



Nordic Welfare
Centre



Conference report:

Network seminar for the Nordic Networks on Deafblindness 2024

Table of Contents

Conference report: Network seminar for the Nordic Networks on Deafblindness 2024	3
1. Introduction	4
The Nordic networks on deafblindness: their histories, focus areas, and approaches	10
A new way to conduct video analysis: The power of multiple perspectives	27
Six perspectives: Analysing the same video through different lenses	30
Dr Paul Hart: Analysis and comments	49
Conclusions, suggestions, and plans for the future	54
About the publication	60

Conference report: Network seminar for the Nordic Networks on Deafblindness 2024

"Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability."

– Nordic definition of deafblindness

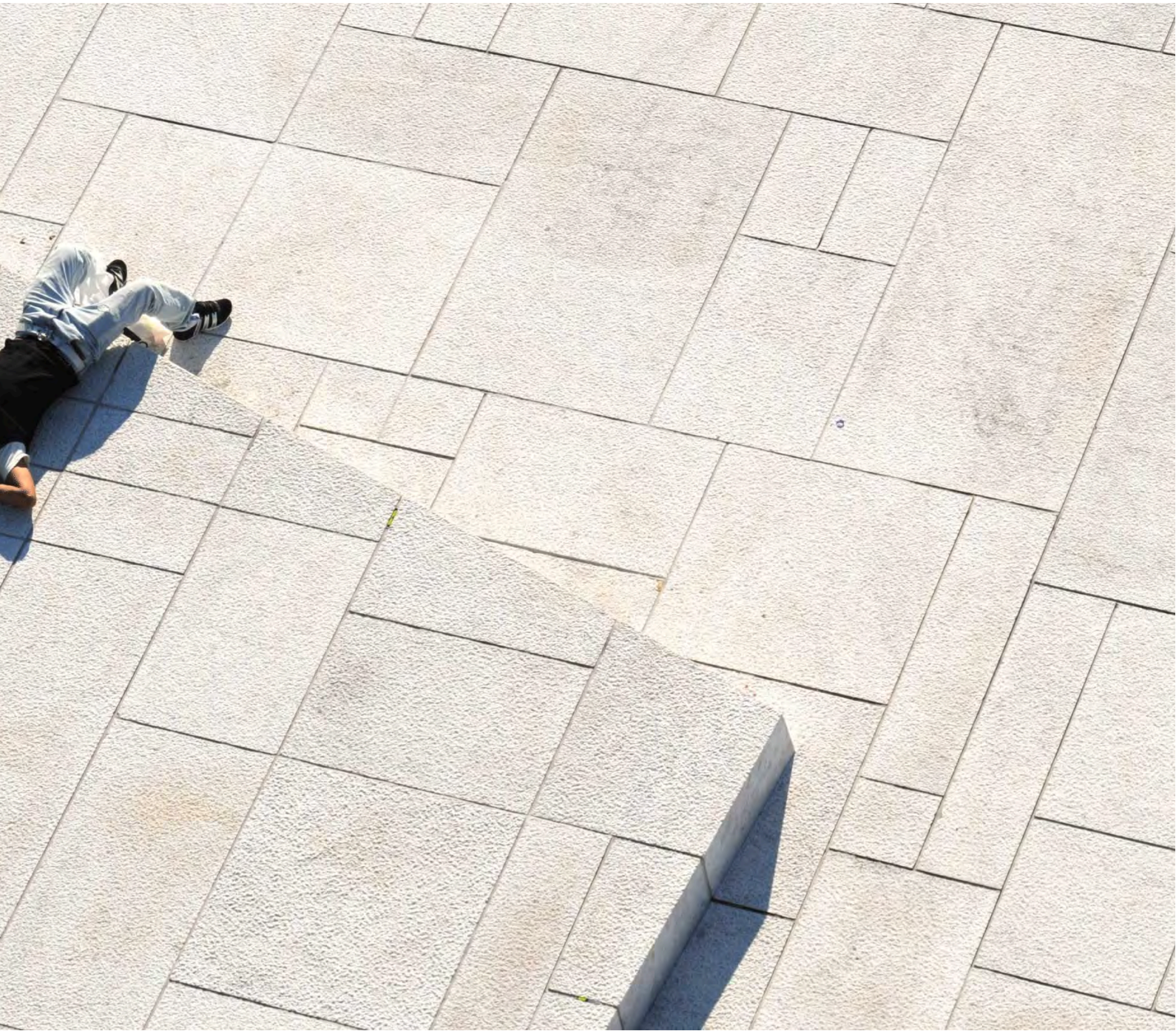




Photo: Mostphotos

Introduction

1. Introduction

Deafblindness exists on a spectrum. Few individuals are entirely deaf and blind; most experience some level of residual vision and/or hearing. Consequently, the number of undiagnosed cases of deafblindness is significant, and many people who meet the criteria are not documented as such but rather as being separately either hearing or visually impaired.

The Nordic Welfare Centre plays a crucial role in supporting organisations and professionals working with individuals with deafblindness or combined vision and hearing impairments, across the Nordic region. The work focuses on promoting equal opportunities and societal participation for this group while also facilitating knowledge sharing and collaboration among Nordic countries, recognising the importance of pooling resources in this specialised field.

The activities in the deafblind field at the Nordic Welfare Centre include, among other things, organising conferences, courses, seminars, and development initiatives that complement national educational programmes in each Nordic country. The aim is to enhance cooperation, first and foremost, within the Nordic region but also at a European and global level.

By addressing these areas, the Nordic Welfare Centre strives to improve the lives of deafblind individuals, who often face marginalisation and vulnerability in society. Through its comprehensive approach, the Nordic Welfare Centre works to ensure that this relatively small but significant group receives the attention and resources they need.

Eight networks with distinct focus areas are active within the deafblind field at the Nordic Welfare Centre. The networks consist of people who work with deafblind individuals in various ways - either hands-on, as researchers or in organisations that arrange training for personnel working in the field.

Six of the networks participated in the first joint network seminar for all Nordic networks on deafblindness, held in Malmö, Sweden, from 6th to 8th November 2024. The event was organised by Gøran Andreas Gregor Caspian Forsgren, Senior Adviser on deafblind issues at the Nordic Welfare Centre.

The main theme of the seminar centred around video analysis, an established tool within the deafblind field. With the help of video analysis, a deeper understanding of individuals with deafblindness can be reached.

All the participating networks conducted a video analysis of the same video from their unique field of expertise. This gave an unprecedentedly deep understanding of the person with deafblindness being analysed in the video.

This report aims to summarise the key takeaways from the network seminar and the video analyses and give a historical and theoretical background of the networks. This report also aims to convey the main themes raised during the discussions at the conference, as well as the commentary provided by the participants.



Photo: Sigve Nedredal

1.1 History and mission: "We are standing on the shoulders of pioneers"

The field of deafblindness is still young as an academic field, but over its relatively short existence, major developments have already taken place. From initial discussions centring mainly around imitation and affective attunement to today's focus on linguistics and psychology, every stage of development builds on the previous work.

