This book is intended for everyone who wants to learn more about deafblindness, the consequences of living with deafblindness, and the specific life conditions that this impairment implies.

What does everyday life look like for a person with deafblindness? How is the social life affected for a person who acquires deafblindness? What does it mean for a family to share the life with professionals? How does deafblindness influence the choice of education and profession for an adolescent? What needs to be done in order to make the geriatric care accessible to elderly people with deafblindness?

To live with deafblindness, whether you are a child, an adolescent, or an adult, is specific and individual, and it always takes place in a certain cultural and social context, in a specific environment, and at a certain time. In this book, the author seeks to capture individual persons’ descriptions of their life situations, and use this as a basis for developing and building up good forms for support. The work is a project, carried out within Habilitation and Assistive Technology in Region Skåne in co-operation with the Association of the Swedish Deafblind (FSDB) and the Skåne Association of Local Authorities, and with financial support from the Swedish Inheritance Fund.

With this book the reader is provided with an insight into the everyday living conditions for people with deafblindness and their relatives. There is a huge demand for research and continued development work and the book inspires the reader to develop new knowledge within the field.

Lena Göransson is a special needs teacher and Head of the Deafblind Team, and has worked at the Vision, Hearing and Deafness Division within Habilitation and Assistive Technology in Region Skåne for several years.
DEAFBLINDNESS IN A LIFE PERSPECTIVE

Strategies and Methods for Support
DEAFBLINDNESS IN A LIFE PERSPECTIVE

STRATEGIES AND METHODS FOR SUPPORT

Lena Göransson
SUMMARY

“We had never heard of the term deafblindness, what it means and how you can live with it.” (Father of a child with deafblindness)

For four years, Region Skåne has been working on a project to develop qualified psychosocial and pedagogical habilitation and rehabilitation for children, adolescents and adults with deafblindness, as well as for their families. At the beginning of this project, this kind of support did not exist neither on county council nor on regional level. The project has been carried out in co-operation with client organizations as well as public authorities on local, regional, national and Nordic level.

“When I was diagnosed, I completely lost my foothold and all my plans for the future were ruined. It has been a major and very demanding adaptation, which has affected my whole way of living.” (Adult woman with deafblindness)

Deafblindness can be congenital or develop later in life and it is often a progressive process. There are also varieties as to whether vision or hearing is the primary impairment. The differences in background cause large variations in terms of needs required, which is why resources for people with deafblindness must be characterized by great flexibility and also be available recurrently.

The overall purpose of this project has been to capture individual persons’ descriptions of their life situations, and to use them as a basis when developing and creating good means of support. Deafblindness implies inevitable life changes that affect everyday life and life as a whole, also for the families. Deafblindness always poses a threat to interhuman communication and interaction. There is a huge risk of becoming isolated from social life. Lacking access to information and having difficulties finding the way freely, are yet other consequences that affect the possibility of living an active life with a sense of participation. Therefore, deafblindness in this report uses functional aspects as a basis: experiences from everyday life, the individual life adjustment, the individual’s strategic inner work, the social context, and the environment’s importance for how the impairment is experienced.

“The worst thing is that you become reliant on help, even though you don’t want to. It’s kind of unavoidable. If you live in a family, you can’t always rely on the family members to be there for you exactly when you need them to. You have to find a balance in your everyday life.” (Adult man with deafblindness)
Interviews have been carried out with children, adolescents, adults, and elderly people with varying degrees of and different causes for their deafblindness, as well as with their relatives. In order to form an idea of the social support system that is necessary, the personal stories have been analyzed in accordance with existing national and international value systems (UN, WHO), where citizenship and participation play a significant role. We have chosen theories from the field of social sciences based on what we consider to be important for people with impairments in today’s society.

The theories have worked as guidelines, but in order to apply them to practical work with people with deafblindness and their networks, we have broken down the theories and turned them into instruments. By using these instruments, we have then been able to identify areas that are significant for habilitation and rehabilitation. However, the individual’s needs must always be discussed in a close dialogue with the individual in question. We have arranged dialogue seminars with the clients where we have discussed, tried and evaluated the theories and the results that we have come up with.

“I am afraid of falling ill and become reliant on health care. The interpreter can’t always be by my side. How will I understand what the staff is saying, or be able to tell them if I’m feeling unwell or if something hurts?” (Elderly woman with deafblindness)

The project process has consisted of alternately collecting interview material, reading literature, analyzing, conducting new interviews, going on study trips, having discussions with colleagues, organizing dialogue seminars with clients, exchanging experiences within the Nordic countries, further analyzing, etc. This process has deepened and developed our knowledge of the issues through continuous theoretical analyzing, which has then been tried on an individual level in the practical work.

The project has led to the establishment of a regional resource team for people with deafblindness. Methods and professional networks have been developed, the group has been made visible, and knowledge about deafblindness has developed and been documented.

“It’s better to live your life while you still have some vision and hearing left. When it gets worse you have to start thinking. I feel that I’m living my life right now and that I can do what I want. When you get older you have to take more responsibility and also start thinking more of the impairment.” (Adolescent with deafblindness)
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preface</td>
<td>11</td>
</tr>
<tr>
<td>Turning a Thought into a Deafblind Team</td>
<td>13</td>
</tr>
<tr>
<td>Introduction</td>
<td>14</td>
</tr>
<tr>
<td><strong>Background</strong></td>
<td>17</td>
</tr>
<tr>
<td>Pedagogical visions of the 19th century</td>
<td>17</td>
</tr>
<tr>
<td>Counsellors for People with Deafblindness</td>
<td>18</td>
</tr>
<tr>
<td>The Swedish Resource Centre for Matters Regarding Deafblindness</td>
<td>19</td>
</tr>
<tr>
<td>Pedagogical Support for Children and Adolescents</td>
<td>19</td>
</tr>
<tr>
<td>Creating Regional Deafblind Teams</td>
<td>20</td>
</tr>
<tr>
<td>Employment Resources</td>
<td>21</td>
</tr>
<tr>
<td>Courses at Swedish Folk High Schools</td>
<td>21</td>
</tr>
<tr>
<td>The Association of the Swedish Deafblind</td>
<td>21</td>
</tr>
<tr>
<td>Nordic Co-operation</td>
<td>22</td>
</tr>
<tr>
<td>The Definition of Deafblindness</td>
<td>22</td>
</tr>
<tr>
<td>Prevalence</td>
<td>23</td>
</tr>
<tr>
<td>Some Consequences of Deafblindness</td>
<td>24</td>
</tr>
<tr>
<td>Deafblindness Always Poses a Threat to Communication</td>
<td>26</td>
</tr>
<tr>
<td>Sign Language and Deaf Culture</td>
<td>27</td>
</tr>
<tr>
<td>Interpretation for People with Deafblindness</td>
<td>29</td>
</tr>
<tr>
<td>The Importance of the Tactile Sense</td>
<td>30</td>
</tr>
<tr>
<td><strong>The Aim and Purpose of this Project</strong></td>
<td>32</td>
</tr>
<tr>
<td><strong>Structure and Division of Responsibility</strong></td>
<td>33</td>
</tr>
<tr>
<td>The Project Team</td>
<td>33</td>
</tr>
<tr>
<td>Supervision</td>
<td>33</td>
</tr>
<tr>
<td>The Steering Group</td>
<td>33</td>
</tr>
<tr>
<td>The Reference Group</td>
<td>34</td>
</tr>
<tr>
<td>Client Co-operation</td>
<td>34</td>
</tr>
<tr>
<td><strong>The Project Process</strong></td>
<td>35</td>
</tr>
<tr>
<td>Methods and Strategies</td>
<td>36</td>
</tr>
<tr>
<td><em>Charting Experiences of Living with Deafblindness</em></td>
<td>36</td>
</tr>
<tr>
<td><em>Selection</em></td>
<td>36</td>
</tr>
<tr>
<td><em>In-depth Interviews</em></td>
<td>36</td>
</tr>
<tr>
<td><em>Interviews Based on ICF</em></td>
<td>37</td>
</tr>
<tr>
<td><em>Interviews in Focus Groups</em></td>
<td>38</td>
</tr>
<tr>
<td>Processing and Analyzing</td>
<td>39</td>
</tr>
<tr>
<td>Evaluation in Dialogue Seminars</td>
<td>40</td>
</tr>
</tbody>
</table>
Our vision and hearing provides us with most of the information about what is going on around us. Reduced vision and hearing drastically limits the chances of having a social life, of interacting with others, and of acquiring knowledge of important events around the world. Being both deaf and blind is a complex and naturally very severe impairment. In this book, Lena Göransson gives a vivid and comprehensible account of how deafblindness is perceived in different age groups and different stages of life, based on everyday situations. Focus lies on the experiences of deafblindness in particular, but the book’s theoretical approach makes it valid for other impairments as well. This study benefits the knowledge development within the field and is particularly interesting thanks to the practically based methods used.

Our world is constantly developing – economically, medically, socially, and technically. We are, as individuals, all part of a social development, which creates new needs, a fact that increases the demands on the different types of support provided by the public sector. People are treated differently today compared to only 20–30 years ago. International conventions, national legislations, and guiding documents now emphasize the citizens’ perspective, and participation is a central concept. This kind of approach includes everyone and is clearly expressed within the disability field. After four years of research and development work within Region Skåne, this book is a presentation of what qualified psychosocial and pedagogical support for people with deafblindness can look like, including children, adolescents, adults, families, and relatives. Lena Göransson has lead the work, and in this book she shares her own and her project associates’ experiences and knowledge.

The work has been carried out within Region Skåne, however, other significant groups have also participated – for example the Association of the Swedish Deafblind (FSDB), which represents and organizes people with this severe impairment in a truly committed way, something that has also been manifested in the project. The Skåne Association of Local Authorities, representing the 33 local authorities in Skåne, has also been an important part of the project’s steering group. The Swedish Inheritance Fund’s financing of half the project has been necessary for its realization.

Even though the project has been carried out on a local and regional level, we are certain that we can learn from it both nationally and in—
ternationally. We would like to thank everyone who has contributed to the work and in making this publication real.

Lund and Malmö, April 2007

Kerstin Liljedahl
Certified psychologist, Ph.D
Head of R&D
Habilitation and Assistive Technology
Region Skåne

Stig Larsson
Professor
Director of HAREC, The Disability and Rehabilitation Research Center
TURNING A THOUGHT INTO A DEAFBLIND TEAM
INTRODUCTION

During the autumn of 2002, a regional development project was launched in Skåne, a project focused on people with deafblindness and their relatives. The administration of Habilitation and Assistive Technology in Region Skåne, together with the Association of the Swedish Deafblind (FSDB), was responsible for the project, which was financed partly by The Swedish Inheritance Fund and partly by Habilitation and Assistive Technology in Region Skåne. Region Skåne is the county council of Skåne and, just like all other county councils, has the responsibility for health and medical care. Region Skåne also has the responsibility for development within the region, including trade and industry, communications and culture.

The project started with a pre-study about people with deafblindness in Skåne (Dövblinda i Skåne, Göransson 2003), during the period between 1 October 2002 and 30 June 2003. During the pre-study period, we found that there was a need for comprehensive work in order to form a clear picture of the consequences of deafblindness in all ages, and – using this as a basis for developing and building up permanent resources – project funding was applied for and was granted for another three years. During 2006, the project was completed and turned into a permanent part of the work with establishing Region Skåne’s Deafblind Team, a regional resource team for people with deafblindness and their networks.

Up until today, people with deafblindness living in Sweden have had very limited access to habilitation, rehabilitation and appropriate pedagogical and psychosocial support. When the project started in the autumn of 2002, there was no support available on a regional level specifically intended for people with deafblindness, and the counsellors for people with deafblindness were being discontinued. The needs of people with deafblindness ought to have a high priority both on a local and regional level. Apart from the lack of dedicated resources, the major problems seemed to be the lack of competence regarding the consequences of living with deafblindness, as well as a lack of coordination within the area. It was in the light of this situation that the administration of Habilitation and Assistive Technology in Region Skåne, together with the Association of the Swedish Deafblind (FSDB), initiated a development work, which later led to permanent resources.

The county councils’ responsibility for habilitation and rehabilitation for people with impairments was made clear when the Swedish Par-
liament, the Riksdag, decided on a new disability reform which came into force in 1994. The reform led to two new paragraphs in the Health and Medical Services Act (HSL, Hälso- och sjukvårdslagen), § 3 b and § 18 b, as well as a new law: the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS). The local and regional authorities’ responsibilities towards people with impairments were made clear, and the new paragraphs in HSL state that responsible authorities within the health care system must provide habilitation and rehabilitation, assistance for people with impairments, as well as interpretation services for everyday interpretation for people with deafness, deafblindness and hearing impairments. Habilitation and rehabilitation have to consist of early, co-ordinated, and comprehensive efforts from different competence and work areas. The individual’s influence over planning, realization and follow-up is emphasized. It is also important to pay attention to the individual’s situation and relationships (SoS-report 1993:10).

The terms habilitation and rehabilitation can both be used in relation to support for children and adolescents as well as for adults and elderly people. In relation to deafblindness, which can be congenital or acquired later in life, we have decided to use both terms in this report. For many people with deafblindness, one of the impairments is congenital, whereas the other is acquired later in life. When speaking of elderly people with visual and hearing impairments, both age related, the term rehabilitation is often the most relevant.

“People are actors who form their lives one way or another, even when their space is profoundly limited and the difficulties are substantial. They make choices. The individual is never just a ‘victim’ or an ‘object’ of the circumstances, but is always a subject as well.” (Jeppsson Grassman 2003:9)

The fundamental outlook on people in this project is the one advocated by Jeppsson Grassman. A person with deafblindness, whether a child, adolescent, adult, or elderly person, is a subject with individual goals and dreams. The feasible level of activity and participation largely depends on the environment. The environment can either prevent or facilitate a person’s ability to develop and achieve individual goals. This approach is a typical feature of our modern democratic era, nonetheless, it is far from obvious to everyone (cf. the UN Convention on the rights of persons with disabilities, 2006). From a scientific point of view, we can draw parallels to Berger and Luckman (1966), who developed the term social construction, a concept of how the world is actively
created by people/subjects in a social context. This aspect has inspired many researchers within the social sciences field who analyze how people develop in interaction with others. In this project, we have chosen to focus on the individual and the context that the individual lives in, in order to see the person as an entity in his or her everyday life. We have also emphasized the continuously ongoing process between the individual and the environment, with mutual active influence (Jarvis 1992). Communication and interaction with other people are primary factors in relation to both deafblindness and our starting points. It is the basis of what has already been documented within the area of deafblindness (Preisler 1998, Mesch 1998, Nafstad & Rødbroe 1999, Nyling 2003, Lahtinen & Palmer 2005, Ask Larsen & Nafstad 2006, Raanes 2006, and others). From this point of view, deafblindness can never be regarded as something static, but rather as a process with constant interaction with the environment, and where the individual as well as the environment are constantly developing.

“Everything is a new language, and that makes me feel immensely lonely. All sounds and different environments, smells and echoes are new and I tumble between fear and the joy of discovering. In the beginning, fear blocks out everything else, but slowly a new world emerges and I might just as well feel at home in it.” (Täppas Fogelberg 1994:23)

When a family, an adolescent, or an adult becomes afflicted by deafblindness, it is a specific and individual process, but it always takes place in a certain cultural and social context, in a specific environment, and at a certain time. With this report, we wish to shed some light over the individual’s life adjustment process in relation to his or her environment, and how this process evolves over time. These three perspectives characterize the whole report, both the theoretical part and the parts about experiencing and living with deafblindness, as well as the discussions regarding strategies for support. The report includes all age groups and different kinds of deafblindness. When reading about deafblindness in different reports and texts, the diagnosis is often the starting point. However, in this report, we have chosen to describe deafblindness as an impairment based on the great variations we have encountered during the project. We have also chosen to proceed from a pedagogical and psychosocial process perspective.

“Life can only be understood backwards, but it must be lived forwards.” (Sören Kierkegaard 1813–1855)
BACKGROUND

Pedagogical visions of the 19th century

The first Nordic school for people with deafblindness was opened in 1886 by Elisabeth Anrep Nordin. In 1887, Anrep Nordin became the first female teacher for deaf students in Sweden, and thanks to her experiences she was able to see new possibilities concerning the upbringing and education of the so called ‘students with three senses’. She formed her educational approach according to the latest developments of that time, and took active part in the school debate. Her educational approach was founded on the three senses – touch, smell, and taste. In Kerstin Liljedahl’s doctoral thesis (1993), the school’s educational approach, as well as the nationally and internationally known teacher and her pioneering work is described and analyzed. Some parts of the thesis will be accentuated in order to give a perspective on today through the eyes of history.

At the beginning of the 19th century, Per Aron Borg founded the school Manillaskolan in Stockholm. The education was intended for deaf students. From the early 19th century up until 1888 when the school Tomtebodaskolan for the blind was established, teaching of blind students was in periods integrated with the teaching of the deaf at Manillaskolan. The education act from 1889 on mandatory teaching of deaf children, as well as the act from 1896 on mandatory teaching of blind children excluded children with deafblindness. That was the driving force and the reason for Anrep-Nordin to start her school home for the deafblind in 1886.

In order to incorporate the latest pedagogical ideas, she traveled to Boston, USA, in 1885 to, among other things, study the education of the well known woman with deafblindness – Laura Bridgman. She also went to Germany to observe Froebel’s Kindergarten education, with systematic training of the senses of small children. The experiences from these journeys became an important basis, together with the school’s educational approach for the deaf, which was further developed in the practical everyday life at the school.

The school home was unique in the Nordic countries and in the western civilisation, and it was run as a foundation financed by private donations and government support. Anrep-Nordin firmly stood by her conviction that the government should take on the responsibility for this group of pupils too.
Anrep-Nordin gradually showed that it was possible to teach children with deafblindness. Her pedagogical visions for the pupils were to learn the mother tongue, to develop the ability to work, and to have a Christian fosterage. These issues were emphasized for all school children and would also apply for the school home’s children with deafblindness. Anrep-Nordin considered the mother tongue as an indispensable link between the individual person and the surrounding world. The task of the teacher was to break through the barrier created by deafblindness, which existed between the pupil and the surrounding world, as well as to develop the student’s possibilities to explore the world. The language development was of superior importance in the teaching, according to Anrep-Nordin. In order to develop a creative mind and adjust to society, the so-called *speech method* was considered to be outstanding within the deaf methodology at the end of the 19th century. However, the starting point for the education for the pupils with deafblindness was the so-called *sign method*, claimed Anrep-Nordin with great emphasis on individual training. To support her opinion in this question she referred, for example, to the teaching of Helen Keller.

Over the years, the small school home grew into a large institution for 280 people in all different age groups with different impairments and with the visual impairment as the uniting definition. In 1922, the government finally took over the responsibility of the school. In 1965, the school part moved from Lund to Örebro and became Ekeskolan, a special school for visually impaired pupils with additional impairments. The part of the school intended for adults remained in Lund and in 1967 the responsibility was transferred from the government to the regional authorities and the institution became a nursing home called Annetorpshemmet. Gradually, other group homes came to substitute the large institutions, day centre activities were developed and Annetorpshemmet and other similar establishments in Sweden were placed under the local authorities’ responsibility.

**Counsellors for People with Deafblindness**

From the end of the 1960s and up until 1980, the Red Cross and the Swedish Association of the Visually Impaired, actively worked with people with deafblindness. From 1980 until 2002, counsellors for adults with deafblindness were available all over Sweden. Initially, five counsellors were employed. The purpose was to provide pedagogical support for adults with deafblindness. The number of advisers was
eventually extended to 10.5. In 2002, the adviser posts for adults with deafblindness were discontinued, and public funds were allocated to establish a national resource for questions regarding deafblind issues (Möller 2002).

Through Möller’s report (2002), it became clear that the advisers for adult people with deafblindness had worked mostly with counseling and support to facilitate everyday life for individual persons, even though their work was primarily intended to include questions relating to education and pedagogical support. According to Möller, the discrepancy between the work task and the actual work could originate from the needs that people with deafblindness have and that had not been met by other authorities, but it could also be due to the fact that only very few people with deafblindness had studied as adults. Up until today, people with deafblindness living in Sweden have had very limited access to qualified counselling and support as well as habilitation and rehabilitation.

**The Swedish Resource Centre for Matters Regarding Deafblindness**

During 2002, public funds from The Ministry of Health and Social Affairs were allocated to establish a national resource for deafblind issues. This resulted in The Swedish Resource Centre for Matters Regarding Deafblindness in 2003, which is a part of the Mo Gård Group. The purpose of the centre is to provide support in deafblind issues, primarily to local and regional authorities. Its main focus should be on guidance, education, consultation, networking, and information. The work also includes the National Expert Team for Diagnosing Deafblindness. Through the team of experts, people with deafblindness can have a well founded diagnosis, prognosis, and functional capacity assessment.

The Mo Gård Group also provides housing, habilitation and rehabilitation, work, education, and leisure time activities. They provide their services nationwide, and are regularly employed by local and regional authorities. Their primary target groups are adult deaf people or adult people with deafblindness with additional functional impairments, often with social, psychological, and physical difficulties as a result of different syndromes or other complex functional impairments.

**Pedagogical Support for Children and Adolescents**

Resource Centre Deafblind in Gnesta is a national resource centre for children and adolescents with deafblindness. The resource centre is
a part of the work carried out within the Swedish Institute for Special Needs Education, which is a national authority co-ordinating government support within special needs education. They provide consultations, assessment, support for special needs education, courses and information. Counselling and support for parents and staff groups working with children and adolescents with deafblindness, is also part of their assignment. The Swedish Institute for Special Needs Education also has regional advisers in issues regarding deafblindness.

The National Agency for Special Schools for the Deaf and Hard of Hearing (SPM) has developed a policy document on deafblind related issues for the national special schools, and each school has a contact person who is specifically responsible for students with deafblindness.

The Swedish National Upper Secondary School for the Deaf (RGD) and Hard of Hearing (RGH) in Örebro, has a co-ordinator for students with deafblindness who is responsible for school, housing, and after-school activities.

Creating Regional Deafblind Teams

As a result of this project, a new resource team – the Deafblind Team – was created in 2006 within the Vision, Hearing and Deafness Division in Skåne. The team is the result of a four-year long co-operation project between Habilitation and Assistive Technology and the Association of the Swedish Deafblind (FSDB). It is intended for people of all ages with a pronounced combination of visual and hearing impairment/deafblindness. It came about as a direct consequence of the organizational changes leading to the discontinuation of the commission previously given to the national advisers for people with deafblindness. In Sweden, the regional and local authorities have the ultimate responsibility for habilitation, rehabilitation, counselling and support for people with impairments. At the moment, there is intensive work to develop services for people with deafblindness, especially on a regional level. Region Skåne, Västra Götaland, Stockholm County Council, and Örebro County Council, have established multidisciplinary teams specifically for people with deafblindness and their networks. The teams are responsible for habilitation and rehabilitation, and they also provide counselling and advice on different issues related to the impairment. Also smaller regional authorities have started using aimed resources, and networks and different forms for co-operation are being set up in order to provide good support for people with deafblindness; however, a great deal still remains to be done.
Employment Resources

The Swedish Public Employment Service has special resources for job applicants with impairments. The Swedish Public Employment Service for people with hearing impairments, deafness or visual impairments in Uppsala has a national responsibility towards people who use sign language. An equivalent resource for people with combined visual and hearing impairments in the south and the southwest of Sweden is located at the Public Employment Service Special Resources in Gothenburg, while responsibility for the rest of Sweden lies with the Public Employment Service for People with Hearing Impairments, Deafness, or Visual Impairments in Uppsala. These public employment services have a close co-operation with the regional deaf advisers and local public employment services. For a person with deafblindness to be qualified to use these special resources, a referral from the local public employment service is required.

Courses at Swedish Folk High Schools

Swedish Folk High Schools provide general civic education. Some of the schools arrange courses for adults with deafblindness. These courses are meant to be a complement to the habilitation and rehabilitation work provided by the regional authorities. The Folk High Schools have chosen different profiles for their courses, including for example language and communication, society information, computer knowledge, and health promotion. The idea is that the course should be included in a more long-term individual rehabilitation process.

The Association of the Swedish Deafblind

The Association of the Swedish Deafblind (FSDB) was founded in 1959 and is a national organization for people with deafblindness. There are twelve regional associations spread out over the country. The organization pursues comprehensive political work acting as a pressure group to influence society and decision makers, but also plays an important social role for members by arranging different activities, conferences, and courses. There is a parents’ section within FSDB working with issues concerning children and adolescents with deafblindness and their families. Activities, courses, and parents’ meetings are arranged, and a network of contact parents has been established. FSDB also has a section for children and adolescents, Swedish Deafblind Youth (DBU), that arranges camps, theme nights, and youth conferences for children and adolescents with deafblindness.
Nordic Co-operation

In the autumn of 2006, The Nordic Staff Training Centre for Deafblind Services (NUD) celebrated its 25th anniversary. NUD falls under the Nordic Council of Ministers that provides services to staff and organizations working for and with people with deafblindness, primarily in the Nordic countries but also on European and international level. NUD is located at Dronninglund castle in Danish Jutland and their services include education, conferences, and network meetings within the deafblind field. NUD also contributes to international co-operation and has established a special library for non-fiction literature. The first NUD course for staff working within the deafblind field was arranged in 1981 in Uddevalla, Sweden, and was six weeks long. (NUD’s Jubilæumsskrift, 2006). For the following 25 years, staff from the Nordic countries were able to train and exchange multidisciplinary experiences on deafblindness. NUD also provides a great opportunity for developing, documenting, and spreading new knowledge within the Nordic deafblind field.

The Definition of Deafblindness

In the Nordic countries, the common definition of deafblindness adopted by the five Nordic countries in the Nordic Council of Ministers in 1980, has been used up until now. It was a clearly functional definition based on everyday life and the different types of functional difficulties that people with a combined visual and hearing impairment encounter. The definition was published in 1980 by the Nordic Committee on Disability in the report about improved life conditions for people with deafblindness in the Nordic countries (“Bättre livsvillkor för dövblindor i Norden”).

“A person is deafblind when he or she has a severe degree of combined visual and auditory impairment. Some deafblind people are totally deaf and blind, while others have residual hearing and residual vision.

The combination of impairments mutually reduces the prospect of using the potential residual vision or hearing. This means that people with deafblindness cannot automatically utilize services for people with visual impairments or with hearing impairments. Thus deafblindness entails extreme difficulties with regard to schooling, further education, working life, family and social life, cultural activi-
ties and information. For those who are born deafblind or acquire deafblindness at an early age, the situation is complicated by the fact that they have additional problems affecting their personality or behaviour. Such complications further reduce their chances of using any residual vision or hearing and also make the development of other functions more difficult.

Deafblindness must therefore be regarded as a separate disability which requires special methods for communication and special methods for coping with the functions of everyday life.”

The Association of the Swedish Deafblind (FSDB) also stresses the functional aspects of the definition. According to their statutes “a person is deafblind if he or she has so impaired sight and hearing as to give him obvious difficulties in his daily life”.

When speaking of deafblindness it is common to separate people who are born with deafblindness or have lost parts of both vision and hearing at an early age, and people who have acquired deafblindness and have developed one or both impairments later in life. People with deafblindness can also have additional impairments.

The Nordic definition has recently been revised and the new proposition is based on WHO’s latest classification, ICF (International Classification of Functioning, Disability and Health). This includes functioning, disability and health from both a biological and a social perspective (The National Board of Health and Welfare 2003). The new Nordic definition of deafblindness is based on ICF’s terms and concepts and states that:

“Deafblindness is a distinct 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.” (www.dbcent.dk)

Prevalence

In the 1980s, there was an ambition in the Nordic countries to find out how many people with deafblindness that were living in each country. According to the Swedish charting finished in 1985 (National Council on Disability 1984, 1985), the estimated number of people with deafblindness in Sweden amounted to 1 246, an equivalent of 14/100 000 persons. A Danish demographic study carried out by the Information
Center for Acquired Deafblindness in Århus county in 1994–1995, showed 22/100 000 persons with acquired deafblindness (information from Jansbøl, 2001). During the years 2000–2006, The Danish Resource Centre on Congenital Deafblindness in Aalborg made a population study on the presence of congenital deafblindness in all of Denmark’s counties and came up with the number 3.3/100 000. The single largest diagnosed group is people with Usher syndrome, and according to the recently published doctoral thesis by Sadeghi (2005) the number amounts to 3.3/100 000 in Sweden. Previously published numbers for Usher syndrome vary between 2.4 and 6.2/100 000. According to Sadeghi, 3.3/100 000 is likely to be a low number since there are probably children and adults without a correct diagnosis. Lyng & Svingen (2001) have charted the group of elderly people with combined visual and hearing impairments/deafblindness in Norway. According to their calculations, this group covers 1–3% of the population over 67 in Norway. A Swedish study by Bergman & Rosenhall (2001) shows that 3–6% of the population between the ages of 81 and 82, as well as 8–13% at the age of 88, have moderate to severe visual and hearing impairments.

The population in Skåne today is 1.2 million in total, and 206 000 of these are over 65. No charting of deafblindness in Skåne has been carried out, but based on the figures in the above mentioned studies, we may estimate the number of people with deafblindness according to the Nordic definition to be slightly more than 300 under 67. In this charting, we have not included elderly people with a distinct combined visual and hearing impairment due to age related functional impairments. Based on the Norwegian figures, 1–3% of the population over 67, another 2 000–6 000 elderly people with combined visual and hearing impairments of various degrees should be added.

Since the definition of deafblindness is functional and not based on quantitative data about the extent of the visual and hearing impairment, it is impossible to give a precise figure of the number of people who actually live with deafblindness. Moreover, professionals within the different authorities often lack knowledge about deafblindness, and there is no register of people with deafblindness in Sweden. Therefore, the hidden statistics are probably substantial.

Some Consequences of Deafblindness

People with deafblindness constitute a group with great differences and varieties. The consequences of deafblindness largely depend on when in life a person develops deafblindness, whether the visual im-
pairment or the hearing impairment comes first, and how severe the hearing and visual impairment is. It is often said that the loss of independence and freedom, leading to the need of asking others for help in different situations, is the most difficult thing with losing vision. The most difficult thing with losing hearing is that it makes communication, human interaction, and thus social contact with other people difficult. Furthermore, some people also have additional functional impairments.

Losing both distance senses, vision and hearing, poses a serious threat to having an active life and limits the possibilities to participate. One important factor that greatly influences the transition to a life with deafblindness is whether the native language is sign language or spoken language. Another factor that influences a person's chances to learn to live with deafblindness is that the impairment often is progressive, i.e. that hearing and/or vision deteriorates over time. When a person has finally learnt to live and deal with the deafblindness, it deteriorates and new strategies have to be found in order to deal with everyday life and life in general. It is not rare for deafblindness to appear during adolescence or in the early adult life, with tremendous psychosocial consequences. The future becomes uncertain, goals and dreams must perhaps be redefined, and many things need to be relearnt. Skills that have been learnt naturally during early childhood, such as moving about freely and independently, being able to communicate, and read and write, must now be relearnt, often using completely different methods.

When a person is afflicted by a combined visual and hearing impairment, it becomes more difficult to compensate. Things that take place outside the body are no longer accessible, and instead smell, taste and touch, must start compensating to various degrees. For people with deafblindness it is particularly touch, the tactile sense that becomes important. To sum it up, deafblindness leads to difficulties in communicating with others, getting access to information, and maintaining 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 thoughts, and experiencing identity crises. The whole life situation, including many activities and the possibility to participate, are profoundly affected. When talking of deafblindness, it is often said that the problem as a whole becomes significantly larger than the sum of the individual parts. It is a question of profound change in everyday life and in life in general.
Deafblindness Always Poses a Threat to Communication

Regardless of the severity of deafblindness and when in life it develops, it always seems to pose a threat to communication and interaction with other people.

