome type II and type III. One of the aims is to identify health promoting factors, which is of great value when drawing up a rehabilitation plan. Another study within the same research programme, shows that persons with Usher syndrome type II have a higher prevalence of health related problems than the general public. This includes asthma, allergies, headaches, skin problems, and tinnitus in the 30-44 age group. The study also shows that suicidal thoughts and attempted suicides are more frequent compared to others (Eriksson, 2008). These results indicate that persons with Usher syndrome type II are more inclined than others to have an inferior health state in general, and that the risk factors therefore need to be examined more closely.

Recently, we have had the chance to learn about how deafblindness influences life through a personal perspective. One contribution to this knowledge is a comprehensive Nordic study called *Erfarenheter från människor med dövblindhet* (Ravn Olesen & Jansbøl, 2005), where a total of 20 people (ten women and ten men) with progressive functional impairments were studied during a five-year period. The altered life conditions caused by deafblindness, both from a personal and a social perspective, were in focus. The stories show that the access to counselling, support, follow-ups, and co-ordination is crucial for the person's ability to be active. It is also established that this includes both practical support to deal with different situations in daily life, and emotional support to create a feeling of context and meaningfulness in life.

In a comprehensive Swedish intervention study carried out in Region Skåne, Lena Göransson and her co-workers (2007) interviewed persons with deafblindness in various age groups. The overall aim of the project was to gather personal descriptions of how it is to live with deafblindness, and use these as a basis for the development of different kinds of support and habilitation/rehabilitation. Through the project, it became obvious that deafblindness must never be regarded as a static condition, but as a process continuously interacting with the environment, where both the person and the environment are in constant development. *Life adjustment* (Gullacksen, 1998, 2002), *environmental factors* (the National Board of Health and Welfare, 2003; Möller, 2005), and *time* (Jeppsson Grassman, 2001, 2003) became fundamental terms in that study, and made up the framework for describing living with deafblindness and the balance between the person and the environment over time.

A recently completed study *Plus & Minus* (Edberg, Joge Johansson & Nylander, 2010), shows that a combination of *external* environmental factors and *internal* personal factors affect the experience and the adjustment of life when adapting to the new conditions caused by deafblindness. The external factors are predominant, both in terms of success and restrictions. Meeting other persons with deafblindness, meeting professionals with knowledge of deafblindness, and seeing that relatives acquire knowledge of the consequences of deafblindness, are all examples of success factors. A lack of an overall view in the meeting with professionals, a general lack of information, an inadequate adaptation of public space or not being provided with an interpreter, personal guide or transport services when needed, are all examples of restricting factors. In the above mentioned study, Göransson (2007) also states that environmental factors are crucial for people's possibilities to be active and participate, despite deafblindness. The environment can both be restricting and facilitating.

The most important source of knowledge when it comes to understanding experiences related to acquired deafblindness and how people cope with a life with deafblindness, are the people who actually experience it. In the last few years, a growing number of persons with acquired deafblindness have shared their experiences and reflections in different contexts. One such important contribution comes from Femke Krijger from the Netherlands. She shares her profound insight of the struggle towards acknowledging that deafblindness causes daily difficulties, the reality of a ruthless awakening, grief over what is lost, followed by the process of rebuilding oneself and the new world in an ”everlasting training process”. During her long journey, she has changed her focus in life, but has kept her inner core and has learned to balance the demands and consequences of deafblindness with the life she wants to lead. Losing one’s abilities is not the same as losing one’s competence. According to Femke Krijger, this is an important insight when re-establishing identity and self-image (Krijger, 2009, 2010a, 2010b).

Maartje de Kok from the Netherlands also has personal experience of deafblindness, and she has described acquired deafblindness as something more than the sum of the visual and the hearing impairment. By using interviews with other persons with deafblindness, she shows that it is impossible to understand acquired deafblindness by summing up experiences of a hearing impairment/deafness and a visual impairment/blindness. Deafblindness is something else and exceeds the sum of the two parts (de Kok, 2008). During her plenary session *The experiences of being deafblind 1+1≠2*, at the ADBN-conference in Bergen (Norway), she illustrated how deafblindness affects life as a whole. She concluded by saying that it is necessary to integrate deafblindness into one’s own identity to be able to deal with deafblindness.

Developing deafblindness constitutes a threat and a challenge to a person’s identity and self-image. In an interview study (2008), Ilene Miner, a clinical social worker in New York, described the identity related experience for persons with Usher syndrome. She describes the reactions on a diagnosis as the starting point of a long process leading up to developing a new identity or reconstructing the old one. An important basis in this process, according to Miner, is the contact with other persons with deafblindness, participation and involvement in different organizations for persons with deafblindness, as well as contact with professionals who have specific knowledge of deafblindness. Rights and access to different kinds of services make a huge difference for identity and self-image.

In a recent thesis from Australia, *Becoming deafblind: Negotiating a place in a hostile world* (2006), Julie Schneider emphasizes problems related to the fact that persons with deafblindness feel powerless with regard to society, as well as a need for professional support to be able to create a functioning life situation. She comes to the conclusion that both personal factors and environmental factors are significant in order to succeed. Schneider finds four interacting strategies used actively by persons with acquired deafblindness. It is a question of doing things differently than before, for example with regard to communication and mobility, choosing which aspects of oneself to show depending on the context, dealing with others' attitudes, and accepting support. Professionals are required to supply information and support, and must be aware of the complex needs of persons with deafblindness (Schneider, 2006).

Persons with deafblindness share their experiences of what it is like to make choices and act on uncertain grounds as a consequence of only perceiving fragments when it comes to information about the surrounding world as well as in different communication situations. In her article on getting things right *Det handler om å få bitene på plass* (2009), Gunilla H. Rönnblom uses a gestalt therapy perspective to describe how to help persons with deafblindness maintain their ability to be active by means of various adjustments: adjusted information and communication, time to reflect and process experiences, and the significance of individual support in that context.

The above mentioned sources of knowledge highlight different aspects of living with deafblindness. Based on the knowledge that already exists on social and psychosocial aspects of acquiring and living with deafblindness, our aim with this project has been to deepen the knowledge of the life adjustments that this implies.

LIFE ADJUSTMENT

We will continue with a presentation of knowledge regarding *life adjustment* related to prolonged illness and permanent impairments in general, a presentation of the model that we have used, as well as how this model has been used in previous projects on deafblindness. We hope that our project will be a contribution to the development of systematic knowledge regarding acquired deafblindness, and making the knowledge applicable in the professional work.

> *”Who is that, stumbling and fumbling? Is it me or the visual impairment? You might say that we try to co-exist, but I struggle not to become one with it. There is a tug-of-war where the winner is certain, but still I refuse to FEEL defeated.”*
> *(From the book Blindstyre by Täppas Fogelberg, p. 156)*

Life Adjustment – an Internal Process over Time

Life adjustment related to acquired deafblindness is the main focus of this study. We have chosen the life adjustment model described by Gullacksen (1998) and used by Lena Göransson and her co-workers in *Deafblindness in a life perspective* (2007, 2008) as a starting point. This life adjustment theory refers to international research on social and psychosocial consequences for the person affected by a life long illness and a functional impairment.

Some of the researchers, primarily in the US, Canada, and the UK, who launched their research thirty years ago, can be considered to be classics within their field of research. Their search for knowledge has been focused on quality and on the person's experiences, descriptions, and reflections of the functional impairment's significance in life in general.

The social psychological research issues have touched upon the altered self-image and identity, dependency, support and control, stigmatization and social exclusion, coping with stress, and quality of life. Both internal and external factors, and the relationship between the two, have been emphasized. Some of the prominent people worth mentioning are Katy Charmaz and her research on how the self-image and identity is subjected to stress, as well as Anselm Strauss and his colleague Juliette Corbin, who have described ”life transition” as a process over a long period of time, and all the work that this change implies. Another researcher is Michael Bury who has emphasized the biographical perspective and considers the illness to be a biographical disruption in the important feeling of continuity in life. This research has given birth to a term bank with strong roots in the person's own experience. Examples of such terms are ”coming to terms with”, ”coming-out process”, ”coming back”, ”illness trajectory”, ”biographical disruption” and ”illness work” (see Gullacksen, 1998, for a more detailed description of and references to this research tradition). This research is based more on a person's individual and social changing process than the medical diagnosis and physical changes. In recent years, this perspective has become the foundation in the ICF approach, i.e. seeing how the illness and the functional impairment affect the person's activities and participation (The National Board of Health and Welfare, 2003).

In some countries, this field of knowledge has previously been dominated by psychological models of explanation, resulting in comprehensive changes in life in connection with illness primarily being interpreted and understood based on theories of internal psychological factors. In the professional field in Sweden, for example, a crisis intervention model with roots in a psychodynamic theory has been used for a long time. More recent research has chosen a social psychological perspective, where human interaction is central for emotional experiences and life changes. Therefore, there is a wide scope of theories on life adjustment related to prolonged illness and continued functional impairments, comprising different life situations affected by the altered conditions. Critical areas for the person being affected may include, for example, the notion of the self-image and identity, relationships to others who are close, competence in working life, plans for the future, and social activities. Pressure on vital safety factors in life may result in overwhelming feelings of stress, depression and crisis reactions.

Accounts from persons who have experienced an extensive life adjustment related to illness or functional impairment, reveal that much of the work involved in the adjustment is kept hidden from the surroundings. This shows that there is a need for knowledge of the adjustment process, in order to be able to offer the right support at the right time. The beginning is particularly important, since the functional impairment has significant consequences on the life situation. Early support can be crucial for the adjustment process that follows. The need for support can be manifested before, at the same time, or long after the diagnosis has been given. It is not obvious that a person shows his or her need for support, and the reasons for this may vary. To understand the full extent of this kind of unfinished event in a person’s life, this must be seen in a life perspective. A biographical perspective gives us a possibility to understand how life’s continuity is disturbed and must be repaired. This is important knowledge for professionals who meet people during rehabilitation (Gullacksen, 2002).

Life adjustment related to prolonged illness and functional impairment is a lengthy process running parallel with life in general. It should result in a functional integration of the new conditions in life. It is largely an individual work process to change the self-image and regain one’s identity. It is also a process of adapting and gaining control over conditions and possibilities in the surrounding environment. Living with a functional impairment, implies having to constantly maintain the remaining abilities. It also entails being exposed to risks and challenges when adaptation strategies cease to function due to a worsening of the functional impairment, or due to barriers in the surrounding environment that are out of one's own control. New adjustments may be needed, but the fundamental experience from the previous life adjustment may facilitate the process.

The Life Adjustment Model

The life adjustment model used in this study (Gullacksen, 1998, 2002) describes different stages of the life adjustment process. The model should be considered a tool in understanding the adjustment process, which becomes necessary for the person subjected to extensive functional impairments. It provides a structure or a framework to facilitate the understanding of this long and very complex process, and shall not be considered a detailed description of how a person deals with difficulties. Everyone has a unique life situation, social and personal conditions affecting reactions, coping, and planning. Despite this fact, there are studies and rehabilitation work showing that there are many similarities between individuals, even though the problems are dealt with in different ways.

The life adjustment model is based on a *salutogenic* approach, which means that the life adjustment can be considered as something natural when someone is affected by a chronic illness or a functional impairment (Antonovsky, 1991). This way, life adjustment becomes a natural part of the continuous life course. The salutogenic approach is based on the notion that humans strive to find a meaning in life. Two significant steps towards this goal are *comprehending* and *understanding* what is going on in life, which in turn is a condition for being able to *deal with* problems that arise.

In order to make sense of the extremely complex work that the life adjustment constitutes for most people, the process has been described in different stages (phases). The process is not necessarily continuous from one stage to the next. Their duration may be longer or shorter; a person may stop and reverse in the process, but in a successful adjustment all stages will be experienced at some point. This implies that it is impossible to give a time limit for the entire adjustment process. It is particularly important to illustrate how people deal with the first stage, with insidious symptoms and problems that are vague and inexplicable for a long time. Denial and excuses are common. During this period, information and other support may be of great importance, if they are adequate and in time. A crucial turning point in the initial stage is the *recognition*, which becomes a turning point in the process. *Recognition* in this context is used to signify that a person is taking in the fact that vital functions are severely impaired and that this will affect the entire life situation. It is no longer possible to hide or disregard the problems. This implies that life can no longer go back to what it used to be. Stories from this stage reveal that a person's ambition to restore life and resume previous roles that gradually have become increasingly difficult to maintain, are abandoned in favour for a *change*. This leads to a painful insight that may be described as a life crisis, and for some even lead to depression. At the same time, the change gradually becomes the main motivation for a continued adjustment of the life situation.

The life adjustment process is illustrated like this in the model:

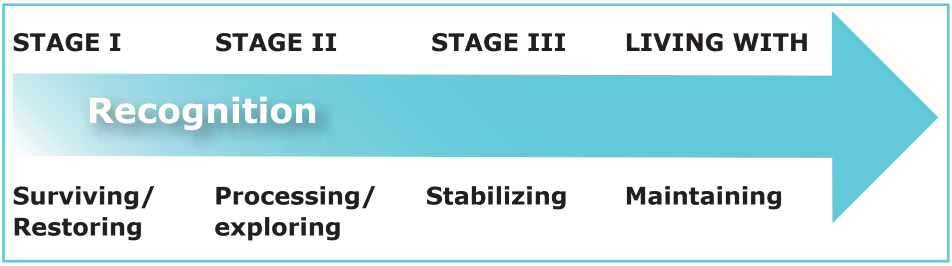

Figure 1. The life adjustment model (Gullacksen, 1998, 2002).

Now follows a brief description of the model:

I. *The initial stage* often begins when you find out, and perhaps are given a diagnosis. However, an incipient functional impairment can sneak its way into life long before that, leading to vague consequences. At the beginning of the life adjustment process, all energy is aimed towards *surviving*, coping with daily life, and dealing with all the emotions. Focus lies on the functional impairment, and it is difficult to grasp everything that is going on; you hope to be cured, recovered, or keep everything from getting worse. The strategies are focused on hiding and denying any problems and trying to cope with everyday situations. Daily life is filled with stress, especially emotional stress. Old ingrained ways of dealing with different everyday situations no longer work. Previous strategies for solving problems are not sufficient any more. At this stage, there is a strong focus on *restoring* life to what it used to be

- when it worked. This first stage can go on for a very long time. The list of professionals encountered is long, and there is often a lack of continuity and co-operation in the professional contacts.

Eventually you reach a turning point, which is described as the *recognition* in the model, an important and critical point in the life adjustment process. For some persons, this point can be characterized by an emotional crisis. They gradually realize that they will not regain their lost function. For others, this is an *awakening*, and they realize that the deterioration is a fact. During this stage, stress is often predominant. Something has been lost, but you do not know how to live with the new situation. In order to understand and acknowledge what is going on in the body, it is important to be given a correct diagnosis and prognosis. Objective information and emotional support is important during this stage. The recognition is necessary in order to change the life situation and be prepared to accept support from others.

II. *The second stage* often starts with grief – you grieve your lost functions. However, a changing process may start successively from this point. The power and the motivation have a new focus and are aimed towards the future – from restoring to *changing*. The second stage is spent *dealing with* what has now become a fact, as well as *exploring* the possibilities. The freedom of movement is restricted, and you may feel tied up and dependent on others. You must now realize that this new situation has consequences for your life situation, now and in the future. You need to find new strategies, which is a lonely as well as time and energy consuming process. You still grieve and miss what is lost, and feel worried about the future. The thinking process is focused on change, and the obstacles and possibilities may be explored. You gradually become aware of the new obstacles linked to the functional impairment, and how to compensate them. Strategies that no longer work are being abandoned in favour of new, lasting ones. Little by little, control is regained, and daily life begins to work again, only this time you are subject to new life conditions. There is a need for reflection during this stage, and an active rehabilitation process should be under way. People around must show understanding. Many consider that affirmation from meeting others who are in the same situation, with the same impairment, is very valuable. This can be the start of repairing the self-image. This stage can last for years.