– We are standing on the shoulders of pioneers. I have been in the field since 1995, and the first pioneers I met were also standing on the shoulders of others.

Henriette Hermann Olesen, leading manager at the Centre of Communication and Special Needs in Northern Jutland, Denmark, opened the network seminar with a lecture on the history of the deafblind field.

– People with deafblindness form a small population in every country. Deafblindness is a unique and complex disability that arises from a wide range of syndromes or diagnoses. This necessitates broad collaboration, both with common and different focuses.

Dr Paul Hart, former Head of Operational Support, Practice Development and Quality at Sense Scotland, who has been in the field since the late 1980s, says initially, there was a great focus on how to develop communication and impart it to

deafblind people, but this focus has shifted in later years.

– In the beginning, there was a sense that we needed to develop communication tools and provide them to people. However, what the field has learned from other disciplines is to determine how we can develop communication in partnership with people who are deafblind. This has led us to examine other fields, such as autism and language development, and adapt their theories.

The Nordic countries have long played a significant role in shaping deafblind education through decades of collaboration and innovation. From the beginning, people within the field saw the need for international networks in order to share knowledge. Since the population affected by this unique disability is small, a centralised approach to knowledge has always been important.

– At the same time, some form of decentralisation has also always been important in order not to lose the human aspect, and the unique needs of the people affected. Both centralisation and decentralisation have been prevalent since the beginning of the Nordic collaboration in this field, Henriette Hermann Olesen explains.

Early beginnings

The beginnings of international collaboration on issues regarding deafblindness started in the 1950s, with correspondence between countries all over the world. In 1962, the first formal conference on the topic was held, focusing on the education of children affected by deafblindness. This started a trend throughout the 1960s, where the main focus for many international meetings was on education.

– In 1976, the International Association for the Education of the Deafblind (IAEDB) was formed. Over the years, the focus broadened to also encompass adults with deafblindness and the social aspects of living with deafblindness. In 1997, the name of IAEDB was changed to Deafblind International (DbI), Henriette Hermann Olesen says.

The Nordic countries have been active in this field from the beginning. In 1977, an expert group on deafblindness was formed, and the following years held important milestones for the development of the field in the Nordics. In 1978, the planning of Nordic education about deafblindness started under the Nordic Council of Culture.

– The argument for the need to work together was then the same as it is today: the need for both centralisation and decentralisation, diversity and commonalities, and the small population with this unique disability, Henriette Hermann Olesen explains.

The first Nordic definition of deafblindness was formulated in 1980. In 1981, The Nordic Staff Training Centre for the Deafblind Services (NUD) was initiated by the Nordic Council of Ministers. It was made permanent in 1985.

During the 1980s and 1990s, European collaboration within the deafblind field also became increasingly important for the work that is now done in the Nordic countries under the Nordic Welfare Centre umbrella. In 1989, the European network on communication with people with congenital deafblindness was founded. The European Network was coordinated and hosted by the Nordic Staff Training Centre for the Deafblind Services (NUD).

– Video analysis became a prominent tool for the network, and they produced video material on VHS. This was revolutionary. We gained a much deeper understanding of what was important to know about bodily expression in interaction and communication.

During this time, the deafblind research field went through a period of broadening through input from other disciplines. Henriette Hermann Olesen says the European network also started to hold conferences, bringing in experts in theoretical research in linguistics, communication and psychology, and interpreters, linguists, and psychologists joined the deafblind field.

– Knowledge from these fields was, to an ever-growing extent, transferred to the field of deafblindness.

Giving back to other fields

The Nordic Staff Training Centre for the Deafblind Services (NUD) ceased to exist after it merged with several Nordic organisations on January 1, 2009, to become the Nordic Centre for Welfare and Social Issues, which later was renamed the Nordic Welfare Centre. Some of the working groups formed within the NUD continue in today's networks within the deafblind field of the Nordic Welfare Centre.

While having reached an ever more established position, the academic field of deafblindness is constantly evolving, and developing. During the last 10–15 years, a big focus has been on linguistics and language development.

– There are still shifts in this young field, and it is rapidly developing. Today we see the field moving towards a more psychology-based approach, Gøran Forsgren says.

Pauls Hart adds that the deafblind field is now starting to generate knowledge that can be used in other fields, which makes it an especially interesting time.

– Research on deafblindness can reveal aspects of human cognition that we can now feed back into the field of developmental psychology. Deafblindness offers a unique perspective and can render original theories within psychology inaccurate or in need of refinement. Psychologists and linguists who join the deafblind field nowadays are usually quite surprised at the extent to which deafblindness research can contribute to other academic fields. It is an exciting time to be working within the deafblind field.



Photo: Mostphotos

Chapter 2

The Nordic networks on deafblindness: their histories, focus areas, and approaches

Establishing institutional networks to support the subjects and areas of focus is crucial to the work of the Nordic Welfare Centre in collaboration with the Nordic Leadership Forum on Deafblindness. These networks are an important aspect of the Centre's efforts.

The networks encompass a range of competencies and profiles, including subject specialists, researchers, and professionals from user associations and stakeholder organisations. They contribute by generating new knowledge and offering insights to decision-makers on areas that require further initiatives.

Eight networks operate within the deafblind field under the Nordic Welfare Centre. Six of them participated in the network seminar in Malmö in November 2024.

The Nordic Network for Psychologists Working on Deafblindness and the Nordic Research Network on Deafblindness were the two networks not represented at the conference. More information on all eight networks can be

found [here](#).

The main task of the seminar was to conduct a new and unique way of doing video analysis. When all six of the networks present analysed the same video from their own perspective, the depth of the analysis reached new levels, showcasing the strengths of interdisciplinary work.

Before undertaking the video analysis, the networks were asked to present their focus areas, history, key milestones, and future plans. The following chapter of this report gives a presentation of each network in the same order and based on how representatives from the networks presented them during the seminar in Malmö.



Photo: Sigve Nedredal

2.1 The Nordic Network on Communicative Relations

Within the deafblind field, Communicative relations refer to how individuals with congenital deafblindness can develop both communicatively and personally through interactive relationships with sighted and hearing partners.

The Nordic Network on Communicative Relations is guided by the United Nations Convention on the Rights of Persons with Disabilities, which affirms everyone's right to be heard. People with disabilities are often part of a vulnerable group, relying

on others to communicate, engage, and grow as individuals. The work of the [Nordic Network on Communicative Relations](#) focuses on supporting people in exercising their right to communicate through their own unique means.

The theoretical framework of the network's approach centres on the book [Communicative Relations by Inger Rødbroe and Anne Nafstad, published in 2013](#).

The network on Communicative Relations emerged from efforts to spread and communicate the findings of the book. Courses were organised to share the insights from the book, providing the foundation for the network's creation. To foster ongoing knowledge development and professional collaboration, the network was formally established in 2015.

Sanne Brink, a specialist in special education from Denmark, is one of the network's founding members.