It is through our vision that we see the environment, other people, and things that are going on. We interpret body language and feelings, and in conversations, the turn-taking is widely determined by eye contact and intonation. A person with a visual impairment compensates the impairment by focusing on what he or she can hear. Through our hearing, we hear the language, the words that are said, how they are said, and the surrounding sounds. A person with a hearing impairment learns to be attentive and interpret what he or she sees. Compensation is possible by reading other people’s lips, facial expressions, and body language. All together this gives us a context, which is very important in order to interpret what is being said. For people with deafblindness it is more difficult to initiate contact and find strategies to compensate for the loss of vision and hearing in a conversation. Losing vision and hearing is very likely to have a negative influence on the communicative competence and the ability to socialize with others.

People with deafblindness use different methods to communicate with other people and to take in information. Sometimes these methods are very personal and individual. It has already been mentioned that the consequences of the impairment vary. Based on communication and language identity, the following groups may be discerned:

- Most people with deafblindness have their own culture’s spoken language as their first language, and they have been raised in an environment where the majority of people can hear. They are born with a hearing impairment, visual impairment or with normal vision and hearing, and have developed deafblindness later in life. This group includes the large number of people who are affected by a combined visual and hearing impairment when they get older. The ability to speak often remains intact but the way to perceive what others say may vary. Most people use assistive technology and different strategies to compensate for the hearing loss. Some people prefer to have words spelled to them tactually using the manual alphabet, whereas others learn some signs and mix them with finger spelling using the manual alphabet. The manual alphabet is a part of the Swedish sign language and is mainly used for spelling names and words that there are no signs for. Some people prefer
to have the letters written in the hand or on other parts of the body, others want the information in Braille or large print. However, most people use their residual vision and hearing as far as possible.

- Another group has sign language as their first language and has grown up in a deaf environment and in a deaf culture. They are deaf or have a severe hearing impairment from birth or from an early age. Sign language is used visually if the vision allows for it. If there is no residual vision left to use, sign language is received tactually, i.e. by feeling the signs with the hands. Sign language is used for direct communication with other people. Few deaf people speak Swedish, as it is practically impossible to learn to speak a language one cannot hear. Therefore, this group only uses Swedish as a written language.

- For people with congenital deafblindness, and for people who are on a pre-linguistic communication level, it is essential to use social interaction, closeness and exploring of the close environment as a basis when working towards developing tactually based communication, all according to each individual’s conditions. Qualified support of all kinds is required, as well as early, continuous and recurrent work to help the child develop his or her interaction, communication and notion of the surrounding world, as well as to provide adequate support to parents, siblings, and other relatives. A positive development largely depends on how others are capable of handling and adjusting to the individual’s needs.

Today, people with deafblindness use computer based assistive technology extensively to find information and communicate with others. This is an area of rapid development, which opens the door to new, previously non-existent ways of communicating.

**Sign Language and Deaf Culture**

Since some people with deafblindness are primarily deaf and have sign language as their first language, it is important to emphasize the concepts sign language and deaf culture. This group of people also needs specific competence in the deafblind work. Meeting people who use sign language and meeting them on their own terms requires both knowledge and proficiency in sign language, as well as knowledge about conditions, culture and history of everyday life and of childhood conditions. In 2003, the Swedish Government decided to review the
rights and possibilities to use sign language, and in 2006 the final report called *Sign language and sign language users (Teckenspråk och teckenspråkiga)* was completed. The report states that access to information in sign language and the possibility to make oneself understood using sign language, is fundamental when it comes to accessibility and participation for people using sign language.

*Sign language* is not international. Just like all other languages, it has grown and developed in different cultures and has been passed down from generation to generation. Like in all languages, there are dialectal variations and sign language is constantly developing concurrently with changes in society. Sign language is communicated by gestures and vision, using hands, body movements, facial expressions and looks, and it is perceived visually or tactually, as opposed to spoken language that is communicated by voice and perceived by hearing. The language has its own organization with its own grammar, dictionary and alphabet, and the word order is different compared to spoken Swedish. Sign language is the first language for deaf people, and the language they acquire through communication and interaction with others, i.e. the same way that hearing children learn their first language (Göransson & Malmström 2002). Nowadays, deaf children can go to pre-schools and schools where sign language is used, and all parents have the right to learn sign language. Recent years’ medical and technical development of cochlear implant (CI), a hearing aid where parts are surgically inserted in the ear (see chapter Terms and Abbreviations) is likely to change the development of sign language, but it is too early to say how. However, it is known that most of the deaf children have the surgery early, which means that many of them spontaneously develop Swedish as their first language. Some then choose to be bilingual, others choose to use some sign language as support to the spoken language. Some families also choose not to learn sign language. There are children who, for some reason, cannot undergo the surgery needed to insert the cochlear implant. An important question for the future is how these children can find a way to develop and communicate using sign language, and what will happen to the sign language.

*Deaf culture* is described within the deaf community as a life pattern dependent on the visual language, childhood conditions, history and traditions. A common history and a common language is the basis of a common culture. The deaf schools have been the primary place where sign language and a common culture has been founded, developed and transferred, from one generation to the next. Deaf culture is
about having a common history, and common childhood conditions, values and norms. The fundamental factor in this culture is the social community and the free and unobstructed communication, the feeling of belonging together and the common identity. All deaf people also have hearing families, relatives, friends and colleagues. Therefore, everyday life for deaf people consists of two languages and two cultures that they have their own individual approach to (Göransson & Malmström 2002).

**Interpretation for People with Deafblindness**

People with deafblindness need access to interpreters in order to facilitate their communication with others, to be able to live an active life, and to feel involved in different situations. When The Health and Medical Services Act (HSL) came into force in 1994, organizing, financing, and supplying interpretation services became a regional, county council, obligation. Today, all county councils in Sweden have interpretation services free of charge. Occasionally, there is a lack of interpreters for people with deafblindness, which means that people with deafblindness are not always granted an interpreter in situations where they need one. Another reason for an interpreter not always being granted when needed, is different restrictions and priorities within the county councils.

The interpreter’s task is to convey what is being said in both directions, to make a conversation possible. Hearing people and people with deafblindness are in equal need of the interpreter to understand the other. The interpreters must be impartial and they serve under professional secrecy. The interpreter for people with deafblindness has a more extensive work task than the sign language interpreter. They must also put the visual information into words, the information that people with deafblindness cannot perceive. This is called visual interpretation. In the interpretation situation, the interpreter often has to work as a guide as well. Students at the schools of interpretation are taught that the following three components constitute interpretation for people with deafblindness.

- Interpretation – conveying spoken language and sign language
- Visual interpretation – interpretation compensating for the loss of visual impressions
- Guiding – assistance in orientation and mobility
Interpretation for people with deafblindness can include different methods. There are people who use speech-to-type interpreters with modified text on screen or an interpreter using voice interpretation at a close distance. Some use visual sign language but at an adjusted distance and with a limited amount of signs, and others need tactile sign language. Some people can communicate using assistive technology but need visual interpretation and guiding. It is becoming more and more common that people with deafblindness want interpretation of the environment and situation by use of haptic signals. This will be thoroughly described in the chapter Theoretical Perspectives. Other, sometimes very individual interpretation methods, also exist.

Separating the county councils’ interpretation services from the local authorities’ guiding services creates problems, especially for the person using the interpretation services. Having both an interpreter and a guide at the same time is impractical and should be avoided. The Swedish Association of Local Authorities (SK registration number: 2004/0487, 1984) together with The Swedish Federation of County Councils (Lf registration number: 0313/04, 1984) have written a communication on the need for local and regional authorities to co-ordinate their work so that the individual person is not affected and the overall resources are put to best use. The best solution, according to these authorities, is for the interpreter to take on the role of a guide as well and for the cost to be divided between the two responsible authorities. That way, all three components constituting interpretation for people with deafblindness would be integrated in one process with one professional.

The Importance of the Tactile Sense

The ability to hear, see, feel, smell and taste, as well as being able to orientate oneself in a room, is essential for a person’s survival, adjustment to the environment, and ability to interact and communicate with others. For people with deafblindness, the tactile sense becomes very important and it must often compensate the loss of vision and hearing in different ways. The child who is born with deafblindness must use the tactile sense together with smell and taste to explore the world and develop concepts. For some people language, both the written and the directly communicated language, must be received tactually. Tactile communication includes touching and body contact, and it is necessary to break cultural rules regarding conversation distance, confirming each other, turn-taking in conversations, etc. A division is often made
between intimate distance, ranging from touching to half a metre, the personal distance from 45 cm to 1.2 metres, and an acquaintance distance or public distance stretching from 1 metre to 3.5 metres (SRF 1995). In a conversation with a person using tactile sign language for direct communication, the parties are always at an intimate distance. However, there are rules for touching, ranging from professional, social, friendly touching to loving and sexual touching (SRF 1995). Lahtinen (2007) mentions norms regarding touching within the professional field of deafblindness. The arm, the hand, the shoulder, and the upper part of the back are considered the most neutral parts of the body (Lahtinen 2007). In situations where direct communication is used, and also when tactile deafblind interpretation is required, as well as in guiding situations, body contact is necessary. This means that people must have body contact with others who they do not have a close relationship to and who they have not chosen themselves. The tactile sense is very important for people with deafblindness, and needs to be discussed and illustrated more than it has been this far.
THE AIM AND PURPOSE OF THIS PROJECT

The overall aim of the project as a whole has been to form a deeper understanding of what life looks like for people with deafblindness and their relatives, as well as of the need for social support services in the different age groups. Based on this knowledge, the aim has been to ensure people with deafblindness, living in Skåne, individually adapted habilitation and rehabilitation, as well as good counselling and support. The project has been intended for people with deafblindness of all ages, and their relatives.

In order to realize this work, it has been fundamental to involve people with deafblindness, relatives, and professionals in the entire project process. One way has been to create networks for the future. This includes client co-operation, on a local as well as national level, and different forms of professional networks and co-operations.

Another essential part of the aim has been to develop knowledge and competence around deafblindness. People with deafblindness that we met during the pre-study, emphasized that all professionals need specific competence about deafblindness. It is not enough to have knowledge of visual and hearing impairments separately, but knowledge of the specific conditions that this particular combination leads to is also required.

Based on this overall aim, the purpose has focused on the following three parts:

- developing good support strategies for people with deafblindness and their relatives (habilitation and rehabilitation)
- developing networks and forms of co-operation between professionals but also between people with deafblindness and professionals (co-ordination)
- developing and spreading knowledge about deafblindness (knowledge spreading).
STRUCTURE AND DIVISION OF RESPONSIBILITY

The Project Team

The composition of the project team reflects the pedagogical and psychosocial perspective that we have chosen as a basis for the project. The composition of the group also reflects the assignment within The Vision, Hearing and Deafness Division in Region Skåne’s administration Habilitation and Assistive Technology. The aim was for everyone in the project team to be able to communicate directly with people with deafblindness, therefore everyone was required to know both spoken language and sign language. This requirement was met by all members of the project group consisting of Lena Göransson, Lena Sjölin, Elisabeth Lindström, Helene Engh and Fredric Dacke.

The project leader, Lena Göransson, has led the project team, organized the work and been responsible for the project’s budget as well as the yearly accounts to The Swedish Inheritance Fund and the end report.

Supervision

In order to ensure the quality of the project – theoretically and methodically – we have had continuous method supervision once a month during the whole project with Kerstin Liljedahl, head of research and development within Habilitation and Assistive Technology, Region Skåne. In addition, we have had supervision once a month, specifically intended for the team’s development and inner work in relation to the clients and their networks. The licensed psychologist Lennart Siegfeldt has been supervisor for this work.

Apart from the continuous supervision, a number of researchers from the network The Disability and Rehabilitation Research Centre HAREC in Skåne, have been tied to the project: Ann-Christine Gullacksen, lecturer at Malmö University, Lotta Anderson, lecturer at Malmö University, and Anna-Lena Tvingstedt, senior lecturer and lecturer at Malmö University. It has felt important for the future to establish contacts and establish a co-operation between the field of research and the actual work.

The Steering Group

A steering group has been tied to the project with the task of observing and having the ultimate responsibility for realizing the project. The
group has consisted of representatives from FSDB on national level, the Skåne Association of Local Authorities, the Research and Development Unit within Habilitation and Assistive Technology, The Vision, Hearing and Deafness Division, and the project leader (see appendix 1). The group has met approximately four times per year during the run of the project, and in between the meetings there has been a continuous dialogue between the project leader and the members of the group.

The Reference Group

A reference group has also been tied to the project, consisting of representatives from FSDB’s regional associations, the parents’ section of FSDB and DeafBlind Youth, together with professionals from departments in Skåne who meet the target group. The reference group has represented people with deafblindness, their relatives, as well as local, regional and national authorities, and can be considered to be a good basis for a future network around people with deafblindness and their relatives (see appendix 1). The reference group has worked as a discussion partner for the project team and as a channel both for spreading information about the project to the different organizations that the members of the group represent, and for gathering information from these organizations to the project. This has contributed to a mutual exchange of experiences and competence development.

Client Co-operation

The project has been carried out in close co-operation with both the client organization (FSDB) and other related fields. To secure the clients’ long-term influence over the development, we have had a number of open dialogue seminars during the project, initiated during the pre-study. The seminars will be thoroughly described in the next chapter. Having a continuous dialogue with people with deafblindness and their relatives has been considered fundamental within the project, as it has been a way for us to test and evaluate the results we have come to all through the project. During the whole project, we have also had a continuous dialogue with members of the local clients’ organization (FSDB Skåne). We have met twice a year to exchange thoughts and experiences and to discuss the development of the project and the future services for people with deafblindness in Skåne.
THE PROJECT PROCESS

The project as a whole may be described as a process, starting from the collecting of information about deafblindness to the creation of a regional team for people with deafblindness. The process can be described as consisting of three phases: gathering information, analyzing, and finally testing and evaluating methods and strategies for support.

During the pre-study and the first year, the project was focused on gathering information about deafblindness, and on the conditions and consequences relating to deafblindness. This was achieved by conducting interviews and by studying other kinds of work, projects, as well as research and development work.

The second year was more focused on analyzing and working with material from the interviews and other sources, and then finding forms for assessments, habilitation, rehabilitation, support, and follow-up.

The third and last year of the project was aimed at testing and evaluating methods for assessment, habilitation, rehabilitation, support, and follow-up. A great deal of effort was also put on trying, evaluating, and implementing professional team work and co-operation with client organizations and different professional networks.

Developing and spreading information about deafblindness and its consequences for the individual people and their close ones, runs through the whole project and has been necessary for creating and providing high quality services. During the whole project, great efforts have also been made to create networks, both on a local and regional level as well as on a national and Nordic level.

The project process has consisted of alternately collecting interview material, reading literature, analyzing, conducting new interviews, going on study visits, having discussions with colleagues, organizing dialogue seminars with clients, reading more literature, doing practical work with people with deafblindness and their network, exchanging experiences within the Nordic countries, further analyzing, etc. This process has deepened and developed our knowledge of the issues through continuous theoretical analyzing in relation to literature and research, which has then been tried in practical work.
Methods and Strategies

Charting Experiences of Living with Deafblindness

The purpose of the survey during the first phase of the project was to gain insight into people’s experiences of living with deafblindness, in order to have a basis for developing support strategies. We wanted to deepen our understanding of how people with deafblindness in different ages and their relatives learn to cope with the new life conditions that deafblindness imply, or how they cope with having a child with deafblindness. We also wanted to know what strategies people develop to handle different everyday situations, and to see what kind of counselling, support, habilitation and rehabilitation people with deafblindness and their families need during different stages in life.

Selection

When we selected people for the interviews, we wanted to have a large variety amongst the participants. Our aim was to have a group with differences regarding means of communicating, gender, age, geographic distribution, primary impairment, and when in life deafblindness developed, etc. We have also interviewed parents of children and adolescents with deafblindness. In all, we conducted eight in-depth interviews, eight ICF-interviews and had two focus groups with five and thirteen participants respectively. A brief description of the interview methods used during the project can be found below.

During the project more and more people with deafblindness in different ages as well as their relatives, contacted us about individual need of support. For ethical reasons, concrete efforts have therefore become an integrated part of the project work, the longer the project has been going on. These meetings, concerning actual needs of support, have given us a great variation in terms of experience and knowledge of the consequences of living with deafblindness. We have therefore chosen to take this knowledge into account when presenting the different age groups in the report: The Child and the Family, Adolescence, Adult Life, and Ageing with Deafblindness. In these four chapters, we try to portray and describe everyday life as people with deafblindness and their relatives experience it.

In-depth Interviews

In order to gain an inside perspective, we chose to start off by using an interview method where the person being interviewed was allowed
to guide the conversation and where his or her silent inner knowledge and experiences could come out, a so called *qualitative research interview* (Kvale 1997). We chose to conduct the in-depth interviews using an overall view and a life perspective as starting point. Furthermore, we wanted to focus on deafblindness from an individual, family and society perspective. The main subjects were the individuals’ possibility to be active and participate on these different levels. We wanted to get a picture of the participants’ strategies for dealing with deafblindness in everyday life (coping) and to see what these adjustment processes looked like over time. As a support during the interviews, we developed an interview guide (see appendix 2). The interviews had the character of life stories, a free narrative, where the person being interviewed was allowed to control the conversation and we only interfered to change the subject or focus during the interview. Each in-depth interview took approximately eight hours, spread out over three or four occasions. Interviews where spoken language was used were recorded on tape, and interviews where sign language was used were video filmed. The project team worked in pairs when conducting the interviews, and all interviews were carried out through direct communication, i.e. without an interpreter. All of the interviews were printed out and then processed and analyzed.

*Interviews Based on ICF*

In August 2003, the National Board of Health and Welfare’s Swedish translation of WHO’s International Classification of Functioning, Disability and Health – ICF – was completed. In this project, we have tried different ways of using the ICF concepts to get an overall picture of the participants’ life situation as it is today. Using different codes and evaluation factors, it is possible to describe the level of difficulty of different problems. The participants give their own estimation of different problems using a scale. That way it is possible to describe how they experience the impairment in a certain situation. The first model we created was based on 12 domains and a total of 64 questions, where the participant was allowed to estimate possible obstacles based on ICF’s evaluation scale and then, in a dialogue with the interviewer, identify possibilities and obstacles and see how environmental factors have a positive or negative impact. Thereafter, the participants were given time to think of aims, how they would like for it to be, and finally discuss possible methods for reaching these aims. Domains and problems were worked out in co-operation with some people
with deafblindness. In all four chartings following this model were conducted during the project. When evaluating these chartings, we noticed that they lacked information about the participants’ self-image and psychological health, which is why we had to revise the model and add domains covering these areas. The revised model was then tried on four other persons with deafblindness. Each ICF charting, including discussion, took about eight hours to conduct, spread out over three or four occasions.

We used the following ICF domains as a basis in the chartings:

**Body functions:**
- Vision
- Hearing and vestibular functions
- Additional sensory functions
- Mental functions

**Activities and participation:**
- Purposeful sensory experiences
- Basic learning
- Applying knowledge
- Communication
- Mobility
- Self-care
- Domestic life
- Major life areas
- Interpersonal interactions and relationships
- Community, social and civic life

Apart from using ICF as an interview and charting tool together with people with deafblindness, we have also used the concepts from ICF as framework and structure in the in-depth interviews and the focus groups. Above all, we have used the concepts connected to the level of activity and participation.

**Interviews in Focus Groups**

In order to interview a larger number of people with deafblindness and their relatives, we decided to supplement the individual interviews with focus groups (Kitzinger 1994, 1995). Focus groups are a form of group interviews, a qualitative research method based on interaction between participants, with the aim of studying the participants’ expe-
riences with focus on a particular subject or area. What characterizes this method is that it takes the interaction between the participants into account. The process within the group also provides richer associations, and the participants strengthen each other and practise activity and participation (Kitzinger 1994, 1995). During the project, we worked with two focus groups. One group consisted of five persons with deafblindness using spoken language, three men and two women, all of working age. The other group consisted of thirteen parents of children and adolescents with deafblindness. The focus groups gave us the opportunity to plunge deeper into certain subjects and central questions that had appeared during the in-depth interviews, and some generalizations could be made. The interviews were evaluated together with the participants during the next meeting, when we had written down and summarized what had been said. That way, we recapitulated what we thought to be important and let the group confirm, change, and add information, etc. In total, the groups met for two hours on six occasions.

Processing and Analyzing

Already during the pre-study, theories emerged through the interviews about individual life adjustment processes in relation to the environment. Therefore, we have chosen three overall perspectives to use as support in order to analyze and sort through the interview material. Based on the material collected during the project, we believe that knowledge of individual life adjustment processes (Gullacksen 1998, 2002), is of superior importance when analyzing and understanding the consequences of living with deafblindness. When a person develops deafblindness, he or she undergoes several adjustment processes since the vision and/or hearing in most cases deteriorates gradually. Life adjustment is unavoidable when it comes to deafblindness and it often affects the whole life situation. In order to describe the significance of the environment in the life of a person with deafblindness, we have used ICF as a basis, WHO’s classification of functioning, disability and health, which was described previously. We have illustrated the perspective of time by using Jeppsson Grassman’s studies about living with a severe visual impairment during a long period of time, as well as the life-course perspective (2001, 2003), and the work carried out by the Helen Keller National Center in the US (Wynne 2001). These perspectives make up a theoretical basis and a framework for our analysis, when we describe deafblindness and the balance between
an individual and the environment over time. In the next chapter, we will further develop these perspectives.

**Evaluation in Dialogue Seminars**

National seminars that we have arranged with clients and their relatives on different subjects, have given us the opportunity to reflect on and evaluate our conclusions, but they have also inspired us to use new approaches. As for the project, the seminars have been a way to test and evaluate thoughts, strategies and theories that we have found useful. Trying the conclusions on other people, in this case the clients, is what Kvale (1997) calls *communicative validity*. The seminars have also been a way to give the clients a more profound insight into concepts like life adjustment, coping, motivation, habilitation/rehabilitation, communication, and ICF, which we have considered to be an important requirement for an active client influence. At the end of the last project year, we arranged a national seminar for FSDB members. We were very keen to spread the knowledge and the experiences gathered and analyzed within the project, particularly through the interviews with people with deafblindness and their relatives. The purpose of the seminar was to give members a summary of what we had been working with, and the results we had come to during the project, but it was also an opportunity to discuss a number of issues raised by many people with deafblindness during the project. We had intense group discussions on the following subjects:

- Life adjustment in connection with deafblindness
- Communication
- Social support services and professional networks
- Health and stress management
- Studies and work
- Technology and environment
- Relatives’ needs
- Client co-operation

The participants were clearly absorbed by the discussions. The seminar was a good evaluation of what we had come up with during the project.
Results

Strategies for Support on an Individual Level

... developing good support strategies for people with deafblindness and their relatives (habilitation and rehabilitation)

The three perspectives mentioned earlier have also worked as guidelines in developing methods and strategies in the deafblind work, and this will be elucidated in the following chapters. Gullacksen's model for life adjustment processes (1998, 2002) has been important to identify where in the adjustment process a person is, and also to see what the motivation is focused on. This is important in order to understand when an individual is susceptible to different kinds of support and habilitation/rehabilitation work – what we call timing. The model for life adjustment also forms a basis for the individual's work when trying to find new strategies to cope with everyday life. Consciously working to find appropriate coping strategies (Hallberg 1992, 1996, Gullacksen 1998, 2002, Fredriksson 2001, Riddersporre 2005) ought to be an important part of the habilitation and rehabilitation process for people with deafblindness. In the project, we have tried to use cognitive methods originating from a cognitive psychotherapeutic approach (Perris 1996, Freeman et al. 1994, d'Elia 2003). We have used the relationship between thought – feeling – action as a basis in different situations in the habilitation and rehabilitation process. Each person was given time to reflect on his or her thoughts and feelings in different problem situations, set up aims, and try to find alternatives to change thoughts and behavioural patterns. We have found that the cognitive methods are useful tools in helping people with deafblindness identify dysfunctional strategies and thoughts and provide support in finding more appropriate coping strategies.

If people are to gain control over their situation as well as the surrounding conditions, knowledge is required. This includes knowledge of themselves, their own situation, the impairment, and the environment. Knowledge is necessary in order to have control and influence over their own lives, and this is called empowerment (Askheim 2005, Gullacksen 2002). Another way of improving their own awareness of the impairment in relation to themselves and the environment is to share experiences with others. An important part of the habilitation/rehabilitation process is to use the group consisting of people who are in a similar situation, so called peer groups, as a resource.
Communication, in the widest sense of the word, permeates the specific habilitation and rehabilitation work around deafblindness, in all age groups. This may mean developing sign language or tactile communication for a small child with deafblindness, as well as supporting and motivating parents and other relatives to learn to communicate in a new way – creating a basis for interaction and communication (Nafstad & Rødbroe 1999, Preisler 1998, Nyling 2003, Ask Larsen 2004, 2006, Ask Larsen & Nafstad 2006, Arman 2006). The work may also include a transition from visual to tactile sign language, or learning a new method or a new language as an adult in order to be able to communicate with others. It is especially important to find alternative strategies to compensate for what is lost in terms of turn-taking in a dialogue, how to make contact, how to maintain relationships, in short, how to compensate for what is lost when it is not possible to make out nuances in intonation, emphasis, etc., and when it is not possible to ‘read’ other people visually any more – altered communicative competence (Nilsson & Waldermarsson 1990, Mesch 1998, Magnusson 2003, Danermark 2005, Raanes 2006, Lahtinen & Palmer 2005, 2007, and others). For people with deafblindness and their network, conscious strategic work is required to create conditions for developing interaction and communication, or to change an already established communicative competence.

In order to identify and chart the environmental factors for a family with a child with deafblindness or a person with deafblindness, we have used ICF (2003) as a tool. It is very beneficial to distinguish which factors constitute possibilities and which constitute obstacles, when choosing and prioritizing work in a habilitation/rehabilitation process. We find network chartings very useful for charting the network around an individual, both the personal and the professional, but also to look at the quality of the relationships as well as changes in the network over time (Wynne 2001). Charting the network gives a good overview and makes co-ordination of professional support easier. Knowledge of the network is also important for developing the individual’s communicative competence and network with the purpose of strengthening the relationships.

To include the perspective of time and to be able to form a picture of the individual’s background, we have chosen to use so called life-course lines, based on a model by Helen Keller National Center in the US (Wynne 2001). This shows the individual’s previous experiences and makes it possible to pin-point crucial events and important peo-
ple from the past. Life-course lines provide an overview of the individual’s life and previous experiences and show how he or she has experienced it all.

From 1 January 2007, the project about People with deafblindness in Skåne (“Dövblind i Skåne”) has become a permanent part of the work as a regional Deafblind Team located within The Vision, Hearing and Deafness Division in Regions Skåne’s administration Habilitation and Assistive Technology.

During the project, and as a direct result of it, the administration has decided to create six permanent full-time posts working for people with deafblindness and their network. Communicative competence, in the sense of being able to meet and communicate directly with people with deafblindness of all ages who either use spoken language or sign language, is an important condition, and it has therefore been a requirement when recruiting professionals. The team is mobile and meets people with deafblindness and their network all over Skåne. Posts have been created and staff has been recruited, at the same time as the research work within the project has been going on, all in a simultaneous and integrated process. That way, a Deafblind Team has gradually been established, formed, and implemented over time. The above presented perspectives and methods form a basis for a professional attitude in the work with people with deafblindness and their relatives. They can be used differently in different situations and with different people. In the following chapters, we shall go deeper into these perspectives and illustrate how they can be used in the practical work.

**Networks and Forms of Co-operation**

… developing networks and forms of co-operation between professionals but also between people with deafblindness and professionals (co-ordination)

What networks are necessary locally and regionally – close to the individual, and what networks are needed on national, Nordic, and international level?

Great importance has been attached to creating networks during the whole project. Part of the work with the interviews was to learn more about how people with deafblindness and parents experience the networks, both the *personal* and the *professional* network. Already during the pre-study we could see that people with deafblindness that
we met in different contexts, often had many contacts with authorities on different levels in society. This is particularly true for families who have children with deafblindness. There is a lack of co-ordination of resources as well as co-operation between different authorities. In most cases, there are no professional networks around people with deafblindness, and there is not enough knowledge of what other departments are working with. In a Deafblind Team, it is necessary to develop knowledge and routines around a network based way of working. During the project, we have also come to the conclusion that one of the major tasks in a regional Deafblind Team ought to be to have a co-ordinating role when it comes to deafblind issues on a functional level. Networks around an individual person with deafblindness can differ depending on the needs and the professional conditions locally and regionally close to the individual. Networks can also be formed in order to develop mutual knowledge, methods and routines. During the project, different networks on local, regional and national level have been initiated and developed. The project has also established networks with Danish and Norwegian colleagues, and the theoretical basis, method development and need for common competence development within the field has been particularly discussed.

Knowledge Development

... developing and spreading knowledge about deafblindness (knowledge spreading)

What knowledge of deafblindness is required on a local and regional level, close to the individual, and what knowledge is needed on a national and international level?

Knowledge development has been a central part of the whole project and we have been able to distinguish a need for knowledge on three different levels: the individual’s need for knowledge of his or her own deafblindness, the environment’s need for knowledge of the individual, including both the personal and the professional environment, and finally the need for a more general knowledge development about deafblindness in society. Developing and spreading deafblindness-specific knowledge related to an individual’s needs is an important task for a Deafblind Team, something which will also become evident in the following chapters of the report. It mainly concerns the need for knowledge on local and regional levels, but also on a national level. We have noticed a great need for continuous development and spreading
of knowledge about deafblindness, both *specific knowledge* within the professional field of deafblindness and *general knowledge* in society as a whole.
THEORETICAL PERSPECTIVES
INTRODUCTION

Developing deafblindness or having a child with deafblindness leads to major changes in life, both for the individual person and for the environment. The changes can be of emotional character or affect relationships, but they can also involve changes in practical everyday life, at home, in school, at work, and in society in general. Being an active citizen who feels part of the surrounding world and lives on the same terms as other people, is a huge challenge for a person with deafblindness. It requires others to be flexible and prepared to make changes in order to facilitate different situations. This means that deafblindness has consequences both for the individual person and for the environment. A third important factor when talking about deafblindness is time. Time is a central factor when trying to understand how life is developed and formed through interaction between the individual person and the environment. Some people are born with deafblindness, others develop deafblindness later in life. Some of the people with deafblindness that we have met during the project have recently been diagnosed, others have lived with the diagnosis for several years, and there are those who live with the knowledge that they will develop deafblindness at some point in life. Work life, social relationships, communication, a lack of understanding in the surrounding world as a result of a lack of information, are some examples of the consequences of deafblindness. Things that are natural for others become a problem for people with deafblindness, who often more or less depend on others in different ways. Henceforward, these perspectives will work as a framework when we describe deafblindness and they will symbolize the balance between the individual and the environment over time.

LIFE ADJUSTMENT – INNER PROCESSES OVER TIME

Deafblindness is a life adjustment that people do not choose for themselves. A person develops deafblindness and it is necessary to learn to live with it, in some way or another. Most parts of life are affected, ranging from simple, concrete everyday situations to more complex
social contexts. A life adjustment can be described as an adjustment to new living conditions. Something in life has changed and everything that was previously taken for granted is turned upside down, including the ability to move about freely outdoors, reading, talking and socializing. Many things become uncertain, and the afflicted person faces new conditions in life that have to be dealt with in the best possible way – often in a completely new way. Many things may have to be relearnt in order to regain control and have a functioning everyday life. Life adjustment can be compared to an imbalance between the individual and the environment. A chronic and often progressive impairment such as deafblindness inevitably leads to overwhelming and recurrent life adjustments (Gullacksen 1998, 2002). A family with a child who is born with deafblindness experiences a huge emotional and practical burden. The family has to cope with a situation it is not prepared for and has no previous experience of, which makes the parents ordinary parents under extraordinary circumstances.

Parents of a child with deafblindness, or a person who develops deafblindness later in life, may experience a crisis reaction, in particular at the beginning of the adjustment process (Cullberg 1996). The person with deafblindness faces a situation where everything is turned upside down and grieves the loss of his or her vision or hearing. Since the conditions have changed and will remain changed in one way or another for the rest of the life, a wider perspective, stretching over a longer period of time than in the crisis theory, is required (Cullberg 1996). To interpret what happens to the individual person or the family afflicted by deafblindness, we have chosen Ann-Christine Gullacksen’s model for life adjustment (1998, 2002). Berndtsson (2001) also gives a thorough description of how a visual impairment changes a person’s life situation and the adjustment process an afflicted person goes through.