III. During *the third stage*, daily life begins to feel familiar again. You begin to plan for the future. Gradually you regain control in life, and new priorities and life projects can take form. You feel more rooted in yourself and have started finding your way back to your core identity. The strategic work becomes increasingly conscious and planned. You have acquired new kinds of competences to deal with the functional impairment and its consequences, and you put yourself to the test in different situations and contexts. You have now obtained some distance to what was previously perceived as difficult and impossible, and the restrictions in daily life seem smaller. There is a growing balance between the demands of daily life and the conditions of the impairment. The strategies developed during the life adjustment process to reduce stress become more and more of a routine. However, life will still contain many uncertain situations, perhaps every day, and this leads to insecurity, vulnerability, and stress. Rehabilitation during this stage is focused on helping people to help themselves, and recurrent support should be offered when needed.

When you have developed functioning strategies for dealing with the remaining difficulties – difficulties that will always remain – the adjustment process can be considered to be over. Life has a future again. Now, it is a question of living with the functional impairment day by day and finding your own way. ”Living with” may be regarded as a *maintenance work*. You have developed a preparedness for unforeseen situations, and have created you own order in life. The self-image is restored and the self-confidence regained. You have the competence to change and have become your own expert. The stress margins are often small, but you have learned to live with the functional impairment. You have now found your own strategies to deal with different situations influenced by the impairment in daily life (Gullacksen, 1998, 2002).

Learning to live with your impairment is a long process when it comes to finding emotional and practical attitudes towards the functional impairment. It is often a question of repeatedly having to adapt to altered or impaired functions. The life adjustment process implies stretching the boundaries of what is possible, and finding new strategies to cope with daily life and life in general. Trying and learning new strategies in social situations means daring to meet the environment. You need to be open-minded and courageous. This takes time and energy, and different kinds of recurrent advice and support is needed along the way, both practical and concrete support, but also emotional support.

Life Adjustment and Deafblindness

The project presented by Lena Göransson and Region Skåne (Göransson, 2007), used the life adjustment model to understand how people learn to live with deafblindness. This was not the focus of the project, but the issue became evident in the informants' stories. A chronic and often progressive functional disability such as deafblindness, requires thorough and recurrent adjustments. You face new and unknown conditions, and finding new strategies as well as regaining control over daily life requires a great deal of energy. It is not only everything that happens when a person is given a diagnosis that counts, the implications of living with deafblindness over time are just as significant. Most persons affected by acquired deafblindness go through long periods of deteriorating functions, often with only a vague idea of what is going on and what will happen. The life adjustment model helped identifying and describing the different stages (Göransson, 2007).

The life adjustment model has also been used by Region Skåne's Deafblind Team in the direct rehabilitation work. The model has been used to identify where in the adjustment process a person is, with the purpose of offering the right support. It has also been used as a basis for discussions, both in conversations with individuals and in groups. Gullacksen's theory about life adjustment includes persons with deafblindness and is considered important within this group – they recognize themselves in the model and can relate their own life situation to it. Life adjustment has become a useful term for persons with deafblindness in Sweden. This was a conclusion drawn from the project (Göransson, 2007).

However, further knowledge is required in order to seize and describe a more modulated image of life adjustment related to acquired deafblindness. The studies, reports, and experiences presented in this paper unanimously show that persons who acquire deafblindness depend on adjustments of both the physical and the social environment, and of services provided. Failure to do so will restrict persons with deafblindness from leading an active life and from participating in society – a fundamental right for all people. This leads us to the aim of the project which is to *gain an increased knowledge of what life adjustment may look like for persons with acquired deafblindness and, based on this knowledge, be able to meet the person's needs and offer the right support at the right time.*

A PRESENTATION OF THE PROJECT

INTRODUCTION

The project group co-operation was established in 2007, and since 2009, we have co-operated with a reference group consisting of four persons with personal experience of living with deafblindness. We gathered material during the first half of 2010. The majority of our material comes from focus group interviews carried out in Denmark, Norway and Sweden, where all in all fifteen persons have participated. Apart from that, the reference group has allowed the conversations that we have had with them to be used as data in our study.

THE REFERENCE GROUP

The purpose of the project has been to deepen the existing knowledge about life adjustment related to deafblindness (Göransson, 2007). To achieve this, we found it crucial to collaborate with a reference group consisting of people with personal experience of deafblindness. We needed their reflections on their personal experiences of life adjustment, as well as their point of view on which questions and conditions they saw as important to discuss in the focus group interviews. Furthermore, we needed support from the reference group when analysing the interviews.

The participants were selected based on our personal knowledge of them as persons who are aware of their deafblindness, and who have the ability to reflect on the process that they have been through. The reference group consisted of four people from all the Scandinavian countries, i.e. one from Denmark and Norway, and two from Sweden.

The reference group met at three occasions, once before the data collection and twice during the analysis work. The meetings lasted from lunchtime until lunchtime the following day. The participants received the material previous to each meeting to have a common basis for the discussions. For the first meeting, the group received a summary of the life adjustment process (appendix 1), as described in a previous study (Göransson, 2007). For the second meeting, we asked the reference group to reflect upon the topics that were important to the participants in the reference group. Finally, at the last meeting, the reference group studied and shared their views on the analysed text developed by the project group, and also reflected on the overall results of the project.

METHOD

The method used in our study is qualitative group interviews, so called focus groups. The advantage of the focus group model is that the participants interact with each other during the discussions, which gives the stories additional dimensions compared to if the persons were interviewed individually (Wibeck, 2000; Ahrne & Svensson, 2011). The purpose is to achieve a so-called mutual understanding for, in this case, the process in connection with acquiring a severe, lifelong functional disability such as deafblindness.

Since we wanted the participants to share their individual experiences, memories, and reflections related to the topics of the discussion, it was important to create an atmosphere that stimulated the participants to interact with each other on issues they found important. That way, we could expect varied and intense discussions. The discussions are similar to life stories (Denzin, 1986; Öberg, 2011), including the past, the present, and the future, thus making it possible to focus on the person’s memories of suspecting that he or she had, or would develop, a combined visual and hearing disability.

All group discussions followed an interview guide (Appendix 2) put together in co-operation with the reference group. The interview guide provides many opportunities for the participants’ own stories, as well as dialogues inspired by these stories. The guide follows the different stages and parts of the life adjustment course. The topics emphasized by the focus groups during the first meeting were: the term deafblindness, progression, crucial events, loneliness and vulnerability, dependency and independency, communication and relationships, as well as loss of energy.

SELECTION AND DESCRIPTION OF THE PARTICIPANTS IN THE FOCUS GROUPS

The project group discussed how to select the three focus groups in each country, and the ambition was to have a good dispersion of the participants’ experiences. The variables we focused on were age (working age) and communication method (sign language and spoken language). Apart from that, we also searched for persons who would be interested in discussing and reflecting on how it is to develop and live with deafblindness. We also based this selection on our personal knowledge of persons in each country, but were also aided by counsellor for persons with deafblindness to find others who were interested. Since the group of persons with deafblindness is a small group, it was impossible to avoid relationships to and between some of the informants.

Since we have had three different focus groups, we have been able to make the groups similar *within* the group itself but not necessarily *between* the groups. Hence, all participants in the Swedish group were women communicating via sign language. The Danish group consisted of three women and one man, all communicating via spoken Danish. In the Norwegian group, the number of men and women were the same, and they all used different means of communicating. Consequently, there was a certain homogeneity within each group, but a wished for dispersion within the participant group as a whole.

The persons that were asked to participate were all positive to participate. They were informed of the purpose of the study, of the reference group, and of how the discussions were to be arranged from a practical point of view.

All in all, fifteen persons participated, four men and eleven women in the ages 25-65. The majority were between 35 and 50. Eleven of the participants have a congenital hearing impairment/deafness and four have a visual impairment/blindness from childhood. What all the participants have in common is that they have a progressive impairment. Most of the participants have Usher syndrome, whereas some have an unknown diagnosis.

Nine of the participants use spoken language to communicate, and six of the participants use sign language. All speaking participants use hearing aids and other kinds of hearing assistive technology. One participant has a cochlear implant (CI) and three participants use haptic signals (Lahtinen, 2008; Næss, 2006) and other kinds of tactile support in their communication. Two of the six participants using sign language perceive via tactile sign language, and four perceive via visual sign language.

FOCUS GROUP INTERVIEWS

The focus group interviews took place during the spring of 2010. The discussions were held in premises where the physical environment was accessible with regard to light and sound conditions. In Sweden and Norway, the participants met at a conference facility and stayed overnight so that two half days could be dedicated to the group discussions. The Norwegian group had two such meetings. In Denmark, where the group met up during two afternoons, the participants could come just for the day. In all 17 interpreters and personal guides were involved during the interviews. In Sweden and Norway, the discussions were documented in writing, and in Denmark they were recorded on tape. The participants did not receive any particular compensation for participating since the project did not have any such means. However, their expenses were compensated through grants from each country.

ANALYSING THE INTERVIEWS

The discussions in the three focus groups have several similarities, since they all involve similar examples of events, experiences, treatments, and attitudes. Regardless of whether sign language or spoken language is being used, and whether the hearing or visual impairment is the primary impairment, there are similarities in the images, atmospheres, and direct experiences conveyed. The descriptions also hold similarities to results from previous studies where persons with deafblindness explain their life situations (e.g. Ravn Olesen & Jansbøl, 2005; Edberg, Joge Johansson & Nylander, 2010).

The life adjustment model (Gullacksen, 1998) has been used as guidance and a frame for interpretation throughout the whole study, from interviews to analysis. The intention has been to describe the conditions particularly associated with deafblindness. This means that the original framework and concepts of the model have been adapted to the life adjustment process related to acquired deafblindness. The original theoretical model has been adjusted to these conditions, leading to more precise terms and a more profound knowledge (Alvesson & Sköldberg, 2009).

Each focus group interview has been revised by the discussion leader, first into an account, and then as a summary based on the topics of the discussion guide. Everyone in the project group has read each other’s interviews and compilations. This way, an analysis model (Appendix 3) for the life adjustment process related to deafblindness, using a process perspective, has gradually been developed. It includes central topics from the interview material, for example: progression and the life course, self-image and identity, uncertainty and vulnerability, the term deafblindness, loneliness, communication, energy balance, control of the surrounding world, social exclusion and participation, sharing experiences with others, the significance of support and assistive technology, and professional support. During the analysis work and through the discussions with the reference group, these topics were further elaborated and have eventually resulted in the topics constituting one part of the results of the study.

The final analysis was then sent out to the participants of the reference groups before a final meeting in August of 2011, when we all discussed and revised the results further.

RESULTS

In the following chapter, we will present the results from the focus groups and the discussions with the participants of the reference group. The results are presented in two parts: *The Life Adjustment Process,* based on Gullacksen's life adjustment model (1998), and *Central Topics related to Life Adjustment,* including topics that have been particularly significant during the life adjustment process.

The Life Adjustment Process

INTRODUCTION

This chapter begins with the informants' impressions and memories regarding vision and hearing related issues from childhood and adolescence. This is followed by a description of the life adjustment process using more precise terms and based on the in-depth knowledge provided by this study. The account follows the stages used in the model, and has the following headlines:

- Towards the Recognition (stage I – holding on).
- Gathering Strength for Future Life (stage II – processing/exploring).
- Being rooted in oneself (stage III – rooted in oneself).
- Living with deafblindness (maintaining).

EXPERIENCES IN EARLY LIFE

Some of the participants in the focus groups are deaf since childhood and have grown up with sign language as their first language. They have stories from school about noticing differences between themselves and their friends, differences that they had trouble understanding. Some have a visual impairment/blindness from childhood and talk about problems from that perspective. Others share their experiences of growing up with a hearing impairment.

The child who begins to realize that he or she is different from others at an early stage in life, has its particular way of learning to cope with the deafblindness. Their life has only just begun and has not yet been shaped. They must form their lives and their identities based on a phenomenon that they do not quite understand or recognize, neither in themselves nor in others.

Several of our informants have childhood memories of events that have left deep marks. It is striking how strong these early every day events stick to memory. Many cannot find an answer to their questions and thoughts until they reach adult life. These experiences from childhood and adolescence were very important for the informants. From their point of view, these early experiences have significance to them later on, when they must adjust their adult life to the conditions of deafblindness. Therefore, their childhood and adolescence memories are valuable sources of knowledge in understanding the development of deafblindness in a biographical perspective.

Childhood

Some parents, often the mother, had explained to the child that his or her problems were the result of an eye condition. Other children were given no information whatsoever. The children claim that they knew that they were different from other children in some way. Many explain how they contacted adults to get an explanation, because they felt that they were somehow different compared to other children. Apart from the parents, school staff members are mentioned as significant adults. The childhood stories show that the children carried their burden all alone. Now, years later, they feel that they lacked contact with adults and could even feel rejected when asking questions. One of them felt that there was a lot of hush-hush around these issues. They also wanted to have contact with other children who experienced something similar and searched among their friends to see who showed similar signs. Several of them talk, almost lyrically, of the so-called ”family weeks” and what these weeks meant to them. They gave them an opportunity to play with other children in the same situation and they felt less lonely.

When our informants talk of support during the childhood years, it is often the parents and in particular the mother who provides security. The parents may have completely different attitudes towards the symptoms, anything from denial to involvement. The most important seems to be that the parents are involved emotionally, that they are an element of security and are supportive. There are examples of when the parents simply were not informed or did not understand the fact that, apart from the visual and hearing impairments, the child also risked severe deterioration of these functions later on in life. Not surprisingly, this, as well as the reluctance to talk about the problems, was a negative experience for the child, and for some of the children this has affected their relationship to the parents even into adult life. When the parents did not accept the diagnosis, some of the informants felt as though they themselves were being questioned, and that has been hard for them.

The emotions that have stuck to the mind all come from the whole experience being so inexplicable, and have caused feelings of unease and differentness. The child has been busy trying to find an explanation, but nobody has understood the child’s need to talk about his or her thoughts. Some of the emotions that are mentioned are shock, embarrassment, helplessness, social exclusion, and loneliness. Not just adolescents but smaller children as well were looking for someone to relate to.

There are several examples of sport experiences gone wrong, without the young person understanding why. One likely explanation for many children was their own inability. They thought that they were unable, clumsy or not very interested. When others started to perceive the child in the same way, it could lead to the child being excluded or even bullied. As a consequence of this, many chose to play on their own.

One possible dilemma was if the child admitted that he or she had trouble taking part in an activity because of visual problems. Then the child might have been dissuaded from participating altogether. The adults decided that it could be dangerous for the child to participate. This dilemma appears in several of the stories, and for some, that was a reason not to say anything about their problems.

The stories show that the children became skilled at finding strategies regarding how to interact socially with their friends. For some children, the primary functional impairment was something natural, and they dealt with it by steering activities towards situations that they knew they could handle. Memories also reveal that many had quite a carefree life with their functional impairments and even challenged their impairments. Several venturesome stories show how fearless the children could be, perhaps because they did not understand their limitations.