– We use the models from the book as the foundation for our work. While some of these models are theoretical, we still define ourselves as a practice-oriented network, with a particular focus on supporting and inspiring interventions that foster communication with people with deafblindness. This is achieved through close collaboration with the staff who work directly with them.

Specialist psychologist Anne Nafstad, co-author of the book *Communicative Relations*, was an active member of the network for many years and continues to serve as a senior adviser. During the network's presentation at the seminar, she addressed the audience via video and answered the question of what the network has brought to her work.

– The network has contributed to a shared and universal discourse, allowing us to think about communicative development for congenital deafblindness from the same theoretical background, Anne Nafstad said.

One particularly important theoretical model central to the network's work is the Diamond Model, an intervention model used to analyse and support the communicative development of individuals with congenital deafblindness. The book *Communicative Relations* describes the model: "The Diamond

focuses especially on the relational prerequisites for deafblind persons to develop communicative agency."

– Many of the persons with congenital deafblindness never fully develop much cultural language. We try to focus on them being communicative, using their authentic expressions and voices. The Diamond Model really helps us to understand these authentic expressions, says Håkon Lie, a member of the network.

One of the main theoretical focuses of the Network on Communicative Relations has been video analysis, carried out according to the principles outlined in the book *Communicative Relations*. This method provides a deeper understanding of individuals' unique ways of interacting and expressing themselves, which may not be readily apparent to partners due to the challenges of low readability.

– One of the most rewarding aspects of our network seminars is the video analysis we conduct together. We always find that it helps us make connections to our own practices. Video analysis is like a muscle—it must be strengthened to be maintained, Sanne Brink says.

The network highlights the importance of having a group leader to guide and facilitate the video analysis process, ensuring it is specific, useful, and conducted with respect to those featured in the video clips.

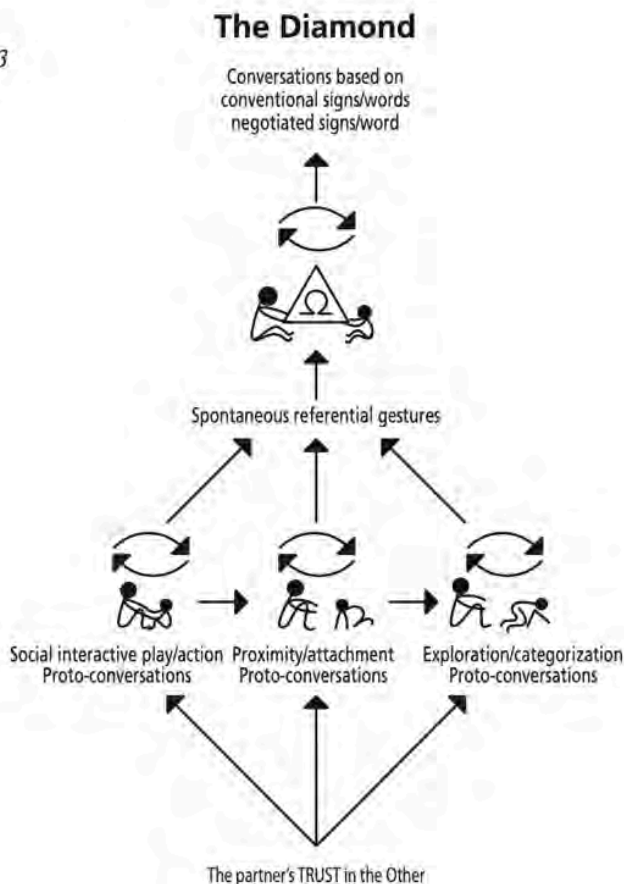
Sanne Brink emphasises the importance of conducting video analysis face-to-face. However, due to financial challenges and the travelling constraints of the pandemic, the network has not been able to meet as often as they would like. While they conduct video analysis online, which is less than ideal, they strive to meet in person at least once a year and online every two or three months.

Over the years, the network has organised several courses, workshops, and webinars. In the future, it aims to continue the video analysis work to practise and sustain the knowledge within the network, enabling its further development and sharing.

The network is also working on an e-learning course to make

the theoretical models from the book *Communicative Relations* more accessible to the general public.

Illustration 3



Picture: Diamond model

2.2 The Nordic Network on Tactile Language

All people are born with different capabilities, but everyone possesses an instinct to communicate with their fellow human beings, regardless of language or form of communication. This perspective is grounded in a dialogical approach, which assumes that all individuals wish to share their feelings, thoughts, and experiences with others. Creating the right conditions for individuals with congenital deafblindness to develop a language is complex.

The Network on Tactile Language began at a conference in Italy in 2009, where the question was raised: why do so few people with congenital deafblindness use sign language

despite being exposed to signs?

The Nordic Staff Training Centre (NUD), which merged into the Nordic Welfare Centre that same year, initiated meetings, workshops, working groups, and seminars to gather knowledge on the subject.

This continued until 2014, when the Nordic Network on Linguality was formalised. At that time, we did not refer to it as a tactile language but rather as something resembling a language, which is why the term "linguality" was used, explains network member Helle Buelund Selling.

During the same period, significant developments occurred within the field across the Nordics and Europe. The book *Communicative Relations* (mentioned in the previous chapter) was published, and many groups in the Nordic region were exploring tactile language. Master's students from the University of Groningen in the Netherlands, who examined the language through various modalities, also contributed to the knowledge base on tactile language.

A major breakthrough came in 2016 when Icelandic Sign Language linguist Nedelina Ivanova concluded that the "linguality" the network had been exploring met the language criteria.

– We found it very exciting. Ivanova discovered that this form of communication contains many small units that are similar to phonemes in spoken language or lexical units in sign language. The unit in the tactile language is called a "nema", Helle Buelund Selling explains.

This breakthrough answered the question of why people with congenital deafblindness do not use sign language – they use a different language. The network began calling itself the Nordic Network on Tactile Language, and two years later, in 2018, the Scandinavian version of the book [If You Can See It, You Can Support It](#), written by members of the network, was published, followed by an English version the following year.

The book contains the Circle model for tactile language. The Circle model scaffolds and helps to understand and remember the many elements of tactile language. The model is

presented as a dynamic tool and can be expanded to include new elements as knowledge of tactile language grows. This model has been a big part of the work that is done within the network.

Since then, the network has focused on spreading the knowledge contained in the book through a webinar series based on its various chapters [Webinars: Tactile Language - YouTube](#). The network has also collaborated with numerous experts within and beyond the Nordic region and presented their work at various conferences around the globe.

International collaboration has been invaluable, as the field of tactile language is too complex for any single country to develop independently. There is insufficient expertise in each country, and the population size is too small for national studies. [Nordic Network on Tactile Language | NVC](#)

– When the book was released, we deliberately left tactile language undefined. Claiming it was a language was challenging enough, as there was opposition to the idea. However, over the years, we have grown braver and have since developed a definition, Helle Buelund Selling says.

Network member Caroline Lindström shared the current suggestion for the definition of tactile language at the seminar.