Gullacksen’s model describes a course divided into four stages. At the beginning of a person’s life adjustment, all energy is focused on surviving, coping with everyday life, and dealing with the emotions. The strategies are focused on hiding and denying, trying to survive. Previous strategies for solving problems become inadequate. People try to restore life to how it was before (1). Eventually, they reach the turning point that Gullacksen calls recognition, an important and crucial point in the life adjustment process, since that is when a process of change can start. The second stage is focused on exploring and finding new ways and strategies to cope with everyday life, a job that must be done
individually and requires a lot of time and energy. People grieve their loss and are very worried about the future, but they have now entered a new phase where they have started to think about changes and explore obstacles and possibilities (2). It is not until the third stage that a certain amount of strength and motivation can be directed towards the future. The strategies are now focused on stabilizing, making new priorities, finding a new self-image and new goals in life (3). Stage four is focused on maintaining everything, continuing to live with the impairment one day at a time. People have now acquired the competence to change and they have become experts of their own situation. The self-image is reinstated and the confidence regained. They have learnt to live with deafblindness, but the stress tolerance is often small (4), (Gullacksen 1998, 2002). In order to make decisions about what support to give, from whom, as well as when to give it, it is important to be able to identify at what stage in this process a person finds himself/herself at a certain point in time. It also provides valuable knowledge of what the person with deafblindness is focusing his or her energy and motivation on.

![The Life Adjustment Model](image)

*Figure 1. The Life Adjustment Model, according to Gullaksen 2002.*

The adjustment to deafblindness, as well as the strategic work and the time process, vary from one person to another. An important factor is when in life deafblindness develops; whether it is during childhood or adolescence, at the beginning or at the end of a working life, or if it affects the parents of small or grown up children, etc. Life adjustment also varies depending on whether the visual impairment or the hearing impairment is the primary impairment, if the vision and hearing are deteriorating gradually or rapidly, and the severity of the visual and hearing impairment. One important factor that often influences a person’s chances of learning to live with deafblindness is that his or
her vision and hearing often deteriorate gradually. When the afflicted person finally has got used to or learnt to deal with the deafblindness, it deteriorates and new strategies must be found once again since the old ones no longer work. This leads to new life adjustments where the person goes through a new adjustment process, enriched by the knowledge and experiences from previous adjustments.

**Coping – the Strategic Inner Work**

The biological process has its own pace and can usually not be influenced. The life adjustment process on the other hand, ‘belong to’ the individual person. Everyone has an inner desire to regain control, according to Gullacksen (2002). One important part of this process, particularly in stage two, is coping. Coping is a concept signifying the way people deal with situations that they really feel they cannot handle, i.e. what they think or do in order to cope with a stressful situation (Riddersporre 2003). During the last few years, the coping concept has often been used to describe a process of change in connection with different impairments (Hallberg 1992, 1996, Fredriksson 2001, Gullacksen 2002). In the Nordic project about experiences from people with deafblindness, *Erfarenheter från människor med dövblindhet*, (Olesen och Jansbøl 2005), the coping concept also plays an important part for the interpretation of the results. Coping can be described as possible ways of dealing with a situation in order to minimize the level of effort in different parts of everyday life. A person with an impairment such as deafblindness, must learn to deal with uncertain situations, perhaps on a daily basis. This leads to a feeling of insecurity and stress. How can I best learn to live with my deafblindness? How can I emphasize and strengthen things that are working and that I do well? How can I find new and more appropriate strategies? These questions have been crucial in this project.

Coping strategies can be either focused on problems or focused on emotions (Riddersporre 2003). Problem focused strategies are aimed at changing a situation that is perceived as a burden and emotion focused strategies are meant to reduce the psychological imbalance. Escaping, or strategies focused on avoiding are usually associated with psychological discomfort. Cognitive restructuring, ways of creating meaning, and positive reevaluation of the situation on the other hand, are associated with psychological comfort. Hallberg uses the concepts “avoiding the social scene” and “controlling the social scene” (Hallberg 1992).
Deliberately working to find appropriate coping strategies ought to be an important part of a habilitation/rehabilitation process for people with deafblindness. Strategies acquired along the way are aimed at reducing the level of stress. We need strategies to cope with everything from simple everyday situations to more complex social situations. However, this requires strength, energy and time. Patience and courage are important personal assets, since the adjustment process implies stretching the boundaries and finding new strategies to cope with everyday life and life as a whole. The coping process is based on the individual person and it is therefore an important part of the inner adjustment process (Gullacksen 2002).

**Empowerment as a Strength in Habilitation and Rehabilitation**

Empowerment is a concept that is used more and more frequently in connection with functional impairments. According to Gullacksen (2002), it means that people with impairments become aware of their situation and mobilize their own strength to deal with the situation, the impairment, and with meeting others – being in control of the situation as well as the environmental factors. Gullacksen also means that it implies trusting one’s own ability to live an independent life and being able to co-operate in the habilitation/rehabilitation work. Empowerment can be described as the ability to re-establish a dignified life situation and a good quality of life – two concepts that are often described as the ultimate purpose of habilitation and rehabilitation. It is possible to create a basis for the transition of power enabling people with deafblindness to take control over their own habilitation and rehabilitation as well as their own lives. However, it is not possible to give empowerment to somebody else. Consequently, empowerment can only be attained individually, but it can be strengthened in a collective environment, for example in the client group. As a professional, it is necessary to take on the role of a conversational partner, on equal terms with the person with deafblindness. The person’s knowledge and professional competence must be equalled and the professional approach focused on individual resources, not on problems and obstacles (Askheim 2005).

The so called *salutogenic* approach is the basis of Antonovsky’s theory on the sense of coherence, SOC (1991). In the actual habilitation and rehabilitation work, this means identifying success factors and using the individual’s resources as a basis – all important factors for the empowerment process.
When seeking to establish an equal relationship between a person with deafblindness and the professional, the professional ought to be more generous in terms of personal reactions – i.e. how they perceive a certain situation, what they think or what they feel – to a higher extent than what is customary in habilitation and rehabilitation work. The purpose of this is to make the situation more understandable and manageable for a person who cannot read you as a professional, neither through vision nor through hearing, thus missing out on important information. This way of thinking is well in line with cognitive theories and is strengthened by, amongst others, Freeman et al (1994) and d’Elia (2003).

THE ENVIRONMENT
– EXTERNAL PROCESSES IN CONSTANT CHANGE

Developing an impairment such as deafblindness is always a specific and individual process that takes place in a special context and environment. A person with deafblindness, whether a child or an adult, is a subject with his or her own goals and dreams. People are active beings who form their lives in different ways, even when the personal difficulties are overwhelming (Jeppsson Grassman 2003). But people always form their lives in interaction with others, with the environment (Berger & Luckmann 1966, Jarvis 1992). A central factor when talking of deafblindness is interaction and communication with other people.

Social Life – Interaction and Communication

The common denominator for people with deafblindness seems to be the meeting with others, which is characterized by communication difficulties. The last few years, a systematic research and development work has been under way in the Nordic countries, in particular concerning methods for working with interaction and communication for people with congenital deafblindness (Preisler 1998, Nafstad & Rødbroe 1999, Nyling 2003, Arman 2006, and others) and there seems to be a broad agreement on theories and methods in the Nordic deafblind field. Cognitive semiotics (Ask Larsen 2004, 2006, Ask Larsen & Nafstad 2006), a theory on how we create meaning and cohesion when meeting the surrounding world and how we attach meaning to a word in order to develop a mutual language, has aroused great interest within the Nordic field of deafblindness and has also spread to other fields.
As for the need of changes within the communicative and interactive competence for people who are afflicted by or who develop deafblindness later in life, research and development work seems to pull in different directions, and we have not found any common Nordic strategies. Tactile use of the Swedish sign language is analyzed by Mesch in a doctoral thesis (1998), and Raanes (2006) bases her thesis on interaction and creating meaning in dialogues using Norwegian sign language in tactile form. In 1998, the Nordic Staff Training Centre for Deafblind Services published a series of articles on language and ways of communicating for people who have developed deafblindness late in life, Communication with people with acquired deafblindness (Kommunikation med døvblindblevne 1998). Within the hearing field, Danermark (2005) has done research on what consequences reduced hearing will have on a conversation and what can be done to regain the conversation. Magnusson’s doctoral thesis (2003) concerns blind people’s non-verbal communication and it is a study of blind people’s body language, non-verbal conversation regulations, and non-verbal expressions. It would be interesting to connect these communication related areas of knowledge and study the consequences of the loss of both vision and hearing. One method that seems to have had a breakthrough in the Nordic countries during the last few years, and that connects the loss of the senses vision and hearing, is the development of so called social-haptic interactive communication (Lahtinen & Palmer 2005, Lahtinen 2007). Haptic comes from the Greek word haptikus, and signifies perception through the tactile sense. Lahtinen’s research (2007) is about developing tactile signals that can work as a complement to the spoken or signed language in a communication situation in order to create meaning and cohesion and to convey emotional signals. The purpose of the signals is to give information about the non-linguistic parts of the communication, i.e. the way that something is said. The tactile signals also give an idea of what is going on in the room at the same time as the communication takes place. There is a great deal of literature on interaction and communication between people in general, see for example Nilsson & Waldermarsson (1990). However, we could certainly do with much more literature about the changed conditions for communication and interaction that arise when a person develops deafblindness later in life. There is also a crucial lack of documented methods that could provide appropriate habilitation/rehabilitation within this field.
ICF

The environment is a complex concept that includes several dimensions. The fundamental factor is that it creates the conditions for people’s chances of being active and participate. A person’s ability to be active largely depends on environmental factors that may facilitate or obstruct a situation. The environment is constantly changing, just like the individual. Friends and relatives change, new kinds of assistive technology are developed, the environment changes, social support services change, new laws are written, and so on, and these changes can facilitate or obstruct the life of a person with an impairment.

In August 2003, the National Board of Health and Welfare’s Swedish translation of WHO’s International Classification of Functioning, Disability and Health – ICF – was completed. This new definition includes all people. Impairments are no longer considered a deviation from what is ‘normal’. ICF consists of two parts: the first part includes body functions and structures, activities and participation, and the other part is focused on environmental and personal factors (The National Board of Health and Welfare 2003, Möller 2005). Activities relate to a person performing an act, whereas participation involves a person’s commitment in a life situation. ICF stresses an overall view, which means combining the biological and social perspectives.

Figure 2. Analysis of the interaction between ICF’s components, based on the National Board of Health and Welfare, 2003.
Möller has contributed to the introduction of the ICF-perspective in the Nordic deafblind field, and the new definition of deafblindness is using ICF’s framework as a starting point and it is also based on the terms and concepts of ICF. In this project, we have tried different ways of using the concepts from ICF to get an overall picture of the individual’s current life situation. We have chosen to use the part of ICF that focuses on environmental factors as a complement to Gullacksen’s model for life adjustment (2002), which is more focused on the individual’s inner process of adjusting to the impairment. One major advantage of ICF is that it is the individual person who evaluates his or her abilities and difficulties, as opposed to most other instruments where it is the expert who makes the assessment.

When the concept *environmental factors* is mentioned within the framework of ICF, it includes everything from close family and friends to political standpoints on disability issues and the social support system.

ICF gives us a means of procuring information about the individual person's situation at any given moment in life, a so-called momentary view. In order to find out what role a person’s background and thoughts about the future play for the current life situation, and to see what the network around the individual person looks like, how it is perceived and has changed over time, other complementary instruments are required.
The Personal and the Professional Network

We have been able to observe that the networks around people with deafblindness and their families change over time. The personal network tends to become smaller while the professional network seems to grow. The quality of the relationships within the network also seems to change, and according to many of the people that we have met during the project this is related to the increasing communication problems. The methods used for charting networks around a person with deafblindness and for looking at how the relationships are perceived, come from the Helen Keller National Center in the US (Wynne 2001). A person's ability to interact with others, including both established relationships and new ones, is reduced as vision and hearing deteriorates. The codes for communication, what we sometimes call body language, become more and more difficult to perceive, which makes it more difficult to follow the rules of communication. For some people it also becomes more difficult to perceive spoken or signed language; the words/signs are no longer perceived, resulting in misunderstand-
ings and a limited ability to have conversations. This influences social relationships in different ways. As for the professional network around a person with deafblindness, it is not only the amount of contacts that may be considered a problem, but also the lack of co-operation and accordance between different authorities, the lack of co-ordination between different types of work carried out, and the lack of knowledge and understanding.

Figure 4. Network maps, according to Wynne 2001
In families where a child is born with deafblindness, there is often a need for extensive and continuous support from society and there is often a number of contacts with different authorities. During this project, we have also noticed that there is a lack of co-operation and basic accordance regarding the child’s and the parents’ needs, the assessments that are made, and the support that the professional world can provide. This discussion is confirmed by Riddersporre (2003), who gives a thorough description of the family’s encounter with the habilitation world. In 2005, the National Board of Health and Welfare and the Swedish Institute for Special Needs Education published a report about responsibility for co-operation (Ansvar för samverkan), on behalf of the Swedish Government. The purpose was to illustrate how the responsibility is divided and make the co-operation between different responsible authorities more efficient when it comes to support for children and adolescents with severe impairments. The report shows that children and adolescents and their families depend on different social support services on different levels:

- Individual level – the child and the family, including staff from different activities that they meet on an everyday basis
- Organizational level – the organizational fields where the above mentioned staff works
- Society level – laws, statutes and overall structures in society.

The report uses the child’s and the family’s overall perspective as a basis, which means that conclusions about the complex question of responsibility and co-operation are put in relation to consequences for the child’s and the family’s everyday life. The report (2005) states that professionals ought to have an overall view of social support structures and provide the child’s parents with this information, since they cannot be expected to have that knowledge. As it is today, according to the report (2005), it is actually the parents who have the overall responsibility to co-operate in making sure that the children and the adolescents have access to the support they need. It is also the parents who relay the information between different areas, within one and the same responsible authority, for example the health care services, as well as between different responsible authorities, all of which is confirmed by parents of children with deafblindness.
THE LIFE-COURSE
– LIVING WITH DEAFBLINDNESS OVER TIME

We have chosen to illustrate the perspective of time by using Jeppsson Grassman’s research of time, the so called life-course perspectives (2001, 2003). For 18 years, Jeppsson Grassman has followed a group of people who are blind or who have severe visual impairments. She describes how the individual’s strategies, knowledge, wishes and priorities change over time, and how this in turn affects the environment. Jeppsson Grassman (2003) also points at the importance of the time period for the person with the impairment, i.e. the person’s age at a certain time in history and society. Attitudes, disability policies, the financial situation, the situation on the employment market, and reforms within different areas, are all examples of fields that constantly change and that affect the lives of people with impairments. Ways of interacting, language, and fundamental ideas also change (Jeppsson Grassman 2001, 2003). Today, we embrace personal freedom, independence, flexibility and social competence. It is considered a good thing to have many friends, at the same time as independence is considered to be important. For people with deafblindness, this can enhance the feeling of being an outsider and of being dependent. All this makes it difficult to find well founded solutions to difficulties encountered by people with impairments (Jeppsson Grassman 2003).

During the project, several time aspects have come up in the meetings with people with deafblindness. This includes the fact that many people have an impairment that changes with time, what we call progression, and that influences different parts of life and requires constant re-evaluations of priorities. There could also be a discrepancy between the individual’s inner process and the environment’s aims and ambitions, an aspect that we have chosen to call timing in relation to the environment. This becomes evident when there is a discrepancy between the professional world and the person with deafblindness in the habilitation/rehabilitation process. One consequence of this may be that the person with deafblindness rejects an offer of support or aid, sometimes with negative feelings towards the professional world as a consequence. Another example is when an aid is accepted only to be put away not to be used. Yet another time aspect concerns the fact that the pace of every day life changes. Many people with deafblindness say that the spontaneity in life disappears as a consequence
of always having to plan the day to make it work. There is not enough time to do everything they want and dream of, since everything is much more time-consuming. There is a discrepancy between what a person is able to do and what he or she wants to do and dreams of doing. For most people, deafblindness is a process that changes over time. It is not only what happens when an individual or a family is afflicted by deafblindness that is important, but also what it actually means to live with an impairment over time. How is school, work and the social network affected when a person has been living with deafblindness for several years? Besides, everything in life is constantly changing, and that influences the individual’s possibilities and chances of being active.

COMMENTS ON THE FOLLOWING CHAPTERS

In the theories and perspectives mentioned in this chapter, many important areas related to people’s living conditions have been brought forward. We have used these perspectives as a support when analyzing and sorting through the information given to us by children, adolescents, adults and elderly people with deafblindness, as well as their relatives, and all of this will be presented in the following chapters of the report. Our aim was to increase the understanding of the living conditions for people with deafblindness and what kind of social services the different age groups need.

In the following chapters of this report, we will go deeper into the perspectives already presented, including the individual life adjustment process, environmental factors, and living with deafblindness over time. These perspectives reappear in different ways during the accounts of the different age groups. In order to avoid too many repetitions, some of the perspectives are presented more in one chapter and less in another.

During the interviews, focus groups, and other meetings with people with deafblindness and their relatives, many wise words and important thoughts have been shared with us. We have put together quotes and personal descriptions based on typical variations. All personal descriptions are de-identified for ethical reasons so that the participants cannot be recognized.
"We had never heard of the term deafblindness, what it means or how you can live with it."
(Father of Erik, 10 years)
Anna, 3 years

“Soon after Anna’s birth, we found out that her hearing wasn’t normal. Nowadays, they check all new-born babies. It came as a shock to us. After that, more examinations and assessments followed. A lot of specialists were involved. We were very worried but also sad. It wasn’t quite the start that we had dreamt of and fantasized about. The doctors started talking about surgery (cochlear implant) and Anna had her surgery when she was 8 months old. They said that she would probably be able to hear and develop speech, but that she also may need sign language. There were so many new things to consider and so much information from different specialists. They actually gave us some inconsistent messages too. During the assessment, it became clear that Anna wasn’t only deaf but that she also had a special visual condition. She has Usher syndrome, the doctor said, and she will have a visual impairment, but not yet. This was a new crisis for us and from time to time it has really felt as though we were going to lose our foothold. We just want to be an ordinary family, but sometimes it feels like we don’t have time to just relax and have a good time together, because then we lose time in Anna’s development. What if you don’t practise enough, or if you practise too much, how are you supposed to know when it’s right? There are so many specialists involved in our lives, and sometimes it’s difficult to see who’s responsible for what and who we should listen to the most. It feels as though they know more about our child than we do. At the Department of Audiology, they know everything about Anna’s hearing, and at the Low Vision Clinic they have told us of her visual impairment, but what will it all mean for Anna in the future? When should Anna be told that she is going to have a visual impairment as well? Some people think that it’s important to have this information from the beginning, and others think that Anna should be allowed to live happily unaware of what’s coming. It’s difficult to live with this knowledge. Luckily, there is
a parents’ group where we can get in contact with other parents and discuss these things. There are so many thoughts, questions and most of all emotions surrounding Anna’s condition.” (Parents of Anna, who is profoundly deaf, but hasn’t developed the visual impairment yet.)

Anton, 5 years

“Anton is the second of our three children. We understood straight away that something wasn’t right. In the beginning, we went to see a lot of doctors and had several examinations. A button was surgically inserted on Anton’s belly since he wasn’t able to eat normally, and he had heart surgery before he was one. It felt as though we were at the hospital all the time. Now, when some time has passed, I realize how sad and stressed we were, but when everything was going on there was no time to feel anything. The crisis came later, when things had calmed down around us. The doctors suspected that Anton had CHARGE syndrome. We had never heard of that. We looked it up on the Internet and were shocked when we realized all the problems that were associated with that diagnosis. Pretty soon they confirmed that Anton couldn’t hear, with everything that such a diagnosis implies. His speech organ was also damaged, so they said that he wouldn’t be able to learn to speak. A social counsellor came to our house, and we spoke to a special needs teacher from the Hearing and Deafness Division in Lund and we learnt how we should communicate with Anton. We felt that finally something positive was happening. My husband and I started to learn sign language together with other parents of deaf children and children with hearing impairments. It was more difficult than we would have thought, but it was also fun and good to meet other parents. The circumstances around Anton’s visual impairment remained uncertain for a rather long time. Today, we know that both his eyes are affected but that he has peripheral vision on both eyes. The low vision therapist has explained how Anton sees and what we must think of in different situations. We have contact with the child habilitation as well. We have a physiotherapist who shows us how to practise with Anton since he can’t walk on his own. In the beginning, we saw a speech therapist and a special needs teacher from the child habilitation centre as well. The dietician has been a support, especially in the beginning. We were really unsure about
the food and if he ate what he needed. In the beginning, neither my
carents nor my mother-in-law dared to pick Anton up. That was quite
devastating. They were no support whatsoever, on the contrary, we
felt even worse when we saw how sad they were. It got better after
they had been to a meeting for relatives at the Hearing and Deafness
Division. They were given information and met other relatives. As
you probably understand, during these first years, it’s been more
or less a full time job for us. Anton goes to a sign language school
in Malmö now and he has developed a lot. Sometimes we can’t
keep up with him. He learns more and more sign language and
most of the time he uses his vision. But the special needs teacher
in the Deafblind Team also teaches us how to communicate using
tactile. It’s amazing to see the progress he’s making. Sometimes
you need to just stop and enjoy everything a little too. That’s easy
to forget that when you’re all stressed and sad.” (Mother of Anton,
who was born with CHARGE syndrome.)

Finding Out – Adjusting

Anna and Anton are examples of how parents experience having a child
with deafblindness or who will develop deafblindness. Parents that we
have met, describe how sorrows and crises come and go in different
stages of life and how important it is to meet other parents who are in
the same situation to share experiences, feel support, or just be able to
spend some time together and laugh. Most parents feel that they have
not been offered any professional counselling where they could talk
about their child’s deafblindness, although many would have wanted
that. They have met many professionals, but no one who has specific
knowledge about their child’s all impairments or has a clear picture of
the family’s needs. There has been a lack of both emotional support
and strategies to cope with everyday life in the family.

“Now, when some time has passed, I realize how sad and stressed
we were, but when everything was going on there was no time to
feel anything. The crisis came later, when things had calmed down
around us.”

“It wasn’t quite the start that we had dreamt of and fantasized
about. We just wanted to be an ordinary family!”

In the parents’ focus group, we discussed mothers’ and fathers’ differ-
ent reactions in connection with finding out. “One thing at a time,” was
a typical father reaction, whereas “I tried to deal with all the problems at once,” was a mother reaction. An adult woman with deafblindness expresses how she experienced her mother’s emotional reactions:

“Mum cried a lot. She often went aside to cry, but I thought I managed well. I didn’t understand it then, but today I understand how much grief and guilt my deafblindness has caused my parents.”

We have also met children with deafblindness who have expressed grief over their impairments and who have contacted us because they needed to talk to someone outside of their family. The child has wanted to talk about his or her impairment and has felt that it was not possible to do that with mum or dad because it is too sensitive or because it upsets the parents. Children have also contacted us because they are worried. Not because of the impairment, but because they are thinking of why the parents are arguing or because one of the parents is upset and the children feel responsible for it. Like all children, they have many questions about their relationships with friends, the parents’ relationship and reactions, and questions about the future. Sometimes, the discussions are about distinguishing which difficulties are related to the impairment and which are related to the age.

“We never talk about my problems at home. There’s no point. When I want to talk to my mum, I see that she gets sad and sometimes she starts crying.”

The parents’ focus group made a summary of how they would have wanted it to work when they found out that their child had a combined visual and hearing impairment/deafblindness.

“It is important:

• to receive straightforward and clear information on the medical aspects of the visual and hearing impairment – diagnosis and prognosis,

• to receive information about which authorities to turn to with different questions about the child’s impairment,

• to receive help to co-ordinate all contacts with different authorities relating to the child’s impairment,

• that the pre-school/school receives information about the child’s impairment and adjusts the environment in the best possible way so that the child has a chance to develop on the same terms as other children,
• that the parents receive information about interest organizations and parents’ associations that they can turn to in order to meet other parents and to get support,

• to have the opportunity to meet another family where a child has a visual and hearing impairment/deafblindness, in order to discuss how they have solved different problems in everyday life – contact parents,

• that the child is given the support he/she needs in the transition to adulthood, that there is someone there when it is time to choose an education, look for a job, start a family, and in other situations where support may be needed.”

The Relationship with Friends and Relatives

Several parents have told us about how the personal network, including relatives, friends and neighbours, changed when they had a child with deafblindness, and they give different reasons for this. Some describe not having enough time, or lacking the energy to socialize with friends and family in the same way as before. This is due to all the new things that the family has to learn and relate to. Maybe they take a sign language course, or perhaps regularly see the physiotherapist, the doctor, the dietician, the counsellor, etc. It could also be that they have spent a lot of time at the hospital with a child that has other problems besides deafblindness that require health care, or the parents simply have to take turns sleeping. To find the time and energy under these circumstances, and see neighbours, friends, or attend family gatherings, can be hard, according to the parents.

Another reason may be that parents feel that relatives and friends do not have enough knowledge of the child’s impairment, and that they do not understand and are not able to fully grasp the situation, and therefore cannot treat the child and the family in a way that is comfortable for the family. Grandparents and others, who would normally be good role models and a natural support, feel uncertain and are worried about doing the wrong thing and thus are afraid to baby-sit or give advice. Many of the parents that we have met, say that if the child communicates by sign language, and if people around them do not know sign language, it can be difficult to establish a deeper contact.

“At family gatherings, my son mostly sits with his comic magazine. I know it’s because nobody can talk to him, except for me and my husband. I never get used to it. But he says that it doesn’t matter.”
Parents of children with congenital deafblindness and other impairments that further complicate the situation, often feel that grandparents and other relatives lack the knowledge to treat the child in a good way. They feel inadequate and therefore they are afraid of getting involved, according to parents that we have interviewed.

Many parents are worried about the child’s social network and the relationships with friends, both now and in the future. Several parents feel that the child’s network is becoming smaller already at an early stage and that the child does not go along with friends on activities as much as other children do. Parents are worried and scared of loneliness and isolation. We have also met children who have told us that they do not have a close friend to be with, not in school and not after school. It seems to be most difficult for the children who have a severe visual impairment and who have an assistant during school hours. They tell us that they cannot go out with the other children during the breaks, and that they cannot go to the corner shop to buy sweets without the assistant coming along. The assistant’s role is to facilitate the child’s ability to be active and participate, but that is sometimes an obstacle in the company of other children of the same age. Several parents have also expressed how worried they are that they will become the child’s best friend, which does not feel quite right. According to some parents, the child’s network of friends is quite similar to other children’s in the early childhood years, but during the school years it gradually becomes more difficult to establish new friendships and maintain old ones.

Sharing your Life with Experts

The parents’ descriptions also show how the social support system is perceived, how the professional network becomes a part of the family, and how the personal network can change when having a child with deafblindness. Our interviews show that the treatment and the attitudes from the professional world can vary. Most of the parents that we have met, feel that there is a lack of knowledge of deafblindness and of what it actually means in different everyday life situations, something which, according to the parents, can have consequences on how they are treated. If the professionals lack specific knowledge and if they do not realize what the child’s and the family’s situation looks like, their decisions may be perceived as wrong and insulting by the parents. As an example, we can mention a rejection on a grant application based on the fact that the administrative professional does not take into consideration that vision and hearing supplement each
other and in case of a loss of one sense, the other will compensate. Another example is when transport service is denied on the basis of the child having full use of the legs. The Department of Audiology gives advice that are not useful since the child cannot see, and at the Low Vision Clinic there is often a lack of knowledge of how to communicate with people with deafblindness in a satisfying way.

All the parents we have met are busy upholding contacts with all the different authorities and the habilitation staff. Some parents feel that the habilitation staff and the experts claim to know what is best for the child in different situations and stages during childhood, and they also feel that their experiences as parents are not taken into account or are considered less important than the experts’. This is very annoying for many parents.

“At the child habilitation, they told us what was best for Maria. They gave us a training programme to follow and lots of information, but they never told us how to establish contact with her. We had a lot of support, but not the kind we actually wanted.”

Most of the parents that we have met during the project, feel that there is a lack of co-operation between the different people working with the family, and they find it difficult to get a general view of who is responsible for what when it comes to the family’s needs. Many of the families that we have met have a number of professionals to co-operate with, and it is quite time consuming for the parents to co-ordinate and relate to the social network around the child, a network that sometimes consists of up to 40–50 different parties.

“It’s a full time job to have a child with deafblindness. There are so many contacts with different authorities to think of and so many new things to learn.”

The lack of co-ordination in the habilitation work, and the lack of co-operation and accordance between the different parties around the family, is a huge problem according to the parents. A family can have several meetings with professionals in only one week. If the child has several impairments it can be very difficult to sustain a job, according to some parents. Many parents feel inadequate and feel that they do not have enough time. Some parents experience that they have double roles in their parenthood. At the same time as they have to train and support the child with deafblindness in different ways, they also have to be ‘ordinary’ parents to siblings if there are any, as well as having
time to keep up with all the other roles and tasks of everyday life. It is not uncommon for parents to actually contact even more experts and professionals, only because they are worried or scared that the people who are already around the child and the family are not competent enough.

“There is so much to practise at home and so many appointments to keep track of. What happens if we just run out of energy?”

Some parents also experience that the information from professionals is contradictory, in particular when it comes to the child’s chances of developing communication and language. One and the same family can be confronted with several different methods for the child’s communication development. All parents agree that there is a lack of coordination between different parties and that co-operation about the family’s needs is only experienced on rare occasions.

Families who have to share their everyday life with assistants and other professionals, due to the child’s extensive need of care, are especially subjected to stress. That has become evident during the project when we have met parents both in Skåne and on national parents’ conferences.

“Everyone who works with Kalle, thinks that he or she is the most important for him. But for us they are all important in different ways, in different periods, and in different situations.”

We have noticed another dimension of the families’ meeting with the social support system in our meetings with families who have a different cultural background. The professional attitude is considered to be vague. The family feels that there is a lack of straightforward information on what is best for their child and what choices to make, for example when choosing what school the child should go to. On a few occasions, the parents’ opinion about the reason for the child’s deafblindness has been different to the medical explanation of the diagnosis. The families that we have met, feel that the Swedish professional attitude and approach is not always consistent with their own idea of the expert’s role.

“You’re the expert, teach him what you think is best. You decide what’s best.”
Thoughts about the Future

Most parents that we have met are worried about the future. Preschool and school, and later on studies and work—these are issues that most parents we have met have been thinking of, from an early stage when the child is in pre-school, but sometimes already from infancy. When choosing pre-school and school, parents sometimes feel that the professionals give them contradictory advice.

“Should my child go to day care together with the other children who live close to us and who all have normal hearing and vision? In that case, where is she going to learn sign language? Should we choose a section for children with hearing impairments where the environment is adjusted and the staff has special competence? If so, what will happen to the friends at home? Should we choose an environment where most of the communication takes place in sign language? But then, what will happen with her speech development that they said had to be practised?”

“The best thing that could happen is if he got a job. But most companies probably hesitate to hire someone who can’t hear and who has a visual impairment as well. They are probably worried about all the problems it could lead to.”

Another topic that many parents have raised is relationships and their child marrying and settling down.

“Will my son find a girl to share his life with?”

“How is my daughter going to take care of a small child, will she be able to do it when the time comes?”

For families where the child has a very complex impairment, where deafblindness is one of several impairments, a lot of effort is usually put into adjusting the living environment as much as possible and into having proper assistive technology. For these families, the children’s future housing becomes an issue at a relatively early age. Many parents that we have met soon become aware of the difficulties in finding the right school for the child. They are also aware of the problems with finding group housing with the specific competence required, such as an adjusted environment, deafblind competence about interaction and communication, and an awareness of the impairment deafblindness. We have met parents who start thinking of these questions early on in the child’s life.
Parents express their thoughts about the future; how they have to dare to let go of the child with deafblindness, and that they must not worry or interfere with the child’s life when he or she grows up. In the focus group, we noticed that many parents need to air these thoughts and feelings with other parents, something which they also confirmed themselves.
STRATEGIES FOR SUPPORT

Having a child with deafblindness or knowing that a child will develop deafblindness, is a major life adjustment that influences everyday life and life as a whole for the child, the family and other relatives. The family and its network need information and support. A competent environment, both the personal and the professional environment, is important for the child’s development. In order for the family to get the support it needs, it may be necessary to have contact with several, sometimes many, different professionals working with the child’s habilitation. The family becomes more or less dependent on habilitation, something that they have not chosen or wished for themselves.