Adolescence

The adolescents’ stories show how some adolescents refrained from activities that they knew were difficult. Those who had balance disorders and reduced night vision planned their social life accordingly. Some examples of this could be avoiding coming home after dark, refraining from riding a moped, and other situations that were considered difficult or uncertain. Just how significant these milestones could be for the adolescents, is illustrated by examples. If you were unable to ride a moped, you could pretend that you were riding a moped by observing how your friends did, or you could sit at the back of the moped. One informant remembers that her parents gave her a camera instead of a moped. During the adolescent years, it was also delicate not being able to take part in sports and team sports. One way to compensate the differentness was to do something where vision and hearing was not significant and become all the better at it. Several informants had a hard time following lessons at school, especially adolescents with hearing impairments mention that. But they developed strategies to hide it and compensate in different situations.

Already as children, the informants could see through the adults’ attempts to smooth things over or give exaggerated praise. ”They don’t listen to the real problem”, one of them said and others agreed that ”It’s just as bad as feeling sorry for you”.

What kind of problems do the young people face when they do not have anyone to talk to about deafblindness, such a fundamental and at the same time incomprehensible factor in their lives? The adolescents want to emancipate themselves from the parents’ secure embrace, which up until now probably used to be enough for them, but now it must be replaced with friendships to lay the foundations of their adult identity. The circle of friends is described as narrow but positive. The adolescents look for more quiet activities and for people with similar interests, which is quite natural. For deaf people, the solidarity within the deaf community can still be enough, despite increasing problems. This is a place to find role models, in order to develop one’s own identity. For persons with a primary hearing or visual impairment, it might be more difficult to find a secure sense of belonging within a circle of friends. They do not have a natural group to identify with. Many grow up struggling to find a place among hearing and seeing people. For them, an additional impairment can be very difficult to cope with.

When it was time to start thinking about future work and education, several of the adolescents talk about the lack of support from school staff who could describe how deafblindness would affect different choices. There was some sort of guidance, but when thinking about it now, it was quite vague. Nobody wanted to speak openly about the visual and hearing problem. One person told us how a teacher carefully asked ”Do you think you can manage that?”, without openly mentioning what he meant. The entire transition period is described as a turbulent period in the life of a young person, who is also confronted with the growing consequences of deafblindness.

Conclusion

When our adult informants look back on their childhood and adolescence, most of them describe a good life, despite some agonizing occasions. That could very well be interpreted in a way that negative consequences of visual and hearing impairments in general were subordinated the natural course of growing up. The now adult informants say that they knew more about their situation than the adults around them thought that they knew, or perhaps wanted to think that they knew. They observed and were sensitive to how adults answered their questions, avoidant or exaggeratedly carefully. However, the term deafblindness was not something that they could relate to yet.

These childhood stories all include emotional experiences and reactions that are more or less unavoidable in the initial stage of the life adjustment. *Loneliness* is the result of not having anyone to speak to, to ask questions, and seek comfort with. Several events involve a feeling of *vulnerability*, and that has remained in their memories as a feeling of being different. Some informants have experienced bullying that has led to *social exclusion*. The search for others in the same age group, who experience the same problem, is almost described with a feeling of powerlessness, a feeling of being different without understanding why. Adolescence is all about finding role models in order to build up an identity as an adult, which has been difficult for these adolescents. *Depending* on a secure adult relationship is described as a strong positive factor. *Security* is often expressed as having a secure and stabile family situation. One of the informants appreciates having been taught to see life as a challenge from an early age and not having been overprotected. The family’s environment may also have given a sense of security if, for example, the family has been living in the same place for a long time. The deaf children appreciated the family weeks when several families met. That gave them an opportunity to meet other children with similar experiences.

The children feel that the adults treat them with exaggerated caution, avoidant, and anxiously. They also believe that the adults do not realize that the children actually know more than the adults think. When they approach adolescence, games and activities involve more challenges. That leads to valuable experiences of stretching the boundaries, according to several informants.

The major problem for children and young people whose primary impairment is a hearing disorder, seems to be coming to terms with having a hearing impairment in school and during the adolescent years. The incipient visual impairment starts off in the background somewhere, but becomes more of a problem for these persons too during their first years as young adults. Just as for young deaf people, they often discover that the combined functional disability has consequences in life when they start having problems functioning in their new roles as adults.

TOWARDS THE RECOGNITION

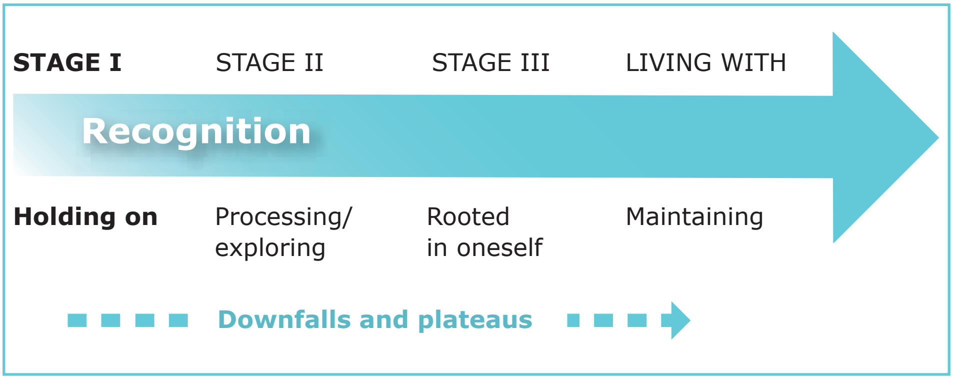

Figure 2. Life adjustment related to deafblindness, Stage I

Being given a diagnosis and an explanation to all one’s symptoms, is generally considered an important and often triggering factor in making the life adjustment possible. However, when it comes to deafblindness the situation is somewhat more complicated since a diagnosis can be made long before any symptoms are noticed or have become bothering. One characteristic is that the insidious symptoms often come gradually, during a long period of time, and they can be hard to identify at first.

The initial stage (I) of deafblindness can be perceived very differently depending on when the diagnosis becomes known, when the consequences become noticeable in daily life, at what age this happens, and the surrounding social conditions at that particular time. Some already know about the diagnosis since childhood, others are given the diagnosis during adolescence or as young adults. The diagnosis may come as a shock, even for those who have already been given the information. ”It feels as though you receive the diagnosis all over again”, one informant said.

For those who are met by the term deafblindness when they receive the information, when the symptoms are not yet apparent, the term itself becomes incomprehensible. Most of them have a natural attitude towards the primary impairment, which can be deafness or a hearing or visual impairment. The additional impairment is perceived as a huge problem causing distress. The two impairments separately are familiar, but not what they cause when they appear together and result in what has been described as 1 + 1 = more than 2. The phenomenon and the term deafblindness are therefore hard to relate to, something new and unknown.

The Insidious Development

The initial stage of life adjustment is characterized by the specific way in which the new impairment, bit by bit, forces its way into the person’s life over a long period of time. During the group discussions, this period is described as very trying and lonely. Since the problems are often repressed, excused, and complex, it can also be difficult to seek support and help.

We have examples of different ways of dealing with the knowledge regarding the new diagnosis, before the combination of the two functional impairments has started to affect life as a whole. For many people, this is a period that lasts for several years, but for others it can be very abrupt. Some people become active and decide to live intensely to experience as much as possible before their functions deteriorate. Another strategy is to prepare by learning alternative ways of communicating, for example Braille and sign language. Such intense actions can sometimes be a way of keeping the deafblindness at bay for a while, but it does not seem to give a complete protection against all emotions once the disability eventually starts having radical consequences on daily life. There are also examples of a less intense way, namely ”taking the day as it comes”, not worrying beforehand.

These attitudes are often a secret hope that the visual and/or hearing impairment will not progress. It is impossible to grasp the fullness of the combined functional disability since its consequences, at that point, probably have not revealed themselves fully yet. Since progression cannot be foreseen with certainty, there is always a realistic hope to cling to. Despite the outward denial, the stories reveal some signs of the person possibly having prepared on a pre-conscious level, which manifests itself in a less dramatic turning-point.

These self-chosen attitudes towards the menacing deafblindness are repeatedly put to trial in different ways. One way is by deteriorated vision and/or hearing, but it can also be by a deteriorated ability to communicate, exhaustion due to trying to maintain a satisfactory facade, not being able to trust one’s senses, misunderstandings, and many other things. The endeavour to hold on to the existing satisfactory level takes a lot of energy and challenges the self-confidence, at the same time as the struggle to hold on to one’s social life becomes increasingly intense.

Plateaus, Downfalls, and the Sustaining Power

The initial stage of life adjustment is the period of time when you are struggling to sustain things that have been functioning and that you are used to. In the beginning, the gradual deteriorations that are part of the developing deafblindness can often take place without much awareness. It is natural to constantly adapt life to new conditions without necessarily performing any major changes. That is what happens when the first signs of a visual and hearing disability become evident. But gradually, more profound changes are required to make everyday life work again, and the life situation a person has settled into is more and more affected.

Because of this, the person experiences that the deafblindness develops in stages: some periods are working better, but during other periods everything deteriorates. In order to make these alterations clearer, we call them *plateaus* and *downfalls* here. A *plateau* is the level of acceptable functioning at the moment, and it may include increasing deterioration to a point when strategies are no longer effective or able to cope with the deterioration as a whole. This is described, by the informants, as losing one's foothold, panic or a strong anxiety about how to cope with the situation. A critical stage like this is what we consider to be a *downfall*, when the person is forced into a period of active processing in order to find other strategies to meet the new conditions of the deafblindness. It is also a question of raising courage and strength to keep going.

We have identified a power behind the wish to hold on to the satisfactory life situation for as long as possible, i.e. sustain the conquered plateau. The power is strengthened by the anxiety regarding a further deterioration of the visual and/or hearing impairment that might come. We call this a *sustaining* power, holding on to the past. Its driving force is keeping the reality of deafblindness at bay. Several informants mention the enormous amount of energy they spend when daily life is not working well any more, and the strategies are stretched to avoid stress and strains. The effort required to maintain a level of function outwards is often hidden from others, which also takes energy. The motivation to sustain the present situation can be strong, and each step in the development towards deafblindness can be met by such resistance.

Typical of the life adjustment related to deafblindness, is having to deal with these recurrent types of contrasts between plateaus and downfalls, which for many is something that happens frequently during the life adjustment process.

Heading for the Unavoidable

The downfalls may be experienced as more or less dramatic, sometimes as critical developments. They can be caused by a deterioration of hearing or vision, or by an alteration of the surrounding environment, for example moving away from home or changing environment for some other reason, a new job or losing a job, health problems or becoming a parent, i.e. events that are all natural parts of life.

For as long as possible, people try to maintain their way of living and hope that the visual and/or hearing impairment will not deteriorate. Several informants recognize the tendency to test oneself, to find different ways of controlling if the vision or the hearing has deteriorated. It can be by reading a sign that they pass on their way to and from work, or reading the text on the coffee jar that they hold every day. A lot of emotional energy is invested in these *self-tests* since there is a lot at stake. These tests are important to feel safe and secure, but at the same time they always risk exposing deteriorations.

Gradual deteriorations can be dealt with by finding new strategies within a person's social and personal life space. Changes between plateaus and downfalls appear to be going on for years, for some people they may even begin during childhood. Eventually, this will lead to an improved insight regarding the fact that the combined visual and hearing disability is behind it all.

The stories describe an increasingly strained life situation with stress that is difficult to deal with and which leads to insecurity, uncertainty, and vulnerability. The struggle to lead the life you want and have planned might be lost. *Insecurity* about when the next downfall will come - what is the future going to be like? *Uncertainty* as a result of repeated mistakes and lost control in daily life. *Vulnerability* when you realize you can no longer deal with situations the way you are used to. *Loneliness* that is partly self-chosen – a way to limit the exposure to risks and mistakes, but at the same time having no one to share your emotions with and no one who understands things that you cannot put into words. Eventually, a feeling of being excluded starts creeping up, or a *feeling of homelessness*, intensifying the feeling of being different and lonely.

There is an increased pressure on the self-image and the personal and social identity. The image of a future becomes hazy when you no longer trust your own abilities. This causes a disruption in the otherwise obvious continuity between things in the past, the present, and the future, the so-called *biographical life trajectory*. Life does not turn out the way you expected it to. When there are no ways left of adjusting on your own, the only thing that remains is more noticeable and thorough support, and that is a sign of deterioration both to oneself and to others. The sustaining power can no longer be preserved. The increased stress becomes overwhelming, and recognition, which is described as a crucial turning point in the life adjustment process, becomes unavoidable.

The Turning Point – Recognition

In the life adjustment process, the recognition is described as a turning point. This is when the attitude towards the functional impairment goes from being focused on “holding on” to “changing”. It is not until after this turning point, that it becomes possible to start processing the life changes. People who used to consider the visual and hearing impairments as two distinct impairments, must now try to grasp it as a whole, as deafblindness.

The recognition is a question of admitting the loss of what has been. Despite having been given a diagnosis, perhaps ten years ago or more, the problem of how to manage living with deafblindness has not yet become clear. It is a learning process that is yet to come, but that can begin now. The unavoidable recognition becomes the turning point, as the self-image and identity is fundamentally threatened by the functional disability’s consequences on the life situation, now and in the future. The informants mention periods of 5, 10, 20 years or more before having come this far. The turning point opens to the possibility of commencing a changing process, far more thorough than during the previous downfalls. This includes getting to know oneself, one’s own activities and environment, based on the new conditions in life. The gradual downfalls will probably continue for a long time to come.

The recognition is characterized by two problems or realizations you must relate to. One is that life can no longer continue as before. The other is that the future will not turn out as planned. The vital connection between the past and the present is lost, and it is hard to imagine the future, something which may cause a person to lose his or her foothold in life. It is also known that the reason for this is the increased visual and hearing disability. One informant said: ”You realize things that you have been repressing for so long.”

The recognition does not necessarily mean that a person has recognized that he or she has, or will develop deafblindness. That can take years to realize. For most people, deafblindness is still a completely unfamiliar concept, something that feels impossible to identify with.

Triggering Events

We can distinguish several critical events that may trigger a turning point. One common example is a severe accident or an almost-accident, after which a person is forced to see the seriousness and his or her own responsibility in the situation. Several informants have experienced falling off a bike or driving into others. There are other examples that show increasing numbers of mistakes and accidents, making it impossible to keep on trivialising the reasons behind it.

Others describe situations that they found very embarrassing, for example communication difficulties leading to conflicts and misunderstandings. For some, the recognition was unavoidable when their social situation changed, for example when they moved away from home or met a partner, and it became impossible to keep covering up.

Several informants talk of the shock of not being able to get a driving licence or to be asked to return their licence. This pointed out that their visual impairment was more serious than they had thought. For some, this left deep marks in their self-image as independent adults. ”It was the worst day of my life”, one informant said. For another informant, this meant that he could not continue with his occupation. Some kept their driving licence even though they could no longer drive, which says something about the symbolic value a driving licence holds in the adult’s life.

Too many misunderstandings in social contexts lead to an insight that the communication is no longer working. For those who have been used to reading others visually when communicating, the visual impairment becomes devastating. For those who use hearing when communicating with others, the hearing impairment is the problem. There is a limit to how much the strategies can compensate. The increased difficulty to orientate in darkness can cause problems when going to work. When one winter is over, you just hope that you will manage the next one. But when that autumn finally comes when the remaining vision is not enough, the only answer is to face the fact that the vision has deteriorated.