– Tactile language is an early language in the making. It is a language used by people with CDB (congenital deafblindness). It is an authentic natural language from within. A language based on bodily engagement in the world. It is also a language that involves the tactile, kinesthetics, and proprioceptive senses.

The future of the network involves continuing to spread knowledge and refining the models in the book into practical tools.

– We would like to develop more guidelines and tools for video analysis based on the tactile language circle. A tool for using the circle would be helpful. Another plan is to further develop the circle from a more multimodal perspective, Caroline Lindström says.

The circle model on tactile language



2.3 The Nordic Network on CHARGE Syndrome

The Nordic Network for CHARGE syndrome was established in 2002, and has since focused on gathering, sharing, and disseminating knowledge about CHARGE syndrome while scientific advancements in the field have also progressed.

– In 2002, there was a need for knowledge about a rare and, at the time, relatively new diagnosis. In those times, the mutation in the CHD7 gene had not yet been identified. Today, we know that this mutation is present in over 75 per cent of people with CHARGE, says network member Frida Racksäter Nerback.

One persistent challenge is that CHARGE syndrome affects very few people, resulting in limited knowledge within the healthcare system. Some professionals are unaware of the syndrome, while others rely on outdated medical understandings.

– Here, the Nordic Network on CHARGE Syndrome plays a vital role in spreading information – not only among professionals within the healthcare field but also to families with a member affected by the syndrome.

Frida Racksäter Nerback says the network has met annually in person throughout its existence, except during the COVID years when meetings were held online. In some cases, conferences have been connected to the network seminars. A key aspect of the in-person meetings held in different countries has been the opportunity to meet individuals with CHARGE and their families.

– We have addressed various topics, including friendships and social skills, stress and pain, with one of the more recent focuses being transitions. These transitions can involve changes in life, activities, living arrangements, or schools, and we discuss how best to support individuals during these transitions, Frida Racksäter Nerback says.

Support is a significant focus of the Network's publication, [Re-CHARGE](#), published in 2024. The publication includes studies from everyday practice and interviews with people with CHARGE syndrome and their families. It aims to provide a comprehensive overview of individuals living with CHARGE syndrome's daily experiences, challenges, and achievements.

CHARGE Syndrome

The name "CHARGE syndrome" comes from an acronym coined in 1981. This acronym represents six key features observed in individuals with the syndrome, and a diagnosis requires the presence of four of them.

However, this acronym is no longer the basis for diagnosing CHARGE syndrome. Advancements in genetic testing have allowed for a more accurate diagnosis through the identification of a mutation in the CHD7 gene. This means that a blood sample can determine the presence of the syndrome.

The symptoms affect multiple organs in the body and often include hearing loss, visual impairment, and balance difficulties, necessitating extensive medical care and specialised educational support. Children with CHARGE syndrome often have life-threatening conditions from birth, such as heart problems and breathing difficulties. They commonly undergo frequent and lengthy hospital stays, and surgery and treatments are often necessary.

CHARGE syndrome does not always lead to deafblindness. While combined vision and hearing impairments are frequent, the severity varies. Some individuals retain functional vision and/or hearing with the aid of assistive devices. People with CHARGE can lead fulfilling and meaningful lives with proper support and a focus on functionality and individual strengths.

The prevalence of individuals born with CHARGE syndrome in the Nordic region is approximately 1 in 10,000 births annually, resulting in a very small population in each country. As a result, the support network around the individual often has no prior experience or knowledge of the condition. For this reason, sharing knowledge and examples of best practices has great benefits in the Nordic region.

2.4 The Nordic Network on Self-Regulation

Self-regulation refers to a person's ability to manage or adapt their thoughts, feelings, and actions to meet their environment's demands, challenges, and opportunities. This is an ability we all possess, and it is essential for functioning in everyday life.

Self-regulation can be challenging for everyone, especially for those with deafblindness, intellectual disabilities, or atypical communication. Within the deafblind population, these difficulties are common and varied. To navigate complex emotions and behaviours, both theory and practical knowledge are needed to help create a sense of balance.

[The Nordic Network on Self-Regulation](#) aims to enhance and disseminate knowledge about how professionals, carers, and relatives can help individuals with congenital deafblindness achieve balance and manage emotions.

Initially established as a working group, the Network on Self-Regulation was approved as a Nordic Network by the Nordic Leadership Forum in 2020. The initial aim of the working group was to study challenging behaviours in people with deafblindness caused by the Rubella virus. Over time, the target group expanded to include individuals with other conditions involving congenital combined vision and hearing loss/deafblindness.

– We wanted to explore whether self-regulating behaviour could be understood from a deafblind perspective. Increasingly, we began focusing on challenging behaviour in people with congenital deafblindness from a self-regulation and communication perspective, Network member Dr Jude Nicholas says.

The Nordic Network on Self-Regulation's approach is to educate people working with or close to someone with congenital deafblindness on how to interpret self-regulation functions. Jude Nicholas says there is a lot of knowledge to be disseminated for medical staff, teachers, and parents.

– Self-regulation has many definitions, but one of them involves examining the sub-components of behaviour, emotions, and cognitions. First, we need to identify them and then interpret them. The more those around the target person understand these aspects, the better it will be for the individual with deafblindness.

The goal is to understand complex conditions such as pain, depression, and psychosis in people with congenital deafblindness from a self-regulation perspective.

The network also aims to understand self-regulation issues through a neuropsychological or neuro-pedagogical approach, thereby developing appropriate interventions and adaptations. Also, questions regarding medication are part of

the holistic approach to self-regulation.

As many of the concepts overlap with the focus areas of the other networks, collaboration is of great importance to the Network on Self-Regulation, particularly the networks focusing on Cognition, Tactile Language, Communicative Relations, and CHARGE.

In 2023, the network arranged a course titled "When Emotions and Expressions Become a Challenge." Members of the network have, separately, also written a handbook for professional caregivers titled "[SOS Side-by-side On Self-harm](#)".

– The focus is on investigating self-harm as a phenomenon, understanding what happens when a person engages in self-harm, and exploring how we can provide support. This is crucial, as many people feel frustrated when working with individuals who self-harm, says Lone Rømer Jensen, one of the authors of the book.

The original Danish version of the book won a prize, and the prize money was used to publish the book in English.

The future aims of the network include further cooperation with other networks and disseminating knowledge, possibly by arranging a webinar in the future. The network also prioritises ongoing internal education.

– We want to deepen our understanding about self-regulation by working more extensively with video analysis while using the self-regulation glasses, network coordinator Anette Moen states.

2.5 The Nordic Network on Cognition in Relation to Congenital Deafblindness

Assessing cognitive ability in individuals with deafblindness is challenging, as expressions can be difficult to interpret, particularly in young children with congenital deafblindness.

The objective of the Nordic Network on Cognition in Relation to Congenital Deafblindness is to enhance the competence of professionals, enabling them to more effectively understand, observe, describe, and assess cognitive abilities in people with deafblindness.

The network was established in 2008. Dr Jude Nicholas is a member of both the Self-Regulation and Cognition networks. He explains that the Cognition network emerged from extensive discussions on cognition among professionals working in fields related to deafblindness.