For parents who have a child with deafblindness it is often difficult to find people with similar experiences within their own family or circle of friends, something that was expressed in the interviews with the parents. Instead of finding the natural support from their own parents, the parents become dependent on professional support. To limit the influence of the professional world in the family’s life, it is important to create good forms for co-operation between the different parties around the family. With a good and continuous co-operation between the family and the professionals, the family is more likely to be provided with the right help at the right time, what we previously referred to as timing in the habilitation work.

General Views on Support

Children with deafblindness and their families often need support on several different levels: from the personal social network consisting of friends and relatives, from local and regional authorities, and from authorities and participants on national level.

Families who have a child with deafblindness usually need comprehensive and continuous support from society, and often have contact with several authorities. Some parents almost feel as though they are swamped in different habilitation programmes, while others describe that they only receive very little support or the ‘wrong’ habilitation support. Families with a child with deafblindness constitute a small group in society, and the parents say that they are often met by ignorance. In this project, we have also noticed a lack of a mutual basic accordance regarding the child’s and the parents’ needs, the assessments made, and the assistance provided by the professional world. These contra-
dictory messages can create a feeling of insecurity for the families and make it difficult for them to choose how to form their own lives. This line of argument is confirmed by Riddersporre (2003), who gives a detailed description of the family’s encounter with the professional world. Our project shows how important it is to treat the family with respect, openness and great flexibility for the family’s needs. Riddersporre’s research (2003) shows that the professionals’ treatment of the parents influences the parents’ perception of their own situation. The parents’ attitude on the other hand, influences the professionals’ treatment. The parents’ role develops in co-ordination with their personal and professional network. The family should take full part in the habilitation, but ought not take on the role as a ‘coach’ for the child. Nor should the parents need to be responsible for co-operation or take on the role as an ‘instructor’ for the professionals that they meet in the different environments around the child, just because the professionals lack appropriate knowledge and experience of deafblindness.

At present, there are no habilitation programmes or guidelines on how to work with families who have a child with deafblindness. The norms on local and regional levels are not designed with the needs of people with deafblindness in mind, and therefore parents of children with deafblindness as well as adults with deafblindness experience that they do not fit in. In the existing systems, there is a risk that deafblindness is considered to be an additional impairment, which may have negative consequences for the child’s development, especially in the development of interaction and communication.

The Child’s and the Family’s Needs for Specific Habilitation and Support

Experiences from the project show that the complexity of the impairment deafblindness calls for a separate organization with specific knowledge, methods and strategies for habilitation, as well as co-ordination of professional work. In working with the families and children, we can see that there is a need for both emotional and practical support depending on the family’s life situation. The families must form their own everyday life in this new situation. In some cases, deafblindness is the child’s sole impairment, and in other cases deafblindness is one of several impairments. But in all cases, deafblindness poses a threat to the ability to interact and communicate with the environment and it is therefore also a threat to establishing and maintaining relationships. If the family has somebody with psychosocial, pedagogical and
deafblind specific competence present when they get the diagnosis, it is possible to follow up on and continue the discussion on what consequences it will have for the family, both on an emotional and on a practical level. Most parents that we have met say that the earlier they learn more about their child’s impairment, the better. And at the same time we know that this kind of information is followed by natural feelings of grief, hopelessness, and a feeling of not knowing what to do. Since it is often possible to make a diagnosis early in a child’s life today, sometimes already during the first couple of days, it is even more important that the family is given emotional support and an opportunity to discuss natural strategies for interaction at an early stage. It is not enough just to inform the parents. A family is not an isolated island, but it is surrounded by grandparents, siblings, friends, and others.

The project has shown that children with deafblindness may need someone to talk with about their feelings themselves. Some children have asked for a professional contact person to share thoughts and emotions with, someone who can also act as support when needed. It is crucial to have someone to talk with who can help to distinguish problems that are typical for the age from problems that are connected to the impairment, especially when it comes to developing one’s own identity and self-image. It is also important that the child gradually learns more about the impairment as he or she grows up, in order to develop a realistic image of the impairment as well as good strategies in relation to the surrounding environment. Children’s influence and participation is also clearly stated in the UN Convention on the Rights of the Child (United Nations 1989).

The early interaction between parents and children comes from a fundamental need to be able to meet and share experiences in different ways. This interaction takes place mainly by vision and hearing, and in most cases the development takes place on its own, without interference from professionals. It is mainly through these two senses that we learn to orientate ourselves in the environment and communicate with others. As for a child with congenital deafblindness, attention has to be divided in other ways. It is not done by itself instinctively, but requires conscious strategies in order to be able to orientate, develop interaction, and establish communication. The work method must be flexible and individual, since the conditions vary from one child to another. It is often possible to decide what can be done only when different strategies have been tried. In some cases, the focus is set on learning to know the environment and develop interaction, communi-
cation and language using the tactile sense, smell and taste. In other cases, there may be some residual vision and/or hearing that can be of use in developing communication. The child's cognitive ability also influences the choice of strategies, as well as the possibility to have a cochlear implant (CI) and other kinds of assistive technology.

This work is best carried out in the child's own environment, first at home together with the family. Later on, when pre-school, school and after school activities become a part of the child's everyday life, it is important that the staff working with the child has the competence to meet the child where he or she is in the communicative development. In the literature, this is described as competent partners (Nafstad and RøDbroe 1999). Methods for working with interaction and communication in connection to congenital deafblindness, are well documented in the Nordic countries, and recent research within this field has received considerable international attention. There are also professional networks for the pedagogical work, both national and between the Nordic countries.

If the child acquires deafblindness later in life, when the language is already established, another kind of habilitation will partly be required. When deciding on what methods and strategies to use, it is crucial to know whether it is the visual or the hearing impairment that is the primary impairment. Has the child developed spoken language or sign language? Another important factor is if the child has developed deafblindness quickly or if it is a progressive deafblindness, that is to say if the deafblindness deteriorates gradually. If the visual impairment is progressive, the child could start using sign language tactually with the hands, instead of visually like before. If the child has a spoken language as a first language, it is a great advantage if the child can learn sign language while he or she still can make use of the vision in the learning process. The prognosis is important when deciding on and prioritizing what work is needed and in what order. Conscious strategies are necessary in order to develop interaction and establish communication. The work method must be individual since the conditions vary from one child to another. There are several ways to communicate, something which the parents need to find out. The best way depends on the individual, and parents, siblings, and other relatives need help to develop interaction and communication with the child.

Within the parents’ group, there is a widespread awareness of the documented experiences regarding interaction and communication developed within the deafblind field in the Nordic countries. How-
ever, few parents feel that they have taken part of this knowledge in the actual habilitation work. At the annual national parents’ education programmes, researchers and pedagogues have given lectures about the success within the field of interaction and communication but, according to the parents, the regional authorities have not been able to meet these demands.

Many parents have expressed feelings of stress, of not feeling adequate, and of not having enough time. In those cases, the support may consist of discussing and sorting through what could be dropped or at least put aside for the moment, because other things need to be prioritized. The family support must be based on the child’s and family’s actual needs, using everyday life as a starting point. Most of the parents that we have interviewed, missed meeting professionals with knowledge of deafblindness in everyday life. The support may consist of having discussions with the family and trying different strategies in everyday life. It could involve trying out and practising the usage of different visual and hearing aids, as well as discussing ways to adapt the environments where the child spends time. The support could also consist of training the child’s orientating ability in the environment or developing alternative strategies for reading and writing. This kind of habilitation often has to be a part of a co-operation between different fields, such as the local Low Vision Clinic or Department of Audiology, pre-school or school. For many children with deafblindness, the computer is a good aid, both for school work and private use. The computer can be used for many things and opens the door to new ways of communication at an early stage.

Parents express a strong need for support and knowledge from professionals who know what it is all about and who have specific knowledge about deafblindness. But, according to the parents, the professional world that the child and the parents meet on a local and regional level, often lack this kind of knowledge. This makes the parents insecure of whether their child really gets the best habilitation and support, and therefore they themselves often look for knowledge and people who can provide other and better solutions. This sometimes results in a further expansion of the professional network.

**The Environment – Networking and Co-ordinating**

Charting the family’s network gives an image of the child’s and the family’s relationships and of how these relationships are perceived, which in turn gives a basis for strengthening the communicative development
and thus the relationships around the child. It is important to have good conditions for interaction and communication, not only when the child is with the family, but the same conditions ought to apply at pre-school, school, after-school activities, short-term housing, etc as well. Who are the people around the child? Where does the child spend time? What does the different environments look like? What adjustments are needed? What information and knowledge do siblings, relatives, staff, and other people around the child need in order to communicate and interact with the child? Charting the different environments around the child, and looking at what the child’s environment looks like, in order to distinguish possibilities and obstacles for development, is an important dimension of the charting work.

Figure 5. Examples of the child’s/adolescent’s environments in everyday life.

One part of the individual interviews and the focus groups consisted of deepening the knowledge of how parents experience the networks, both the personal and the professional, the society network. Earlier in this chapter we showed how the family network changes. During the project, it has become clear that families with a child with deafblindness often have many different authority contacts. It is also evident that there is a lack of co-ordination of resources, as well as a lack of co-operation and accordance between different authorities. In most cases, there is no network between the professionals working with
the child and the family. The parents feel that the professionals lack knowledge of what other professionals are doing. It is often up to the parents to make sure that everything is co-ordinated, and the parents have to take responsibility for providing information about the child’s impairment to different authorities and professionals. Therefore, it is important to co-ordinate the specific deafblind work together with the family and other people around the child. It is also important to clarify the professional network so that the parents know who is responsible for what. Important aspects brought forward by the parents when it comes to co-ordination are that the family’s and the child’s needs are to be considered as a whole and from a life perspective. It is considered important that professionals pay attention to the whole family situation and that there is a long term planning of the habilitation and support. Knowledge of the family’s network is a tool for making priorities and planning different kinds of work. It is also the basis for networking and co-ordinating resources.

Figure 6. Examples of professionals and others who, directly or indirectly, work with children/adolescents and their families.

One example of a network created during the project is our regional network around school children with deafblindness in Skåne. It includes representatives from the Swedish Institute for Special Needs
Education, Östervångsskolan – a special school for the deaf and hard of hearing, Silviaskolan for the hard of hearing, the Swedish National Upper Secondary School for the Deaf and the Hard of Hearing (RGD/RGH), the parents’ section within the Association of the Swedish Deafblind (FSDB), Swedish Deafblind Youth, and representatives from Region Skåne’s Deafblind Team. The network was initiated during the project and was aimed at co-ordinating resources and developing a better co-operation around school children with deafblindness. For a child with deafblindness, it is extremely demanding to follow the teaching at school and to play with other children. Keeping up with the teacher’s and the other children’s communication is demanding when vision and hearing is not functioning properly. In order for things to work in best possible way, knowledge is required, both of the consequences of living with deafblindness and of how to make the environment accessible in different ways. The network has met to discuss more general needs, our different tasks and roles, as well as policy issues regarding school children with deafblindness. We have also worked together with individual children, in order to co-ordinate and plan the work around the family and to provide information and knowledge to the child’s environment. At the moment, plans are being made within the network to gather the children in group activities.

Sharing Experiences with Others

A very important part of the support for both children and parents, is to have the opportunity to meet others and share experiences of living with deafblindness. Sharing experiences with other children with deafblindness and having mutual activities of different kinds, is an important part of the habilitation process. It ought to be especially important for individually integrated children, since they have a more difficult social situation and more often experience a feeling of being outsiders and of lacking friends of the same age. Swedish Deafblind Youth (DBU) plays an important role in this work, by giving children the chance to identify with others and establish friendships. For a period, the special school’s Knowledge Centre arranged special camps for children and adolescents with deafblindness, but when their function was changed it stopped. The National Agency for Special Schools for the Deaf and Hard of Hearing, has now started to arrange annual national meetings again for students with visual and hearing impairments/deafblindness, but, unfortunately, these meetings are only for students in national special schools. Individually integrated students do not have this opportunity,
which is why something similar ought to be arranged close to their homes, or together with the National Agency for Special Schools for the Deaf and Hard of Hearing in order to include this group as well.

The annual parents’ education has meant a lot to many of the parents that we have met. It includes both new parents and parents whose children are now grown up. The parents say that they need each other during different stages of life, not only when they have just found out about the child’s impairment. The annual parents’ education is held at Almåsa Conference Facility outside of Stockholm, during one weekend every autumn, and it is arranged through a co-operation between the parent section the Association of the Swedish Deafblind, the Swedish Institute for Special Needs Education (SIT), the National Agency for Special Schools for the Deaf and Hard of Hearing (SPM), and The Mo Gård Group. Other important activities mentioned by the parents are the mum and dad meetings arranged by the parent section within the Association of the Swedish Deafblind, theme conferences, etc. Some parents within the association also have the special task of being contact parents. The idea is that parents who find out that their child has developed deafblindness, or that their child has a diagnosis which will eventually lead to deafblindness, can get in touch with a contact parent. This parent’s role is to support, share experiences, and provide information about where to turn with different questions.

There is also a demand for letting grandparents, siblings, other friends and relatives around a specific child have the opportunity to meet and learn more about deafblindness. Many express a need for information, but also for being able to discuss how to give support in the best way, now and in the future. Many parents also ask for the opportunity to meet adults with deafblindness. They consider it important to have adult role models since it inspires hope and there are many thoughts and ideas about the future, things that one may wish to discuss with adults with deafblindness.

One important task is to create forms of exchanging experiences. This can be achieved through different forms of group activities, such as parent meetings, meetings for children with deafblindness, sibling meetings, baby cafés, network meetings around individual children, and theme discussions.

Spreading Information and Knowledge

Most of the parents that we have met agree that everyone in the child’s/family’s network, both the personal and the professional network,
needs knowledge about deafblindness; the family, children, parents, siblings, all need knowledge. Grandparents and other people close to the family need knowledge in order to meet the family’s needs and be a good support when needed, an invaluable resource according to many parents. One way can be to arrange network meetings around the individual child, during which the people close to the child receive information and are given the opportunity to discuss different issues. All of this serves to deepen the understanding and knowledge of the child’s impairment and special needs.

It is also important that the child with deafblindness gradually learns more about his or her impairment in order to increase awareness of its consequences in different situations. That improves the child’s chances of finding appropriate strategies and developing a flexibility in his or her attitude towards the environment. More profound knowledge is also important in order to take control of everyday life and the life situation in general, an important step in the empowerment process.

According to the parents, professionals that the family meets in different situations need knowledge of deafblindness in order to make well founded decisions on the right grounds and to treat the family with competence, respect and understanding. These professionals include administrative professionals, assistants, guides and other local professionals, staff at pre-school/school/after-school as well as habilitation staff on the regional level, just to mention a few. The knowledge includes individual knowledge of a particular child, but there is also a need for a general knowledge development regarding children with deafblindness. When it comes to sharing the knowledge with other professionals, the Deafblind Team plays an important part. However, all in all several parties are responsible for sharing knowledge, both on a national and Nordic level.

**CONCLUSION**

Being a parent of a child with deafblindness means being an ordinary parent under extraordinary circumstances. Having a child with deafblindness is life changing, and sometimes the change is very drastic. The change involves recurrent life adjustments, both emotional and practical. Families where a child is born with deafblindness or develops deafblindness during childhood, want a continuous support and habilitation from professionals with specific knowledge about deafblind-
ness and with the competence to communicate by using the different methods that children with deafblindness need. The complexity of the impairment and the fact that this is a relatively unusual impairment, resulting in a lack of knowledge, is a recurrent theme in the meetings with parents, as well as the lack of co-ordination, co-operation and accordance between professionals. Families with a child with deafblindness constitute a very heterogeneous group, showing great varieties when it comes to the needs of support and habilitation. Still, it is possible to distinguish some recurring issues in our conversations with the parents – issues that have become guidelines in our work with children and families within Regions Skåne’s Deafblind Team.

- One of the aims of the habilitation should be to strengthen the parents and the rest of the network, in order to give them strategies for dealing with emotions relating to the new situation, and knowledge to understand the consequences of the impairment in different situations in everyday life.

- It is important that the child, the family, and other people co-operate around a long-term habilitation process and support.

- Co-ordination, co-operation, accordance, and a clear division of responsibilities between professionals is needed.

- The development of interaction and communication requires conscious strategies, as well as early, continuous and close assistance.

- Different forms of exchanging experiences, both for children and for parents and other people close to them, must be developed.

- The child, the family, as well as the close personal network and the professional network, need knowledge of the individual child and of deafblindness in general.

- Information and support for the child, the family and the close network is needed to strengthen the relationships, to make it possible for relatives to be a good support, and to strengthen the empowerment process.

- In order to improve the approach of the professional support in society, increased knowledge of deafblindness and its consequences in everyday life is needed.
"I used to be able to flirt and wink at the guys at the disco, but not any more, because I can’t see if they’re interested!"

(Linn, 21 years)
EXPERIENCES OF DEVELOPING AND LIVING WITH DEAFBLINDNESS

Filip, 18 years

“I’m 18 and I’m in my second year at the Hotel and Restaurant Programme in Örebro at the Swedish National Upper Secondary School for the Deaf (RGD). They discovered that I was deaf already when I was about one year old. Mum and dad had suspected it since I didn’t react to loud sounds. But it wasn’t until fourth grade that the visual impairment was discovered. I was diagnosed with Usher syndrome. I didn’t think it was such a big deal then, but my parents really reacted to it, and I remember that mum had quite a crisis. My parents have always worried about my future. When I was in school, I went to some different camps with other deaf and visually impaired students. It was pretty fun. We got to meet others and learned a lot about vision and hearing. There were quite a few of us from all over Sweden. I remember that we tried walking with a cane late at night when it was dark. And of course, there were a lot of games and chatting about all kinds of things. Sometimes, I think that there is too much focus on my visual impairment, and that’s both a bit sad and tiresome. Once, I think I was 14, a low vision therapist wanted to teach me to use a white cane. I mean, what was I supposed to do with that? I’m not blind! I’m deaf, all my friends are deaf, so what would they think if I had a white cane.

Before I moved to the school in Örebro, my parents had a lot of contact with the local authorities and others about what support they thought I’d need when I moved away from home. They were really anxious and worried about my moving away. They actually seriously considered moving to Örebro the whole family. Especially my mum didn’t think that I’d manage without their support, but that’s what parents are like I guess. Most things have actually worked really well. Sure, there have been some teachers and other members of the staff who haven’t realized that my vision is reduced, but I’ve had some contact with the co-ordinator for students with deafblindness.
at RGD. He has arranged some means of assistance for me. But apart from that I’ve managed to do most things on my own or with help from my friends. I know that mum and dad worry if I don’t use transport services when I’m out at night. But I want to be just like everyone else and take the bus. Sometimes a friend helps me to get home from the movies or the disco. It always works out one way or another, you always get home somehow! I have quite a lot of friends here in Örebro. We hang out a lot after school, but ball games like football or floorball doesn’t work for me. I miss the ball when it’s passed to me and I can’t follow, which just makes me feel stupid and clumsy. Apart from that, most things are ok here. I don’t think that the teachers have enough knowledge about for example different visual aids, and of how to make the teaching situation easier for me. Some classes are ok, but others I could might as well be without. Much comes down to the teacher. I have some different means of assistance, but not many people at school know how to use them or how they work, and that can be a bit annoying sometimes.

Lately, I have actually started to think a bit about the future and if the restaurant business really is the right place for me. After two weeks of work-place training at a restaurant where everyone else was hearing, I started to doubt. The environment in the restaurant wasn’t very good and I was knackered when I got home. They tried to be nice to me, but no matter how much I concentrated, I couldn’t keep up. I’m afraid I missed quite a lot of information. I have seriously started to think of switching programmes, but I don’t know, I don’t really have anyone to talk with about what’s best for me. How are you supposed to know what to become and what you’re best suited for?

Life Adjustment, Communication and Identity Development

What Filip tells us it rather typical for the adolescents with deafblindness that we have met during the project and who also have Usher syndrome. He is deaf since birth and has a visual impairment that leads to a gradual deterioration of his vision. He has decreased night vision, his field of vision becomes more and more limited, he is sensitive to glare from bright lights, and has problems with his balance, especially in the dark.

The linguistic and cultural identity among adolescents with deafblindness is quite varying. Those who are primarily deaf belong to a lin-
guistic minority in society and for most of these adolescents it seems important to try to keep their sign language environment intact. If the hearing impairment is the primary impairment, the ability to speak often remains, but later on in life it may become necessary to complete the speech with other strategies in order to be able to communicate in the best possible way.

Adolescence is a period in life when you want to identify with others who are just like you; you want to be part of a group, and you definitely do not want to be different or deviate from the norm. All children and adolescents create their identity through interaction with the environment, regardless of whether they can hear or have visual and hearing impairments/deafblindness. Belonging to a group, clothes, music, language, etc, are all important components in the search for an identity. The adolescents that we have met during the project, and who have sign language as their first language, often identify strongly with others who are deaf. The mutual language and the obvious identification within the deaf group, are probably important reasons for the adolescents to keep together and share a feeling of unity. This is also confirmed by Nordeng (1993), who addresses a number of psychosocial aspects in connection to Usher syndrome among children and adolescents in Norway.

“It's not as though you can speak to anyone you meet. It doesn’t work that way when you’re deaf. Instead, it’s easier with friends from school because they’re deaf too.”

At the school in Hässleholm, the deaf and the hard of hearing students go to separate classes. The hard of hearing students often have spoken language as their first language, but many of them also know some sign language. Among these adolescents, we have not been able to see the same sense of belonging to a group. One young man described it in the way that some students spend more time with hearing friends, others spend more time with those who are also hard of hearing, whereas a third group of students spend most of their time with deaf adolescents after school. However, we have not met enough adolescents during the project to be able to form a clear picture of the situation.

“I spend a lot of time with my deaf friends after school, even if I see myself as being hard of hearing and I go to RGH. Sometimes it’s nice to use sign language and not having to talk.”

The children and adolescents that we have met who have a visual im-
pairment as a primary impairment, often go to individually integrated schools, or, like in some cases, to hearing classes. But we do not have enough material to be able to say something about their feelings of group belonging and identification, even though many parents say that their children have a difficult time coping with the social interaction, for example during breaks at school, and according to the parents they get lonely.

Nobody among the adolescents with combined visual and hearing impairment/deafblindness that we have met during the project, identifies as being deafblind. This is probably due to the fact that they often have a primary and a secondary impairment, and that the secondary impairment is still less pronounced. They say that they are deaf and have a visual impairment, or that they have a combined visual and hearing impairment. It is in this age that the identity is established; you are meant to find a group to which you can belong, and the gender role is modelled. This can only be achieved in interaction with others. It is also during this age that some of the adolescents with deafblindness, those with Usher syndrome, experience that the visual problems become more pronounced. Nordeng (1993) also describes that the demands and the expectations from the environment on the young person tends to decrease when the visual impairment becomes more pronounced, which may in turn influence the young person's self-image and have consequences on his or her future adult life. Most of the adolescents that we have met seem to put off the thoughts of their impairment, which, as we have noticed, worries some parents. But we have also met young people who do not feel well at all and need support in finding themselves as well as an approach towards the impairment and the environment. Nordeng (1993) confirms that it is important to have contact with adults during this age, and to have a natural chance of having supporting conversations when needed.

"It’s better to be open and tell people that you have a hearing and visual impairment, otherwise people might think you’re acting weird. I feel that I need someone to talk with about my disability."

During the project, we have also met adolescents whose visual and hearing impairments are part of a more complex functional impairment. Some of these adolescents do not have a proper way of communicating today. We have met young people who have never been given qualified support in developing interaction and communication. There has probably been a lack of knowledge of these children's specific needs
and chances of developing during childhood, leading to huge problems in the interaction and communication competence. That makes it difficult to establish relationships and identify with other adolescents with similar impairments. Based on what Nordeng (1993) writes, there is a significant risk of the impairment becoming a central and dominating part of the adolescent’s self-image in such cases.

**Family and Friends**

During childhood, the parents play a central role in the child’s life, but during adolescence, friends become more and more important. Evidently, it is the same for adolescents with deafblindness. Deaf adolescents like Filip often have many friends. Many come from the same ten-year compulsory school, and continue to the same upper secondary school in Örebro, and many of the adolescents that we have met during the project say that they are united and held together by their mutual language, the sign language.

> “When I first came to Örebro, it was all crazy. I could just go out to town and meet loads of people.”

But we have also met adolescents and adults who describe that the circle of friends becomes smaller and smaller as the years go by. There are probably several reasons for this, but many have described that progressive visual deterioration may create a feeling of insecurity in some situations, for example when it is dark. Some also say that it becomes more difficult to take part in after school activities on the same terms as the others when the vision deteriorates.

> “I feel lonelier since I started upper secondary school. Everyone else goes to the disco and hangs out in town, but it’s hard for me to come along when it’s dark.”

Contacts with friends and class mates seem to be more complicated for adolescents who go to integrated schools. This has been particularly clear to see among children and adolescents who have the visual impairment as their primary impairment and when it is so severe that they have a hard time moving around freely and independently. Parents and school staff have told us that children, who need assistants at school due to their impairments, run a risk of being left outside of playing and social interactions. They are not able to come along when the other children go out during the breaks and they find it hard to initiate contact. The subtle interaction that takes place in the class-
room just before the break, when it is agreed on who to be with and what to do, easily passes students with deafblindness by. Some of the parents that we have met during the project are worried that their children do not have friends at school and outside of school, and that their social interaction largely consists of adults. Some children who go to a school far from home often have long school days. That makes it difficult to have enough time and energy for after school activities and interaction at home.

“He can’t take part in ball games and other activities in the same way any more. The others get fed up and continue without Erik and we feel that he falls behind in his group of friends.”

“I don’t have as many friends any more. It has become too difficult to keep up with their pace now that my vision is worse.”

The relationship with the family can be somewhat different for adolescents with deafblindness compared to other adolescents. The biggest difference that we have noticed in the project is related to the family’s communication situation. Filip and his friends in Örebro, who are also deaf, have sign language as their first language, whereas the other members of their families usually have a spoken language as their first language. We have met families where parents and adolescents only have a very superficial communication due to the fact that the parents are unable to communicate through sign language. One young woman said that it was better to talk about feelings with her parents via the computer than face to face. She felt that the face to face communication was too superficial, whereas the written communication via computer was more on equal terms. Several adults and elderly persons with deafblindness have told us how the lack of communication with parents and other relatives while growing up, has influenced their relationships in a negative way. In other cases it is quite the opposite, and the communication between adolescents and adults works very well and they have found strategies for managing the communication. The parents that we have met during the project are very involved in their children’s and adolescents’ lives. The have substantial knowledge of their child’s impairment, and many of them attend and take active part in parents’ meetings, sign language courses, etc. But many of them are worried about the future, and part of that worry is a fear of their children having difficulties establishing and maintaining close relationships, resulting in loneliness. We have noticed a gap between the parents’ worries and the adolescents’ experiences of having many
friends and not worrying about it at the moment.

“It hurts to see that look when we're at a party and he can't follow. Sometimes he says: you're having such fun, what are you laughing about?”

“Even today, after all these years, it's difficult for me to grasp what it's going to mean for Nina in the future. It feels difficult.”

Both adolescents and parents have emphasized the importance of meeting other young people with the same impairments. For many adolescents, it is in that environment that they find friends, a sense of community, and someone to talk with about their impairments. Many of the adolescents talk positively of having been to different kinds of camps. The purpose of these camps has been to gain insight into one's own impairment, but also to meet others who are in the same situation. Today, there is something similar arranged by the National Agency for Special Schools for the Deafblind and Hard of Hearing (SPM). Swedish Deafblind Youth (DBU) also plays an important role for adolescents with deafblindness as they regularly arrange youth meetings and camps for children and adolescents from different age groups.

“There were quite a few of us from all over Sweden I remember that we tried walking with a cane late at night when it was dark. And of course, there were a lot of games and chatting about all kinds of things.”

“Sometimes you find yourself in a situation that feels difficult. Then it's good to meet others and discuss the situation. You can often relate to the other person's experiences.”

The Professional Network
– Habilitation, Education and Choosing Profession

For Filip and others of his generation who are born deaf or with a severe hearing impairment and who have sign language as their first language, schooling has been rather natural. They have attended ten years of compulsory school at special school for the deaf, and then continued to the Swedish National Upper Secondary School for the Deaf and for the Hard of Hearing (RGD/RGH) in Örebro. Adolescents with moderate hearing impairment, visual impairment, or combined visual and hearing impairment, usually go to individually integrated schools close to their home. During the project, we have also met adolescents who have
studied at the school Silviaskolan in Hässleholm, a school for children and adolescents with hearing impairments. The adolescents with a combined visual and hearing impairment that we have met during the project have either chosen an upper secondary school close to home or RGH in Örebro. We have also met adolescents with visual and hearing impairment/deafblindness and further functional impairments, who go to special compulsory and upper secondary school.

“I have seriously started to think of switching programmes, but I don’t know, I don’t really have anyone to talk with about what’s best for me. How are you supposed to know what to become and what you’re best suited for?”

Choosing upper secondary school is difficult for all adolescents, but adolescents with a combined visual and hearing impairment/deafblindness also face the choice of whether to go to an integrated school close to home, or move to the national school in Örebro. A decision has to be made on whether to choose a theoretical programme as a basis for further studies, or a vocational programme if they do not want to continue their studies. Another issue for adolescents with deafblindness is if they consider their impairment to be an obstacle that limits their options. For children with cochlear implant (CI), which is becoming more and more common, the choice of moving to Örebro is probably not as obvious as it has been for the slightly older adolescents.

“My teacher knew from the beginning that I had a visual impairment too. She wears the right colour clothing and asks all the time if I can see what she’s writing on the board. I usually get all written material on grey paper instead of white, it’s easier for me to see.”

“I have some different means of assistance, but not many people at school know how to use them or how they work, and that can be a bit annoying sometimes.”

In general, adolescents who go to one of the special schools or who attend a special hearing class seem more satisfied with their time in school than individually integrated students. Adolescents who go to RGD/ RHG in Örebro get support from the school’s co-ordinator for students with deafblindness during their school time. Many of the adolescents that we have spoken to say that they have a good support at school, in their housing, and after school, but obviously, that can never replace the parents’ support in everyday life. However, parents
of individually integrated students say that some schools do not have enough knowledge of the different impairments separately and definitely not in combination, and that has consequences for what kind of support the student receives. Sometimes it is the parents or the student who initiate and run the process of acquiring the right assistive technology in the education as well as arranges further education for school staff, etc. There is a lack of knowledge about deafblindness within the special schools too, according to the parents and students. But unlike the local schools, RGD/RGH has a co-ordinator for students with deafblindness whose task it is to see to the adolescents’ needs in school, housing and after school activities.

“Most things have actually worked really well. Sure, there have been some teachers and other members of the staff who haven’t realized that my vision is reduced, but I’ve had some contact with the co-ordinator for students with deafblindness at RGD. He has arranged some means of assistance for me. But apart from that I’ve managed to do most things on my own or with help from my friends.”

For some adolescents, a visual and hearing impairment/deafblindness may limit the scope of options. Selecting an education and a profession is not only a question of what you are interested in and dream of, but it is also influenced by the impairment.

- To what extent should parents and professionals interfere in the adolescents’ choice?
- Are we supposed to just stand by and watch as adolescents with deafblindness choose educations that lead to jobs that they probably won’t be able to sustain?
- What should an adequate guidance for young people look like when it comes to making choices about education and profession?