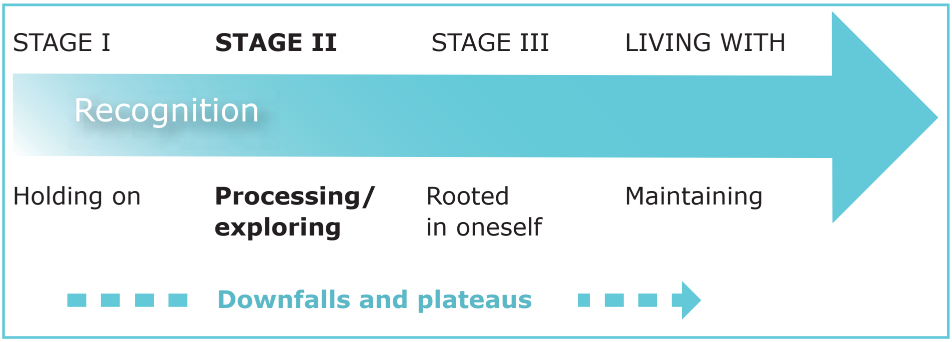

Figure 3. Life adjustment related to deafblindness, Stage II

The recognition leads to the second stage (II) of the life adjustment process, and that can be a prolonged and energy consuming period. The reactions to recognizing the reality you are facing, often stir up strong emotions. You feel *grief and regret* for how life used to be. New in this situation is that you now realize that the combined visual and hearing disability will have consequences for your future life. These consequences have probably not revealed themselves fully yet. Many people still have some vision and/or hearing that can be used to maintain activities. You worry about subsequent downfalls with gradual deteriorations, perhaps of both vision and hearing. The downfalls become emotionally more difficult and the margins for compensating become more narrow if the functional impairments deteriorate further. Unlike previous downfalls, during the initial stage, you are now aware of the reasons behind the difficulties and you can no longer hide the reality from yourself. The personal processing eventually re-creates an inner trust towards the person you are, which makes it possible to keep going, despite the deteriorated vision and/or hearing.

Deafblindness does not develop as something isolated from the rest of life, but its consequences are interwoven in life, family life, working life, social life, and leisure activities. Therefore, the consequences are also characterized by what period in life you are in. There must be room for other events too, which can sometimes make the adjustment more complicated. This is both good and bad, according to the informants. It might mean that you have to “take a break from yourself” for a while and postpone your own processing, thus having a badly needed break from focusing on your own concerns. On the other hand, the deteriorating functional disability becomes a challenge to social life, independence, and safety and security.

New for this second stage is that you consciously begin to alter your life situation by *processing* your attitude towards deafblindness, and by *exploring* yourself and the deafblindness in relation to the world around you. This is fundamentally a question of repairing your self-image and identity to make deafblindness a part of yourself and your life.

It is also a question of regaining what you have lost by finding strategies that facilitate activities or replace them with others. The basic strategies in this stage, are accepting different kinds of support, for example using different kinds of assistive technology, alternative ways of communicating, as well as interpreters. The motivation is now focused on the future, and energy is not spent on hoping to be able to do things as before. You are facing a strenuous and energy consuming work, both physically and mentally.

Grief and Regret

The disrupted continuity in life that can become evident in connection with the recognition, leads to a re-evaluation of life so far. Since there are no clear stages to cling to in the future, the future can be perceived as vague and uncertain. Many people describe how lonely they feel once they realize this. It is difficult to talk about emotions with others. Not only because it is difficult to put emotions into words, but also due to the functional disability's inherent communication difficulties. For many, it is difficult to find others with knowledge of their situation. You are all alone with your emotions and the frightening future. The way to keep on going is described by many as simply ”having to get on”. Perhaps, it is our natural survival instincts that are activated.

Finding Oneself Again

Fundamental for all life crises is the struggle to find the way back to oneself and one's own life. Learning to live with deafblindness is therefore largely about re-establishing the faith in oneself and one's own abilities, finding one's core identity, and adjusting one's self-image to the new conditions. Just because you have acknowledged the deafblindness to yourself, it does not mean that you are ready to talk about it with others, and many continue to conceal it as well as possible.

Questions such as ”Who am I?” and ”Who have I become?” arise from the insecurity relating to self-image and identity. The previous sense of belonging is fading and the threat of homelessness, of not belonging anywhere, becomes real. When former friends and other significant people no longer understand your difficulties, a feeling of being excluded is born. This feeling can also emerge in the contact with the family.

The self-image is shaped in contact with other people and it can vary in different contexts and roles. This means that the functional disability can influence the self-image itself in different ways, depending on which social roles a person has. Some roles work well, whereas others do not. This makes other people uncertain about the limitations that deafblindness actually causes, and leads to difficulties in controlling the self-image and the self-image perceived by others. It is an increasing uncertainty concerning others’ perception of me as a person. Many informants also think about other people’s beliefs and preconceived ideas about persons with deafblindness in general. This is an issue that many informants have struggled with and that they keep coming back to during the interviews.

More or less reluctantly, people start looking for a new social context. For deaf people, it can be difficult to leave the linguistic and cultural community in which they have grown up and which has provided safety and security in life and society. Several of our informants mention this. During this delicate stage, it is a huge step just to contact an organization for persons with deafblindness and other persons with deafblindness. This first step can take quite some time. Initially, you might feel that you do not belong there at all - yet. Many describe how they approach these persons with curiosity to see how they manage. One informant was given a job at an organization for persons with deafblindness, but that did not make her feel as a member. Another informant was told by her relatives to become a member, but did not read any of the letters she received from the organization. You are struggling with a strong feeling of ambivalence; on the one hand you want to keep deafblindness at bay, and on the other hand you realize that contact can be a valuable help in understanding yourself.

During this second stage, you are also confronted with some new roles that come with being dependent on others. Becoming a user, patient, someone who needs help from professionals and authority representatives, can be a completely new situation. Depending on other people’s assessments of one’s own life situation can be tough on the self-image, but it becomes more and more inevitable. Several informants talk about their struggle with these contacts and their feeling of vulnerability and helplessness.

Exploring the Conditions of Deafblindness

It is absolutely necessary to explore oneself in different contexts and situations to be able to move on in the adjustment process. One significant factor when the processing becomes more active is objective and personal information about the functional disability and its consequences, both medical and functional. This is necessary to understand the situation at hand, and make use of experiences. Others with deafblindness are more or less the only ones who are able to understand and discuss personal reflections about deafblindness. That is why these contacts are so significant.

Each downfall leads to stress and overloading when the strategies or the support, that used to be good enough, no longer works. When the consequences of the visual and hearing disability increase, you experience several downfalls when you must abandon a plateau that no longer works. Each new plateau is based on experiences from the previous stages. When a new, satisfactory plateau is established, energy is set free; energy that can be used in processing the new problem areas. By using assistive technology and by developing individual strategies, a possibility to eventually become active again emerges. However, there is an emotional price to pay. The assistive technology becomes the inevitable proof of the deafblindness. It also becomes a visible proof to others, indicating that the problems are now so extensive that it is impossible to manage without support. This particular exposure is sometimes the most difficult thing to deal with, according to several informants. In order to let the assistive technology and the support be shown to others, and to be able to cope with others reactions and questions, you have to feel quite safe in your own identity and self-image. You explore which image of yourself you want to show to others, and how to introduce that image. This is the processing of the second stage.

All the examples given by our informants about building up a life with the right assistive technology, underline the fact that, apart from emotional preparedness, time, strength, and energy is also required. Several informants have personal stories regarding for example the white cane. These stories show what a struggle it is to get used to the idea of having to start using assistive technology. It is often a huge step to actually learn how to use them. As the life adjustment gradually evolves and the need for assistive technology increases, there is also an increased openness to accept the assistive technology that exists. Initially by secretly checking out what others use, but eventually, as the contact with other persons with deafblindness becomes more established, by a more active search for the right support.

Several kinds of services, for example starting to use a computer to communicate or learning Braille, is time consuming and requires expert training. In some of the stories we can note a feeling of racing against the clock to learn everything before vision and/or hearing deteriorates. This can be one reason why it is easy to become irritated with the professional support system, because it does not run smooth enough.

During this stage of the life adjustment, people gradually increase their awareness of the complicated and complex consequences of deafblindness. Communication problems, difficulties getting access to information, and limited ability to move around freely eventually become huge challenges.

The ability to communicate with the environment is absolutely necessary for a continued social life. This gives the motivation to build up a satisfactory self-image, find a new sense of belonging, and find nourishment for a new independent life. Establishing adequate ways of communicating with the environment such as family members, employees, and citizens in society is fundamental in the processing and exploring phase of the second stage.

It also becomes increasingly difficult to perceive the continuous information flow, both significant and less significant information. This revelation can be frightening and lead to uncertainty in the interaction with others. An initial strategy could be to withdraw from others, but eventually new strategies are required to meet the need to feel a part of what is going on around, both in the close environment and in the world at large.

Another discovery described by the informants is the experience of gradually losing one's feeling of freedom. Orientation and moving around freely, becomes more problematic. For some, this is a dramatic and difficult discovery since it makes them more dependent on others. The longing for freedom means having to get used to interpreters/personal guides, contact persons, and transport services. This kind of support is necessary, especially to maintain a social life. It also takes some time to learn how to use the kind of support in a positive way.

The discoveries and processing during the second stage, evolve around the consequences of a deteriorated communication with the surrounding world and the dependency on others to be able to participate. By exploring new possibilities, the uncertainty regarding the future is gradually reduced. You can see the possibility of having a satisfactory life if you learn how to use assistive technology, support and services. However, there is still much work to be done with regard to self-image and belonging, uncertainty, and vulnerability.

The transition to the third stage is manifested by the fact that you now know what it is like to live with deafblindness, and that you can control its conditions. The last stage in the learning process remains, and it can be described as making these strategies a natural part of life.

BEING ROOTED IN ONESELF

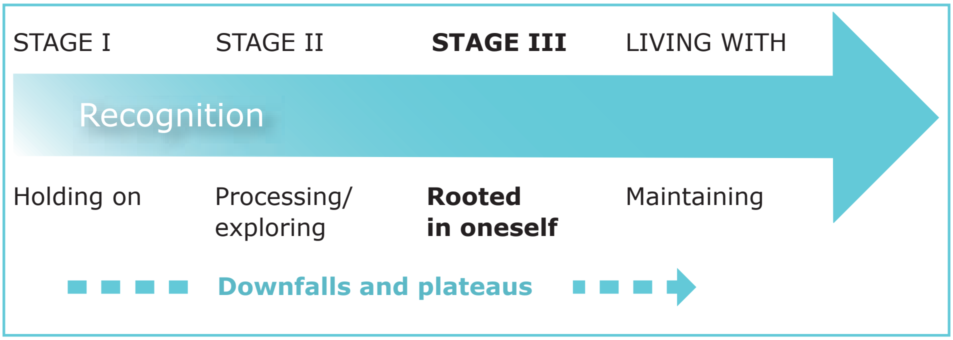

Figure 4. Life adjustment related to deafblindness, Stage III

The third stage of the life adjustment process is characterized by the fact that you have now retrieved your core identity and been able to incorporate the conditions of deafblindness in your life situation, the significant factor being that person and life is once again a functioning unity, regardless of the degree of the visual and hearing impairments. The reference group talked about finding a *fundament* which is necessary in order to tackle future challenges, and these challenges will in their turn demand further processing and adaptations. It is a question of living with the uncertainty of what deafblindness will lead to in the future.

Many of the experiences from the previous stages of the adjustment process must now become integrated in life, and within yourself. You are now dealing with the situation regarding deafblindness in a more purposeful way. You have remedied yourself, and you have become more rooted in your own course of life, you have healed your identity and your self-image, and perhaps found a new sense of belonging. Visible results emerging are that you respect yourself, you can see what rights you have, and you can speak openly about the problems related to deafblindness.

It is often during this stage of the life adjustment process that the family and others who are close also realize that the deafblindness will affect them too, as well as the life they share. There are several examples in the informants' stories of how relations, communication, and social interaction with their close ones change. Some informants also describe how the roles and the responsibilities within the family are affected and must be adjusted. One example is when the partner has to take on the role as a personal guide or an interpreter in social contexts, or has to take over more and more tasks in the family's daily life.

The new openness leads to a more relaxed attitude towards assistive technology and other kinds of support, such as the use of interpreter, personal guide, transport services, learning Braille or accepting counselling. As it becomes easier to use assistive technology and personal support, the ability to take action and to participate in the environment and in other people's lives also improves. It becomes possible to picture oneself in a potential future, which is important to re-establish the biographical unity.

The informants' stories illustrate what a tough period they have been part of. It might not be until now that they feel some distance with regard to everything that has happened. The following phrase captures how difficult it has been: ”It would have been better to lose everything overnight”. That shows how exhausting the previous stage in particular has been, the downfalls and the wish to re-establish a satisfactory plateau, and how much energy it has taken from life as a whole.

You have to build up a new faith in relation to things that were previously taken for granted. Many talk of having to find a new pace in life. Everyday chores require more time and energy. You avoid having many activities going on at once. You learn to plan your time and the different situations of daily life. It is also evident that you can now control your life again by making priorities and stretching the boundaries when you want to or need to, and have a break or retire when needed.

Experiences from the life adjustment process make it easier to explain your situation to others, which is valuable in order to introduce yourself *as the person you are* – not as *deafblind*. The informants keep coming back to the difficult task of making others see beyond the functional disability. When you have re-established your own belief in yourself, it is possible to actively start addressing others' pre-conceptions and negative attitudes. You must convince others of what you are able to do.

You can now make demands and define your needs in the contact with professionals and authorities, for example when it comes to assistive technology, interpreter, transport services, and a contact person. This also means that there is a risk of confrontations, which the informants have several examples of. In these circumstances, you have great use of your contact with others in similar situations and the deafblind specific support, to muster the courage and to stand your ground. Despite this, several informants talk of feeling powerless with regard to society when authority representatives, rules and regulations cannot appreciate the person's situation.

LIVING WITH DEAFBLINDNESS

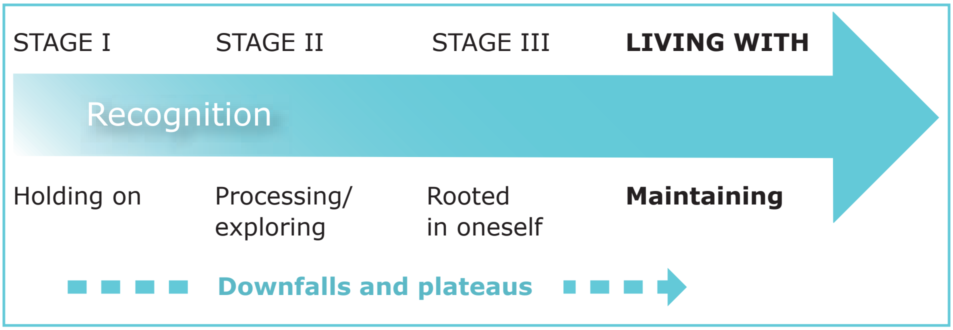

Figure 5. Life adjustment related to deafblindness, Living with

The last stage of the life adjustment model is described as a transition into *living with* the disability, i.e. not as something that has been accomplished. The model involves periods of *maintenance work* with recurrent adjustments, which will still be needed in the future, in order to lead the life you want and to make life work. Persons with deafblindness often say that a life with deafblindness requires both psychological and physical energy to compensate the lost vision and hearing. The maintenance work includes continued contacts with professionals, keeping up to date with the latest developments in assistive technology, as well as disposing your strength by planning and prioritizing activities. Some informants claim that it is largely up to themselves to seek information about the development in the technical and medical field. This also includes new or modified laws, rules and regulations concerning the right to use the social support system. Many do not quite trust the public support system. They feel that they have to rely on themselves, and they strive to become their own experts on these important issues. However, people who have had access to deafblind specific support, for example contact with counsellors for persons with deafblindness or a deafblind team, say that these contacts have been a significant relief for them.