– We wanted to help people understand cognition, not just to assess and categorise or give a label, but with a more multidisciplinary, multi-approach focus, placing it in the context of deafblindness. There is no one way to understand cognition; it is a complex concept.

Since individuals with congenital deafblindness form a diverse, small-scale, and heterogeneous group, collaboration and knowledge sharing at both Nordic and international levels provide substantial benefits. Therefore, the network adopts an interdisciplinary approach, drawing on knowledge from various research fields such as physiology, neuroscience, neuropsychology, developmental psychology, social psychology, educational sciences, and semiotics.

The network's main purposes are research, collaboration, and knowledge sharing. Because tactile modality is of considerable importance for individuals with deafblindness, the network has focused intensively on increasing knowledge about physical and tactile cognition.

– Our aim is to identify the role of cognition in everyday learning and functioning for deafblind individuals, cascade this information outwards to professionals, demystify the concept of cognition, and promote professional competencies in this area, network coordinator Jonathan Reid says.

The network has explored cognition from various perspectives. Examples include the theory of mind, arousal, executive functions, working memory, and the diamond model

(mentioned in the chapter on the Network on Communicative Relations). Over the years, the network has offered courses, arranged webinars and seminars, and produced several publications exploring how different cognitive perspectives relate to people with deafblindness.

Three of the books were specially mentioned during the presentation at the network seminar: [Tactile Working Memory Scale – A Professional Manual](#), [Revealing Hidden Potentials – Assessing Cognition in Individuals with Congenital Deafblindness](#), and [Psychological Assessment of Individuals with Deafblindness](#).

Working memory, the ability to retain information for a short period, is a key function in cognition. For individuals with congenital deafblindness, a bodily-tactile perspective on working memory is essential. The book [Tactile Working Memory Scale – A Professional Manual](#) provides a theoretical overview and introduces a scale for professionals to identify and assess tactile working memory. It also offers tools and strategies to help individuals with deafblindness fully develop and utilise their cognitive and linguistic potential.

Cognitive delays are common in individuals with congenital deafblindness, and standard assessment tools are often unsuitable. But at the same time, people with congenital deafblindness often have hidden cognitive potential that those around them fail to detect. To address this, the network developed specialised tools, culminating in the publication of [Revealing Hidden Potentials – Assessing Cognition in Individuals with Congenital Deafblindness](#) in 2020.

Psychological assessment supports learning, health, and development in children with congenital deafblindness by identifying their developmental levels, strengths, and challenges and guiding tailored interventions. The book [Psychological Assessment of Individuals with Deafblindness](#) explores the complexity of psychological assessment in the field, offering insights to help psychologists design strategies that enable these individuals to reach their full potential.

– The books, articles, and webinars published by the network

have led to its work becoming more interdisciplinary, incorporating more diverse aspects, growing in ambition, expanding in scope, and involving participants from outside the Nordic countries.

Jonathan Reid notes that the network's interdisciplinary growth and international collaboration signify a healthy progression in the emerging field of cognition related to deafblindness.

As the progression of the network's work over time has evolved from understanding cognition in the early network seminars to revealing cognition in publications and webinars, the future aim is to focus on supporting cognition.

– The focus going forward is on supporting cognition. This includes recognising the importance of engaging with practitioners and supporting the network's work in the field.

More publications, webinars, training and collaboration with the other networks are also planned for the network's future.

– Perhaps we can work towards deeper research into areas such as AI; it is currently one of our discussion topics, Jonathan Reid says.

2.6 The Nordic network on Usher syndrome

Usher syndrome is a group of inherited conditions that cause hearing impairment or deafness, combined with visual impairment and, in some cases, balance issues.

Before the Nordic Network on Usher Syndrome was formally established, individuals in the field met in working groups, developed courses and seminars, and attended conferences, building relationships with organisations worldwide. The network, who began as a study group, was officially established in 2023.

– We are a new network raising awareness about Usher

syndrome in the Nordic countries. Our members come from diverse backgrounds: researchers, special educators, consultants, and teachers. Collaborating across different areas of expertise is very important, says network member Rasmus Hougaard Pedersen.

The goal of the network is to provide a platform for raising awareness and sharing knowledge and experiences among professionals in the Nordic countries regarding the living conditions and support for people with Usher syndrome, as well as for parents of children with Usher syndrome.

Technological developments, such as the cochlear implant (CI), which can provide a sense of sound to people who are deaf or hard of hearing, have benefited those with Usher syndrome. However, these advancements do not address all the unique challenges faced by people with Usher syndrome.

– Many people with Usher syndrome do not experience visual impairment at the start of their lives, and if they have a cochlear implant, the community might assume they do not need any form of support. This is a significant issue, as they face challenges similar to those with congenital deafblindness, particularly with communication, says network coordinator Bettina Kastrup Pedersen.

Since its establishment, the network has actively developed plans for its activities, with many ideas and initiatives for the future—one of which involves a more in-depth exploration of the cochlear implant. The network has also examined how the COVID-19 pandemic has affected people with Usher syndrome. In November 2024, the network held a webinar on Usher syndrome in a digital world.

– We are still working towards becoming a more formalised group. We are also keen to collaborate with those working with congenital deafblindness to explore the similarities and differences in communication between people with Usher syndrome and those with congenital deafblindness, Bettina Kastrup Pedersen says.

Another main focus area for future work is children with Usher

syndrome. Advancements in genetic testing can reveal the condition at an early age, which presents challenges for professionals.

– The impact of Usher syndrome is typically identified during the teenage years, but with modern genetic testing, it can be detected much earlier, around 1–2 years of age. How do we communicate this to parents? This is a significant dilemma in the field and could be a potential topic for future discussion, Bettina Kastrup Pedersen says.

Usher syndrome

Usher syndrome is the most common genetic cause of combined vision and hearing loss and deafblindness. It is a rare inherited condition passed from parents to children that affects the three major senses: vision, hearing, and balance.

Children with Usher syndrome are born either deaf or with a hearing impairment that gradually worsens over time. Everyone with Usher syndrome also has the eye condition retinitis pigmentosa, which causes the retina to deteriorate progressively.

The rarity of Usher syndrome can make it difficult for professionals to acquire knowledge about the conditions experienced by those living with it.

Everyone with Usher syndrome requires habilitation and rehabilitation, supported by coordinated vision and hearing initiatives. This is why it is essential for various organisations in society to have adequate knowledge.



Photo: Mostphotos

Chapter 3

A new way to conduct video analysis: The power of multiple perspectives

The main purpose of the network seminar was to conduct and present a video analysis. All the networks were tasked with analysing the same video, and each offered a unique perspective based on its distinct theoretical framework.

Before proceeding to the results and discussions of the video analyses in chapter 4 of this report, this chapter provides a theoretical background to video analysis and how it is being used within the deafblind field.

The camera gives you several sets of eyes

Video analysis has been used for better understanding deafblind individuals since the 1980s. It is widely regarded as a very powerful tool for gaining a deeper understanding of a deafblind person and what he or she is communicating.