These are some of the many questions that we have discussed with the parents of adolescents during the project. Some of the adolescents experience, just like Filip, that they have been unable to discuss their future studies and profession with someone who has appropriate knowledge. The adolescents who go to school in Örebro do not have the same opportunities as other adolescents to have spontaneous discussions with their parents. An adolescent who does not have the opportunity to discuss and share ideas with an adult when needed, or
who does not receive any study and vocational guidance where the disability can be weighed in, runs the risk of not having a good enough basis for making choices.

"Half-way into the course, my vision deteriorated so much that I had to quit school."

When you begin an education in another school form, at, for example, university, there are new issues and considerations that you need to bear in mind. It could be purely practical issues regarding interpreter, assistive technology, help in taking notes, etc. Some adolescents have described how unused they were to having to think for the first time of what they needed in order for it to work, and to take responsibility for arranging it too.

"When I started university, I had to fix everything myself. I was used to everything just happening by itself, whether I wanted it or not. Now it was up to me if my class mates were to get the information on what help I might need."

All universities have some form of disability co-ordinator, but the problem is that the students have to express their needs themselves and decide how to arrange the situation so that it becomes as good as possible. Several of the adolescents that we have met during the project talk about the importance of other people being informed. Some find it difficult and hard to inform others about their situation. They find it difficult to put it into words and express the actual problems and they are afraid of something coming out the wrong way and of being regarded as too different and strange. Others mean that it is necessary to inform people. If others do not understand and make the environment accessible, the situation becomes too difficult to handle.

"I never wanted to tell others before. I suppose I just wanted to hide the fact that I couldn’t see very well either. Now I talk about it more and more. I have noticed that it’s a win-win situation and it’s best for others to know as well."

"It’s important to be open and inform others about yourself and your needs straight away. You have to learn how to do it in a good way so that others understand what it’s like but don’t get so scared that they won’t dare to make contact later."

Nordeng (1993) confirms that it is important to have adult contacts during this age, and to have supporting conversations when needed, just
like we mentioned earlier in this chapter. Some of the young people we have spoken to have also talked of the need of having a good adult contact close by, someone to talk to when there is a need for it.

“It’s important to have someone who can help you and who you can discuss things with. I remember that we talked a lot about self-esteem and other peoples’ attitudes and behaviour.”

Today, computer based assistive technology and text telephones are natural for adolescents with deafblindness. Having a computer prescribed for habilitation purposes is not considered negative, at least not as far as we have been able to see. But being offered the chance to learn to read Braille or trying out a white cane has caused reactions among the adolescents that we have met during the project.

“If it’s dark outside, it’s difficult and it’s not very fun having to go with transport services whenever you want to go somewhere. I do have a white cane but I don’t really use it … People stare at me and I think that’s horrible. It feels as though you’re more visually impaired than you really are if you have to use the cane. Usually a friend helps me to the bus.”

“You hardly ever see young people using a white cane. There must be many who have reduced vision but who don’t want to use the cane. Perhaps they’ll start using it when they get older.”

We have also met a few adolescents who have cochlear implants (CI). One of them has chosen not to use it. She hoped that she would be able to hear a little when it was dark, but for most parts she thought it was difficult with all the sounds. She thinks that sign language works in all situations, at school, with friends, at home, etc, so she was not very motivated. A young man that we have met has chosen to use his CI, even though he feels that he has limited use of it.

“I think I had too high expectations on my CI and it didn’t quite turn out the way I’d hoped. But in any case, I think it works better with it than without it. It gives some support, especially when I meet my hearing class mates.”

Learning to read Braille just to be prepared when the day eventually comes when it will be needed is rarely a successful method according to many of the participants that we have met during the project. Attitudes like “I won’t need it for a long time” and “I won’t lose all my vision according to the doctors,” are not uncommon, and they show the
gap between the professional world and the young person. It is also a sign of how the young person’s motivation is aimed at something completely different, something which is considered more meaningful at the moment.

“I ought to use my white cane when it’s dark outside, but it’s usually at the bottom of my bag and I don’t want to take it out.”

The Future – The Transition from Adolescence into Adulthood

Most of the parents that we have met who have adolescent children are worried about their child’s future. They have to struggle with thoughts of the child’s future life including everything from housing arrangements to work and family. Parents of children with deafblindness have expressed a need of support when their child is entering adulthood, including both emotional support and help in the contact with different authorities.

“Parents and other relatives need information based on facts as well as emotional support.”

“Who will take over when we can’t cope any more? Can’t the DeafblindTeam see my daughter for a yearly check-up, like MOT for cars, so that I know that someone cares?”

The parents’ worries about the child’s future quite often clashes with the adolescents’ wish to break free, stand on their own two feet, and live an independent life. This is completely natural, but parents of a child with an impairment find it more difficult. Filip’s parents had no other choice than to let go of Filip when he moved to Örebro. Deaf and hearing impaired adolescents who choose to move to the upper secondary school in Örebro often take the step towards a more independent life earlier than most other adolescents. Finding themselves beyond their parents’ reach, a completely new world opens up with less parent control and increased individual responsibility.

“The world at home with mum and dad is so small. In Örebro, it suddenly became much bigger!”

It is not altogether uncommon for the adolescents to move back to their home town again after having lived on their own in Örebro for a few years. Some find their own flat, whereas others move back home to their parents, something which may cause problems in the
relationship between the parents and the adolescent. After four years of living on one’s own and after emancipating from the family, it is not all that easy to move back home and to find new roles and patterns in the family and everyday life. Others may have met a partner or feel that they have all their friends in Örebro and therefore choose to stay there to work or continue their studies.

Parents of adolescents with visual and hearing impairments/deaf-blindness and other functional impairments are often faced with other challenges. The parents that we have met during the project are very worried about their child’s future once the child has finished special upper secondary school. Housing and occupation are some of the things that are on the parents’ minds, and the choice of specific support and services in the home town is considered very limited. Housing without support from society is not an option, so the home town becomes a key actor in the process. If administrative professionals and other professionals have the required knowledge of the specific deaf-blind issues, there is every chance of having a functioning everyday life. However, most parents in this situation feel that there is a lack of both knowledge and co-ordination. Several parents that we have met have told us that it is impossible to let go of the parent responsibility if they also have to be responsible for providing information about the child’s impairment and needs in different situations, take care of the co-ordination between different departments, make sure that the right kind of assistive technology is available, and push the staff to go sign language courses, etc.

Work, housing and social relations, are things that parents of adolescents with deafblindness worry about. They fear that their child is going to feel lonely.

“My child doesn’t have the same common social rules for taking part in a conversation as other children of the same age.”

Work is an important part of many people’s identity and social status today, and work also creates an important part of the social network. Work leads to a better financial situation than having early retirement pension and other forms of allowances, thus making it easier to find housing and start a family (Nordeng 1993). The following quotation shows the gap that often exists between parents’ and adolescents’ thoughts about the future:
“The best thing would be if he got a real job. But most companies probably hesitate to hire someone who can’t hear and who has a visual impairment as well. They are probably worried about all the problems it could lead to.”

“I’m sure that there are jobs that wouldn’t suite me, but that’s not really anything I have given any thought to. I can’t see any obstacles for continuing my studies and getting an education.”

“You tend to think more about work when you get older. But it’s important to take it easy as well and not think too much of things like that, because it just makes you worried. It’s better to live your life while you still have some vision and hearing left. When it gets worse, I have to start thinking. I feel that I’m living my life right now and that I can do what I want. When you get older you have to take more responsibility and also start thinking more of the impairment.”
STRATEGIES FOR SUPPORT

Adolescence, which is what we have chosen to call the period between the ages of 13 and 25, is an important period in many ways. It includes everything from selecting a programme for upper secondary school, to developing one’s own identity and taking the step into adulthood, and all of this involves making decisions, taking responsibility, having relationships, etc. It is also a period in life that is characterized by emancipation and testing boundaries towards the environment and the adult world. Adolescence is a huge transformation process for all young people, and it can be even more difficult for young people with deafblindness since deafblindness often is a progressive impairment.

General Support

Just like families who have small children with deafblindness and adults with deafblindness, adolescents also need to have contact with authorities on different levels in society. On a local level it may involve contacts with administrative professionals working with the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) and transport services. The Social Insurance Agency and the Employment Agency are other important parts of the young person’s life. On a regional level, the contact includes for example the Low Vision Clinic and the Department of Audiology, the Child and Adolescent Habilitation Services, a Deafblind Team and interpretation services. Adolescents who attend some form of education also have contacts on a national level, for example with the Swedish Institute for Special Needs Education or the disability co-ordinator at the university. The list can be made long for adolescents with deafblindness.

Apart from this, contacts with different authorities are not a prioritized area when talking to adolescents with deafblindness. Many young people feel that parents or school staff knows a lot about their impairment, but that they themselves are less active when it comes to looking for information about the impairment. Often it is also the parents who initiate and keep the contact with different authorities. Most adolescents with deafblindness that we have met agree that an early knowledge of the impairment is an advantage. Life often becomes more intelligible and the adolescents learn to find strategies that facilitate everyday life early on. In order to make this work, many adolescents say that there must be adults available who can give simple and
understandable information about the visual and hearing impairment, as well as information about the consequences of this combination, and it has to be done on the adolescents’ own terms and not be forced upon them. It is also important to be given the opportunity to identify with other adolescents with visual and hearing impairments/deafblindness, according to both parents and adolescents.

Strengthening the self-image and providing young people with deafblindness the opportunity to have a positive identity development, is an important task during adolescence.

The Adolescent’s and the Family’s Need for Specific Support

Adolescents with deafblindness and their relatives need to meet professionals with special knowledge about deafblindness, both during the adolescent years and when entering adulthood. In periods, parents may need someone to talk to, especially when the child is moving away from home to go to school in Örebro. Most of the parents that we have met are worried and have many thoughts about the adolescent’s future. They worry about things like education, work and future family life. Parents who have a child with deafblindness go through different stages, and some of these are more difficult to cope with than others. Many parents say that after the first stage, which comes just after finding out about the child’s impairment, the most difficult stage is when the child enters adulthood. The future, not knowing whether the visual and/or hearing impairment will deteriorate, and the fact that they have to start letting go, that their child has grown up and must cope on his or her own, are things that occupy the parents’ minds during this period.

During the project, we have found that parents of adolescents with deafblindness often are very aware of their child’s impairment as well as of its consequences in different situations. They have got used to putting the young person’s needs into words and often have substantial knowledge of deafblindness. This role will now fall on the young person instead. For many adolescents, an increased knowledge of the impairment means a more comprehensible and manageable situation. Increased knowledge and awareness about deafblindness is useful in different situations where choices and decisions have to be made, and is likely to lead to more appropriate strategies in everyday life. The choices that are made should be based on interest, wishes and dreams, however, knowledge of the consequences of the visual and hearing impairment/deafblindness should also be considered to
avoid too many failures. In order to do this, there have to be discussions with friends, parents and other adults. It is important to find ways of meeting adolescents on their own terms and based on their own needs. It is also necessary for the meeting to take place at the right time and in the right way, otherwise the support from the adult world may be dismissed with “that doesn’t concern me”.

When the young person with deafblindness finishes upper secondary school, many of the resources disappear, resources that up until that point “have just been there”, without the adolescent ever having to think of where they come from or why. Students who have attended a special school have had a large network of adults around them, and those who have gone to individually integrated schools have probably had different kinds of extra resources too. Due to this, the transition into adulthood, working life or university, becomes rather significant. Many adolescents that we have met during the project say that the difference is so significant that in the beginning it is hard to keep up with, have an overview of, and cope with everything that is expected of you. It can involve everything from being able to arrange means of assistance, transport services and interpreters, to having a dialogue with teachers and students at the university course, or living in student housing together with other students where nobody knows what deafblindness means. For others, parenthood at this stage in life can be a profound change that leads to a huge need for support, both on a concrete level and an emotional level. Experiences from the project clearly show a need to have a supporting contact after finishing school, irrespective of whether the adolescent is continuing the studies or starting to work. The adolescents are faced with many new situations where the deafblindness is tried and new strategies must be developed. And at the same time they must let go of their parents and the parents have to let go of them. In this situation, it may be useful to have someone to talk to or to have a mentor for a period of time, someone who is there to give advice, provide support or just to talk with for a while when needed. It is the adolescents who must control this ‘journey’ and not the professionals or parents.

The Environment – Networks and Participation

It is not unusual for an adolescent with deafblindness to have contact with many professionals. And if the adolescent has an additional impairment, the number of professionals can become close to unlimited. There is a number of professionals around the young person, but the
The most important thing is the cooperation between the professionals and the adolescent. The support must never pass the young person by, instead there must always be a cooperation. Someone must take responsibility for the cooperation together with the young person. If there is a Deafblind Team in the home town, or something similar, it is natural for them to take on the responsibility for coordinating the resources. In Skåne, we have created a network around students with deafblindness, and routines are being developed for how to cooperate with the children and adolescents, as we have mentioned before. For many schools, this is very important since they may be unfamiliar with the external resources around children and adolescents with deafblindness. At the upper secondary school RGD/RGH in Örebro, a post for a co-ordinator for students with a combined visual and hearing impairment/deafblindness has been established. It is a national resource that we have involved in our regional network of school children in Skåne. The idea is that there should be an established cooperation between resources at home and at the upper secondary school, prior to the young person’s move to Örebro to study and later on when it is time to move back home again. The purpose with establishing contact with the young person at an early stage is to be able to provide a continuous support during the time in school and after school. Also when the young person is studying in Örebro, Region Skåne has the responsibility for habilitation/rehabilitating, which means that we have to be available if the adolescent or the parents need advice and support.

Adolescents have many decisions to make, often about the future, involving for example education and work. In the project, we have met adolescents with deafblindness who feel that they have not been provided with the right guidance before making these choices. They have based their decisions for upper secondary school or university on feeble grounds. They do not feel that they have had enough information about how the impairment will influence their studies and future work life. They have had to make these experiences themselves, often through failure and sometimes with damaged self-esteem as a result. The chance of combining dreams with a cynical reality would probably be better if an education and work guidance with specific knowledge of deafblindness was available. Experiences from discussions with adolescents also show that there is a wish for a close co-operation between the education and work guidance and those responsible for more general counselling and support in the adolescent’s life, for example the regional Deafblind Team.
The DUA project about people with deafblindness in education and work life (Arsenovic-Vasiljevic & Lundh 2006), confirms that the move from upper secondary school to work life or continued studies is a critical point in a young person’s life. In the report, it is stated that adolescents with deafblindness are unable to study on the same terms as students without impairments and that they are more often unemployed compared to other adolescents. Experiences from the project show that there are many authorities on national, regional and local level connected to the young people, but that there is no co-ordination between school, work life and habilitation/rehabilitation. Besides, legislations, laws and regulations are also interpreted in different ways, which leads to discrepancies in the decisions concerning what the group is entitled to. Trying to create supporting networks in co-operation with the adolescents with deafblindness is important if they are to be able to make their own choices and decisions on solid grounds when it comes to studies and choosing a profession.

Sharing Experiences with Others

Even if most adolescents do not identify with the concept of deafblindness, it is important to share experiences with others who are in the same situation, according to both parents and adolescents. It ought to be especially important for the individually integrated adolescents whose social situation has been described as more problematic, and who more often feel left out and lack friends of the same age. We consider it to be an important part of the habilitation work for adolescents with deafblindness to share experiences and have group discussions on issues like relationships, the impairment, school, education, identity, sexuality, the future, etc. Parents of adolescents with deafblindness have expressed a wish to have group activities for adolescents, led by a couple of adults with deafblindness, all in order to have a chance to talk about issues and subjects that adolescents may find difficult to talk with parents and professionals about.

Swedish Deafblind Youth (DBU) plays an important part in giving children and adolescents the chance to identify with others who have the same impairment, and in giving them the chance to create social networks. For a period of time, the special schools’ Knowledge Centre organized special camps for children and adolescents with deafblindness, but when their function was changed, it stopped. The adolescents that we have met during the project and who have been to these or similar camps for raising awareness, have purely positive ex-
experiences. The feeling of not being alone and the chance to broaden
the knowledge of one’s own impairment have been described as a
positive experience. The National Agency for Special Schools for the
Deaf and Hard of Hearing have now started to invite students with vis-
ual and hearing impairments/deafblindness to annual national meet-
ings again, but unfortunately these meetings only include students in
national special schools. Individually integrated students do not have
this opportunity, which is why something similar ought to be arranged
close to their homes or in co-operation with the National Agency for
Special Schools for the Deaf and Hard of Hearing in order to include
this group as well.

Parents too have a need to meet other parents and share experi-
ences and feel some support in discussions with others who also have
children with deafblindness. This has been mentioned earlier on in this
report and it is something that has come up in the meetings with sev-
eral parents. On a local level, it is possible to contact one of FSDB’s
contact parents. Another option is to take part in the annual parents’
education at Almåsa which we described earlier in the report. Even if
the children are adolescents, or even adults, it is not uncommon that
parents take part in the parents’ section’s activities. It may also be a
good idea to arrange parents’ meetings, discussions on certain issues,
and other activities on a more local level. During the project, we have
noticed that parents of adolescents with deafblindness have many
thoughts and questions regarding the future that they want to discuss,
and these discussions can very well be held in groups.

An important kind of support during adolescence, both for the ado-
lescent and for the parents, is to share experiences with others who
are in a similar situation. The feeling of not being alone, and the chance
to increase the knowledge and awareness of deafblindness, is some-
thing that both adolescents and parents describe as positive.

Information and Knowledge Development

Nordeng (1993) stresses that just as parents need to be given detailed
information based on facts about their child’s diagnosis, prognosis,
and the consequences of the impairment, it is very important that
the adolescent also receives the information. According to Nordeng,
the information should be adapted to suit the adolescent’s age and
maturity. It is also important to give concrete examples so that the
adolescent has a realistic idea of the impairment and is able to develop
good strategies in relation to the environment that he or she lives in.
Receiving information about one’s impairment, and in particular about the prognosis, is a process that must be allowed to take time. Everything does not have to be told at once, things that will happen in the future and that are not of immediate interest for the adolescent may very well wait according to Nordeng (1993). The adolescent ought to know more about his or her impairment than others, which is why the information should be very thorough, detailed, and frequent. This way, the adolescent is also provided with tools to pass the information on in different situations. Based on our interviews with both parents and adolescents, we know that competence to inform will be needed in many different situations. We also believe that it is important for friends, class mates, and others who are close to the young person with deafblindness to receive information, and they should also be given the chance to discuss, talk, and thus create openness around the impairment. Hush-hush just increases speculations, which may lead to uncertainty and insecurity, something that a couple of adolescents that we have spoken to also confirm.

In everyday interaction with the environment, questions about the consequences of deafblindness in different situations will appear sooner or later. It may be the housing staff or school staff wondering about how to adjust the environment and the tuition, or it may be someone at work who has questions on how to treat the young person with deafblindness or how to adjust the work place. A lack of knowledge about deafblindness is something that adolescents and their parents meet all the time in their contact with different authorities. Individual administrative professionals often lack knowledge about the consequences of living with deafblindness, which may lead to decisions being made on false grounds. It is often the parents who represent the young person in the contact with different authorities and it is also they who carry the information about the impairment and its consequences in different situations, a role that the young person gradually should take over. A Deafblind Team or something similar should work as a support for the young person in his or her meeting with different authorities, both directly and indirectly, depending on how well equipped the individual is when it comes to describing and giving information about his or her situation and needs. We consider it to be of great importance in the adolescents’ habilitation process that they learn how to describe the impairment and its consequences, as well as adjusting the information to different situations. As a professional, it is possible to complete the young person’s information by adding more general
information about deafblindness. This way it is possible to co-operate in order to increase the level of knowledge in the network surrounding the adolescent. If a person has knowledge of the impairment early in life, and finds ways of informing others about it in a natural way in situations where it is needed, it will probably lead to a larger understanding, improved attitudes, and a better treatment from others.

**CONCLUSION**

What kind of support can we, the professionals, be for adolescents and their families, and on what conditions, in what way, and when? These are questions that we have often asked ourselves during the project. Timing – in the sense of providing the right support at the right time – is crucial, especially when it comes to adolescents. Adolescents may not always experience a need for support concerning their impairment, but the consequences of deafblindness are difficult to ignore. They influence everyday life in different ways, even during adolescence. Our experience of adolescents’ needs can be summed up in the following paragraphs:

- One important task during adolescence is to strengthen the self-image and make it possible for adolescents with deafblindness to develop their identity in a positive way.

- Adolescents with deafblindness and their relatives need to meet professionals with special knowledge about deafblindness, both during adolescence and during the transition into adulthood. The young person should also have access to a professional contact to talk with.

- In order to make it possible for the adolescents to make their own choices for the future and to make well-founded decisions, it is important to create supporting networks together with the adolescents with deafblindness.

- In order to be a good support during adolescence and in the transition into adulthood, the work around the young person with deafblindness ought to be co-ordinated and made available for the adolescents.
• An important part of the support during adolescence, both for the young person and for the parents, is to share experiences with others who are in a similar situation.

• Adolescents with deafblindness need to know more about their impairment than others, in order to develop good strategies in relation to the environment and in order to become better at informing others about the impairment in different situations.
"When I got the diagnosis, I completely lost my foothold, everything went black and all plans for the future came crashing down. It has been a huge and demanding transition in many ways.” (Janne, 53 years)
EXPERIENCES OF DEVELOPING AND LIVING WITH DEAFBLINDNESS

Janne, 53 years

“I didn’t find out until I was going to take my driving licence. The doctor told me that I couldn’t do it because I had an eye disease that would make me blind. He said that there were a lot of good means of assistance nowadays, and that I should learn to use a white cane! I completely lost my foothold, everything became meaningless.

I studied at the technical programme at the upper secondary school and after school I started working as a carpenter. I didn’t tell them at the time that my vision already was a bit poor, but I guess they understood that my hearing wasn’t perfect. But surely, I must have missed quite a bit during staff meetings and coffee breaks. Instead, I worked all the more. I worked until I turned 43. Then the company had to let a few people go. Those who were close to retirement had to go, and then it was me. I had to go because they felt that I couldn’t do the same things anymore, and that I wasn’t as fast as before because my vision had got worse. They said that it was a matter of safety too. Now I have been at home for ten years and would prefer to have early retirement pension. I’ve applied for some different jobs but without any success. I don’t think I could manage a job anymore now, and besides, what would I do, I don’t exactly know anything else.

When I was 24, I got married to Kerstin and we had two children who are grown up now. We never talked so much about my visual and hearing problems at home. I never wanted my family to feel that we were different in any way; I didn’t want to stand out with my impairment, or what I should call it. You don’t want your children to be ashamed of you. But then again, it was always Kerstin who had to deal with most things at home with the children and so. I wasn’t exactly useful when it came to picking them up and dropping them off at different activities, or taking part in parent-teacher meetings and other things. I guess that has affected the relationship with my
children too. They rarely come to me when they want to discuss something or if they need help.

I have told Kerstin that she can meet relatives and friends, but that I don’t feel like it most of the time. Somehow, it’s even lonelier to be around people when you can’t take part, than to be at home alone. It’s strange, but that’s how it feels. I’ve noticed that it’s more difficult for me to follow a conversation now that I can’t read the other person’s face very well any more.

At least I don’t need a white cane, not yet. People would take me for someone who’s completely blind and assume that I can’t do anything. Everyone would see from a distance how disabled and helpless the poor fellow is. No, that’s not for me. But I do notice that my vision is getting worse. Earlier, when I worked, I was quite active and a member of different associations and clubs, but now I don’t leave the house very often. It makes me feel insecure and I feel that people are bad at showing consideration. So my days feel pretty long and I often think of what it will be like when I eventually lose all of my vision.”

Helena, 31 years

“I’ve always had very poor vision, and that’s something I’ve adapted to. It’s natural for me to use a cane and to read Braille. Otherwise I wouldn’t be able to manage in my everyday life. Thanks to different adjustments, I’ve managed to work at the hospital’s central archive without any major problems. But the last few years, my hearing has deteriorated. In the beginning I didn’t notice it very much, but now it’s becoming a real problem. It started when I noticed that I had problems outdoors, in the traffic. It didn’t sound the same when my cane tapped against the ground. I felt insecure and decided to have my hearing checked out. They say that I have a moderate hearing impairment, and I’m trying out different hearing aids. At work, they get annoyed with me sometimes and think that I don’t pay enough attention. The other day, one of my colleagues thought that I showed a lack of interest during a discussion in the break room. It wasn’t like me, she said. I also notice that I’ve started to miss information that I shouldn’t miss, and that scares me. I feel that there are a lot of misunderstandings, people get annoyed with me, and I’m absolutely exhausted when I get home from work. When my children, Sara who’s 7 and Anton who’s 4, talk at the same time,
or if they fight and the TV is on, I don’t know how to manage. I’ve actually been on sick leave in periods the last year. I have never felt this tired before. I don’t see other people, I simply haven’t got the energy for that.

As a child I was quite lonely. I wasn’t able to go out after school and play with the other children without having an adult with me. It was the same in school. I was completely dependent on having an assistant with me during the breaks. As a teenager, it was very important for me to become independent. I guess I got a bit carried away sometimes. Thinking about it, things were quite dangerous for a few years. I had to struggle more than others to break free from my parents, and our relationship has never really quite picked up since that. But then I met Andreas and settled down. We had two kids. It’s very practical to have a husband who can both see and hear! Many people wonder how I can manage to take care of two children being almost blind. You manage, but you need different strategies compared to other mums in order to manage. Right now it’s a bit difficult but I think it’s mainly because of my hearing. It’s difficult for me to cope with all the demands of everyday life, and I need a lot of motivation to start a new day. The worst thing is that it affects the self-esteem.”

Kalle, 39 years

“We knew from the beginning that Kalle was blind. But it took three or four years before we started to suspect that he didn’t hear either. Those were two major set-backs. It was awful! We noticed that he wasn’t developing at all like other children, but in the beginning we didn’t understand why. Other blind children learned things, but not Kalle. The communication never started properly and nobody spoke of sign language with us in those days. When Kalle reached puberty it became really hard. He hit us, broke things and tore things down at home, and when he had been home from school for the weekend, we were completely scratched to bits. This lasted for several years, but it’s better now. He lives in a group home now and is surrounded by people who understand what it’s all about, and he has also learned some signs. Thanks to this, he is now able to express his needs more and more, which makes him calmer. When Kalle was a child, we went to several doctors and had different examinations, but we were never given any other support. We were lucky to
have each other. Many friends disappeared; they didn’t know how to deal with the situation and nobody wanted to talk about Kalle.

Deafblindness was something that nobody had heard of. In the beginning we were all alone and we never had a babysitter. It was a full time job that has really limited our lives. We have always struggled to live a normal family life, but naturally, Kalle’s impairment has affected most things in our everyday life. Kalle has two older siblings, and we have talked a lot about them not getting caught in the middle because they have a brother with functional impairments. They are both adults now and take a lot of responsibility for their brother. It has been a great relief to meet other families who have children with deafblindness. We have met others through FDSB. Kalle’s siblings have also had the chance to meet other siblings. You feel that you’re not all alone in the world, and the feeling of having someone else who understands what it’s like is impossible to describe. We still meet, even though the children are grown up now. Nowadays we worry about who will take responsibility of Kalle when we can’t cope anymore or when we are gone.” (Parents of Kalle, 39, who was born with deafblindness and has additional functional impairments.)

Finding out

Janne, Helena and Kalle represent three adults with three very different experiences of deafblindness. During this project, we have interviewed several people with deafblindness who have grown up without knowing about the diagnosis and the prognosis of the impairment. Many have had a hearing impairment or have been deaf all their lives. Around the age of 20, or in connection with taking the driving licence, many have been given the diagnosis and have been told about the visual impairment. At the same time they have found out that their vision will gradually deteriorate and that they can expect to be blind or severely visually impaired.

“I was 20 and had my whole life ahead of me when I found out that I would probably become blind. He just said it, the doctor. 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.”

In some cases, the parents have been aware of the diagnosis, but have
chosen not to tell the children in order to protect them. When they have found out later on in life, they have suddenly found an explanation to all the things that have seemed strange, for example not being able to find their way home in the dusk, not seeing the pass from a friend when playing football, or constantly bumping into things. Most of the people that we have interviewed feel that it is important to have the diagnosis as early as possible, so they do not have to think of and speculate about why they do not function like others in different situations. Some feel that if they know from the beginning, they do not have to experience the shock and the crisis later on in life, and they have the chance of making other choices, for example when it comes to education and profession. Many have talked of the feeling of insecurity and of not being like everyone else, without knowing why, and how they would have wanted to spare themselves that feeling.

“Mum cried a lot. She often went aside to cry, but I thought I managed well. I didn’t understand it then, but today I understand how much grief and guilt my deafblindness has caused my parents.”

Some of the people that we have interviewed, say that the diagnosis worked as a confirmation and a relief. Others describe the shock, the disappointment and the shattered dreams they experienced when they were given the diagnosis in the late teenage years, just when they were entering adulthood.

“I was 19 and that’s when the doctor first told me about something called RP (retinitis pigmentosa). She (the doctor) had never said a single word, neither to my parents nor to me, about me having this visual impairment. So there was no talk of driving cars or doing anything any more … no, I had to drop all that. Everything was turned upside down.”

Life Adjustment

The adults with deafblindness that we have met during the project talk of the necessity of finding new ways and new strategies to cope with everyday life when both vision and hearing is lost. When interviewing adults with deafblindness, it is remarkable what a huge life adjustment deafblindness is for the individual person and his or her relatives.

“Losing my hearing was both impractical and sad. But what I was really scared of was losing my vision. Today, I know it’s completely the opposite. But as it turned out, I lost both…”
Many have said that when they have finally “started to get used to” or “learnt to live with” the impairment, the vision and/or hearing deteriorates further. They describe that the emotional change is complicated when vision and hearing constantly deteriorates. Many of the people that we have interviewed find it very hard and threatening to slowly move towards a more severe kind of deafblindness, and sometimes it can cause great worries. Such a progressive course leads to repeated life adjustments during a person’s life. Nearly everything in life is influenced and changed as a consequence of the deafblindness, according to the people that we have interviewed, and many things that were previously taken for granted and that they have had their whole lives to learn, now have to be relearnt again. It has to be done during a short period of time and often in a completely new and unfamiliar way. Some of the people that we have interviewed, have had to learn to read and write in a completely new way, others have had to learn a new method or a completely new language to be able to communicate. Some people have had to learn to use a white cane to be able to move around independently, without constantly depending on somebody coming along to guide them. Communicating with others, reading, writing and moving around freely, are fundamental abilities that most people learn during their early childhood and that are then taken for granted for the rest of their lives. Exercising, putting on make-up, choosing design and colours on clothes, choosing clothes depending on the weather, finding the right spice on the spice shelf, are some other examples of everyday activities that have been mentioned during the interviews and that require modified strategies for the person with deafblindness. Being denied having a driving license or having it withdrawn, is considered by many to be a major disappointment or failure.

“I live in a reduced world nowadays. A lot of the things I used to do, I’ve had to give up. It took me several years to come around to getting rid of the car.”

“Sometimes I can dream that I’m driving the car through a beautiful landscape.”

The interviews made it clear that developing deafblindness also implies a huge emotional change. Many have talked of the profound feeling of hopelessness and despair when the doctor has given them the diagnosis and they have realized that they will develop deafblindness. None of the adults with deafblindness that we have interviewed have been offered any emotional support from the health care services in
connection with finding out about the diagnosis, and many wish that they would have been given more and detailed information about the diagnosis.

“Deafblindness can lead to feelings of sorrow, anger, frustration, stress, a feeling of loneliness and great fatigue. You need help in dealing with this, otherwise the emotions will turn into walls between the person with deafblindness and the surrounding environment.”

“It is difficult for others to understand the consequences of deafblindness and in particular the emotions you experience in connection with the disability.”

In both Janne’s and Helena’s stories you could read about how the deafblindness influences the self-esteem and the self-image, both in working life and private life. When the vision and/or hearing deteriorates, everyday life is affected, both practically and emotionally. Many describe how they lack the energy or the time to live up to the same expectations as previously. Many have also expressed a feeling of stress in different situations; stress in not being able to communicate with others, not being able to move around freely and independently, not keeping up with all the work tasks like before, or not being able to choose what to do and when to do it.