The informants have furthermore experienced disappointments and downfalls, but also personal success. One important kind of support comes from other persons with deafblindness, and many want to share their own experiences.

Most of the participants in this study have the life adjustment process behind them, which means that they have experiences of living with and creating a life with deafblindness. They all describe how deafblindness has become a relatively natural part of their lives. Nevertheless, there are constantly many adjustments to make in different situations. According to the majority, it is impossible to gain complete control over experiences of downfalls, failure and helplessness.

All of these stories provide expressive and detailed insights into how it might be to live with deafblindness. We will therefore let the following quotes and extracts from the interviews speak for themselves.

”It’s difficult to say how you do to live with it, it’s part of your daily life.”

”It can’t be too much at once. A minor trifle at the same time as I’m having a ”deafblind crisis” can turn everything upside down. It just gets too much. Other people don’t understand that minor things can make everything go pear shaped, and it’s difficult to explain that to them.”

”I arrived at the hotel, but the interpreter wasn’t there. I just couldn’t manage at breakfast the following day. That made me sad. The margins are really narrow.”

”The biggest thing was to stop working. If I had continued working, some of the things I do now would have been impossible. But my work was part of my identity. The first autumn, there was a feeling of emptiness. Gradually, I got my energy back and I got the strength to do more.”

”Where do I want to use my energy today? – I must make priorities. Today, I want to save my energy for work for example, not waste it on getting to work.”

”Sometimes you choose to do something that you know is hard, just because you really want to be part of it.”

”There is no room for things that aren’t related to vision and hearing. The margins are narrow.”

”But life is full of uncertainties. Will it get worse? Will I be able to cope with the situation then?”

”The thought of what’s going to happen if my vision deteriorates – it’s not as stressful any more. I know that there is something to take from and that I’ll see the possibilities once I’m there.”

”Social life gets more limited during the winter. Going out when it’s dark makes me feel helpless. I have stopped going to gym classes when it’s dark. A friend has offered to pick me up. For her, it’s ”just” picking up – but for me it means depending on someone.”

”In the deaf culture, you sit in a ring and talk – deafblind persons sit in pairs. The pace can be too high among the deaf. Tactile sign language makes it easier, but it’s difficult for someone who is deafblind to walk around and talk. It makes me so tired afterwards, so I don’t go there.”

”I don’t have any close friends to go out for coffee with. It’s too difficult to communicate. I can bring an interpreter or a personal guide, but it’s hard to get one on a Saturday or a Sunday.”

”I miss not being able to follow my impulses, be spontaneous. Everything has to be planned in detail. I really miss it. I’m not free to do what I want when I want to.”

”It would be nice to just jump in the car to go and buy flowers. Now I have to plan that – perhaps I can get an interpreter in two days, but come two days later and I might be worn out and not as motivated.”

”I’m scared that there won’t be as much support available. How will I make life work then?”

”I think we learn to deal with difficult situations. But at the same time you never know what will happen next. I often feel safe and I get many comments on that. I manage alright, but I don’t know how I’ll react next time. You never know!”

”There’s always a dilemma with things I want to do. I should have rested yesterday instead of going to town. But I want to experience things too. When I get really knackered, I get a physical pain, my skin aches. I think it’s mental exhaustion. Then I must rest for two days before my batteries are charged again!”

”If I’m rested I can use my vision and compensate better, which means I can also keep up better. When I’m tired I easily misunderstand things.”

”You have to move on – that’s just the way it is! For everyone else’s sake, I pull myself together, but sure, sometimes I get depressed.”

Central Topics Related to Life Adjustment

INTRODUCTION

When processing the stories, we have been able to see how significant factors in the adjustment process related to deafblindness have changed their meaning, from the initial stage to the last. It involves basic human expressions for identity, security, and control in life. They form a complex socio-psychological pattern in the life adjustment, and are significant in repairing and joining the individual life continuity. We have been able to distinguish a number of topics in the life adjustment process that we want to emphasize and develop. All topics interact and depend upon each other in different ways during the adjustment process, but in order to describe their development and eventually their change we mark a distinction.

- Progression and the life course
- Uncertainty and vulnerability
- Identity and self-image
- The charged meaning of the term deafblindness
- The different images of loneliness
- Social life and communication
- Strength and energy
- Sharing experiences with others
- The significance of support and assistive technology
- Meeting professionals

PROGRESSION AND THE LIFE COURSE

The most difficult thing to deal with when it comes to developing deafblindness, is considered to be the gradual, long-term, and sometimes alternately deteriorating vision and hearing. The downfalls and the plateaus described earlier, try to catch this character of progressing deafblindness. The medical and functional deterioration is unavoidably interwoven with the person’s life long situation, and has psychosocial consequences.

Once you have realized that the combined visual and hearing disability is an unavoidable problem, focus can be aimed towards signs of deterioration. You check your abilities by performing different self-tests, and try to confirm that everything is as before. Possible signs of change are taken into account and evaluated. You look for an answer, but at the same time you are afraid that the tests will show a deterioration of vision or hearing.

> *”Often, I stand and look at myself in the mirror. Then I check with my hands when I start seeing them. There are periods when I do this often. I don’t really know if I can use it somehow, but I do it anyway.”*

One informant shares her thoughts about an upcoming doctor’s visit. She reasons with herself about the different options: that she is imagining it all, that it is just a temporary dip, or that it is a real deterioration. Another person asks: ”The doctor’s sentence – when will it come?”. One informant even feels guilty about having waited so long before going to the doctor for help.

> *”I’m very unhappy and annoyed and sad about it, but also angry with myself, that I haven’t noticed it and taken it seriously and asked for help in time.”*

Going from periods of deterioration to periods of stabilization is psychologically strenuous. Add to that the demands of having to shift between adapting to a visual deterioration and adapting to a hearing deterioration. These changes require different strategies to cope with everyday life. The informants make it clear just how demanding it is to cope with these recurrent deteriorations of vision and/or hearing.

> *”My wife asked if I would say yes to being ”cured”, if it were possible. But I don’t think I could go through this process once more. The last three years, I have felt safe. Imagine having to go through it all again!”*

Our informants have many examples of how changes in the environment affect the experience of the progressing deafblindness. Environmental factors can include natural changes during the course of life, or occasional events that break the ingrained habits. Regardless of which, the stories show that these kinds of changes can have a significant role in how a person perceives his or her visual and hearing disability. Professor Eva Jeppsson Grassman’s research is focused on how a severe visual impairment affects people’s lives during the course of life (2001). By studying the same persons for a period of

20 years, she has been able to observe their attitudes towards the impairment during the natural course of life. Social conditions such as family, work and ageing, are examples of what she calls ”a context which creates a sense of belonging” during the course of life. Since deafblindness develops gradually during a long period of time, these contexts become significant for how a person experiences the impairment, which consequences it has, and how the problems can be dealt with. Natural events in life, such as studying, moving, the children starting school or a reorganization at work; all this can create a feeling of uncertainty where you face new demands and expectations. Changes of this kind can become crucial turning points during the life adjustment process, since they can provide sudden insights and perspectives on what it is like to live with deafblindness.

> *”When I moved away from home, I couldn’t understand why things weren’t working all of a sudden. What had everyone else around me meant to me? What had they done that made it easy for me?*
>
> *”It’s best to stay with the job I have. I know where every switch is and I know each step.”*

UNCERTAINTY AND VULNERABILITY

During the entire adjustment process, there are feelings of uncertainty and vulnerability. The uncertainty emerges in situations that confirm that you can no longer trust your vision and hearing. Children feel different when they are unable to recognize themselves in their friends. Adults feel that their self-image is threatened, and their self-esteem wavers due to inexplicable misunderstandings in social relationships with others. Eventually these problems find their way into the daily life and can no longer be regarded as merely occasional. For many, the solution to this uncertainty is to make excuses for, or reduce the importance of the things that happen. These reactions are common, regardless of whether a person at that point has received a diagnosis or not.

During the first stage of the life adjustment process, one common strategy is to hide and deny the difficulties. However, the more the visual and hearing disability affects daily life, the more difficult it is to conceal the problems. This development leads to the recognition of how serious the situation is.

> *"I had told them that I couldn't see very well. But on Thursdays, I had my break together with two colleagues who spoke very quietly. Each time, I went to the bathroom or I just went outside to make a phone call or whatever… because I couldn't hear what they were saying and I didn't know how to tell them, not now when I was already working there…Then I started realizing that I had to do something."*

The recognition implies that you have been forced to understand how serious your problems are, and that they can no longer be trivialized and disregarded. What is shocking about this turning point is that the trust in yourself and your environment starts wavering, and you become scared that your whole existence will fall apart. Things that used to be predictable and taken for granted, no longer work, and so it becomes more of an effort to cope with daily life. Uncertainty comes creeping into the fundamental feeling of safety that has, so far, kept life together. The continuity between the past, the present, and the future is disrupted, which is described as a biographical disruption in the life adjustment model (Gullacksen, 1998).

During the second stage of the life adjustment process, a comprehensive processing takes place, involving several areas of life simultaneously in order to regain the feeling of control and continuity in life. Rehabilitation work during this stage is very important to reduce the feeling of uncertainty and vulnerability with regard to unknown elements in life. By having access to psychosocial support, learning to use assistive technology, and receiving other forms of support, a feeling of connection in life is re-created and the biographical break can be mended.

The uncertainty starts off as a feeling without focus, but eventually it becomes more related to distinct situations and activities. Thus, it also becomes possible to constructively work with reducing the uncertainty and regaining control.

The main problem regarding deafblindness is that the feeling of uncertainty can never be completely avoided; you have to learn to live with the uncertainty. Researchers who have studied how acquired deafblindness affects the life situation, have emphasized the significance of a *basic safety* and *security* in life (Danermark & Möller, 2008). What is being described as re-creating *a* *fundament in life* by the informants can be compared to such a basic feeling of security. A fundament provides possibilities to maintain a life with deafblindness and the uncertainty that it entails, however, the uncertainty will not be considered just as menacing as during the initial stages. The informants often talk of strategies to control their uncertainty and to handle this feeling as part of living with deafblindness.

> *”I’m always well prepared. Yesterday evening, I memorized this room before I went to bed. I feel uncertain in situations where I haven’t been able to prepare.”*

The informants give many examples of the vulnerability they have to live with. Unforeseen events, when the meticulous planning comes to nothing, or when you fail to make others understand your situation, are all examples of situations you need to learn to deal with. The vulnerability is also a part of depending on support and help from others, as well as the risk of meeting people who do not understand what deafblindness implies. Our informants have several examples from their contacts with professionals and authority representatives. The evaluations of the need for assistive technology or other kinds of support, such as interpreter, personal guide or transport services, often lack empathy and sensitivity with regard to how it is to live with deafblindness. This vulnerability lies beyond one’s own control and deeply affects the feeling of security and the self-confidence. Even though you have gone through your personal life adjustment process and are on your way of finding stability in life, the feeling of not having any influence over your own life can be a true burden. It is easy to arouse a feeling of uncertainty, but you become increasingly aware of which factors you are able to influence yourself, and which depend on the environment.

> *”I have applied for transport services home when I work evenings during the winter. My application has been rejected four times. You feel vulnerable when things that could make you stronger are rejected.”*

IDENTITY AND SELF-IMAGE

Working with your identity is one of the most fundamental parts of the life adjustment. Self-confidence is affected early on in the adjustment process due to the misunderstandings and difficulties that arise. The uncertainty and the vulnerability seriously affect identity and self-image. The self-image is no longer correct, and some people focus the disappointment inwards, towards themselves. Who am I? Who have I become? Who can I become? How do others perceive me? These are crucial existential questions that the person is facing, and they need to be answered. In the initial stage, it is common to have negative thoughts about others' preconceived ideas regarding persons with deafblindness in general. These thoughts are a reason for hiding the problems and trying to maintain the established image of oneself to others for as long as possible. One person puts the doubt into words: ”Will they still see the same things that they have always seen in me?”

The fundamental part of the processing during the second stage is finding your core identity again. This means being able to include the visual and hearing disability in your identity so that your self-image becomes an image you are willing to accept. It is a question of adjusting the way you look at yourself, and how you experience that others look at you.

> *”The identity as someone with a visual and hearing disability is a part of me. But if I use a white cane, I become visible, and then I start wondering about what people will think of me?”*

The process of adjusting and finding your identity again is not isolated. It is closely linked to the work that involves learning to live with the new conditions in life and adjusting your view of life in order to see a positive development. This dimension of life adjustment related to prolonged illness or functional impairment has been studied with the aim of seeing how it is possible to have a good quality of life despite a severe physical situation. The phenomenon is called response shifts and indicates how the person's basis for evaluating quality of life has been adjusted. The adjustment is a consequence of how personal values and conceptions of a good life have been adapted to the circumstances, to facilitate the experience of a good quality of life (Sprangers & Schwartz, 1999; Boström, 2005).

Processing may lead to changes in some parts of the personality. Some people say that it becomes impossible to be as spontaneous as before. Others have learned to value moments of solitude. The stories show that people often lower their expectations in life. An example of that is renouncing from activities that you used to be interested in but that you can no longer take part in as before. One person says: ”I loved walking around in shops but I have had to give that up”. The reason for it was the difficulties with being assigned a personal guide.

During the third stage, it is time to show others who you are today. It turns out that this particular step is often connected to meeting others with similar conditions, i.e. other persons with deafblindness of roughly the same age. The persons who were interviewed in Miner’s study *Døvblindblevne og selvidentitet* (2008), say that the new identity is developed during the contact with other persons with deafblindness. You explore their world in order to feel safe in your own identity. But at the same time, our interviews show that there is a distinction between the social identity inspired by others who are ”equals”, and a personal and deeper identity that you have lived with your whole life.

> *”Deep down, I’m a lively person who likes to talk to others. Now, I can’t do that any more. And that’s hard… having to restrain myself.”*

Having an open attitude towards deafblindness, for example by accepting special support from society, is associated with being categorized; categorized by the world around you and in a way that you do not necessarily recognize. In some contexts, the main focus lies on the deafblindness and not on the person. ”Clients”, ”Braille-readers”, ”interpreter users” and ”white cane users” are all examples of this kind of labelling. The informants are well aware of this. However, in some contexts it is necessary to accept the categories made up by society, in order to get access to help.

One dilemma during the whole life adjustment process is to know who you feel connected to. We all have one or several self-chosen groups that we feel connected to. When the communication no longer works as before, it becomes more difficult to maintain a valuable sense of solidarity within the group. During the first stage of the adjustment process, this has probably not yet become a problem, but when you recognize the dual functional disability, it might lead to a gnawing feeling of unease. The increasing difficulties communicating can make you withdraw from the secure social group that used to be a central part of your life. There can even be mechanisms within the group leading to other members marginalizing the person with deafblindness as a deviant within the group. Several informants who used to belong to the deaf community, have told us of the difficulties of making other deaf persons facilitate the communication, for example by using tactile sign language or by using the right kind of lighting during the meetings. The marginalization can lead to a feeling of homelessness before finding a new sense of belonging among persons with deafblindness. These new contacts are often found through the user organizations, which mean that these organizations have an important task during the adjustment process. The informants describe what a slow process it is to approach the new group, often associated with a great emotional resistance. It is important for the organizations to be very sensitive to these kinds of approaches.

The informants' stories relating to the third stage show an awareness of the personal adjustments that have been made in order to solve the problems concerning: What can I do? What do I want to do? When you start respecting yourself again, you can start struggling to make others see your full potential. Several stories evolve around the difficulties of making others realize that you CAN and have the competence, despite the deafblindness.