Gøran Forsgren, Senior Adviser on deafblind issues at the Nordic Welfare Centre, who arranged the network seminar, describes video analysis as the "camera giving you several sets of eyes".

– In a real-life face-to-face interaction with a client, the partner will see only a fraction of the communication. 80–90% is usually missed. In contrast, by looking at a video and being able to go back and forth, change speed, stop, and look at certain parts of the interaction in depth, the understanding of the situation becomes much deeper.

In the field of deafblindness, video analysis has frequently been used to understand various aspects of an individual's development and the relationships they form. Traditionally, video analysis has focused on a single perspective at a time, such as social relations or communication. [Course: Video analysis – A holistic perspective | NVC](#)

But in recent years, voices have been raised within the deafblind field on the importance of video analysis from a more holistic perspective. Different viewpoints can add different layers of analysis, and thus, a more nuanced and multi-faceted view of the deafblind person being analysed emerges. [Holistic video analysis gives deeper insights into the communication of persons with deafblindness | NVC](#)

A rare abundance of perspectives

The type of analysis conducted at the network meeting, where six networks all bring their unique perspective to the same video analysis, is rare.

– Video analysis has been utilised in the field for quite some time, but very often, the focus is on one particular aspect of the person, which reflects the interest and expertise of the people coming together to conduct the analysis. Bringing together multiple perspectives has been done before, but not with as many diverse viewpoints nor over a period of several days, says Dr Paul Hart.

Gøran Forsgren adds that Olle, the boy who was the subject of the video analysis at the network seminar, really stood out as a person when viewed from so many perspectives.

– It was amazing. Sometimes, the deafblind field can seem like floating islands of knowledge, and this exercise strengthened the bridges between them. The way each

network conducted the analysis in the same setting allowed us to see the person in a more holistic way, which is something we have not done extensively previously, Gøran Forsgren says.

Dr Paul Hart agrees. He underscores the importance of new knowledge and insights that were generated during the network meeting.

– As the days progressed, it revealed more than we initially anticipated. Both in the instances where the networks found similar things and where they discovered something very different, the results were equally powerful.

The following chapter gives an overview of the different perspectives the networks focused on when they analysed the same video clip at the network seminar in Malmö.



Photos: Sigve Nedredal



Photo: Mostphotos

Chapter 4

Six perspectives: Analysing the same video through different lenses

The video analysed by all the networks depicts an interactive play situation between Olle, who has congenital deafblindness and CHARGE syndrome, and his communication partner, someone he knows well.

In the video, we see an example of how variations in play can be adapted to the tactile modality and how this helps sustain the interaction. We observe Olle and his partner touching each other's noses, taking turns and using variations in pressure, tempo, and movement. This adds interest and helps maintain the interaction.

The analysis' goal was to share each network's perspective on a specific case. The networks' contributions highlighted their diversity and unique characteristics. By sharing insights, other networks benefited from the results, helping them develop and refine their own toolkits for video analysis.

The networks were allowed to analyse and present the video analysis using models, theoretical approaches, evidence-based methods, and experience-based knowledge from professionals and individuals with deafblindness. Each network presented its analysis, and the main findings and perspectives from each

analysis are summarised in this chapter of the report.

The video (2.2 d Variation i samspelet) can be found on page 13 in the publication [Lärande och umgänge genom känseln](#) by Nationellt kunskapscenter för dövblindfrågor (NKCDB) in Sweden.

4.1 The Nordic Network on Communicative Relations

The Communicative Relations network emphasised communication's dialogical nature, viewing it as a partnership rather than a one-way process. Concepts like the Cue Model and Diamond Model demonstrate how interaction fosters communication and meaning. These frameworks underscore the collaborative essence of dialogue in creating shared understanding.

During the video analysis, the Network on Communicative Relations noted that the video was unusually long—over one minute—since the network mostly analyses videos that are only a few seconds long. The network members also stated the importance of staying strictly analytical and not getting emotionally engaged with the subject in the video.

– Communicative relations consist of many different theories and models. However, what is distinctive about these different theories is that development is seen as a result of the relation a person is engaged in over time, says network member Johanna Hägglund.

The video analysis of the Network on Communicative Relations was based on three models from the book [Communicative Relations](#) (see chapter 2.1): the Life-Space model, the Diamond Model and the Cue Model.

The Life-Space model shows how the child's life space is established as a dynamic relation and illustrates how the life space gradually expands as they experience an increasing ability to maintain a feeling of security and emotional proximity to their caregiver over greater physical distances.

The Diamond Model identifies four fundamental ways humans relate to the world: social interactive play/action,

proximity/attachment, exploration/categorisation, and conversations.

The Cue Model shows the critical areas of development by accentuating the four environmental relations in the Diamond model.

– This model gives us observational cues that indicate the contribution from the individual with deafblindness, Johanna Hägglund says.

For the video analysis, the Network on Communicative Relations hypothesised that the subject in the video, Olle, was interested in being in a speaking and listening position with his partner. The network highlighted some cues in a part of the video that supported this hypothesis.

– Olle has his left hand under the partner's right hand and also puts his right hand on the partner's hand. The emotional expressions are smiles, and Olle and his partner pay joint attention to each other.

Johanna Hägglund explained that the network found elements described in the theoretical models throughout the video of Olle. The network listed a number of hypotheses which they found in the clip: agency, trust, tactile contact, emotional elements, rhythm, following and responding to the other's expressions, attention to each other, exploration and categorisation, and attention over time.

Using the Diamond model, the network started at the bottom of the diamond, where the importance of trust and agency are described.

– We see that Olle is a strong initiator in the interaction, and it is an interaction with increasing complexity. Olle shows a strong will. His contributions to the interaction are perceived and answered, which we can assume strengthens his agency. Regarding trust, Olle is sitting physically close to his partner, which can be seen as a sign that he dares to trust his partner. The partner is socially available in the play, which perhaps creates security and gives Olle a feeling of being seen by the other, Johanna Hägglund says.

The network also noted that Olle and his partner make tactile contact throughout the whole film clip.

– We see emotional elements. Olle is laughing, biting his thumb, and clapping as an emotional expression, combined with facial expressions. There is rhythm and a shift in tempo during the interaction, initiated both by Olle and his partner, and the clapping games start with patting the nose, and then the game develops further.

The network also saw the clapping game as a dynamic interaction where both Olle and his partner follow each other's initiatives, which shows that they follow and respond to each other's expressions. The network also noted joint attention between Olle and his partner, directed to each other, that is maintained throughout the clip.

Exploration and categorisation are seen in the video by Olle realising that both he and his partner have noses that can be patted on. Regarding attention over time, the network noted that the complexity increased during the clip.

– Olle takes on the role of someone who initiates new aspects of interaction. This possibly means that the activity remains interesting over time, Johanna Hägglund says.

The network also noted turn-taking within the video, where Olle is shifting from being in the listening position to the speaking position using his hands. At one stage, Olle reaches out towards his partner with an open palm as an initiative for conversation.