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

“It’s easy to feel inferior, to feel that you’re not good enough, and not competent enough. Only when you have some knowledge that others want, it gets possible to look beyond the deafblindness.”

The Personal Network

Deafblindness constitutes a major change with various consequences also for relatives and other people close to a person with deafblindness. Relatives have expressed a need for information about deafblindness and its consequences, and they have also expressed a need for emotional support from professionals with experiences of deafblindness. If a person with deafblindness, whether it is a child or an adult, needs to learn sign language or an alternative method for communicating, relatives should also be given the same opportunity.

The people with deafblindness that we have come into contact with during the project and who are in a relationship, have described some-
thing that we may call a changed division of responsibility and work load. In the case descriptions above, this is most evident in Janne’s case. A visual impairment leads to practical difficulties in different situations, for example when picking up and dropping off the children at pre-school or different evening activities. A hearing impairment leads to difficulties in having conversations with more than one person, or in taking part in different social contexts such as parents’ meetings and meetings in the tenant-owner association.

“I avoid complicated communication situations and I have stopped seeing friends and relatives who don’t understand me. I just can’t cope.”

According to many of the people that we have interviewed, other examples of when the division of responsibility and work load in a relationship can change are for example when having a dialogue with the children, discussing existential issues related to life, solving conflicts, or managing to set up boundaries in different situations. As a consequence, the partner may take over these tasks and functions, like in Janne’s case.

“I guess that has affected the relationship with my children too. They rarely come to me when they want to discuss something or if they want any help.”

We have also found that deafblindness leads to a need to make priorities in everyday life. It is common to avoid situations that are demanding from a communication perspective, like in Janne’s and Helena’s cases. This includes both situations that are related to family and friends, and restrictions in leisure time activities. Many feel that it takes too much energy and gives too little in exchange.

“It takes too much energy for example in the pub or at the disco. I’m not able to put all that energy on new contacts or random acquaintances. I get very little in return out of these situations.”

“I’m completely knackered when we’ve had people over. Sometimes I have to sneak away for a while just to have a break.”

One aspect that is mentioned in the interviews is the difficulty in accepting help and the feeling of depending on others. Relatives of adult people with congenital deafblindness who live in group homes, feel that they are completely dependent on the public system to work well and take over the responsibility when they grow old and are unable to
manage any longer, something that is described in Kalle’s case above. The need to be independent and the need to have support and help from others in different situations, is a difficult balancing act, according to many.

“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 wills, as well as their own wishes and needs. It’s necessary to find some sort of balance.”

Many of the people that we have interviewed say that joining FSDB and meeting other people with deafblindness became a turning point in their lives. It is mainly the sense of community and the exchange of experiences within the association that is appreciated. The social interaction and the activities in the local groups, are mentioned in the interviews, as well as the activities and the participation in the political work on national level.

“FSDB has meant a lot to me. It was when I met others with deafblindness that my life turned around again. Earlier on, it had just felt hopeless.”

**Working Life**

The escalating pace and the higher demands on the individual in the working life have influenced the situation for many people with deafblindness that we have met during the project. Some people have had to leave their work because the deteriorated vision and/or hearing have made it impossible to manage the work tasks. Others have felt that the impairment has influenced the work pace and has made it impossible to manage some of the work tasks due to the more pronounced impairment. Some of the people that we have interviewed describe how they have not been able to manage or cope with the working life’s changes and demands on efficiency and flexibility. Others that we have met have had difficulties in finding work because of their functional impairment. Especially the young adults that we have met during the project are very worried about how to find a job and manage working life. Many of the people that we have met have had early retirement pension and do not think that they can manage to work.
“What kind of job could I have and who would hire somebody who can’t see or hear properly?”

The social part of working life, socializing with colleagues, break time, and chatting in the corridors, is also influenced in a negative way when the deafblindness becomes more pronounced, according to many of the people that we have met during the project.

“In the end I just felt like a burden and that was definitely not good for my self-esteem.”

Some of the people that we have met describe how it was when they decided for themselves in the end to stop working. With the progressive deafblindness came a feeling of wanting to have as much time as possible to see and experience as much as possible while there was still time. They meant that work was something that they had put behind them, in order to improve the quality of everyday life. Some people said that work took so much energy that there was nothing left once they came home.

“When I come home from work I’m absolutely exhausted. I don’t have the energy to cook or do the washing up. I can’t even play with the kids or help them with their homework. It’s impossible to feel adequate in all situations.”

The Contact with the Social Support System

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

While conducting the interviews, we realized that even though everyone has a lot of contacts, most people we met lack a supporting contact with whom they can just talk about some of the thoughts and feelings that are a consequence of deafblindness. The communication concerning these kinds of issues is preferably held directly, in one’s own first language. Many people also express a wish for this professional contact person to have the competence needed for understanding and giving advice and support in issues that are specifically related to deafblindness. Many people say that up until today, nobody has had this competence. One person knows about vision, another about
hearing, and someone works with physiotherapy, but nobody works specifically with deafblindness. The contacts seem to be more practically orientated, dealing with issues such as adjusting the house or the flat, trying out assistive technology and different types of training, keeping contact with local administrative professionals or physiotherapists within the habilitation programme. A man with deafblindness expressed it like this:

“The problem is more of a psychological than practical nature, involving assistive technology and such things. The most difficult thing is the relationship with others, who can help me with that…?”

Several people have also expressed a dissatisfaction concerning the organization of interpreters and guides. The dilemma is that the regional authorities provide interpreters for people with deafblindness, whereas the local authorities provide guidance to and from an activity. This means that two responsible authorities need to make decisions when someone wants to go to for example a conference, and that two assisting persons must be involved; one who is guiding to and from the place, and then interpreters who interpret once they are there. During the journey to and from the conference, a guide is provided by the local authorities, and he or she is seldom able to communicate with the person with deafblindness. During the interviews, several participants stressed the importance of being able to communicate also while going to and from a place. Many talked of how insecure they feel when they are guided in unknown places by a person with whom they can not communicate and who does not know of their disability; they do not feel as though they are part of it at all since they do not know what it looks like or what is going on around them.

“What’s the point of going out to buy clothes with a guide that you can’t say a single word to? Sure, I get to and from the shop, but I’m not able to see what the clothes that I try on look like, or if they match.”

Many people that we have interviewed feel that it is difficult to make authority representatives understand what it means to live with deafblindness. Parents of people with deafblindness, where there is also an additional functional impairment involved, often feel that their children, who are now adults, do not receive the specific habilitation needed in order to develop, all because there is no competence about the consequences of deafblindness. They are often placed together with
people with developmental impairments and have to adjust to the models and methods valid for that particular disability. The specific competence that exists within the deafblind field, especially when it comes to communication development, rarely benefits adult people with congenital deafblindness and developmental impairments, since the local authorities often lack this competence. Many people who are born with deafblindness and who are now adults have grown up in institutions. They have not been diagnosed, perhaps the deafblindness has not been known and they have instead been regarded as a person with a developmental impairment. Many people that we have met during the project, both professionals and relatives, have described how the lack of stimulation and the knowledge gaps within the system in many cases have led to severe delays in development and also behavioural disorders for people with deafblindness.

“He hit us, broke things and tore things down at home, and when he had been home from school for the weekend, we were completely scratched to bits. This lasted for several years, but it’s better now. He lives in a group home now and is surrounded by people who understand what it’s all about, and he has also learned some signs.”

When people with deafblindness tell us about meetings and contacts with authorities and individual professionals, there are many examples of negative attitudes and bad approaches. It is common to feel distrusted and to feel as though others think that you are exaggerating in order to get advantages because of the impairment. It may include a feeling of being misunderstood or being disregarded by an authority, or that the conversation is held with the interpreter or the guide instead of directly with the person with deafblindness, you are treated as an incompetent or simple person, or someone to feel ‘sorry for’. The exact opposite also exists, where people are curious and ask many questions about sign language and deafblindness, and this could also be considered as an insult towards the integrity of a person, or mean that focus is moved from what the person actually sought help for. In situations where the communication does not work, people with deafblindness often feel that it is up to them to take all the responsibility for the communication. In these situations it may be difficult for the professional to establish the contact, confidence and sense of security that often constitutes the basis for a mutual agreement, to solve a conflict, or to achieve good treatment results.
"When I’m at the transport service office there’s no problem. Sound and lighting conditions are good, there is one person to talk to, and I know what we are going to talk about. But when I stand in the sunshine outside the central station later on and all the sounds turn into noise in my hearing aid, then I feel really deafblind, and the difference is not visible for other people."

Most of the people that we have interviewed say that there is a huge need to receive and spread information and knowledge about deafblindness to all different levels of society. Many find it tiresome to have to tell their ‘life story’ and describe their impairment in every new situation and to every new professional, and anyway, according to many of the people that we have interviewed it is not always easy to talk of oneself and put one’s own needs into words. It is rarely a positive story to tell, and constantly having to describe what you cannot do is not very good for the self-esteem, especially not if you feel that you are not being trusted.

"It’s difficult to explain and make professionals and others understand what it’s like to live with deafblindness. It’s not always visible on the outside, but it affects all parts of my everyday life. They never see the overall picture – they never see all of me."

**Interaction and Communication**

Many of the people that we have interviewed feel that it becomes more difficult to establish new relationships but also to maintain already existing ones when vision and hearing deteriorates. The codes for communication, what we sometimes refer to as body language, become harder to distinguish, and the rules of communication more difficult to follow. For many, it becomes more difficult to distinguish the spoken word or sign language when they cannot use their vision any more, and the problems with perceiving the words lead to misunderstandings and difficulties in having a conversation.

"I have lost the ability to initiate contact. I can’t make eye contact to see if a person seems interested in talking to me."

Each new meeting with another person can be perceived as a challenge and a stressful situation. Many people describe their anxiety and distress about social situations where they have learnt that misunderstandings easily occur. It is very demanding to listen and try to understand what is being said without too many misunderstandings.
Many people say that some situations and environments are more difficult than others, for example communication in a flight of stairs and in waiting halls or where there is traffic all around. Quite a few people mention ‘family gatherings’ as one of the most distressing situations. Based on the interviews, we have understood that people with deafblindness often feel responsible for misunderstandings that occur or for conversations that do not run smoothly. Stress, tiredness, lack of background knowledge, lack of information, and low concentration, are some examples that may lead to losing focus or context in a conversation. Only one of the people that we have interviewed mentioned the other person’s lack of communicative and interactive skills, or the fact that the responsibility is shared in all kinds of communication.

“Parts of the body language can be interpreted tactually with the hands, but it’s hard to interpret all feelings and humour that way. I perceive the words but can miss the point and the context completely … and that easily leads to misunderstandings.”

“Sometimes you make a fool of yourself, that’s just the way it is. You have to live with that. Sometimes it gets so ridiculous that you just have to laugh at it all.”

Many people with deafblindness depend on body contact to be able to communicate and move about. Tactile communication requires body contact and in that situation it is unavoidable to break our norms and rules for closeness, distance, and touching, something that some of the people that we have interviewed mentioned. For some of them, this is completely natural and does not create a problem. Others react more negatively to the body contact that they feel is forced upon them, especially with people they do not have a personal or close relationship with otherwise.

“I definitely didn’t like to have that interpreter with me to the meeting. Her motions were so stiff and jerky that I lost the thread all the time. I didn’t get much out of that meeting. Next time I want to have Eva. I’m used to her and we work so well together.”

Something that many have mentioned is the importance of small talk and the difficulties in perceiving what people are saying around the dinner table, at coffee breaks, or when they meet in the corridors at work. It may not be very important but it is an important part of creating a sense of community and gives a feeling of belonging, according to many.
"If you can’t take part in the insignificant small talk, you can’t be a part of the important conversations either."

Other aspects on communication that have been mentioned are the problems with keeping eye contact and turn-taking in the conversation. If neither vision nor hearing is very good, it is difficult to make out when a person has stopped talking, if someone else is about to say something, or if the discussion is finished and the conversation is about to change over to another topic. Many examples are mentioned in the interviews. Some people have described how difficult it is to flirt when you cannot make eye contact or if you have to make contact via a third person, an interpreter or guide.

"Earlier on, when my vision was better, I could see if a man was flirting with me. Now I can’t tell any more. I’m not able to see if someone seems interested in me."

Feedback is another main topic related to communication and that has been mentioned during the interviews. People with deafblindness often find it difficult to perceive these signals that may consist of a nod, a hum, a brief smile, etc. That leads to insecurity as to what the other person actually thinks of what they are saying, if they should continue or not, if the other person agrees or disagrees with what they are saying, or if he or she is getting bored with the conversation. Several of the people that we have interviewed say that it also makes it difficult for the person with deafblindness to adjust his or her way of communicating in different situations, and that leads to insecurity and sometimes reluctance to taking part in discussions or conversations involving several people at the same time.

"You often feel more alone when you’re with other people that you can’t communicate with than when you’re on your own."

Many of the people that we have met during the project say that the interpreters are invaluable for them. Without the interpreters it would be impossible to live an active life and participate in different activities. The interpreters’ task is to convey a message in both directions, between the person with deafblindness and the people around him or her. The difficulty is not actually to interpret what is being said, but, according to many of the people that we have interviewed, rather how it is said. They describe that in an interpretation situation it is often the way something is said that gets lost, and that part is often important to understand the context. The problem in an interpretation situation
is that it may be difficult to have the time to interpret how something is said as well as what is going on in the room, and at the same time interpret what is being said. According to many, the interpreter/guide can facilitate the contact by describing and being attentive, but can also be an obstacle if he/she is ignorant or insensitive, or not used to interpreting visual impressions. At the worst, a person with deafblindness does not meet anyone except the interpreter at for example a course or conference. Everyone says that it is important to say how you want things to be, and that there must be an active interaction between the person with deafblindness and the interpreter.

“They must be available and facilitate communication, but not take part and definitely not take over.”

According to many of the people that we have interviewed, one very problematic area that needs much more attention within the deafblind field is how to initiate contact and find a partner to start an intimate relationship with. It is especially complicated for people who depend on at third person to take the initiative and make contact, via an interpreter or guide.

“In exceptional cases, they might also be a hindrance. You get comfortable and it might be difficult and feel a bit hard to make contact through an interpreter, especially if it involves someone you’re a bit interested in.”

Finally, we have chosen to address some aspects on the topic of computer based communication. It belongs to the area of communication since the computer means so much more to people with deafblindness today when it comes to communicating, than merely being able to use it as a telephone. It has opened the door to new possibilities, according to many of the people that we have interviewed. In a computer based communication situation, for example via email or in a data base, everyone participates on their own terms, can read and write in their own pace, and choose what to take part in. According to many of the people that we have interviewed, it is important that those who grant computer equipment are aware of how broad the concept of communication via computer is, as well as what the computer means to people with deafblindness in terms of participation. The difficulty lies in all the new things that have to be taught if a person is to be able to master the computer and use it for individual purposes, and this takes much longer to learn for someone who cannot see or hear.
Progression, Timing and Pace

For both Janne and Helena in the examples earlier, the impairment is changing. They describe the gradual change and how that affects important parts of life such as family, work, relationships to other people, and the possibility to keep up leisure time activities. When vision and hearing deteriorates, what we call *progression*, access to the surrounding world and different kinds of information also becomes limited, something that is very likely to influence choices and decisions. Many people with deafblindness that we have met during the project express how difficult it is to keep informed about what is going on, both in the close environment and in society at large. One man expressed how his knowledge of the world constantly has become smaller since he developed deafblindness.

“For me, the image of a car is still a Volvo Amazon.”

We live in an information society where we are expected to seek information ourselves to stay active and participate in society. People with deafblindness that we have met say that they have no reasonable chance to keep up with the information flow. Many are unable to use TV and radio and many also have very limited access to newspapers. They are not able to hear what other people talk about and perhaps their vision is not good enough to read advertisements, society information, and other information that is sent to all households. This lack of information does not only lead to a lack of knowledge, but may also result in insecurity, uncertainty and low self-esteem. New amazing possibilities have become available thanks to the computer based aids, but it takes profound knowledge and a lot of time to learn to handle and use the computer’s possibilities for information and communication with the surrounding world. So, according to some of the people that we have interviewed, living with deafblindness for a long time influences how they are able to gather information and make their own experiences. The deteriorating vision and/or hearing influences the choice of practical and communicative strategies in everyday life, but also the social and emotional part of life, something which becomes evident from Janne’s and Helena’s descriptions.

“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.”
Another time aspect that has become clear from the interviews is that people with deafblindness often feel that they are not synchronized with their surrounding, so called timing. This means that there is a discrepancy between the focus of the person with deafblindness and that of the environment. One example that is often mentioned by many people is how they are given a white cane or some other kind of aid that they cannot imagine ever using, early on in the adjustment process, when they do not want to recognize the diagnosis. To provide someone with assistive technology when he or she has just received the diagnosis and feels heartbroken, instead of letting him or her meet someone to talk to, is an example of how professionals lack enough knowledge of where the person with deafblindness is in the adjustment process and what his or her motivation is focused on. Many other examples of similar situations when the timing between a person with deafblindness and the professionals is wrong are mentioned in the interviews.

"First they told me briefly what was wrong with my eyes, and then they said that there is a lot of good assistive technology to use. I didn’t want to hear about that, I just wanted my vision back."

A third aspect on time that has emerged during the interviews and in the meetings with people with deafblindness, is that the pace of everyday life changes. You need a lot of patience and time since everything takes so much longer. You need more time when everything takes longer because of the impairment, such as taking in information, orientating oneself, cleaning, cooking, and much more. You are not able to do many things simultaneously, for example listening to what someone is saying at the same time as doing the washing up or folding the laundry. This creates a feeling of stress, according to many.

"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."

"If you’re not a calm and patient person from the beginning, it can be very frustrating that everything takes such a long time. I have always been used to having many things going on at the same time."

**Patience and Courage**

It takes both more time and more patience when you are dependent on other people, for example interpreters, guides, and transport serv-
ices. Besides, these functions may not always be in the right place when you have planned for them to come, or you may have to go on a detour because the transport service includes other people too. It is not rare for meetings and activities to be cancelled and postponed due to a lack of interpreters, or because transport service has been denied, or the maximum amount of guidance hours has been used up for the month. Many people with deafblindness that we have met also describe that they are very stressed and frustrated because they cannot plan their own lives and their own time, but constantly have to depend on planning and co-ordinating everything they want to or have to do with different authorities. There is a feeling of not having enough freedom of choice and the chance to live an independent life.

“Spontaneity disappears – you have to plan everything and you become dependent on others. That affects all parts of everyday life and your whole way of living.”

According to many of the people that we have interviewed, communication difficulties and difficulties in finding one’s own way and being able to move around in the environment, creates a feeling of insecurity and stress. It is not all that uncommon for people with deafblindness to find themselves in more or less risky situations. Courage is a good personal asset to be endowed with, according to many of the people that we have met during the project. Despite a very thorough planning of everyday life, many people with deafblindness feel insecure of whether it will actually turn out the way they have planned. Several reasons have been brought up in the interviews. It can be that the individual’s needs and wishes do not agree with a decision that has been made, for example if an interpreter has not been granted in a particular situation or if transport service is not granted for a journey that goes outside of the home town. Examples of other situations that create insecurity is if the bus that you go with daily, for some reason that you are not aware of, suddenly does not stop where you always get off, or if you have a meeting with an interpreter at a particular place and there is nobody there when you get there, all because of a misunderstanding in the communication. These and similar situations can create insecurity and fear, and many say that they rather stay at home and avoid things than take chances.

“For a person with deafblindness, it takes a lot of time, patience and courage to live an active life.”
Deafblindness involves huge changes in everyday life, both for the individual person and for the relatives. Everyday life for an adult is complex and includes responsibility for a family, work, leisure time, and relationships. We have to relate to an environment in constant change. In working life, the demands on education, flexibility, and personal suitability are increasing. As parents we have to be committed, active, and participate in pre-school, school and, after-school activities. Demands and expectations of everyday life often create stress, something that many people with deafblindness have given examples of during the project. At the same time they are living with an impairment that makes everyday life more complex and problematic. There is no doubt that people with deafblindness need access to support and service.

**General Support**

We already know that people with severe impairments have several authority contacts, something which has also been confirmed during the project. On a regional level, it includes doctors from several different clinics, counsellor, teacher for special needs education, physiotherapist, occupational therapist, low vision therapist, audiologist, and others, both from the Low Vision Clinic, the Department of Audiology and from habilitation services. To this can be added contacts on a local level with transport services and administrative professionals from the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS). For people with congenital deafblindness and other functional impairments, like Kalle, there is also the local habilitation staff, staff at the group homes and daily activities. The Social Insurance Agency is another authority that many have to keep contact with, and for people who study there are even more contacts to keep track of. For people who depend on an interpreter, all of these meetings also include an interpreter, something which requires thorough co-ordination and planning from the individual person. Many people have expressed that it takes a lot of energy and time to co-ordinate and maintain all these contacts. A good help, both for the individual and for the professionals, is the establishment of an individual plan where the needs are clarified and where it is made clear who is responsible for the different kinds of support, what needs to be done, and when it should be done.

During the project, different networks have been initiated, and the different participants are discussing the need of mutual routines to
be able to identify needs, co-ordinate the work, and provide a united support. This includes networks both on a local, regional, and national level.

We described earlier that many people with deafblindness feel that the co-ordination between local and regional authorities fails when it comes to providing interpreters and guides. In many of the interviews, it has been described how the lack of co-operation and the vague guidelines has led to the person with deafblindness not being provided with an interpreter and a guide, which has made it impossible to pursue the planned activities. For many people with deafblindness, interpreter, guide and transport service is necessary to participate. Without them, it would be absolutely impossible to take part in activities outside the home. It is very important that local and regional authorities reach an agreement to find a solution to the problems with co-ordination when it comes to interpreters and guides for people with deafblindness.

From discussions with different professionals during the project it has become clear that there is a lack of competence on how to assess how visual and hearing impairments influence each other. Many are not aware of the fact that the individual’s ability to compensate for the impairments is drastically reduced when both vision and hearing is afflicted. Since the professional usually meets the person with deafblindness either in a calm office or at home, he or she never sees how the same person functions in a situation out in society, for example at a train station, a bank office, or out in traffic. In a well defined situation, where the conversation is held between just a couple of people and the sound and light conditions are good, the person with deafblindness may perceive what is said without any major problems and is able to manage with the residual vision and hearing. But in another situation, the same person may neither hear nor see. People with deafblindness feel that professionals often have a hard time realizing this and they often feel distrusted in such situations. A consequence of this problem may be that the person with deafblindness is denied the right of support according to for example the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), or the Transport Service Act, because the needs are not obvious during the meeting with the administrative professional.

If the general social support system shall be accessible to people with deafblindness, some adjustments have to be made. Specific knowledge, time, structure, access to interpreters for people with deafblindness, co-operation and co-ordination of resources are exam-
The Individual's Need for Specific Habilitation/Rehabilitation and Support

During the project, we have discussed the layout and the contents of deafblind specific habilitation and rehabilitation services, both with people with deafblindness and their relatives, and with professionals. As for the layout of a specific support, factors like time, structure, professional approach, co-ordination, recurrent work, an overall view, and flexibility are constantly recurring. Revising the interviews and meetings with people with deafblindness and relatives, has led to a number of methods and strategies that we have tried during the project. The people that we have interviewed express a need for personal, individual support, but also for support and guidance for the network, both the professional and the personal. Some of the needs and questions that people with deafblindness have turned to us with have been of a more urgent nature. They have involved for example family or work related crises or problems in the contact with different authorities when applying for transport services, guidance, or sickness benefit. It has also involved more long term needs of habilitation/rehabilitation, such as learning to communicate in a new way, learning orientation and mobility, learning how to use new kinds of assistive technology, finding new coping strategies and leaving the old ones that do not work any more, etc. The work with people with deafblindness often has to be carried out on different levels. This is partly about working with an individual direction where the person with deafblindness is right now, but just as much about working with the networks around a person with deafblindness, both the personal and the professional.

The interview material clearly showed what profound changes and life adjustments a person with deafblindness goes through. It includes everything from smaller adjustments in everyday life to more profound changes. A theoretical support for these experiences is found in Gullacksen’s life adjustment model, that describes an adjustment in different stages (1998, 2002). We find it important to know where in the adjustment process a person is, in order to know what support to provide and when. The model also gives valuable knowledge of what the person’s energy is focused on and when it is suitable to work on motivation.

According to Gullacksen (1998, 2002), it is important to have professional support when a person finds out or is given a diagnosis, when
he or she is in a stage of life where vision and/or hearing is deteriorating, or when a person is going through a major change in life. It is particularly important with emotional support but also with information based on facts and guidance. We find it very important that help with crisis treatment is provided in connection with being given the diagnosis. Information and knowledge of the impairment, both for their own sake and for their relatives’, is something that most of the people that we have interviewed have missed, and none of them have been given any emotional support in connection with finding out (1). Eventually, when the person with deafblindness has realized that the impairment will have consequences on the life situation, both now and in the future, a more active rehabilitation process can begin. Consciously working to find appropriate strategies to cope with the demands of everyday life, ought to be an important part of the rehabilitation process for a person with deafblindness. During this active stage of the adjustment process, which can last for several years, confirmation is important, both from professionals and from other people with deafblindness and relatives. Relatives also need support and information during this stage (2). According to most of the people that we have interviewed, it is very valuable for the individual adjustment process to meet other people with deafblindness. Therefore, the rehabilitation process should include both individual and group activities, both for people with deafblindness and for their relatives. When life eventually goes back to being more stable and when control of the situation is regained, new goals and life projects may be formed (3). Competence to deal with the deafblindness and its consequences in different everyday contexts and situations has now been acquired. Now it is all about living with deafblindness from one day to the next (4).

Figure 1. Model of life adjustment, according to Gullaksen 2002.
By now, the results of the rehabilitation ought to be that people have the competence to change things, that they are their own experts, and that they know where to turn for help. They have learnt to “live with deafblindness” but the stress tolerance can be low (Gullacksen 1998, 2002). Many of the people that we have interviewed feel that ‘refills’ are needed recurrently all through life. Especially when hearing and/or vision deteriorates and when entering a new life adjustment stage where the old strategies no longer work in a satisfying way. Working with different strategies to deal with stress in everyday life is also an important part of the habilitation/rehabilitation process for people with deafblindness. Habilitation and rehabilitation work certainly has its ‘sell by date’ and does not always keep for a longer period of time but ought to be recurrent when the situations change.

It does not matter if the rehabilitation work is aimed at finding strategies for communicating with other people, or if it is about being able to orientate oneself in the close environment, learning to use a new aid, or learning to deal with the deafblindness emotionally – the life adjustment model is a good support in the rehabilitation work for people with deafblindness and their relatives. It also constitutes a good basis for a rehabilitation culture where the person with deafblindness is the main character and in charge of the rehabilitation process.

For people with congenital deafblindness it is more a question of dealing with external changes in life than with altered visual and hearing functions. Previously, and for many years, it has been a matter of choosing pre-school and school, relief support, short-term housing, assistants, and later on also group homes, employment, relationships, etc. People with deafblindness and their parents have often needed support, guidance, and help to co-ordinate these issues. Parents of grown up children with deafblindness and additional functional impairments need support when their child is entering into adulthood but also later on. It could involve being a support in the contact with different authorities, but also being an emotional support in the changed parent role when the child moves away from home and others take over the responsibility of the child’s everyday life.

One aim of the habilitation/rehabilitation in connection with deafblindness ought to be to strengthen the person with deafblindness and his/her close relatives during the different stages of the life adjustment process, in order to help them to develop means of dealing with the new situation both emotionally and practically in everyday life.
One main task in all habilitation and rehabilitation work for people with deafblindness, whether it is congenital or developed later in life, is to strengthen the social network around the person with deafblindness by developing strategies for interaction and communication in its widest sense. We have described earlier that conscious strategies are required to develop interaction, and to establish and maintain communication. It is possible to communicate in many different ways, and the most suitable way depends on the individual and a number of other factors. If a person is afflicted by or develops deafblindness later in life, after the spoken language is established, great attention has to be given to the non-verbal communication, what we sometimes call the body language. Difficulties in turn-taking, eye contact, feedback, distance, and perceiving nuances, are important factors that we have addressed previously in this chapter and for these areas it is often necessary to find new strategies for maintaining interaction with other people (Nilsson & Waldemarsson 1990). A number of aspects are important when it comes to deciding which strategies may need to be learned. In the chapter The child and the family, we describe our thoughts on working with communication and interaction further.

In order to form a picture of a person’s life history, we have used life-course lines (Wynne 2001). In this method, an image of the life going from childhood up until today is created and important events and crucial periods in life are emphasized. Significant persons, who and why, have also been circled. Working with life-course lines has given us an overview of the person’s background and especially how it has been perceived.
Born with hearing impairment

Family – mother, father, a sister

Nine-year compulsory school

Upper secondary school – Technical programme

Difficulties playing ball games

Difficulties seeing in the dark

20 yrs

Starts working

Joins a fly fishing club

In connection with taking driving licence – finding out!

Meets Kerstin – falls in love

Huge disappointment – loses foothold

Diagnosis – Usher syndrome

Active in a chess club

Marries Kerstin

Has two children

30 yrs

Deteriorating vision

Has to leave work due to the vision

Difficulties participating in activities concerning the children

Starts avoiding social contacts

Gives up previous leisure activities

Stays at home more and more

Avoids family gatherings

Joins FSDB

49 yrs

Difficulties having conversations with more than one person at a time

Does not want to use a white cane!

Finds new friends in FSDB

Thinks a lot about what will happen if vision deteriorates

The future?

53 yrs

Figure 7. Life-course line with own examples, according to Wynne, 2001.
The Environment – Activity and Participation

ICF chartings proved to be a good way of grasping important factors in the environment, since they provide a clear and concrete description of the present situation for a person with deafblindness. It is a good basis for drawing up a habilitation or rehabilitation plan, in particular when it comes to more assistive technology and pedagogical aid. To get information about other parts of the environment, ICF ought to be completed with methods that take into account individual life adjustment processes and the significance of networks. When dealing with a complex image that is difficult to grasp, ICF is an instrument that uses very concrete situations as its basis. It is a tool that helps people with deafblindness to structure, estimate and prioritize what kind of work that is required and in what order they are needed. Charting the environment together with the individual person and identifying the factors that are considered to be a hindrance or a relief, is very important when deciding what work should be prioritized, but also to involve the individual in discussions about methods and goals. A great advantage with this instrument is that the person with deafblindness becomes involved in assessing the impairment, something that is very important for participation in the habilitation/rehabilitation process.

In order to find out what the network looks like around a person with deafblindness, and how it may change over time, we have chosen to work with network maps (Wynne 2001). We chart both the personal network consisting of friends and relatives, and the professional society network. We have been able to see that the network changes over time. The personal network for people with deafblindness seems to shrink over time, and the professional network seems to grow. We have also noticed that the quality of the relationships changes over time. According to most of the people that we have interviewed, this is connected to the altered conditions for communication.

During the interviews, it became clear that there is a great need to co-ordinate the work around people with deafblindness, and many expressed a wish that someone with knowledge about deafblind issues would co-ordinate the work. Usually, there are no professional networks around people with deafblindness and one part rarely knows what the other is doing. Therefore, great efforts have been made to create networks during the project period. We have also worked on network basis around individual people with deafblindness and their personal and professional networks. Knowledge of the individual’s net-
work is an important tool in the rehabilitation work, both when working with co-ordinating different professional projects and when strengthening the social relationships.