> *"You really have to convince others all the time. You have to be high-performing and be better than everyone else."*

One important and delicate area related to these problems of being appreciated, involves working life and your professional role. Being able to maintain your identity as a professional, can depend solely on your access to the right kind of assistive technology and other kinds of support. Several informants have experienced not being offered the support in time, or simply not having their applications granted. These experiences have become huge restrictions for taking active part in working life. Some people have even been forced to stop working altogether or have to work fewer hours. According to some informants, the possibility to keep working to some extent is very important for a person's quality of life.

THE CHARGED MEANING OF THE TERM DEAFBLINDNESS

All informants have their own perceptions of the terms *deafblind* and *deafblindness*. The discussions in the focus groups clearly show that these terms are very charged. The person's attitude towards the words is partly altered during the life adjustment process, and the informants have different attitudes towards the words. In the beginning of the adjustment process, the words evoke strong emotions for most people and are considered a threat to the personal identity that they are struggling to maintain. They distance themselves from the term deafblind and do not want to become associated with it. Even if they are aware of their functional disability, they have their own criteria for when to use the term deafblindness in relation to themselves. It is not until the turning point of the recognition that this can begin to change.

Through the entire adjustment process, the informants describe how they are struggling and fighting with the term. It appears as though the term deafblindness slowly becomes a part of their identity when they become increasingly dependent on tactile support for information, orientation, and communication. It is also considered a problem making others understand that the term does not imply a complete lack of vision and hearing.

> *”It’s hard to explain what deafblindness is. Others don’t understand it. It’s better to say ”I’m deaf and visually impaired” or ”I don’t see in the dark”. That saves time, because others still don’t know what deafblindness is. It’s not about not having accepted it, but about avoiding misunderstandings.”*

Jesper Dammeyer, a psychologist at the University of Copenhagen, considers deafblindness to be a social construction (2007). According to him, there are no fixed, objective criteria for when a person has deafblindness, unlike many other functional impairments and medical diagnoses. Deafblind is not just something that you are, but also something that you become, according to Dammeyer. It is often external factors that determine whether a person belongs to the deafblind category, factors such as belonging to an organization for persons with deafblindness, using specific communication methods and deafblind interpreting, or accepting specific support for persons with deafblindness. All of this can be compared to belonging to a deafblind culture. According to this way of thinking, deafblindness is more an external social condition, than an internal physiological condition.

> *”I usually say that I have a combined visual and hearing disability, but that I belong to the group of persons with deafblindness.”*

The term *deafblindness* is given a concrete meaning the moment a person seeks contact with others who have the same problem. The name of the user organizations, which often include the term deafblindness, can sometimes become an obstacle in making contact. Terms like *deafblind team* and *counsellors for persons with deafblindness* can become obstacles, according to the informants. Some informants say that these terms stopped them from making contact for a long time, even though they needed it. They simply could not make contact with an organization aimed at persons with deafblindness. Someone said to herself: ”Am I really deafblind?”.

> *”The term deafblindness can delay the rehabilitation process. It’s important to be aware of the context the term is being used in, so it doesn’t feel offensive.”*

Our informants are well aware of the socio-political impact of the terms. They are strong and serious words that express a great demand on society, words that force society to make priorities. That is why it is considered important to keep the terms. There is an evident duality between not wanting to identify with deafblindness on the one hand, and using the word to get one’s own needs and rights met on the other hand. If the group consisting of persons with a combined visual and hearing disability is too widely defined, there is a risk of belittling the specific obstacles for persons with complete or severe visual and hearing disability, according to some informants.

Even if a person is an active member of an organization for persons with deafblindness, there can be diverging opinions about how to use the word. Most people agree that it is better to use the expression *a person with deafblindness,* than *a deafblind person*. Another expression that is being used is a *combined visual and hearing disability.* This duality can in itself increase other people’s confusion of what it really includes.

These opinions and views show how important and complex the question is, and it is a question that our informants are very involved in. The informants all respect one another’s opinions but emphasize that they want to have the right to choose themselves which terms to use when describing their own person. Nobody wants to be given a label that he or she is not able to relate to or identify with. A person’s attitude towards the word appears to be closely related to which stage of the life adjustment process he or she is in. The words used can also vary according to the situation and the context. However, it is absolutely clear that these notions are significant for almost all informants when they try to grasp life with a combined visual and hearing disability – deafblindness.

> *”I have let go of the term deafblindness and come to terms with myself. Today, I have a visual and hearing disability.”*

THE DIFFERENT IMAGES OF LONELINESS

All the stages of the life adjustment process include loneliness in one way or another. During the long initial stage of the life adjustment, loneliness includes all the worry, wondering, and fear that arise when the symptoms become apparent and harder to conceal in daily life. These experiences are not easy to convey to others, since most people still do not have enough knowledge and lack words to describe what is going on. Many describe their ambivalent feelings towards the problem, resulting in them rather being alone with their thoughts than searching for explanations. It is hard to break the loneliness, and it seems that it is not until a person has an inner readiness that he or she can accept support.

The stories about receiving a diagnosis and the period immediately after that, are characterized by an overwhelming loneliness. It is purely coincidental who you come into contact with in connection with finding out, and it is also a coincidence if this person has an understanding of deafblindness and any knowledge of it. There is a lack of follow-ups and support from society, and many informants have struggled on their own for years with their thoughts, questions, fears, and uncertainties regarding the future.

> *”Family and friends… I didn’t know what to say. At work… I didn’t dare to say anything there. I had a lot of unanswered questions… I just had to stick it out and wait.”*

The childhood stories show that children often feel lonely with their thoughts of differentness, despite showing more curiosity than fear. Later on in life, after having recognized that the visual and hearing disability has become a part of life, feelings of grief and regret open up for the possibility to accept support. Meeting others in a similar life situation, and meeting professionals with knowledge of deafblindness, is crucial to be able to accept support.

Gradually, loneliness will involve other aspects. The individual processing is a lonely work because often there is nobody to talk to. Loneliness can easily arise when others do not understand the significance of deafblindness in life, leading to the need of having contact with others who may understand. The contact with other persons with deafblindness becomes a possibility to develop trustful contacts. These contacts can put an end to the feeling of loneliness, the feeling of being different, and they can satisfy a much longed-for sense of community.

Further along in the adjustment process, during the third stage, the struggle to find a way of living with deafblindness continues, a work that includes making priorities and new choices. During this stage, the informants talk of a self-chosen loneliness in that they renounce from contacts and activities if they know that it costs more than it is worth to participate. In a life with deafblindness, there are both times of self-chosen loneliness, perhaps to save strength, and times of loneliness that can be forced upon a person as a result of the environment's insufficient accessibility. Insufficient accessibility is described as a huge problem for our informants, since it limits the person's possibility to participate. For example insufficient transport services, interpretation services, and guiding services are mentioned. One might also say that there is a seasonal loneliness, since the darkness of autumn and winter constitutes a restriction. All of this affects a person's possibilities to be active and participate, which leads to a gradual alteration of the personal network.

> *"Experience has taught me that during the winter, I need to limit my social life. I choose that myself, to avoid getting disappointed."*

The informants talk of experiencing a loneliness that can be compared to looking at the surrounding world from behind a veil, without really being a part of it. Even the close family can be on the other side of the veil. Obviously, how the family is involved in the adjustment process varies according to personal conditions, but it is absolutely certain that their situation is affected as well. There is a great ambivalence between, on the one hand, wanting them to understand what it is like to live with deafblindness, and, on the other hand, wanting to spare them all the anxiety. This leads to a special feeling of loneliness that can be difficult to cope with for people with a strong need to be close to their families; at the same time as they want to save them from worrying. This quote from an informant, who is trying to understand himself, shows how difficult it can be to understand and to make others understand feelings of loneliness.

> *”But the loneliness is my own loneliness, not in relation to my family, but my own loneliness with my situation and my own loneliness with being outside of working life and social life – that’s hard.”*

The stories clearly show that loneliness can have different shapes, meanings, and functions. Our informants share their experiences of loneliness from many different perspectives. They talk of the protective loneliness, the self-chosen loneliness, and the loneliness that is forced upon you. The gradually developing existential loneliness, i.e. being alone with your loneliness, is also something the informants talk about. It is evident that loneliness is a main trait both during and after the adjustment process, both as a self-chosen strategy and as a situation you are forced into.

> *”In a way, loneliness has become a consequence of the choices I have made in life, because of my visual and hearing disability, conscious or unconscious. Loneliness is probably the consequence that affects and influences me the most.”*

SOCIAL LIFE AND COMMUNICATION

Deafblindness affects the two most important long distance senses – vision and hearing – which undoubtedly leads to severe communication problems. All our informants say this. The development of the deafblindness, as well as the underlying diagnosis, are significant factors for how the communication will be affected, as well as how and in which situations it can be supported by compensatory strategies and assistive technology. In general, it is possible to use assistive technology and maintain the primary communication method for a rather long period of time.

The informants who have a congenital deafness and who still have some residual vision left, use that vision to read sign language visually. However, that means that the person with whom he or she is speaking must show special consideration, for example by adjusting the signs to the limited field of vision. That is not always the case though. Even family and friends forget this at times. The informants who have a hearing loss and who use a hearing aid and other assistive technology experience other difficulties. For example, the lip reading ability may have deteriorated, or they might need a hearing loop, or a better auditory environment and better lighting than others.

As the conditions for communicating have changed, the informants have had to compensate in different ways and sometimes they have had to learn new strategies and methods for communication, for example haptic communication (Lahtinen, 2008; Næss 2006). Other informants have started reading sign language tactually instead of visually like before.

The informants emphasize that communication, regardless of how it is undertaken, requires a significant amount of energy and concentration. During the downfalls, when vision and/or hearing deteriorate, it is a laborious task to sustain communication in different social contexts. Some informants describe how they gradually get used to not always keeping up, and sometimes they choose to avoid situations where the communication is too demanding.

Apart from the fact that the communication in itself is demanding for someone with deafblindness, communication is also affected by insecurity and a lack of control over the situation. Communication is made up by so much more than the spoken or signed message. Gestures, facial expressions and intonation are all significant elements of communication, and they are all meaningful. The informants talk about situations that they have found difficult or embarrassing because they have not been able to manage with the turn-taking in the conversation, or because they have not been able to perceive an affirmation from the other person. These kinds of situations have led to numerous misunderstandings for many of the informants, sometimes minor and sometimes more grave ones. Many find it difficult to grasp the context, both from a linguistic point of view and with regard to the actual situation that the communication is taking place in. That affects a person’s ability to be active and take part in the conversation on the same conditions. This is particularly evident when someone does not apprehend the response from the communication partner.

> *”I can’t apprehend the facial expressions on the person I am communicating with, nor the other person’s moods and expressions. I can’t be a good friend since I can’t interpret the other person’s expressions.”*

Most people probably do not become aware of how complex the communication is until it collapses. That is why so many say that it is also very difficult to prepare for it. It is hard to find motivation and energy to learn for example signs or haptic signals, before you have realized the consequences of deafblindness. Several informants have wanted to maintain their primary way of communicating for as long as possible.

Some informants also find it difficult to participate in conversations when the access to information gradually becomes more limited. This affects both the self-confidence and the communicative competence, according to the informants.

> *”I can’t take in all the information, news and TV-series, and that reduces the number of topics to talk about. I would like to contribute with something in a conversation, but then it must be about something that I have experience from and can talk about.”*

Even when a person has established a functioning communication strategy or a completely new communication method, social interaction is still a great effort. He or she chooses and prioritizes which situations to invest energy in. If the conditions for participating are very hard, many will rather choose to refrain from a certain social context. This is a part of deafblindness that can have huge consequences on how a person perceives being a part of the world around him or her. For a person with deafblindness, it is also much more difficult to initiate contacts and maintain previously established relations.

> *”I must say that my communication with others has become reduced since it’s so hard. I notice that as soon as we are three or four persons together, I just think it takes too much of my energy.”*

Some informants reflect on the difference between ordinary sign language interpretation and deafblind interpretation. Their point of view is that the deafblind interpreter becomes someone that they get to know and develop a social relationship to. According to them, this could be due to the fact there is more to this way of interpreting than sign language interpretation, since it requires close physical contact. In her study, Inger Birgitte Torbjørnsen (2009), observed interpretation in a social context for a person with deafblindness. She found that the interpretation process included more than mere language interpretation. For example, it was also about conveying feelings with words and body language, and clarifying the communication and the interaction between the participants in the social situation. When interpreting for persons with deafblindness in social situations, neutrality is not the main trait in the professional role, instead it is the art of understanding and being able to reflect on what is going on in the situation, Torbjørnsen concludes.

Most informants feel that they have to give up a lot when they are not granted an interpreter. In order to maintain a satisfactory life, interpretation support is absolutely vital. The interpretation helps you to become a part of different situations. According to the informants who use interpreters, the interpreter becomes a lifeline to the surrounding world for everyone who lives with deafblindness.

STRENGTH AND ENERGY

During the last few years, persons with deafblindness have started to make others aware of how much strength and energy it actually takes to lead a satisfactory life with deafblindness. Our informants are all well aware of how much energy that is required every day to compensate for the lost vision and hearing. During the life adjustment process, a lot of energy is put on coping with daily life, but in the beginning this is all done unconsciously. The initial stage mainly consists of strategic work to keep stress and worry at bay, which is costly, both in terms of physical and psychological strength. This period can be described as *living to survive*. During the rest of the adjustment process, the person must keep on working hard, often without the environment noticing it. All this hard work is carried out hidden from others. It does not take much to reach the limit for what a person can manage, but other people do not quite understand why the energy has gone and many people find it hard to explain.

> *”But when I think back I can really understand that I was a bit tired sometimes during my education or at work – it required so much energy all the time.”*

All the work with the emotional processing takes energy, and you need a break to cope with it. Several informants stress the need of controlling the pace during the important adjustment work. Exploring a new reality and future, developing and trying strategies, making new contacts, learning to use assistive technology and an interpreter – all of this requires energy. Maybe you need to keep the insight of the situation's gravity at bay for a while. The lack of energy can make you renounce from activities and social interaction, and make you retreat instead. The problem can sometimes be compared to a light or severe depression.

In the interviews, the loss of energy is described as something you simply must learn to live with. The loss will not become any smaller, but you can learn to live with it and control it. The strategies that are needed to manage with everyday life mainly consist of using your energy resources right by making priorities, planning, and making sure you have a plan B just in case things do not turn out the way you thought. Some informants say that sometimes they even choose not to participate in certain activities and relations just to be able to cope.

> *”A good quality in life, that means not being too involved and distributing time and strength wisely. But if I do that, I also feel that I fall behind and that's not fair on people close to me… it's a balancing act every day, how much I should resign from every day, and how much I should take before I must give in.”*

It takes time to become good at prioritizing your activities. Some of the informants say that it is an eternal struggle in their lives, and a struggle that people around them do not always understand. The problem of mustering enough energy for all activities means searching for new strategies, especially appropriate support and adjusted assistive technology, to face the conditions of deafblindness. Apart from prioritizing how to dispose your strength, it is also a question of estimating how much energy something requires, what the cost of that energy loss will be, and to set aside time to recover. This is a new part of life that the informants sometimes feel is more of a functional impairment than the deafblindness itself.

> *”The worst thing for me used to be the knowledge of having a visual and hearing disability. Now, the biggest problem is the lack of energy.”*

SHARING EXPERIENCES WITH OTHERS

The informants all agree that everything becomes easier if you have contact with other persons with deafblindness. The informants, who talk about their childhood memories, relay an uncomplicated image of them asking for someone to talk to and relate to. For those who go through a life adjustment process later on in life, these contacts are more emotionally complicated to begin with. The need to meet others increases in connection with the recognition and the time following that. Despite that, most of them remember the time when they distanced themselves from others with deafblindness, when it was important to emphasize the differences instead of any possible similarities between themselves and the others, the others being persons with deafblindness.