– They are both actively using speaking and listening hands, and the partner is scaffolding the interaction by mirroring Olle in his authentic conversation, adding the use of tactile signs. We are now reaching high up in the Diamond model for proto-conversations, and we're getting closer to what an actual conversation is.

In the analysis, the network initially focused on the deafblind person, but after reviewing the video more, they also noted some of the strategies employed by the partner.

– We saw that we could also use the models when discussing partner strategies, says network member Ingrid Axelhed.

Since Communicative Relations is a tool for video analysis and support in working with communicative interventions, the models can also assist the communication partner in planning an intervention that supports the communicative development of the deafblind person.

The partner strategies identified by the network in the video analysis included trust, tactile contact, emotional elements, rhythm, following and responding to the other's expressions, joint attention on each other, exploration and categorisation, sustained attention over time, positioning of hands, scaffolding, and conversations based on conventional or negotiated signs or words.

The Nordic Network on Communicative Relations also presented some suggestions for interventions to provide further support. One such suggestion focused on how to help Olle internalise an awareness of turn-taking more effectively.

– We observed that he reacted to the different shifts in tempo. We discussed whether he understood when the partner communicated "slowly." While we could see that his reaction was to slow down the tempo of the play, we cannot confirm if he actually understood the tactile sign for "slowly." This could be a suggestion for future work, Ingrid Axelhed says.

4.2 The Nordic Network on Tactile Language

The Tactile Language network illuminated the evolution of tactile communication from rudimentary gestures to sophisticated signs. This progression bolstered confidence in its status as a genuine language, prompting contemplation of the typical genesis and maturation of novel linguistic systems.

The Tactile Language Network based its analysis on the Circle Model for Tactile Language (see Chapter 2.2). The Circle

Model is a dynamic tool used to understand the various elements of tactile language. The model acts as a scaffold that supports analysis by providing cues for understanding tactile dialogue to prepare activities and conversations or to formulate development goals. [If you can see it, you can support it | NVC](#)

– The Circle Model helps to support the analysis, providing cues on what to observe in the present dialogue with the aim of formulating development goals, activities, or conversations. The model is designed as a dynamic tool that can be expanded to incorporate new elements as our knowledge evolves or new perspectives emerge, network member Jessica Jägryd says.

In their video analysis, the network identified elements from all the categories of the Circle except two: multi-party conversations and haptic signals, commenting and describing.

The first thing the network noticed was the clapping game, and they observed that similar games are often seen in comparable contexts. The network had encountered such games many times during visits to schools and preschools for deafblind children. However, upon closer examination and with the Circle Model in mind, the network uncovered much beneath the surface of this seemingly simple game.

– There is a lot happening in this clip. Every second brings a new utterance and plenty of tactile language. The play begins on Olle's face; Olle makes a hand gesture next to his face and touches his partner's face. Then, some form of negotiation occurs, and the tempo shifts. Midway through the clip, the partner interjects and disrupts the flow slightly, but not the relationship, Jessica Jägryd explains.

The network specifically noted a hand gesture that Olle makes nine seconds into the video. Olle holds his thumb and index finger towards his own face while his partner turns his other hand towards her face. The network members identified a potential tactile categorisation aimed at creating an understanding of a mental image.

– We wondered whether he might be attempting to

categorise something. We thought he could be measuring her face compared to his own, network member Theresa Vede says.

The network also observed how the partner tapped Olle's hand to signal that she wanted to say something and then pulled his hands apart. Olle also taps the hands, signalling, "I want to say something, too."

The partner then uses conventional tactile signs, saying "fast" three times, followed by "slowly." The changes in tempo correspond to the rhythm of the tapping on the nose. Olle then raises his hand, signalling that he understands the partner is referring to the tempo, even though he does not have the conventional signs to explain it.

– It seems as though Olle has categorised what they are discussing or what she is trying to teach him. However, we also noticed that it was Olle who initiated the game with the concept of tempo—the "fast" and "slow" originated from him. The partner simply added the conventional signs to it, Theresa Vede says.

In the analysis, the network also focused on the numerous utterances from Olle, where they noticed that he also shows agency with his voice. From a tactile language perspective, the network observed that Olle introduced new initiatives with elements of variation, altering hand shapes, positions, movements, pressure, tempo, and direction.

– In the clip, there is a lot going on with the hands. At one particularly interesting moment, Olle twists his hand to meet his partner's hand. We think this demonstrates Olle's potential for developing tactile language in a bodily tactile modality, network member Linda Henriksen says.

The network summarised their analysis as tactile exploration and categorisation of the concept of "tempo" in a clapping activity. Tempo is understood here as the speed and rhythm of movement: fast versus slow. In addition to "tempo," Olle also explores characteristic differences in various clapping styles.

– It is not only the speed of the tempo but also the different types of clapping, Linda Henriksen explains.

For further analysis and understanding, the network suggests exploring how hand movements influence the form and function of the clapping. They also recommend categorising and comparing differences and similarities between variations within the same category, such as listening, speaking, or thinking positions. They also made some recommendations to support Olle's further development.

– We thought that perhaps the partner could be more involved by providing additional confirmation or engaging in more imitation. Additionally, it might be helpful to recognise Olle's utterances as a form of linguistic competence. The partner could also allow Olle to guide the use of conventional signs by shaping them from his body with his hands. The partner could also work more on the "you and I" perspective.

Linda Henriksen says the network further talked about extending the fast and slow concept to contexts other than the clapping game. Suggestions would be to add another concept, for example, walk or eat.

– Introduce the concept that other actions can also have a tempo, such as "walk fast" or "eat slowly." By adding this additional element, it would be possible to expand and build more language.

4.3 The Nordic Network on CHARGE Syndrome

For their video analysis, the Nordic Network on CHARGE Syndrome chose to focus on four key areas: partner competence and strategies used by the partner, sensory integration, balancing and managing emotions and suggestions for interventions for further support.

The analysis is founded upon the network members' experience from daily work, as well as theoretical knowledge. The network mentions two publications in particular: *You Taught Me...* by Andera Wanka and *Self Regulation for*

Individuals with CHARGE Syndrome by Timothy S. Hartshorne and Jude T. Nicholas.

The network began the analysis by focusing on the partner. Since Olle has CHARGE syndrome, the network assumed that the partner is familiar with the role of a communication partner in interactions with individuals with CHARGE.

– It appears that the partner is well known to Olle and understands how to support him in communication. The partner ensures that Olle is properly physically supported, placing her arm around his entire body. In CHARGE syndrome, stability system challenges are common, and this physical support helps Olle maintain awareness of his own body as well as his partner's body. This support also aids his executive functions, as the stability allows him to concentrate fully on the play, network member Hege Krog explains.

As individuals with CHARGE often struggle with balance issues and dizziness, their development of self-regulation is at a disadvantage.

– One way to help them develop self-regulation is through the so-called sensory diet, which involves a list of different activities. In the video, we see hand clapping, pressure applied to the joints, and laying down with support, network member Susanne Jensen explains.