Figure 4. Network maps, after Wynne 2001.
Sharing Experiences with Others

Something that recurred on several occasions during the interviews was the importance of meeting other people with deafblindness. The group consisting of people in a similar situation was pointed out as an important resource in the individual adjustment process. Some people have described the meeting with other people with deafblindness as a turning point in their lives. The group provides a sense of community, a chance to exchange experiences, a feeling of identification, and many other things. Discussing and exchanging experiences on major and minor issues, hearing how others have dealt with different problems, perhaps gathering the courage and strength to try something new – these are all examples of what can happen in a group when people with similar experiences of an impairment meet and start exchanging experiences. The group process leads to richer associations, and the group members strengthen each other at the same time as they practise activity and participation. The group also provides opportunities to look deeper into certain issues and some generalizations can be made. Examples of issues that may very well be discussed in groups are issues relating to
parenthood, society, working life, communication, everyday strategies, and dealing with stress. Group activity as a part of habilitation/rehabilitation work, requires a professional role with the competence to lead group processes. Those who took part in the focus groups, found it very stimulating and rewarding to meet and discuss important life issues, and during the project requests for continued group activities have been expressed. Outnumbering the professionals may also help creating a rehabilitation culture that strengthens the individual’s empowerment. Therefore, the rehabilitation process should involve both individual work and group activities, for people with deafblindness as well as for their relatives. However, choosing methods, whether individual or in group, should always be considered as a means to efficiently reach the individually set goals for every person with deafblindness.

**Spreading Information and Knowledge**

The need of knowledge about deafblindness runs all through the project. Just like we have mentioned previously, both people with deafblindness and their relatives need profound knowledge about and awareness of the impairment. It is important to be able to describe the functional impairment in a good way in different situations. Knowledge is also necessary in order to participate in the habilitation/rehabilitation process and to have control over one’s own life situation. Relatives of adults with deafblindness also need knowledge and support. Deafblindness leads to different changes in everyday life for the relatives too, which is why they also need support and information.

During the project is has been made clear that the authorities’ and individual professionals’ knowledge of deafblindness is very limited. People with deafblindness have told us about cultural clashes leading to misunderstandings. Therefore, we consider the spreading of knowledge to be an important part of all habilitation and rehabilitation work involving people with deafblindness. This includes both the personal and the professional network. Guidance and supervision for the individual person with deafblindness as well as the network, must be considered to be a part of the habilitation/rehabilitation process. Many people with deafblindness have described how they have felt offended in different situations, by different authorities or by individual professionals. One important task is therefore to improve the professional approach for supporting. Approach related issues must always be discussed and kept open among professionals and also with people with deafblindness, their relatives and in client co-operation groups.
CONCLUSION

When working with people with deafblindness and perhaps in combination with an additional impairment, we find it important to have a professional attitude based on the knowledge and experiences that people with deafblindness and their relatives have shared with us. This knowledge derives from having developed deafblindness and of having lived with it over time. Deafblindness leads to major changes in everyday life, both for the individual and for the relatives. Due to the complex nature of adult life, with responsibility for family, work and leisure, people are forced to make priorities. Demands and expectations of everyday life often create stress. There is no doubt that a specific service is required, but this service always has to be formed based on the individual needs. This calls for flexible and sometimes unconventional solutions, and different kinds of work solutions need to be provided on a regular basis, often for longer periods of time. During the project, it has been made evident that the work needs to be co-ordinated and made available to people with deafblindness. There is also a great need for knowledge development within this field.

• In order to make the social support system available for people with deafblindness, adjustments need to be made. Specific knowledge, time, structure, access to interpreters for people with deafblindness, co-operation and co-ordination of resources are examples of such necessary adjustments, both on organizational and individual level.

• Habilitation and rehabilitation work for a person who has developed deafblindness should be focused on strengthening the individual person with deafblindness and his or her relatives during the different stages of the life adjustment process, thus giving them the means to deal with the new situation both emotionally and practically in everyday life.

• Interaction and communication in its widest sense should be a comprehensive topic in the work with people with deafblindness. In order to strengthen the network around the person with deafblindness, the work ought to involve both the person with deafblindness and the social network.
• Charting the environment and the network around a person with deafblindness, as well as identifying the factors that are considered to be facilitating or hindering, is important when choosing and prioritizing work, methods and goals. It is also a valuable tool in co-ordinating the professional work.

• The group consisting of different people in a similar situation ought to be considered as an important resource for the individual adjustment process in the habilitation/rehabilitation work. The rehabilitation process should therefore include both individual work and group activities, both for people with deafblindness and their relatives.

• The individual as well as relatives and others around the person with deafblindness need knowledge about deafblindness.

• One important task for the Deafblind Team is to ‘build bridges’ and ‘spread information’ between people with deafblindness and the surrounding society.
AGEING WITH DEAFBLINDNESS

“There is a lot of people around me but nobody that I can talk to. It’s like living in a bubble. The staff can’t even tell me what’s for dinner or what the weather is like.”
(Ida, 95 years)
EXPERIENCES OF AGEING WITH DEAFBLINDNESS

Viola, 89 years

“I will never forget the day when my mother and I took the train to the deaf school in Lund. We never travelled anywhere and I didn’t know what was going on. Nobody had been able to explain that to me. I have never really been able to talk to my parents or siblings, which feels quite sad. After a while, my mother gave me a hug, turned around and walked away. I was left on my own with strangers. In the beginning I cried every day, but eventually I realized that it was pointless. My mother wasn’t coming back. It wasn’t until Christmas that I was allowed to go home, and it continued the same way all through school. I learned sign language at school. I trained to become a seamstress and found a job in Malmö. After a few years, I noticed that it became more and more difficult for me to see, especially in the dusk and the dark. The foreman at work noticed that I was insecure and clumsy, and after a while I had to leave. My vision got worse and it was more difficult to spend time with my deaf friends at the deaf club. It became difficult to see their signs and it took time for me to understand what they were talking about. They thought that I was strange and I felt left out. I got into contact with other people with deafblindness through FSDB, and I haven’t felt left outside there. At FSDB, there are people that I can spend time with and who understand me, but now I’m getting too old to participate in their meetings. I started perceiving the sign language tactually instead of visually many years ago. It wasn’t so easy at first. I felt unaccustomed to it and I thought that I missed a lot. Lately, it has become more difficult for me to manage to live on my own. Someone from home care service comes a couple of times a week but they can’t talk to me so it feels rather pointless. It is not very safe to live on your own when you can neither see nor hear. Most of all I would like to live somewhere where they know sign language so I don’t get so isolated. Home care service can come and leave without me noticing it. But the local authorities say that I am too well to live in a senior citizens’ home. It’s not enough to be old and both deaf and blind.”
Gertrud, 81 years

“Well, it all started when I was in my 70s and my vision got worse. My hearing was already quite poor and after that it has gradually deteriorated, not so that I have noticed the difference from one day to the next, but it’s getting worse. I’m used to my hearing aid now but in the beginning it was quite difficult. It was small and fiddly to set it right, and I thought that everything just sounded like noise. It just made me tired. But now it helps me if there’s only one person talking and if there’s no background noise. There’s not much left of my vision now. I can’t make out any details and I can’t go out on my own any more. I have been given some visual aids and someone from the Low Vision Clinic was here to make sure that I had good lighting. I think the tactile sense has become more important to me now that I can’t see that well. That means I can keep working with ceramics. It is so relaxing and I feel calm when I’m in my workroom. What I like best is experimenting with glazing. I used to do that quite a bit, but now there’s not much point in that so I mostly work with shapes. But one thing is sure, ceramics is not a very tidy handicraft. My husband has to clean everything and tidy up after me since he can see. We have been together for nearly 60 years now and we have always helped each other. He helps me in all situations. Sometimes the people close to you are too ambitious and help you even when you don’t need help, but they only mean well. But I’m a very independent person and it’s not fun to become dependent on others. I have some troubles with my back as well now. That makes me feel even more insecure when I go out. And the more I stay at home, the more insecure I feel. It’s no fun going around shops. I can’t see the garments and the colours any more. So no more of that. I just have to use what I’ve got. There’s no pleasure in getting all dressed up when you can’t see what you look like. I used to go to a lot of art exhibitions. I have been very interested in that, but now there’s not much to it. I use the computer though! I thought I was too old to learn how to use a computer; I was coming on to 80 when I got it, but it has been fine. I used to typewrite so I don’t have to see the keys. It was a man with deafblindness who taught me and now I can use it to send emails to my grandchildren who travel everywhere. That’s very nice, but I must say that it is a very bad combination indeed to lose both vision and hearing. When I meet people for the first time and tell them that my vision is very poor, they answer by saying: “then you can hear what people are
saying to you”. If I tell them instead that my hearing is poor and say that they have to speak clearly, I often get the reaction: “but then you can read lips, can’t you.” When I say to them that I can’t do either, then they don’t know what to say or how to treat me.”

Various Conditions for Life Adjustment

It is important to point out the differences also within the group consisting of elderly people. The largest group, seen to the number of people, is people with age related visual and hearing impairments that are so severe that they have problems communicating with other people and finding their way around independently in their environment. This is a combined visual and hearing deterioration that develops in connection with ageing. When vision and hearing alters over a period of time, like in Gertrud’s case, people often experience a gradual adjustment to the impairment.

“I can neither see nor hear very well any more, but that’s all a part of getting as old as I am.”

Many feel that they do not belong to the highly prioritized groups, neither at the Low Vision Clinic nor at the Department of Audiology. Some people describe how they are met by belittling comments such as “that’s part of life for someone your age”, or jokingly comments from friends and relatives like “well yes, but you can hear when you want to, can’t you”. We have also met elderly people who have declined different offers of habilitation.

“I’m so old now and I have actually heard and seen everything I need. I don’t have the energy to learn new things now.”

There is always a risk that an elderly person’s combined visual and hearing impairment is taken for other age related problems like forgetfulness or dementia, something that several of the participants also have pointed out. Understanding is largely related to the ability to take in, interpret and convey verbal messages. Therefore, there is a risk of confusing failing hearing with a failing intellectual or mental capacity (Lyng & Svingen 2001).

“It gets completely ridiculous sometimes when you can’t understand what people say. You answer something or other and then people think you’re becoming senile. That does make you feel a bit silly.”
When meeting elderly people with a combined visual and hearing impairment we find it hard to talk of the concept of deafblindness. Many elderly people see themselves as having ‘a visual impairment and hearing problems’ or ‘a hearing impairment and visual problems’ or simply think that they have ‘slightly poor vision and hearing’ due to their age. The majority has lived most of their lives with both vision and hearing. They are unable to identify with having deafblindness and therefore they will not think of turning to deafblind specific services for help. The same goes for the staff working with the elderly person.

“I’m so old now that I can’t count on being able to see and hear all that well. But of course I feel insecure now and again and quite often I stay at home by myself.”

A smaller group consists of elderly people who have lived with deafblindness over time and have been given a diagnosis that has led to deafblindness, often from earlier on in life. In this group, some communicate with spoken language and different assistive technology, others have had to start using a tactile form of communication, for example having the language spelled in the hands. Some people, like Viola above, have sign language as their first language but have had to start perceiving sign language tactually instead of visually. Before it comes to that, they have often had difficulties perceiving the language visually for several years. Several of the people that we have interviewed describe how dependent they are or have been of having the right distance to the person doing the signing, of the signs not being too large so they go beyond the very limited field of vision, or of the light being just right due to the risk of becoming glared or due to having poor night vision.

“If people just make the signs without thinking of the fact that I don’t see very well, then it’s hard for me to follow. The worst thing is to sit by a candle lit table. It’s supposed to be cosy but for me it’s simply a disaster. I can’t follow the other’s signs at all.”

Not all deaf people have learnt sign language. Some have managed just by reading the face and body language and by using written language. For someone like that, a deteriorated vision is likely to lead to serious communication problems if he or she is not given help to find new strategies for communication at an early stage. During the project, we have only met a couple of persons with deafblindness who have not had any functional methods for communicating with others. In these
cases, individual solutions and strategies must be found in order to develop a way of communicating with others, and it has to be completely based on individual needs and conditions.

The Personal Network – Communication or Loneliness

Several people mention loneliness as one of the major problems when hearing and vision deteriorates with ageing, the problem of not having anyone or just a few people to talk to. Elderly people with deafblindness that we have interviewed talk of an increased risk of pulling out of social contacts and getting more isolated. When vision deteriorates, many become insecure and scared of going out into unfamiliar environments, which makes it more difficult to take initiatives and follow conversations.

“It is important that the signs are made in a calm way nowadays. If there are two people using sign language I can follow, that’s fine, but if there’s more than two it doesn’t work. This is a huge change for me … and because of the deterioration I take it a bit easy. It’s better to stay at home.”

For some people, both people with deafblindness and their relatives, it can also be a difficult process to start using sign language tactually instead of visually. It involves breaking a habit. You have always communicated in a certain way with for example your husband, and now you suddenly have to be close to each other and hold hands each time you want to say something or ‘just’ comment on something. We have seen how this sometimes has led to difficulties in the relationship.

“It’s so annoying, every time I want to ask something or just comment on something that I see, I have to go up to him and take his hands. I have to drop everything else. That’s a bit irritating.”

Just like Gertrud describes it, deteriorated vision affects a person’s ability to read lips and everything else that we usually call body language. A hearing impairment affects a person’s chance of perceiving what is being said, the words and the nuances in the language. Those who use spoken language describe how they depend on just one person speaking at a time, and that the person speaks clearly and not too fast, that there is not too much background noise interfering, and that the lighting conditions are good. Difficulties in perceiving emphasis and other nuances of spoken language are also mentioned, just like difficulties with new words and concepts that come into a language
all the time. It takes a lot of energy to listen and try to perceive things that are said without too many misunderstandings. Some situations and environments are more problematic than others, for example communicating in stair cases, canteens, or out in the traffic.

“When there are many of us in the canteen, it’s difficult to follow what people are saying. It’s ok when there’s just one person talking, but that’s not very common when you go for a meal.”

Loneliness can consist of not having anyone to communicate with in one’s own language, for example at the service accommodation or the day centre. Living together with people that you are unable to communicate with or share activities with, makes you feel even lonelier according to several of the people that we have interviewed. Loneliness can also mean not having any or only very few relationships in life. Some describe that they still have both relatives and friends but that they feel lonely anyway because they cannot communicate with each other. The Association of the Swedish Deafblind is very important to many of the elderly people that we have met during the project. It is primarily described as a social network where you can meet others who know what it is like to live with deafblindness and a place where people can socialize on the same terms.

**Life Adjustment in Relation to Society’s Network**

We have found that elderly people with deafblindness or a more severe combination of visual and hearing impairments that we have met during the project are particularly vulnerable. Several of the people that we have met are cut off from information and participation in society. It can involve information about elderly people’s possibilities and rights, dialogues with doctors, district nurses and home care staff, or participating in different activities. When the need for care increases, problems often arise. Many describe that they feel unsafe in the meeting with the healthcare system. This notion comes from a feeling of not being able to express needs and wishes and of not being understood by others. We have found that elderly people wait as long as possible before they get in contact with the healthcare system. There is a great risk of misunderstanding or of not understanding information relating to the diagnosis, prognosis, medication, and side effects, which leads to worries and insecurity. During the project, we have come across a couple of instances where misunderstandings and a lack of information has led to severe medical consequences. In one case there was a
woman with deafblindness who had not had an interpreter with her to the doctor’s the last few times, and because of that she misunderstood the information about her medication. In the other case, the patient, who was deaf and used sign language, had waited too long before going to an eye specialist, which resulted in permanent visual impairment. The importance of having an interpreter in different situations has also been mentioned earlier in this report.

“I’m scared of becoming ill and having to go to hospital. The interpreter can’t be available all the time. How am I supposed to understand what the staff is saying and how should I be able to tell them if I’m feeling ill or if something hurts?”

Many people also experience problems when it comes to acquiring information about things that are going on, both in the close environment and in the world in general. During the project, we have met some elderly people with deafblindness using sign language who live in residential homes where everyone else is hearing and the staff does not know sign language. These people have felt very isolated. They have not been able to get answers to their questions and have not been able to express their most fundamental needs. This creates a profound feeling of insecurity and leads to misunderstandings which may, in the worst case, lead to mistakes and faults in the care provided. The lack of communication with the home care staff also creates insecurity and frustration. Some people feel that they do not have any influence over the service provided, but simply have to make do with and be grateful for what they get. During the project, we have met elderly people with deafblindness where it has been obvious that the huge lack of sensory impressions and communication with other people have had a negative impact both on their activity and participation, as well as on their psychological health. Elderly people with deafblindness express a great need of having a working communication with the staff in the residential home and within the home care service.

“Sure, I can imagine moving to Lindängelund in Malmö, even if it’s far from home. I’ll have people around me there that I can communicate with and that’s the most important thing for me.”

Quite a few elderly persons with deafblindness have contacted us during the project because the local authorities have not granted them guidance and/or transport services. They find it difficult to describe their situation so that the administrative official really understands their
needs. They say that it is becoming more and more difficult to get access to the local services, and the consequence of that is that they are unable to participate on the same terms as others. For those who have been granted transport services, other problems may arise. If the transport service does not turn up when they are waiting for it at a place where they are unable to find their way around and cannot make contact or communicate with others, it may cause a lot of stress and insecurity, says a man who has been in that situation a few times.

“They said I could only get five hours of guidance per week. But that’s barely enough to go to a meeting in the deaf association’s seniors’ group.”

Several of the elderly people that we have met during the project talk of the importance of having functioning assistive technology, especially to be able to participate and live an active life. In Gertrud’s case, both visual and hearing aids are mentioned. For many people it is important to have good lighting and of having the option to read large print. The chance of having hearing aids with a hearing loop connected to the TV, or having something to help them hear the door bell and the telephone is important for everyday life. Many elderly people have problems handling their assistive technology, particularly if it requires fine motor ability. The controls on the modern hearing aids are small and for someone who is a bit stiff or has reduced sense of feeling in the fingers it is a problem according to many of the people that we have met. Many of the elderly people with deafblindness have also told us that the computer based assistive technology have provided huge possibilities, especially when it comes to keeping in touch with other people and getting access to information about the surrounding world. And at the same time, many have told us of how time consuming it is to learn how to use the different functions on the computer when you cannot see or hear. Gertrud describes how important the computer was for her to be able to communicate with the surrounding world. For her it was not so difficult to learn how to use the computer since she was used to type writing. We have met several elderly persons who have learned to use their computers even though they belong to a generation that have not had any previous contact with computers. However, many think that they need many more hours of training than what they had when they tried the computer out.

Another opinion regarding the prescriptions of different means of assistance that has been made clear during the interviews and in the
rehabilitation work is the feeling of receiving more means of assistance than necessary. Someone told us that he left the Low Vision Clinic with much more means of assistance than he needed. Younger people with deafblindness have told us the same thing. Some say that they receive extra means of assistance because the professional becomes so overwhelmed by the impairment deafblindness that he or she does not know what services to provide. Instead, some extra means of assistance are prescribed, and in that way they feel that at least the have done something.

“I understood that the low vision therapist was overwhelmed when I arrived with two interpreters. I guess she didn’t really know what to do. I think she felt sorry for me because she gave me a lot of means of assistance that I didn’t really know what to do with.”

Thoughts about Time, Pace and Courage

Elderly people with deafblindness have expressed how their own bodies, as well as the environment change. Problems with vision and hearing make it hard to keep up in a society that is constantly changing and putting new demands on the individual. That includes the information flow in particular, which may be difficult to handle for someone who is getting older and whose vision and hearing is deteriorating. Several people have talked of how they are expected to keep up and manage on their own as far as possible, at the same time as they belong to the large group of non-prioritized people who often have to wait longer for visual and hearing aids. Being put on the waiting list when contacting the health care system has also been mentioned as a problem that reduces the possibility to participate and live an active life.

“They said that I would benefit from having some visual aids, but unfortunately there were many people before me on the waiting list. They said it would take a year! I may not even live then, I answered.”

According to many elderly people that we have met during the project, modern society has increasing demands on people to manage on their own. They feel insecure when they can no longer see or hear like they used to. Many elderly persons with deafblindness do not dare go out on their own, especially in unknown environments and when it is dark outside. They feel that it is too risky and that they may not find their way and get lost. This, together with the extensive communication
problems, increases the risk of isolation. We have met elderly people with deafblindness who have expressed a wish to spend their last years in a residential home for this particular reason, but who have been denied a place because their needs have not been considered severe enough. The pace of everyday life also changes dramatically when you get older, and especially if you cannot see or hear, according to many of the elderly people that we have met during the project.

“Everything takes time nowadays! I can’t hurry any more and I can’t keep at something for long. It’s impossible to do two things at once.”
STRATEGIES FOR SUPPORT

Within the group consisting of elderly people, a couple of groupings may be distinguished with different needs for support. One grouping, which is also the largest one, consists of people who have an increasingly harder time managing to communicate with other people, and to read, take in information from radio and TV, and move about independently and without problems, due to age related visual and hearing impairments. The majority of these people have lived most of their lives with vision and hearing. The other group is made up from people with either congenital deafblindness, or a diagnosis leading to deafblindness that is so severe that it leads to major limitations of the person’s chances of being active and participate from an early stage in life. They have lived with deafblindness and all that such an impairment involves in terms of adjustment processes, changed strategies for communicating, and many other factors described earlier in the report. Then there are also people who have lived all their lives with a primary visual impairment/blindness or a primary hearing impairment/deafness, and who acquire an age related visual or hearing impairment when they grow older. During the project, we have noticed that the different groups need help and assistance from society, but of somewhat different character. The first group has more general needs, including transport services, assistive technology, and an environment with knowledge of the impairment and of how to treat a person with a combined visual and hearing impairment. The other groups have more specific needs, including for example support in finding strategies for communication, support, and cultural mediation in the contact with different authorities in society, or emotionally support to be able to deal with the loss of senses. In the later case there is a need for staff with knowledge of deafblindness, as well as specific communication competence to meet their needs.

General Support

Based on our meetings with elderly people with deafblindness as well as our meetings with professionals in different sectors of society, we have found that there is a wide-spread lack of knowledge regarding the situation for elderly people with a combined visual and hearing impairment/deafblindness. This is reflected both in the meetings with the individual person and in the decisions that are made. The problem
areas and needs that have emerged in our meetings with elderly people with deafblindness include issues of responsibility on local and regional level.

If we should try to make a summary of the needs on the local level, they mainly concern the need for accessible elderly care, when the need for it arises. Accessible in terms of the individual person being able to participate in and influence the decisions that are made, but also in terms of a respectful and professional attitude. Elderly people who are primarily deaf and who become deafblind, usually have sign language as their first language. During the project, we have learnt that they find it just as important as others to be able to communicate with the staff around them, whether it is home care staff or staff at the residential home, all in order to have a proper life quality and a safe ageing. This is also confirmed in previous projects carried out in Skåne (Göransson & Malmström 2002). The staff’s awareness and knowledge of deafblindness is greatly important for the large group of elderly people with a combined visual and hearing deterioration too. The staff’s knowledge of the impairment can decide whether an elderly person feels a part of or left out of activities in for example the residential home or the day care. Another issue on local level is the access to transport service and guidance when needed. If a person is not granted transport service or guidance to attend different activities, he or she will not have the chance to live an active life and participate in activities. One condition for participating is that the guide is able to communicate with the person with deafblindness.

It is a regional, county council, responsibility to provide interpreters for people with deafblindness. Just like access to transport service and guidance, access to interpreters is essential to be able to participate in society. In some situations, it is a question of life quality, for example being able to go on an excursion, or taking part in a social activity. In other situations, just like we mentioned earlier, insufficient access to interpreters may create insecurity and in severe cases lead to health risks, for example in the contact with the health care system.

Providing visual and hearing related rehabilitation is mainly a regional, county council, responsibility. Most of the people that we have met during the project, including both elderly people and staff, seem to think that both vision and hearing changes with age. It is considered a natural part of ageing. There is a risk that elderly people’s need of support and assistive technology is also considered to be less urgent and that it is easier to neglect than if a younger person is afflicted. Most of
the elderly people that we have met during the project, ask for early and adequate help and sufficient instructions and support to be able to handle the assistive technology in the best possible way. That way it becomes easier to take in information and the conditions for handling communication with other people improves, even though the assistive technology is limited, especially when it comes to communicating with more than one person. Many of the elderly people that we have met ask for a co-operation between different authorities and co-ordination of the work provided. One example mentioned by several people is a co-ordination of the Department of Audiology and the Low Vision Clinic when it comes to prescribing assistive technology. In cases where the elderly person experiences difficulties despite the above mentioned support and service, more comprehensive pedagogical and psycho-social rehabilitation may be necessary.

The Individual Person’s and the Network’s Needs for Specific Support

There are no given models or routines for how to provide support; instead everything has to be based on the individual person’s situation and condition to find out where in the adjustment process he or she is, and the network, both the personal and the professional, must be charted in order to provide a good support. To get a good picture of the elderly person’s specific needs, we think it is good to start the charting on the elderly person’s own arena with one or, if needed, several house calls. In the home environment, the needs are more clearly connected to the context, involving needs in everyday life, whereas in an office the individual’s needs are simply ‘narrated’ needs, thus giving more limited information of everyday life. The home environment provides a basis for assessing the help that is required. It is also important to form an idea of the elderly person’s network on an early stage, both in order to co-ordinate the work around the individual and to get an idea of what support the network can constitute.

A lot of the things that have been said earlier in the report are valid for elderly people with deafblindness too, but there are some differences, especially when it comes to people with age related combined visual and hearing impairments. Most of the elderly people do not think of themselves as people with deafblindness, and therefore do not seek out the Deafblind Team on their own initiative. The support work should mainly fall on the local authorities, the Low Vision Clinic, and the Department of Audiology, but also, if there are specific needs,
on the Deafblind Team. The Deafblind Team’s role should be consultative towards the elderly person’s network, both the professional and the personal, and especially intended for providing specific knowledge about the impairment in order to strengthen the networks around the individual and improve the professional approach for supporting as much as possible. The Deafblind Team can also function as a link between visual and hearing rehabilitation for the elderly person. In some cases, a more comprehensive pedagogical and psychosocial rehabilitation may be required, for example if someone needs emotional support in the process of learning how to live with the impairment, has drastically deteriorated vision or hearing, or needs support in finding strategies to handle the communication with the environment better. As for computer based assistive technology, it is the Deafblind Team’s responsibility to determine the need of and prescribe assistive technology for people with deafblindness in all ages.

People with congenital deafblindness or with a diagnosis that has lead to deafblindness early on in life, deaf people using sign language and who have developed deafblindness, or elderly people with deafblindness who have major communication problems, should have access to the Deafblind Team’s work. It may include support in changing or developing strategies for communicating, something that calls for specific knowledge about communication, and means that the rehabilitation staff must know sign language and be able to use it both visually and tactually. The same competence is required to give a person with deafblindness using sign language emotional support, for example in the form of a conversation partner, and it is unrealistic to demand of the local and regional authorities to have this competence. In cases when a person does not have a working method for communicating with others, due to deteriorated vision and hearing, individual solutions and strategies must be found in order to develop communication, and they have to be completely based on individual needs and conditions. This requires great flexibility and specific competence within the field of communication and interaction. Support for elderly people with deafblindness may also include being a link between the elderly person and different authorities and transferring knowledge and information in both directions, as well as being a support when applications have to be filled in or when discussing consequences of decisions that are made, etc. However, this role should not be mixed up with the interpreter’s role.
Geriatric Care for Sign Language Users in Skåne

In Skåne, there is now an established geriatric care system specifically developed for elderly deaf people or people with deafblindness using sign language. But there are still people with deafblindness using sign language who are part of the home care service and live in specific homes who cannot communicate with the staff. Because of this, a lot of elderly people do not feel part of the care that is provided or feel unable to influence it. Several of the people that we have met during the project, express how worried, insecure and despairing they are because of this situation. The basic needs of elderly people with deafblindness are no different from those of other elderly people, but in order to reach the national goals for Swedish geriatric care, the local authorities must meet certain quality demands. However, it is not realistic for each local authority to establish service for elderly people with deafblindness and manage to maintain the competence that is required. Therefore, here in Skåne, we have chosen to develop a cooperation that crosses the borders between the local authorities and between local and regional authorities, a cooperation that has proven to have a number of positive consequences.

In 2001, the committee for public health and care in Malmö (Folkhälso-, vård- och omsorgsberedningen i Malmö) decided to give Malmö’s City Office the task of developing a proposition for “a vision regarding the future geriatric care for deaf people using sign language.” The work was to be carried out in cooperation with representatives from different groups in Skåne: Malmö Deaf Association “Svenske,” the Association of the Swedish Deafblind, the Skåne Association of Local Authorities, Lernia Hadar, as well as the Hearing and Deafness Division in Region Skåne. The work group defined a few areas that were particularly important for developing the geriatric care for deaf people and people with deafblindness using sign language in the direction prescribed by the national goals for geriatric care.

- Establishing specific housing
- Developing the home care service
- Establishing a post for a regional seniors guide
- Developing the choice of activities and improving their accessibility

In September 2002, the committee for public health and care in Malmö accepted the work group’s proposition and more detailed plans could be initiated. In June 2003, Malmö’s City Executive Board and the City
Council decided to establish a geriatric care for deaf people and people with deafblindness using sign language. This resulted in the residential home Lindängelund in Malmö, holding ten residential places. The home is also intended for elderly people living in other municipalities than Malmö. People using sign language living in Malmö also have access to home care service in sign language.

Regional counsellors for the elderly, following a Danish model (Gramstrup 1999), was also described in the work groups proposition and resulted in a 3 year project about guides for elderly people using sign language, projekt äldrevägledare för teckenspråkiga, financed by the Swedish Inheritance Fund. The idea for the project was to build up a resource working as a bridge, a link between elderly deaf people and people with deafblindness and the environment. This involves providing elderly people with information about rights and possibilities, being a support in the contact with different authorities, breaking the isolation by helping to establish contacts and initiate activities. It also involves working towards different authorities and providing information about identified needs, informing and educating staff within the local authorities, being there as a support for the elderly people when drawing up care plans, etc.

These parts together constitute a united plan for the care of elderly people using sign language, and it is an important resource and cooperation partner for Region Skåne’s Deaf and Deafblind Team. During the project, we have come into contact with elderly people with deafblindness using sign language, who have been denied specific geriatric care by their home municipality even though they meet all the criteria, and who feel deeply insecure in their present situation and are completely unable to communicate with others in their environment. For the individual person, this has resulted in an uncertain wait and lengthy lawsuits, before finally moving to Lindängelund. In these situations, the Deafblind Team can be a link in the discussions between the elderly person and the local authorities and inform elderly people with deafblindness about the specific resources that are described here.

Sharing Experiences with Others

On several occasions in the report, we have mentioned how important it is to meet others with the same kind of impairment. Elderly people with deafblindness also mention how important it is to be able to discuss things with others who “know what it’s like” or just to see others and have a good time. Many people with deafblindness take
an active part in different associations even as they get older. They travel to annual meetings and conferences and take part in different local activities. We have also seen that members of FSDB take great responsibility for their senior members. They visit them at home, help them in their contacts with authorities, contact the DeafblindTeam for them if needed, and practise computer skills. We have also noticed that a surprisingly large number of elderly people with deafblindness use their computers regularly to communicate with others and to find information. For many of the elderly people that we have met, chatting with friends via the computer is a valuable way to keep in contact with friends and relatives, especially since many elderly people with deafblindness have a difficult time going out on their own.

**Spreading Information and Knowledge**

One of the most important tasks for a DeafblindTeam when it comes to elderly people, is to spread information about deafblindness. Spreading information to the network around the elderly person, to relatives, friends and staff, is likely to increase the understanding and lead to an improved attitude. For example, when it comes to moving to a residential home, it is important that the staff is aware of the person’s needs, difficulties but also possibilities, before he or she moves in. A strong network also makes the situation around the elderly person less vulnerable, and gives more people knowledge of what deafblindness is, what kind of help there is, and where to turn for appropriate assistance. One way may be to create a network of contact persons among the local authorities who contact the DeafblindTeam when necessary, or who know where to turn if an elderly person with a combined visual and hearing impairment/deafblindness needs visual or hearing aids. Another way of spreading knowledge about elderly people and deafblindness is via information handouts containing simple tips and approaches, as well as information on where to turn with questions. The Swedish Resource Centre for Matters Regarding Deafblindness has put together a material about elderly people with combined visual and hearing impairment, deafblindness, called *Äldre med kombinerad syn- och hörselnedsättning – dövblindhet* (2005), which can also be sent for. Local and individual information could very well be added to this material. It is important to spread the information so that it reaches the environment of elderly people with deafblindness.
CONCLUSION

Several elderly persons have told us that they have been met by faulty and negative attitudes from different authorities and individual professionals that they have been in contact with. This includes for example a lack of knowledge of the impairment, which has led to incorrect priorities and decisions. It is important that elderly people with a severe combined visual and hearing impairment/deafblindness have a higher priority when it comes to waiting within the health care system. Having to wait too long for a visual or hearing aid or for cataract surgery if you are deaf or have a severe hearing impairment, may lead to great suffering and severe consequences for the individual person and his or her relatives. Once again, we would like to stress the importance of co-operation between different authorities and actors, especially between the local and the regional authorities (county councils) and in particular when it comes to elderly people with a combination of severe visual and hearing impairment.