> *”My husband suggested that I might as well become a member of the deafblind organization, so I did. But in the beginning, I threw away all the letters I got from them. I wasn’t prepared, I didn’t want to. I wasn’t deafblind!”*

After the recognition and further into the second stage of the adjustment process, other persons with deafblindness become more and more important. It becomes very useful to see how others live with the functional disability, when you are grasping at straws that could lead the way to the future. You look for someone to relate to in order to reduce the feeling of differentness.

> *”Then it’s the network group, where I really feel that I belong together with others who are in a situation similar to mine. That’s where I refill my psychological energy so that I can cope with things. I get a real boost out of it.”*

The contact with others in similar situations appears to become an irreplaceable success factor in learning to live with deafblindness. Everyone approaches their ”equals” in different ways, but there is no doubt about its significance.

> *”Meeting others gave me my life back, before that I lived in a vacuum.”*

Some people are quick to find a user organization, or find contacts in the rehabilitation groups, whereas others have a more hesitant approach and can experience some resistance against contacting their ”equals”. It appears to be important that these meetings take place at the right time to have a positive effect on the person. At the beginning of the life adjustment process, when many people are still defending themselves against any similarities, these meetings can have the complete opposite effect.

When deafblindness is genetic, it is not unusual to have a close relative who also has deafblindness. Several informants have a brother or sister with deafblindness, but the experiences can vary. Some feel strength in being able to share the experience and support each other. For others, it has almost been a frightening experience to compare themselves with a brother or a sister.

The contact with other persons with deafblindness becomes significant in order to learn how to adapt in natural adult roles, such as a parent role or in a professional role. ”I can’t do like my mother did, can I?”, said one informant. With these words, the informant illustrated how the same social roles may have to be performed differently, due to the deafblindness – she was missing a role model. We interpret this as an expression of a kind that only persons with own experiences of deafblindness can understand and discuss. It is a significant example of the feeling of connection shared by people with similar experiences, that can be hard to describe in words.

THE SIGNIFICANCE OF SUPPORT AND ASSISTIVE TECHNOLOGY

Accepting specific support and help from the environment, is, for most people, not completely unproblematic. Often, it is not until after the recognition and during the second stage that the person starts thinking of ways of making daily life easier. Our research shows that due to the lengthy, strained, and complex adjustment process, the rehabilitation must be provided at the right time during this process to be accepted and meaningful. Suggested assistive technology for example, is often rejected if it is offered during a stage when the person cannot yet see it as a part of him or herself. Similarly, there can be devastating consequences if none or the wrong kind of assistive technology is offered when it is needed to build up a new life.

Most people have already used assistive technology for their visual impairment or hearing impairment. Deaf people have already used a sign language interpreter. The difficulty lies in accepting help that is so clearly intended to compensate for the combined visual and hearing disability/deafblindness. Before you come to that, you may feel great resistance. The life adjustment model helps us understand why this can be so difficult. This understanding can help professionals see if a person is susceptible to help and training or if it is better to wait.

It seems as though the first step is to get used to the thought of using assistive technology, and that most people wait a bit before they accept personal support such as personal guides or contact persons. The personal support may initially be thought of as a restriction of one's independence.

> *”The feeling of helplessness is not a feeling I can reconcile with. I avoid situations where I feel helpless. A friend said to me: ”I'll just pick you up.” But it's not ”just” for me. It's being dependent.”*

Gradually, the support becomes part of life and a condition for being able to take active part again. This development is more prominent during the last stage of the life adjustment process. When the self-image and the identity become stable again, it also becomes easier to deal with different kinds of support that are visible to others. The informants describe this as a relief, and regard the assistive technology and the personal support as something very positive. They can both ask for and demand support, and they know what kind of support they need in different situations.

> *”I'm more honest with myself today. I gladly ask for help and it's absolutely necessary too.”*

For our informants, the white cane seems to be the kind of assistive technology that is most difficult to accept. For many, it is a symbol of helplessness and dependency, and is regarded as something stigmatizing. At the same time, those who use it say that they now have a completely different view on it. It gives them a great feeling of safety.

> *”I have used a white cane for 25 years now. It was problematic, and it was a huge step for me to start using the white cane. I cried within and thought that everyone stared at me. But now it's fine.”*

> *”I have been to courses twice but I’m not ready. After 10 years I’m a bit more open-minded about using the white cane and feel like trying. I think more and more that perhaps I could need it.”*

The road towards using support and specific assistive technology can be described in the following way:

Stage I
Many do not ask for assistive technology, reject propositions from professionals.

Stage II
A careful approach, explore the use of assistive technology and support, listen to professionals. ”Equals” show possibilities.

Stage III
Compensating support feels essential, the support is more integrated in the self-image. A growing need of support and assistive technology in step with increased activities and participation. Admitting one’s needs.

The altered attitude towards assistive technology and support is due to the life adjustment process itself being under way, and at the same time the assistive technology and support can facilitate the adjustment. Other persons with deafblindness appear to be able to provide strength and motivation to start learning how to use the white cane or a new method of communicating. Professionals with specific knowledge of deafblindness are considered to be credible and important in implementing these needs and wishes. One common result of the life adjustment is an increased level of activity and participation for the person, which can lead to an increased need for support – a seemingly paradoxical situation. You may need an interpreter, transport services, and a personal guide more often and in different kinds of activities. At work, you may need new and specific kinds of assistive technology in order to perform your work tasks and be able to keep up with the development at work.

MEETING PROFESSIONALS

The support from different professional groups is important when it comes to the life adjustment process related to deafblindness, since this process is so comprehensive. When receiving the diagnosis, most people are also provided with medical information, but the need is more comprehensive than that, according to our study. One thing that several informants have lacked is a continuous *follow-up*, since the symptoms may not be noticeable at the time of the diagnosis. It may also be that you are not able to perceive all information at that point. All of our informants talk of the risk of meeting someone without specific knowledge of deafblindness. These initial contacts are particularly important when you are taking your first hesitant steps towards looking for support. Many informants feel that the people they have met have lacked the right kind if competence to help them. And this often occurs during a stage when they are vulnerable, when they doubt themselves and when they need comprehensive guidance and support. Some of the informants have already experienced far-reaching consequences of deafblindness before they get in contact with special resources for deafblindness.

> *”I found the diagnosis Usher syndrome on the Internet and went back to the social worker to find out more. She was annoyed that I knew so much. We can find much knowledge on our own, but we still need support and someone to talk to. This can be a dilemma.”*

It is not unusual to be sent back and forth between the Low Vision Clinic and the Department of Audiology for various assessments and rehabilitation work. Our informants all stress the difficulty of getting a coherent picture of the combined disability. One example is when you are provided assistive technology that is not at all useful for someone with a combined visual and hearing disability. Despite the good intentions from the professionals you meet, it is not good enough if the co-operation between the vision and hearing field is insufficient, according to our informants. The rehabilitation must be based on co-operation, already during the initial contacts. It must be based on a comprehensive understanding of the consequences of deafblindness and the responsibility must be mutual. According to our informants, the professionals must have knowledge about and an understanding of deafblindness as a distinct disability in order to offer the right kind of support.

A lack of co-operation and co-ordination between different professionals and areas appears to create obstacles for starting the rehabilitation. According to professor Berth Danermark (2009), each professional group use their own overall view as a starting point and have a bio-psychosocial approach, but if they do not co-operate, the rehabilitation work may very well become fragmentary. Body, mind and social life must be attended to simultaneously, according to him. There is only *one* such overall understanding, and that is based on a person's own assessment of his or her situation.

The authorities who grant support such as interpreters, personal guides, transport services, and contact persons are also very significant. The informants all have different experiences of these kinds of need assessments, in particular during the second and third stages and later on. They have several examples of situations where they have become upset and where they have had to struggle, but without any success. Situations when the needs that are so vital in order to sustain an independent life, are met with a lack of understanding, are perceived as very trying, hurtful, and energy consuming. It can be devastating for the self-confidence and for the confidence in the surrounding world, and it can have negative consequences for the new existence that has been built up with great effort.

> *"I applied for a personal assistant, but I was not granted one. I have appealed so now I have to wait. Instead, the council offered me home care for cleaning, but that's not what I need. I have to adjust and wait."*

During the most chaotic phase of the adjustment process, it can be difficult to express what kind of support you need. Even looking back, the informants find it hard to put it into words. One common wish is to be listened to and to be treated in a way that the person's influence over the situation is acknowledged.

> *"I want to be able to do things on my own, it's important what I want and what I can do. I think that we can do more than the professionals expect from us. The goal must be to be able to manage on your own terms.*

Most of the informants eventually had an improved contact with the professionals with specific knowledge of deafblindness, and that made it easier for them to move on in the life adjustment process. These contacts often go on for a long time and help the person to be guided through the adjustment process. The need for this kind of support, especially early on during the adjustment process, can be decisive for the continued adjustment. The consequences of a lack of co-operation and co-ordination between different parties that the person meets in the beginning, can lead to a lack of much needed support to be able to advance in the adjustment process. Knowledge of the life adjustment process can be decisive to offer the right kind of support at the right time during these often delicate stages.

FINAL REFLECTIONS

CONCLUSIONS

During our study, we have used the life adjustment model as a support in analysing the informants' experiences during a time frame stretching from the first signs of a combined visual and hearing disability to the final stages of the adjustment process. These retrospective stories from the life adjustment process, together with the stories of living with deafblindness, have been joined together in an image that can show and give meaning to the insights, thoughts, experiences, and emotions that arise during the adjustment process. This description is an elaboration of the original life adjustment model, and provides in-depth knowledge of the adjustment related to progressive impairments with a development that is similar to that of acquired deafblindness.

The description of how persons with acquired deafblindness perceive and perform the life adjustment, shall be considered a support in understanding the comprehensive adjustment that the person must go through. Since the adjustment often takes place during several years, in a seemingly incoherent process, it is difficult to grasp what is going on. Persons, who have experienced such a journey themselves, can help the rest of us understand what is going on. The onset, realization, and completion are extremely individual experiences that depend on several factors. In our survey, we have looked for things that seem to be of overall relevance for the adjustment, what people recognize even if everyone has not experienced it in the same way. These are turning points, triggering events, personal reflections and thoughts, strategies, the strenuous work, and the overall loneliness of it all. Everyone is sharing a personal story and experiences. The description of the life adjustment, seen as a process with some parts in common, can be helpful to understand this journey.

During the interviews, we have focused on the personal experiences of building up the life situation based on the conditions created by deafblindness. Our results show that periods of deteriorated functions, so called *downfalls*, that may exist before, during and after the life adjustment, are considered particularly demanding. The strain can be extensive when there are signs of an approaching downfall, but also when a new satisfactory level, a so called *plateau*, is being built up. At the same time, this process makes you learn from your experiences, so that you gradually increase your ability to deal with this kind of critical stages. The adjustment work eventually comes to an end when a *foundation* has been established, *the biographical continuity* is re-established, *the life course* is mended, and there is a new possibility to lead a satisfactory life. The downfalls will continue to demand both physical and psychological energy, but the person will gradually come to trust his or her own ability to deal with future challenges.

In the focus groups as well as the reference groups, acquired deafblindness is described based on two parallel processes. One contains the personal and social changes that become necessary, *the personal process*. Its aim is to re-create the feeling of continuity between past, present and future, the person's so-called life course. The other describes the progression of the combined visual and hearing disability, *the biomedical process*. Both processes interact and are easy to identify in the descriptions. If the biomedical process is used to describe the life adjustment, there is a risk that the personal process is understood solely through that perspective. The description will then focus on the vision and hearing loss, and the person will be regarded as being exposed to this huge loss. The personal processing of identity and self-image and the comprehensive effort to learn new strategies risk being concealed by the lost functions. The support offered is focused on the most concrete and compensatory kinds of support, for example assistive technology, while at the same time, psychological and social support becomes secondary.

Our results indicate that work which is directly aimed at compensating for the effects of deafblindness or at facilitating the personal processing, does not have the same priority during the different stages of the life adjustment. In the beginning, when deafblindness is still seen as a threat to the life a person wishes to lead, medical information is important. Later, the deeper psychological and existential issues become highly prioritized. And at the same time we can see how these needs change in a way that is related to the downfalls a person goes through.

Most of the informants who have participated in this project have already gone through their life adjustment process. They have become aware of how the process has affected not only their identity and self-image, but also their fundamental outlook on life. In short, they have also modified their view on life by adapting and adjusting it to the conditions of deafblindness in relation to other conditions in life. The informants describe an optimistic side of their situation, parallel to a darker side that cannot be neglected, since life with deafblindness becomes more complicated. Uncertainty is part of daily life, as well as the energy that is required, and it is common to hide the unavoidable difficulties and strategies from others. The informants talk openly of the difficulties that they have overcome and the concerns that will remain. Many of them are worried that the support they have been granted, for example transport services, contact persons or personal guides, can be re-considered and taken away due to new regulations, or because the authority representative they meet does not have the knowledge to make a correct assessment of their needs. It becomes clear that a satisfactory life is very vulnerable to external changes that lie out of one's own control. Despite this, our opinion is that the informants have a *salutogenic* perspective on life. They describe the future and a life with deafblindness using a modulated confidence and a balance between restrictions and possibilities. Their message is that the life adjustment is a long and tiresome road to travel, but that they learn to live with it. One of the informants uses the following words to describe the relationship to deafblindness: ”I will never accept it, but I have learned to live with it.”

USEFULNESS OF THE LIFE ADJUSTMENT MODEL

One of the purposes of this study is to contribute to the work of systematizing the knowledge regarding acquired deafblindness, and making this knowledge useful in the professional work. We consider the results to be an important compliment to other studies describing experiences of living with deafblindness (Ravn Olesen & Jansbøl, 2005; Göransson, 2007; Edberg, Joge Johansson & Nylander, 2010; and others).

This knowledge is relevant for several professional categories at the Low Vision Clinics and the Departments of Audiology, but also within other kinds of rehabilitation for persons with deafblindness. For people who are in the middle of their life adjustment process, being able to relate to others' descriptions of similar events can also provide a feeling of hope. You realize that you are not alone in developing and living with acquired deafblindness, a realization that can reduce the feeling of loneliness and vulnerability. In order to make it possible for others to understand what it is like to undergo this extensive and time consuming process, an overall perspective is necessary, including all parts of life that may be affected by the onset of deafblindness. Another important part of the rehabilitation is to involve the family and to observe their need of information, support and guidance. Knowledge of the long and demanding life adjustment process is therefore extremely relevant, both for those who meet persons with deafblindness and for those who have their own experiences of living with deafblindness.

Knowledge of how life is affected by the combined visual and hearing disability, from the initial stage until deafblindness is a fact, can be crucial for offering the right kind of support at the moment in time when the person is able to accept it. Now and again, professionals with knowledge of visual and hearing impairments or deafblindness can see the problems that lie ahead of someone and can see that there is support that would make it easier, but the support is rejected. Our study points exactly to this dilemma that the professionals are facing – wanting to make life easier but not being able to reach the person. Being able to wait and at the same time being attentive and present when the right time comes, is a professional challenge. Co-operation and improved co-ordination between professionals working at Low Vision Clinics and Departments of Audiology can be crucial during the adjustment process. With a satisfactory co-operation, it is possible to follow the person's changes in focus between vision and hearing. That way, the professionals can help each other to guide the person through the period, step by step.
A successful result from such a co-operation requires that both parties have knowledge of the life adjustment process related to acquired deafblindness.
In order to offer the right support at the right time during this prolonged process, the life adjustment model can work as a guide in the conversations with the person. The model can make it possible to discover important parts of the problem and provide safer assessments of adequate support.