As we have mentioned earlier, the group consisting of elderly people is a very heterogeneous group, and during the project we have noticed that elderly people with combined visual and hearing impairments/deafblindness need a lot of support from the society. On the one hand there is the general need of for example transport service, assistive technology, and an environment with knowledge of the impairment and of how to best treat a person with combined visual and hearing impairment. On the other hand there are the more specific needs such as the need for support in finding strategies to communicate, support and cultural mediation in the contact with different authorities in society, or support in the emotional processing of losing important senses. In the latter, there is a need for staff with specific knowledge of deafblindness as well as knowledge of how to communicate, in order to meet the needs through dialogues with the individual person. The strategies that meet the demands for support may be concluded in the following paragraphs:

- The group consisting of elderly people includes both people who have a combined visual and hearing impairment/deafblindness as a consequence of ageing, and people who have lived with deafblindness over time. In order to meet their needs, the support needs to be formed in different ways, ranging from general public health information of what it means to live with a combined visual and
hearing impairment when you get older, to a more deafblind specific support.

- The public health perspective about the impairment deafblindness needs to be developed within geriatric care and the health care system, especially to improve and change attitudes.

- The specific needs are probably best met in a specialized Deafblind Team, whereas the more general needs ought to be met by the regional (county council) Low Vision Clinic and Department of Audiology, the home municipality, and the close network.

- The Deafblind Team’s role vis-à-vis the group of elderly people with visual and hearing impairments/deafblindness should primarily be consultative towards the individual’s network and above all spread specific knowledge about the impairment, in order to strengthen the networks around the individual.

- It is a regional (county council) responsibility to provide visual and hearing rehabilitation, interpreter services, and more comprehensive pedagogical and psychosocial rehabilitation in cases where compensatory assistive technology is insufficient.

- It is a local responsibility to meet the needs for adequate geriatric care, access to transport services and guidance when required, as well as staff with knowledge of how to meet these needs.

- Co-ordination and co-operation of the work intended for elderly people with combined visual and hearing impairments/deafblindness is both a regional (county council) and local responsibility.

- A valuable part of rehabilitation for elderly people with deafblindness is to discuss the impairment in groups together with other people and to learn new strategies to manage their everyday life better.
DISCUSSION
When a person or a family becomes afflicted by deafblindness, the consequences are significant both for the individuals themselves and for their environment. Deafblindness in this report uses a functional aspect as a basis: experiences in everyday life, the individual life adjustment process, the individual’s strategic inner work, the social context, and the significance of the environment in the experience of the impairment. The strategies for support that we focus on and describe are based on experiences gathered through interviews and meetings with children, adolescents, adults and elderly people with deafblindness as well as their relatives.

The project process has consisted of alternately collecting interview material, reading literature, analyzing, conducting new interviews, going on study visits, having discussions with colleagues, organizing dialogue seminars with clients, reading more literature, doing practical work with people with deafblindness and their network, exchanging experiences within the Nordic countries, further analyzing etc. This process has deepened and developed our knowledge of the issues through continuous theoretical analyzing in relation to literature and research, which then has been tried in practical work.

The pre-study gave us certain theoretical research perspectives, which we then focused on when we continued the project. We chose theories from the social sciences based on what we think is important for people with impairments in the modern society, theories on individual life adjustment processes, the environmental perspective, and the life course perspective. After that, we divided the theories into methods and instruments, a way to make the theories concrete in the practical work. We found that the instruments that had this function were the life adjustment model (Gullaksen 1998, 2002), ICF (The National Board of Health and Welfare 2003), charting the networks (Wynne 2001), and charting the life course (Wynne 2001). Using these instruments, we were then able to circle the areas that are significant for habilitation and rehabilitation. The theories and the instruments become guiding principles in the practical work with people with deafblindness and their networks, but they do not say anything about the
individual needs. The needs must always be discussed in close dialogue with the individual person. An important factor in strengthening the empowerment process so that the individual can regain or keep control over his or her situation, is that the relationship between the client and the professional is based on equality and sensitivity for each other's knowledge and experiences (cf. The United Nations Convention on the Rights of the Child 1989 and Convention on the Rights of Persons with Disabilities 2006).

Figure 9. The basis for the deafblind specific support.

The Relevance of the Theories

How relevant are the theories that we have chosen in relation to deafblindness? That is a question we asked a large group of people with deafblindness at an early stage of the project process, with the purpose of having some response to our way of using for example the life adjustment model (Gullacksen 1998, 2002). We had also deepened our knowledge of the theories, had seminars with Ann-Christine Gullacksen, used the theory in interviews, tried the model as an instrument, etc. Now, we wanted to return our experiences to the clients in order to find out if we had made an accurate analysis of the model in relation to their experiences of deafblindness. This was done at a national client seminar and was met by great interest. A discussion was started among the clients and we were asked to write an article about the life adjustment model on their web site. Six months later, we took part in another national seminar with the client organizations, on the same topic. On that occasion it became evident that the clients...
had started to think and reflect over their own experiences of the life adjustment process. We have found blogs on the internet where people with deafblindness discuss and write about life adjustment in relation to deafblindness; it has become a familiar and used concept among the clients. We have also used the model as a direct basis for discussions in the actual rehabilitation work, both with individual people and in groups. Our conclusion is that Gullacksen’s theory about the life adjustment process both affect and is considered important for people with deafblindness, something that many can recognize and can relate their own everyday life and situation to. This will work as an example of how we have discussed, tried, and evaluated the theories together with the clients, so called communicative validity (Kvale1997).

We have also had similar dialogue seminars about other topics that have cropped up during the interviews, something that we have addressed previously in the report.

The Individual’s Need of Support

We can ascertain that there is a huge gap between the individual person’s everyday life and society’s goals regarding citizenship, activity, and participation. Despite the extensive inner resources that individual persons with deafblindness possess, their everyday lives are often very exposed in a way that is not always visible to others. This includes a large number of insecurity factors and sometimes actual risks as well. When a person is unable to control the environment using his or her vision and hearing, it can lead to stress related problems and a feeling of insecurity. Most things in society are based on a person being able to see and hear. Special adjustments are required in order to make information, relationships, and contacts with others available to people with deafblindness, all of which are conditions for activity and participation. Specific knowledge, time, structure, access to interpreters for people with deafblindness and guides, co-operation, and co-ordination of resources, are all examples of such necessary adjustments, both on organizational and individual level.

The main purpose of the project was to identify the needs and, based on that, develop and structure pedagogical and psychosocial support to people with deafblindness in Skåne, as well as to their relatives.

Some of the needs and questions that people with deafblindness and their relatives have shared with us are of a more urgent nature. This includes for example problems with life adjustments, crises related to
family or work, problems with different authorities in connection with applying for transport service, guidance or sickness benefit. It has also involved more long-term needs of habilitation and rehabilitation, including for example learning new strategies to communicate, orientating independently, learning how to use new assistive technology, finding new coping strategies and abandoning the old ones that do not work any more. In the interviews, we have not been able to see any clear connection between the way a person deals with the deafblindness or the need of support, and the diagnosis or the degree of deafblindness. However, many of the people that we have interviewed and met during the project, have described how the need of support increases during periods of deteriorated vision and/or hearing. Periods during which the deafblindness is more stable are described as calmer and more manageable. The work with people with deafblindness must be carried out on several levels. On the one hand it is a question of working towards the individual, but it is just as often a question of strengthening and co-ordinating the networks around a person with deafblindness, both the personal network and the professional.

People with deafblindness that we have interviewed and met in different situations during the project, have often emphasized their wish to meet professionals with specific knowledge of deafblindness. It is not enough just to have knowledge of visual and hearing related problems separately, without knowledge of the specific problems that the combination leads to. In order to meet the client in a close dialogue and to establish a genuine relationship based on confidence, professionals working with people with deafblindness also need specific communication competence. This means that they need to be able to communicate directly both with people with deafblindness who use spoken language and with people with deafblindness who use sign language, and they need to be able to use sign language both visually and tactually. This knowledge is also necessary for charting, assessing, motivating, and consciously working with communication and co-ordination strategies, a need that we have encountered in our meetings with several people with deafblindness during the project. However, the proportionately small number of people with deafblindness makes it difficult for professionals to develop this knowledge and experience. Therefore, there is a risk that the service does not have the quality that people with deafblindness and their relatives are entitled to expect. It is also unrealistic to expect each local authority and smaller county council to establish specifically aimed services for people with deaf-
blindness and be able to develop and maintain the required competence. In order to guarantee the quality and to co-ordinate the work, we think that there is a need for regional resource teams for people with deafblindness in Sweden, a structure available in for example Norway. Today, there are three regional teams for people with deafblindness in Sweden: Stockholm County Council, Region Västra Götaland, and Region Skåne. Approximately half of the country’s population lives in these three regions.

Networks

The lack of co-operation and accordance in the professional world has characterized all the interviews. It has become clear that there is a huge need to strengthen the co-operation in different ways and on different levels. We have been able to distinguish an evident need of organizing professional networks around people with deafblindness, among other things in order to achieve a long-term support plan, to develop a sense of accordance and common strategies, and especially to reduce the number of professional contacts around the individual person. Professional networks with clear responsibilities, methods and aims, are great resources in the work with people with deafblindness and their relatives. Another factor that becomes evident in the habilitation/rehabilitation process is the need to work with strengthening the personal network around the individual person with deafblindness. The interviews showed that as the professional network grows and becomes more difficult to deal with, the personal network tends to shrink. That is an indication of the need for a long-term habilitation/rehabilitation plan involving the individual’s closest network. The close network, including relatives and friends, is an invaluable resource when it comes to support in everyday life, according to many of the people that we have interviewed. But relatives and friends may also need support when someone close to them develops deafblindness. The comprehensive adjustment process that we have described affects the person with deafblindness, but it also affects the close environment in different ways. There is a need to deepen and develop the knowledge about network based methods and ways to work, and of implementing these in the work with people with deafblindness.

Sharing Experiences with Others

The group consisting of people who are in a similar situation, peer groups, is considered an important resource, both for people with deaf-
blindness of all ages, and for parents and other relatives. Several people have mentioned that they feel as though they are the only ones with deafblindness or the only ones who have children with deafblindness. Therefore, it becomes especially important to meet others and share experiences. Meeting others appears to have a healing effect and is important for the empowerment process. Many people feel strengthened by meeting other parents or other people with deafblindness, in a way that is only possible with others who know what it is like to live with this impairment. Several people have described the meeting as a turning point in the life adjustment process. A consequence for the professional field is to create possibilities to meet, both for clients and relatives. Group activities ought to be an important part of different kinds of work intended for people with deafblindness, an area that also needs to be developed and studied further.

Knowledge – Knowledge Development – Knowledge Transfer

To enable a person to change his or her life situation and be able to influence his or her environment, knowledge of and insight into the impairment in relation to life is crucial. The habilitation/rehabilitation process itself may be considered to be a learning process where the individual person gradually develops this knowledge. Our opinion is that people with deafblindness need detailed knowledge. They need to become experts of their own impairment in order to meet the environment in different situations. Information about the diagnosis, prognosis, consequences, etc., is all part of a process that must be allowed to take time and that must develop in relation to the person’s age, maturity, and where in the life adjustment process the individual person is.

At the beginning of the report, we referred to the dynamic process that constantly takes place between the individual person and society (Berger & Luckmann 1966, Jarvis 1992). For this process to be meaningful for the individual and the close network, knowledge must be developed and become accessible in all parts of society. People with deafblindness are citizens and should, just like everyone else, have access to the social welfare system. Vision and hearing are our most important senses when it comes to sharing our lives with others and being active and participate in society. This includes both children and adults and ought to involve areas like school, health care, care, habilitation and rehabilitation.

When meeting people with deafblindness and their relatives, it becomes clear that there is a lack of knowledge in society. This has huge
consequences for how different authorities and individual professionals assess the need of support and provide assistance. It becomes clear that knowledge about deafblindness must be developed and spread, and that includes both general knowledge about deafblindness and specific knowledge about an individual person’s needs.

THE NEED FOR CONTINUED STUDIES AND DEVELOPMENT

The theories and perspectives that we have chosen and tried during this project, and that we have found to be of use in the daily work with people with deafblindness and their relatives, are based on a social sciences research perspective. Within the framework of this project, it has been impossible to further develop all the areas that have arisen during the interviews and the meetings. Since the main purpose was to develop and establish pedagogical and psychosocial support to people with deafblindness, we chose to analyze the results of the interviews against theories focused on individual life adjustment processes, the environmental perspective, and the life course perspective.

The Nordic project about experiences from people with deafblindness, Erfarenheter från människor med dövblindhet (Jansbøl & Olesen 2005), is the result of a Nordic co-operation where twenty people with deafblindness from the Nordic countries have been interviewed during a five year period. The project’s starting point was the participants’ experiences of everyday life and the result was analyzed against theoretical concepts like coping, the sense of coherence, creating a meaningful life, health, the ability to act, and communication. Looking at the results of our project and the Nordic project (2005), we are able distinguish some areas to develop.

One subject that became evident during the final analysis of the interviews, was the experience of stress. Thoughts and feelings of stress are present and expressed in different ways during the project, and we consider this to be an area that needs to be further studied. Stress can be regarded as a consequence of an imbalance in the interaction between the individual and the environment, or as a consequence of significant imbalances between the individual’s resources and the environment’s demands, something that we have seen many examples of in our meetings with people with deafblindness. It involved stress in relation to not being able to communicate with others, not being able to move around freely and independently, of not being able to keep up
with the work tasks the same way as before, of not being able to do what you want at any time, etc. The stress concept is closely related to the coping theory presented in the theory chapter which also plays a central part in the Nordic project (Jansbøl & Olesen 2005). The term coping refers to the way a person tries to deal and cope with stress in a particular situation. The purpose of coping strategies is to reduce stress in everyday life. It would be very valuable to develop this further, to look into stress in relation to deafblindness with the purpose of finding good methods to deal with stress in everyday life.

Another area to further develop is knowledge of the factors that make it possible for people with deafblindness to manage with everyday life and their own life situation with the independence they actually have, despite their severe impairment. During the project, we have often thought of the fact that people with deafblindness have large resources to manage with everyday life, to live a social life, and to be active and participate in society in different ways. One approach would be to investigate the so called health factors or success factors, for example based on the sociologist Antonovsky’s theory (1991), sense of coherence (SOC). His research shows that people’s experiences of life as meaningful, understandable and manageable, is decisive for how they deal with crises and difficult misfortunes in life. These concepts are also discussed in the Nordic project (Jansbøl & Olesen 2005). As a basis, Antonovsky bases his work on factors that influence people in a positive way and promote good health – a so called salutogenic perspective – instead of looking for factors that create difficulties and ill-health. Based on this perspective, an important starting point in the habilitation/rehabilitation process is to identify and continue to establish the resources that people have, instead of training and trying to strengthen things that do not work.

During the project, difficulties in communication and social interhuman interaction in a wide sense, is what we have found to be most specific in relation to the impairment deafblindness, irrespective of age. There appears to be a widespread accordance in the Nordic countries around theories and methods in relation to working with interaction and communication development in connection with congenital deafblindness, described earlier on in the theory chapter. However, when it comes to the need for a changed communication and interaction among people with acquired deafblindness, we have not been able to find any common strategies. When losing both vision and hearing, the communicative competence and the competence of being social
with others are negatively affected, to various degrees. We consider it to be an important research and development area that ought to be prioritized on a Nordic level to find alternative strategies and methods for compensating the loss of vision and hearing in situations of communication and interaction with other people.

The development areas discussed above are some examples of areas that need to be further studied. It is of great value that the research takes place as further development work and research on a national and Nordic level, which is why a co-operation between field work and universities ought to be developed.

**CONCLUSION**

We consider the goals and purposes we had for this project to have been achieved, and the theories and methods we have used to have been appropriate. We have a more stable theoretical basis to stand on and we have developed useful methods and tools in working with people with deafblindness and their networks. There is a huge qualitative value in developing and forming a work field through a project process, like the one described in this report. Our hope is also that the project has led to the formation of a solid basis for further discussions within the field and good starting points for co-operation between clients and professionals as well as between different work fields. However, a lot remains to be done, and our hope with this project is to inspire a continued development within the field of deafblindness.

“Deafblindness means a life adjustment that I do not choose myself; it afflicts me. The new condition becomes an uninvited and unwelcome guest. No matter what you think of the guest, you have to learn to live with it.” (Lex Grandia 2002)
THANKS AND ACKNOWLEDGEMENTS

The members of the project group would like to THANK everyone who in some way has been part of and involved in working with this project.

A particular THANKS to all the people with deafblindness and their relatives who have been a committed and generous support and who have made the project possible.

THANKS to the Association of the Swedish Deafblind (FSDB) for the good co-operation, for all the rewarding conversations, and for the warm support in the hard work stretching from project to Deafblind Team.

We would like to THANK everyone who has been involved in the project in some way: the steering group, the reference group, the supervisors, professionals and politicians from Habilitation and Assistive Technology in Region Skåne, the staff at the Hearing and Deafness Unit, and everyone who has supported us with knowledge and experiences in different ways.

Kerstin Liljedahl, head of R&D at Habilitation and Assistive Technology in Region Skåne, has guided us through the whole project process with her extensive knowledge and profound involvement, THANK YOU.

THANK YOU Ann-Christine Gullacksen, for guiding us through your research on life adjustment processes.

Lennart Siegfeldt, certified psychologist and supervisor, THANK YOU for guiding us in having a professional approach and in the process of creating a team.

We would also like to THANK all of our colleagues, both in Sweden and in the other Nordic countries, for rewarding and enriching discussions, and for sharing your knowledge and experiences.

THANKS to the Swedish Inheritance Fund who has been generous in granting means for this project.

THANKS to the Mo Gård Group for the excellent co-operation, and for being willing to publish the English edition of this book.
THANKS Emma Leonard and Anna Aronsson, translators, for a fine co-operation and great commitment during the English translation of the book.

Lena Göransson
Fredric Dacke
Helene Engh
Elisabeth Lindström
Lena Sjölin
<table>
<thead>
<tr>
<th>TERMS AND ABBREVIATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Auditory perception</strong></td>
</tr>
<tr>
<td><strong>CHARGE syndrome</strong></td>
</tr>
<tr>
<td><strong>Cochlear Implant (CI)</strong></td>
</tr>
<tr>
<td><strong>Coping</strong></td>
</tr>
<tr>
<td><strong>DBU</strong></td>
</tr>
<tr>
<td><strong>Empowerment</strong></td>
</tr>
<tr>
<td><strong>FSDB</strong></td>
</tr>
<tr>
<td><strong>Habilitation</strong></td>
</tr>
<tr>
<td><strong>Haptic perception</strong></td>
</tr>
<tr>
<td><strong>HAREC</strong></td>
</tr>
<tr>
<td><strong>HSL</strong></td>
</tr>
<tr>
<td><strong>Long distance senses</strong></td>
</tr>
<tr>
<td><strong>LSS</strong></td>
</tr>
<tr>
<td><strong>Non-verbal signals</strong></td>
</tr>
<tr>
<td><strong>NUD</strong></td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td><strong>Progress</strong></td>
</tr>
<tr>
<td><strong>Rehabilitation</strong></td>
</tr>
<tr>
<td><strong>Retinitis pigmentosa</strong></td>
</tr>
<tr>
<td><strong>Semiotics</strong></td>
</tr>
<tr>
<td><strong>Short distance senses</strong></td>
</tr>
<tr>
<td><strong>SPM</strong></td>
</tr>
<tr>
<td><strong>Tactile perception</strong></td>
</tr>
<tr>
<td><strong>Usher syndrome</strong></td>
</tr>
<tr>
<td><strong>Visual perception</strong></td>
</tr>
<tr>
<td>Author(s)</td>
</tr>
<tr>
<td>-----------------------------------</td>
</tr>
<tr>
<td>Ask Larsen, F.</td>
</tr>
</tbody>
</table>


FSDB’s parents’ council 2006. Föräldrar kan. Om familjer som har barn med dövblindhet, om deras behov och rätt till stöd.


Hild, E. All sculptures in the report. www.2hild.com


<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Year</th>
<th>Title</th>
<th>Institution/Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lie, I.</td>
<td>2001</td>
<td>Rehabilitering og habilitering.</td>
<td>Oslo: Gyldendal Norsk Forlag AS.</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Year</td>
<td>Title</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td>Möller, K.</td>
<td>2002</td>
<td><em>Kartläggning av konsulenter för vuxna med dövblindhet.</em> Örebro.</td>
<td></td>
</tr>
<tr>
<td>Nordic Cooperation on Disability</td>
<td>1980</td>
<td><em>Bättre livsvillkor för dövblinda i Norden.</em> Vällingby.</td>
<td></td>
</tr>
<tr>
<td>Nordic Staff Training Centre for Deafblind Services</td>
<td>2006</td>
<td><em>Jubilæumsskrift.</em> Dronninglund: NUD.</td>
<td></td>
</tr>
</tbody>
</table>


Raanes, E. 2006. Å gripe intrykk og uttrykk. Interaksjon og meningsdanning i døvblindes samtaler. En studie av et utvalg dialoger på taktilt norskteckensprog. Dissertation for the degree of Doctor Artium. The Norwegian University of Science and Technology; The Faculty of History and Philosophy, Department of Language and Communication Studies, Trondheim.


The Information Center for Acquired Deafblindness 1+1=3 Vejledning om ældre døvblindblevne for forebyggende medarbejdere. Herlev.


The Information Center for Acquired Deafblindness and Nordic Staff Training Centre for Deafblind Services 2000. PFP, En guide til Personlig Fremtids Planlægning. Aalborg and Dronninglund.


Wynne, B. 2001. *Rehabiliteringsmodell från Helen Keller National Center, USA.* Lecture from a basic course at NUD.
APPENDIX 1

MEMBERS OF THE STEERING GROUP

Sven Sjöberg, The Association of the Swedish Deafblind, Enskede
Katarina Rasmusson, The Skåne Association of Local Authorities
Helén Holmström, The Vision, Hearing and Deafness Division, Habilitation and Assistive Technology, Region Skåne
Kerstin Liljedahl, R & D, Habilitation and Assistive Technology, Region Skåne
Lena Göransson, The Vision, Hearing and Deafness Division, Habilitation and Assistive Technology, Region Skåne

MEMBERS OF THE REFERENCE GROUP

Peter Lundgren, The Association of the Swedish Deafblind Skåne
Arne Lorentzon, The Association of the Swedish Deafblind Skåne
Helene Sjöberg, The Association of the Swedish Deafblind Skåne
Gertrud Sörensson, The Association of the Swedish Deafblind Skåne
Johan Möller, Swedish DeafBlindYouth
Daniel Olsson, Swedish DeafBlindYouth
Ann-Cecil Olsson, Parents’ section of the Association of the Swedish Deafblind
Birgit Bergström, the Low Vision Clinic, Malmö
Mona Brink, Sofia dagcenter, Lund
Bo Lang, the Municipal Committee of Health care administration, The Municipality of Kristianstad
Ingegerd Sandling, the City of Malmö
Erik Hülphers, Deaf psychiatric care of adult outpatients, Lund
Kerstin Heiling, BUP – Child and Youth Psychiatric Centre for deaf and hard of hearing, Lund
Maria Steen, The School Östervångsskolan in Lund
Sivert Gardell, Swedish Institute for Special Needs Education in Malmö
Inga-Lis Eklöf, Swedish Institute for Special Needs Education in Malmö
Mikael Andersson, National Agency for Special Needs Education and Schools, Malmö
Lena Sjölin, Region Skåne’s Deafblind Team
Elisabeth Lindström, Region Skåne’s Deafblind Team
Helene Engh, Region Skåne’s Deafblind Team
Fredric Dacke, Region Skåne’s Deafblind Team
Lena Göransson, Region Skåne’s Deafblind Team
INTRODUCTION GUIDE

Things to bear in mind during the interviews

Use the life course perspective and think of critical stages in life in particular.

Bear in mind the three levels: individual, family/friends and society – what does the network look like and has it changed?

Bring out significant persons, situations and experiences.

Reflect on the feeling of a sense of community, activity and participation.

Describe your deafblindness

When did you understand that you had or would develop deafblindness?

Who gave you the information and how?

What were your thoughts and feelings?

What kind of professional support did you receive from society after finding out?

Can you describe how your deafblindness has developed over time?

Can you remember how long it took before you started to think about finding new ways and strategies, and before you started to see new possibilities in life?

Was there anyone or anything that was particularly important during the adjustment process?

What could have been done differently?

Are you familiar with your diagnosis and prognosis?

Describe the information and the support from the health care system?

What advice and support have you received, and what resources in terms of habilitation/rehabilitation have you been offered over the years?
Has that been enough or have you lacked any kind of support?
Has your family been given information and knowledge about deafblindness, or received any emotional support?
What consequences have deafblindness had on your life; what has changed?
Which are the biggest problems with developing deafblindness?
Is there anything that you have had to renounce from, something that you would have liked to have done?
What has not changed?
Is there any particular situation in your life that does not work due to the deafblindness, and that you do not think can be influenced?
Have you found anything new in life, has the deafblindness brought something positive?
Is it your opinion that you can do basically what you want today?

**Assistive technology**
What assistive technology do you have, which ones do you use, and how does it work?
Have you received the assistive technology that you want and feel that you need?
What assistive technology is the most valuable to you?
Are you or have you been reluctant to use any particular assistive technology, and what do you think is the reason for it?

**Describe your everyday life**
What does a day look like? Describe as much as you can and in as many details as possible.
What works well (possibilities)?
What does not work so well (obstacles)?
How do you do things, what strategies do you use (coping)? Describe.
What have you had to change if you compare with before the deafblindness developed?
Is there anything that you have had to relearn completely (orientation, reading, writing, etc)?

Who do you meet on a regular day?

Do you have regular contacts? In that case, with whom, how often, and on whose initiative?

Do you have regular activities? If so, what?

Has your everyday life changed due to the deafblindness, and in that case can you describe in which way?

**Childhood**

When did your parents find out about your hearing impairment and/or visual impairment?

When did you become aware of your hearing impairment and/or visual impairment? How did you become aware of it?

Did you ever feel different compared to other children of the same age? In that case, how and in what situations?

Do you have any early memories related to the impairment that you can tell us about?

What about your relationship with parents, siblings, and other relatives?

And your relationship with friends?

A feeling of community and participation, or a feeling of being an outsider – which has dominated?

How did you communicate with others during your childhood?

Have you experienced any obstacles in the communication within or outside the family?

Have you ever experienced that you have been treated or approached differently by relatives or others because of your impairment?

**Compulsory school/further education**

Describe your schooling – integrated in a regular class, special class, or special school?

Was there any special support or adjustments due to your impairment (both personal and practical)? Describe the things that you can remember.
What about your relationships with classmates, teachers, and other school staff?
Do you think that you have missed out on something in the education during you time in school due to you impairment?
According to you, did your impairment influence the social interaction at school?
What strategies did you use in order to manage to keep up at school?
What strategies did you use to manage the social interaction at school?
Were there any activities at school that you were unable to participate in? Which and why?
Did you have any contact with others with the same impairment when you went to school? If so, what were your experiences of that?
Did you have other friends besides the ones at school?
Can you describe your after school activities? What did you do and what did your social life look like?
Do you have any further education? If so, what?
Were you allowed to make your own choices or were you advised against certain educations? In that case, by whom and which ones?
Have you based your choices on interest and dreams, or have you felt restricted by your impairment?
Is your job related to your education?

**Work/occupation**
What work/occupation do you have today?
Did it turn out the way you wanted it to?
Work tasks, working hours, special measures, assistive technology, etc.?
How do you receive information at work?
How is your relationship with colleagues and work leaders?
How does the social part of work function, coffee breaks, staff parties, etc.?
How do you get to and from work?
What are your thoughts and plans when it comes to work life and the future (obstacles and possibilities)?
Have your personal finances and your living standards changed due to the deafblindness?

**Leisure time**
What do you do at your leisure time?
Do you have any scheduled leisure time activities?
Have you had to stop doing something because of your impairment?
Is there anything that you would like to do but that you feel you cannot or do not dare to try?
Has the deafblindness introduced you to activities that are new to you?
What about TV, radio, Internet, newspapers?
Associations – are you active in any association?
Are you a member of FSDB?
According to you, are you generally able to do what you want to?

**Family (as an adult)/relationships**
What does your present life situation look like?
Family relations – have they changed due to the deafblindness?
What is your family’s view on/knowledge of deafblindness?
Have your relatives received support or any other help from society?
Have the roles changed within the family?
Other relationships – colleagues, friends, neighbours, other people with deafblindness, etc.?
Has your social life changed over time? If so, how?
Do you have any relationship with someone with deafblindness? What does that mean to you?
Discuss establishing new relationships and maintaining old ones.
**Communication**
What different means of communication do you know?
Have you had to change how you communicate due to the deafblindness?
What way of communication works best for you?
How, when and where have you learned that/those method/s?
What does the communication look like within the family?
How do you communicate with others, outside of the family?
Have your relationships with others changed due to communication difficulties and in that case, how?
Has the social network changed?

**Identity/self-image**
How do you describe yourself to a new person?
Has your self-confidence, self-esteem and self-image changed as a result of the impairment?
Do you think that the deafblindness has changed your personality in some way?
Where do you feel most at ease, among people with deafblindness who use sign language or among people with deafblindness who speak? Why is that, do you think?
What are your thoughts and feelings towards the word deafblindness?
How do you explain your impairment to a new person who is not familiar with it?
Discuss the balance between a sometimes necessary dependence on others and the need of having an independent life.
Discuss how much room deafblindness takes up in life as a whole. Has it changed over time?
**Personal resources**
Describe your strengths and weaknesses. Have they changed over time?

What situations and environments work best for you considering the deafblindness?

Which are most difficult to cope with?

How do you keep track of what is going on around you and in the world at large?

Has information that has passed you by ever led to any serious consequences for you?

How do you do to create an overview when you are in a new environment or situation; what is important to find out?

Think of a situation that was difficult for you. What did you think? What did you feel? What did you do to handle the situation (strategies)?

**Thoughts of the future**
What are your thoughts for the future, aims, dreams, etc.?

Concrete plans for the future, aims?

How would you like to form society’s resources for people with deafblindness in the future? Use your imagination freely!

What knowledge does the professional world need in order to meet the needs of people with deafblindness?
This book is intended for everyone who wants to learn more about deafblindness, the consequences of living with deafblindness, and the specific life conditions that this impairment implies.

What does everyday life look like for a person with deafblindness? How is the social life affected for a person who acquires deafblindness? What does it mean for a family to share the life with professionals? How does deafblindness influence the choice of education and profession for an adolescent? What needs to be done in order to make the geriatric care accessible to elderly people with deafblindness?

To live with deafblindness, whether you are a child, an adolescent, or an adult, is specific and individual, and it always takes place in a certain cultural and social context, in a specific environment, and at a certain time. In this book, the author seeks to capture individual persons’ descriptions of their life situations, and use this as a basis for developing and building up good forms for support. The work is a project, carried out within Habilitation and Assistive Technology in Region Skåne in cooperation with the Association of the Swedish Deafblind (FSDB) and the Skåne Association of Local Authorities, and with financial support from the Swedish Inheritance Fund.

With this book the reader is provided with an insight into the everyday living conditions for people with deafblindness and their relatives. There is a huge demand for research and continued development work and the book inspires the reader to develop new knowledge within the field.

Lena Göransson is a special needs teacher and Head of the Deafblind Team, and has worked at the Vision, Hearing and Deafness Division within Habilitation and Assistive Technology in Region Skåne for several years.