The life adjustment model may also be used as a *basis for discussions*, both with individual persons and in different kinds of groups. The discussions can be developed on basis of the different stages of the model, or from important issues during the process. We have contemplated using our results to develop a material that can be used as a basis for group discussions in different rehabilitation contexts.

Persons with acquired deafblindness will eventually meet more and more representatives from different parts of society. It can be representatives on local and regional level, from the Social Insurance Agency, school and the Public Employment Service. In all of these contacts, there is an apparent risk of meeting people who lack knowledge of what it is like to live with deafblindness. Authority representatives and administrative professionals outside the deafblind field cannot be expected to have this specific knowledge. There is a lot at stake for the person who seeks contact, and several things can go wrong, which we have exemplified previously. You are vulnerable and it can be difficult to describe the support you need to others. In view of that, professional specialists within the deafblind field must *spread information* in concrete situations, until the persons themselves are able to describe and give information about their situation. It can be difficult to describe what it means to experience recurrent communication problems with others, or to describe how your ability to be active is greatly governed by the access to services and assistive technology. One faulty assessment based on an administrative professional's lack of knowledge of the consequences of deafblindness, can have serious implications for a person's possibility to participate. This is something that several informants mention.

The importance of meeting other persons with deafblindness when you are in the middle of the adjustment process has proven to be quite significant for the person's adjustment to the new parts of life. This experience is shared by several informants, and it is something that they come back to in different contexts. In our study, we came up with the idea that persons who have gone through the life adjustment process themselves and who have learned to live with deafblindness, could be a resource in the rehabilitation work. Persons with these experiences can be particularly well suited to be mentors for others who are still in the middle of the process. They can convey the intuitive strength and compassion of silent knowledge, which is a better way of showing understanding than by merely using words. A mentor's experiences can be a support and act as a cushion against the reality that you have not yet learned to cope with. This resource, together with the user organizations within the deafblind field, could be developed and used more systematically in the rehabilitation work.

In this project, we have numerous examples confirming that the person's internal journey is not always in phase with the environment's ambitions to support and help. The informants also emphasize that the rehabilitation must be seen from a bigger perspective and be integrated with all the other demands and expectations of life.

To conclude, our ambition with the project is that the life adjustment model will become a tool and support for the professional field when it comes to identifying where in the adjustment process a person is, with the purpose of offering *the right support at the right time*.

THE CO-OPERATION WITH THE REFERENCE GROUP

Already during our first meeting with the reference group, we discussed a more extensive co-operation than the consulting character that a reference group normally has. The participants have read summaries of the work material during the course of the project, and have shared their opinions. During the meetings, we have had valuable dialogues, on the one hand between the participants themselves, who all have different experiences, and on the other hand between them and us. At the ADBN-conference in 2010 in Ålborg, Denmark, we arranged a workshop together, where the participants from the reference group shared their own experiences of life adjustment.

The reference group’s opinions have been very valuable to the project’s realization, as well as for the analyses and conclusions. We would like to compare their role to that of a co-researcher (Borg & Kristiansen, 2009), which means that they have been co-operating in all the stages of the knowledge development. This close co-operation makes our results credible and reliable, since the members of the reference group, who have own experiences of deafblindness, continuously have shared their opinions on our work.

THE VALUE OF A NORDIC CO-OPERATION

This project started as a discussion during the NUD development seminar in 2006. During the seminar, the need for further documentation and a knowledge development within the field of acquired deafblindness became evident. In 2007, the so called SNED-group met for the first time in Lund (Sweden), and later that same year in Bergen (Norway), to identify important areas of development. In May of 2008, the SNED-group held a seminar at the NUD on the subject *Stress, coping, and life adjustment processes*, where all the

Nordic countries were represented. During this seminar, Ann-Christine Gullacksen from Malmö University also became a part of the group. During The Nordic Leaders' Forum the same year, the leaders of deafblind services in the Nordic countries were informed of the work performed by the SNED-group, and the group received a continued mandate to pursue the interview study of life adjustment related to acquired deafblindness.

Since deafblindness is a relatively small area of knowledge, co-operation and international contacts become so much more important. Persons with deafblindness are active in both Nordic and international contexts, via their user organizations. It has also become more common for persons with deafblindness to participate in different development projects and as lecturers at conferences. Professionally, the Nordic countries have a long history of co-operating. All of this contributes to different perspectives and a wider, well needed input of experiences and knowledge.

Despite some differences in the Nordic countries' welfare systems, our project has showed that the individual experiences of developing and living with deafblindness are very similar. This became evident during the spontaneous contacts and close dialogues between the participants of the reference group, as well as in the focus groups' discussions.

Just as the members of the reference group express how valuable it has been to get to know each other and share each others' experiences, the members of the SNED-group have also undertaken a *journey* together, with many insights and instructive experiences. We would once again like to humbly THANK the reference group and the focus groups in Denmark, Norway, and Sweden, for the very personal experiences that we have been allowed to take part of. Without their generosity, this project would never have been possible.

> *”There are so many different solutions and ways to life. Everyone has the right to live for their own sake, and according to their own conditions.”*
> *(From the book Blindstyre by Täppas Fogelberg, p. 202)*

POST SCRIPTUM FROM THE REFERENCE GROUP

As a reference group, we would like to write a few words about this Scandinavian project that we have had the privilege of participating in. The project group has consisted of professionals from Sweden, Denmark, and Norway. They all have great knowledge and long experience of working with persons with acquired deafblindness.

The project group has used an interesting approach to develop a material that emphasizes the problems facing persons with acquired deafblindness. Apart from working with focus groups consisting of people from each country, a reference group was also established.

The reference group consists of four women: one from Denmark, two from Sweden, and one from Norway. We represent a great variation in terms of education, age, residence, social relations, and the way that each one of us has worked with our own recognition of our dual functional disability. The unique thing about this project is that the reference group has not only contributed with its own material, thoughts, and reflections. We have also participated actively in the interpretive process, when the material was being analysed and put into words. We believe that this, as well as the contributions from the informants in the different countries, has given the project strength and a credibility that can provide professionals and others who are interested in deafblindness an understanding of the specific framework and conditions we live with. The four of us who have participated, are all happy and proud to have been a part of a project where our thoughts and experiences have been taken so seriously. We can firmly say that the things that are written in this report are TRUE. One of the women in the reference group writes the following words, and we all agree with her:

> *”When my counsellor contacted me, it’s almost two years ago now, and asked if I wanted to be a part of the reference group, I happily agreed to it, but I didn’t really have any expectations as to what I would personally gain from it. I was just glad to be able to contribute with some*

personal experiences that could perhaps be of use for others. Today, as we are getting closer to the end of this process, I can easily say that the process has given me far more than I ever thought possible. When I started, I thought that I had processed the sorrow related to my deaf-blindness, and that I had ”learned to live with it”. And I had, but not as deeply as I thought. Being together with the others in the group and getting to know them all, has meant so much, and I will think of them with joy for the rest of my life. Their strength and the way that they have dealt with and still deal with their life situations, has inspired me and has made me see my situation in a different way. I ”like myself and the person I am more”, and I have learned that the setbacks that I will face sometimes, contribute to making me the person that I am. I would not have wanted to be without these years, and from the bottom of my heart I thank these remarkable and wonderful women in the reference group.”

Linda Eriksson, S	Nina Skorge, N
Monika Steorn, S	Britta Vestergaard, DK

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APPENDIX 1

The Life Adjustment Model – A Brief Summary

(after Göransson, 2007)

When it comes to life adjustment, our basis has been Ann-Christine Gullacksen's research on life adjustment processes, and on how to find new ways and strategies to best cope with daily life and life in general. We find her theories applicable to the life stories and experiences shared by persons with deafblindness that we have met. The life adjustment can be described as an adjustment to the new conditions in life. Something in life has changed. The whole life situation is affected – social life, family life, working life, leisure time etc. Several parts of life are affected – from simple every day situations, to major life projects and goals in life. Different people deal differently with their situation. The following is a brief description of the different stages of the life adjustment process, as well as some quotes from interviews (Göransson, 2007):

1. THE INITIAL STAGE – FINDING OUT – THE RECOGNITION

> *"I was 20 and had my whole life ahead of me when I received the diagnosis. Then he started talking about using a white cane. At that point I went home. It was like going into a big black hole. All plans for the future were crumbled and I couldn't see the point in living. It took me years to get through it all and dare to start living again."*

Your vision and/or hearing has deteriorated. The self-image is threatened – you conceal, deceive yourself as well as others. You hope that you will be cured and recover, that it will pass – the body is in focus. At this stage, you often feel quite bad and it can feel as though life is turned upside down, you cannot see any way out. Old familiar ways of dealing with different situations no longer work. You do not think that you will be able to deal with a normal life again. You feel stressed, and a lot of time is spent concealing and denying what is going on. Eventually, you reach a turning point when you admit to yourself that for example your vision or hearing has deteriorated. It can feel easier if you have a diagnosis and a good explanation to why it is happening. Then it becomes possible to understand what is going on in the body. It can take a long time to recognize it. *The recognition* is necessary in order to be able to change a situation and to be prepared to accept support and help. One condition for rehabilitation is that you have started thinking of a change. It is important to have access to professional support when you reach the turning point. Emotional support is particularly important, as well as objective information and guidance. Information and knowledge about the impairment can bring relief at this stage. You might need professional support when processing the crisis. You survive and keep on living with your disability.

> *”Deafblindness can cause feelings like grief, anger, frustration, stress, feelings of loneliness and great fatigue. You need help dealing with this, otherwise the emotions will turn into walls between the person with deafblindness and the environment.”*

2. PROCESSING - EXPLORING

> *“It’s difficult to have an overview and take control of the situations I’m faced with. It creates a feeling of insecurity.”*

> *“There are so many people to have contact with. It’s impossible to grasp everything. You have to choose and decide what’s important right now ... simply making priorities ... otherwise, there isn’t enough time. Everything takes such a long time for someone with deafblindness!”*

Focus is now on understanding, *processing* the fact that this will have consequences on life, now and in the future. It is for real, it is not going to pass. You might still be sad, and feel worried and insecure about the future, but you are beginning to realize what has happened to you. You grieve and miss your old life. You are not as mobile any more, and you may feel tied-up and dependent on others. Your network changes and the loneliness can be perceived as a huge threat. You need time to reflect (alone). During this stage, an active rehabilitation process ought to get started. You might need someone who actively supports you in organizing and getting some structure in your new life. You need to identify and put into words what you have lost and how to try and compensate it. Eventually, you start understanding the different obstacles that have developed in connection with the disability. You also begin to find new strategies to cope with daily life again – you *explore*. Now it is important to actively leave old strategies behind that no longer work and find new, lasting ones to cope with daily life in a new way. Something that you have had a whole lifetime to learn now has to be re-learned in a short period of time, for example reading, communicating, and orientation. Little by little, you regain control and your daily life can begin to function again, but with new conditions in life. Confirmation, both from professionals and from family, is important. Meeting other persons with deafblindness is very valuable, according to many. This stage of realization and exploring the new life situation, can last for many years.

> *"You become dependent on help even if you don't want to. It's kind of unavoidable. The most difficult thing is the relationships with your close ones. If you live in a family, you can't always take for granted that the family members will be there for you. They aren't always able to be there exactly when you need them. They are not hired to help you and they have their own desires, as well as their own wishes and needs. It's necessary to find some sort of balance."*

3. RETURNING

> *"Today, it's natural for me to use a white cane and to read Braille. Otherwise I wouldn't be able to manage in my everyday life."*

During the third stage, life is becoming *stable* again and you start creating a new plan for the future. You have the competence to learn how to deal with the deafblindness and its consequences in life, and you test yourself in different situations and contexts. The new strategies that you have learned start to become routine. You practise finding a balance between the demands of daily life and the conditions of deafblindness. The restrictions in daily life become smaller. You do not feel as worried and scared about the future. You gradually find a way to let the deafblindness become a part of your life. You have some distance to the things that were so difficult in the beginning. The new life starts to form and you begin to feel at home in it. You regain control over life. New goals and projects can be drawn up. Someone who is *living with* an impairment must learn to deal with a life that involves situations of uncertainty – perhaps on a daily basis. That leads to uncertainty, insecurity, and stress. The strategies that are developed along the way, are aimed at reducing the stress. These strategies are needed to manage everything from simple everyday situations to more complicated social situations. All of this requires strength and energy, and courage is a great asset. The rehabilitation ought to mean ”helping others to help themselves” now, and recurrent support of different sorts should be offered when needed.

At the beginning of the life adjustment process, all energy is focused on surviving, coping with daily life, and dealing with all the emotions. The second stage, is devoted to exploring and finding new ways and strategies – rehabilitation. It is not until the third stage that the strength and motivation can be aimed towards the future. That is when you are ready to think and plan ahead, and set up new goals in life.

LIVING WITH…

> *”When I come home from work, I have to choose. Either I sort through the mail and pay the bills, or I tidy up the kitchen. It’s impossible to do both things the same evening.”*

The final stage can be regarded as a maintenance work. Focus is now on ”living with”, day by day. The self-image is re-created and the self-confidence regained. You now have the competence to change and you have become your own expert. You have learned to live with deafblindness (not necessarily accepted it), but the stress margins are often narrow.

> *”Earlier on, when I could see and hear better, I had a completely different overview of things. But now, I often feel uncertain of whether I have understood a situation right, or if there is something I ought to know but that has passed me by.”*

APPENDIX 2

Discussion Guide for the Focus Groups (spring 2010)

The focus of the interviews is the life adjustment model. The initial stage is particularly emphasized, as well as problems that are important to understand the ”recognition”, for example the progressive development. But focus also lies on the continued process with developing and learning how to relate to deafblindness in different ways, in order to finally find one’s own way and live one’s own life with deafblindness.

During the interviews, we work with one topic at a time, and we try to identify and document changes over time. The topics have been chosen in co-operation with the reference group.

- Diagnosis and prognosis
- The term deafblindness
- Progression as a phenomenon
- Identity and self-image
- Loneliness and vulnerability
- Dependency – independency
- Communication – social interaction
- Energy balance (physical and psychological)
- Professional support

Examples of some comprehensive questions

If you look back on the adjustment process:

a) Can you describe this period of time (the adjustment) in a few short words?
b) Identify crucial situations and events that create or enhance the experience of deafblindness.
c) What was the best support you received and when did you receive it? Alternatively, what support have you missed during the different stages?
d) What makes you feel safe in life despite the deafblindness?
e) What makes things easier and harder in daily life?
f) How do you find your own way through this process?
g) This is what I have learned from this life event.

APPENDIX 3

Analysis model

The stages of the life adjustment process related to deafblindness – with topics from the focus group interviews

STAGE I

Recognition

TOPICS:

Progression	difficult to grasp
Communication	misunderstandings
Energy	uncontrolled loss
Loneliness	concealing
Vulnerability	what, who?
Uncertainty	for the future
Control over the environment	keeping
Identity, self-image	losing oneself
Dependency, support	shuns, avoids
Contact with ”equals”	avoids
Professional support	awaits

STAGE II

scares
social exclusion
taking it easy
personal work (hidden)
guessing
what is working?
compensating
insecure self-image
accepts sometimes
testing contact
need for information

STAGE III **LIVING WITH**

starts to understand the whole picture
new ways of communicating
awareness, control
the significance of one's own group
dependant on the environment
controlled uncertainty
new strategies
finding one's core again
choosing support, participating
experiences support and shared experiences
partnership, one's own expert