The network also noted that the partner has chosen face-to-face positioning, which fosters a sense of closer, more intimate communication than the more commonly used side-by-side position.

– We also assume that the partner is familiar with Olle's interests and knows what he enjoys talking about. She follows his lead to initiate the conversation and provides scaffolding, creating a sense of safety to help prevent him from feeling anxious, Hege Krog says.

By employing her strategies, the network notes that the partner creates a supportive environment that allows her to gently challenge Olle, encouraging him to engage with her

suggestions while feeling secure enough to go along with them. Regarding balancing and managing emotions, play is a safe way to explore what emotions mean.

– We see a lot of emotion in the video. At certain points, Olle appears relaxed and happy, while at other moments, he seems thoughtful or perhaps annoyed. We also observe and hear how he responds to his feelings. The partner mirrors and acknowledges his emotions, providing confirmation and support, network coordinator Frida Racksäter Nerback says.

The network notes that mirroring and confirming emotions is important to building a relationship. When learning to communicate emotions—through words, signs, or movements—the people around an individual with CHARGE can better interpret their needs.

– A safe way to practice this is through play. We see a lot of role-playing in the clip. They take turns deciding who has the initiative. They also give each other space, provide confirmation, and sometimes take the space when needed.

The network also notes a narrative in the tempo shifting and pressure. The Nordic Network on CHARGE Syndrome thinks the partner uses this as a tactile modality in changing pressure.

– When Olle becomes more thoughtful and slows down, she applies more pressure, creating a slightly tighter framework for the game. Olle notices this, then relaxes and re-engages with the game, Frida Racksäter Nerback says.

The network also noted that this tactile modality is a good way to help Olle self-regulate his behaviour, allowing him to learn how to make a small protest appropriately and be heard and acknowledged.

The Nordic Network on CHARGE Syndrome also noted the same hand gesture Olle made, which was commented on by the Nordic Network on Tactile Language in their analysis of the video (see Chapter 4.2). The Tactile Language Network interpreted the hand gesture Olle makes nine seconds into the

video as a form of categorisation, possibly measuring his face against his partner's.

– We also discussed this in our analysis. We interpreted it as Olle recognising that she is doing something and signalling, "Wait a minute, I need to process this. I need time to think about it." This is something we often observe in CHARGE. It doesn't mean this is always the case, but it offers an alternative interpretation to the one proposed by the Tactile Language Network, Hege Krog says.

The Nordic Network on CHARGE Syndrome also provided some suggestions for future support for Olle. Since the partner uses tactile sign language in their communication, one suggestion for further development, the network proposes, would be to introduce signs for Olle's feelings.

– Time is essential. People with CHARGE often require more time to integrate information from different senses. Another intervention is to repeat information in the same order each time, helping to compensate for difficulties with working memory, network member Gry Helen Thomsen says.

4.4 The Nordic Network on Self-Regulation

The Nordic Network on Self-Regulation based its analysis on a model found in the publication *Self Regulation for Individuals with CHARGE Syndrome* by Timothy S. Hartshorne and Jude T. Nicholas, also mentioned by the Nordic Network on CHARGE syndrome (see chapter 4.3).

The four-dimensional model of self-regulation illustrates the complexity of self-regulation as a concept. Self-regulation is not simply a matter of controlling one's thoughts or actions. Rather, it is a multifaceted process that involves the coordination of multiple systems. The four dimensions are cognition, behaviour, emotion, and physiology, as network member Lone Rømer Jensen explains.

– Cognitive regulation focuses on managing thoughts and mental processes, such as being motivated and focusing on a

task or planning. Behaviour regulation is about the ability to use self-control to behave appropriately and adjust to a situation. Emotional regulation is about identifying and adjusting emotions within ourselves. Physiological regulation is about the inner state, for instance, regarding arousal and identifying warning signs.

These dimensions are influenced by underlying mechanisms such as genetic predisposition, biology, neurobiology, and experience.

Regarding physiological regulation, the network noted Olle's change in arousal when the clapping game in the video changed tempo. The partner was regulating Olle by increasing and slowing the speed and also disrupting him by stopping the game at one point. The network's hypothesis is that the partner knows Olle very well and she knows when to stop him to prevent excessive arousal.

Olle also self-regulates by biting his finger at one point. The network hypothesises that this indicates that he needs stronger stimulation at that moment to regulate himself.

Regarding emotional regulation, the network noted that Olle shifts from a positive expression to a more negative one when the partner changes the game, but he still tolerates the disruption. The partner responds to Olle's sounds and bodily movements in a process of co-regulation.

– She influences him with her calmness and physical closeness. We hypothesise that when Olle's emotions are positive and intensifying, he begins biting his fingers, Lone Rømer Jensen says.

Regarding cognitive regulation, the network aimed to answer whether Olle has the cognitive ability to set goals, which provides insight into his cognitive ability and flexibility. The question is whether he has a plan for what he wants to do with his partner.

– Our hypothesis is that he understands the concepts of fast and slow, which also demonstrates his cognitive potential. He comprehends her communicative contributions, and our

interpretation is that he listens intently. At an appropriate level of arousal, he is prepared to engage with her communication and contributions. He transitions from a sensory focus to a more cognitive focus.

Regarding behavioural regulation, the network asked whether Olle has the opportunity to follow a goal and demonstrate behavioural flexibility. The network believes that he is flexible and able to shift focus.

They also questioned how much he controls his movements and how much he follows his partner's movements. The network observed that Olle initiates a new movement at one point in the video and changes it at two other points, which, according to them, demonstrates significant behavioural regulation.

The Nordic Network on Self-Regulation also focused on the partner's regulating strategies in its video analysis. As a form of co-regulation, the partner uses pressure, maintains close contact, and effectively adjusts the pace and intensity of interactions, incorporating appropriate disturbances.

The network also posed some questions on Olle's potential from a number of perspectives.

– The question is whether Olle can later use some of the movements from the activity to self-regulate. For instance, would he be able to use tapping on his nose to increase his arousal? At one point in the clip, his muscles appear tense – could this indicate heightened arousal, and what strategies could he use to calm down again? Additionally, is there potential for co-regulation? How can the partner support him in regulating himself?

Lone Rømer Jensen states that the network noted the importance of availability for interaction as a key factor to consider. This state is achieved through a combination of self-regulation and co-regulation to reach an optimal state of arousal.

– A balanced level of arousal is crucial for being prepared for communication and engaging with others. The ability to

self-regulate is essential for effective interaction. This applies not only to arousal levels but also to emotional and cognitive states.

4.5 The Nordic Network on Cognition in Relation to Congenital Deafblindness

The Network on Cognition in Relation to Congenital Deafblindness based its video analysis on the book *Revealing Hidden Potentials: Assessing Cognition in Individuals with Congenital Deafblindness* (2020), which the network produced (see Chapter 2.5). The network decided to analyse the video using perspectives from two specific chapters of the book: Chapter 2 on Humour and Chapter 8 on the Tactile Working Memory Scale.

The network adopted a strengths-based perspective, emphasising individuals' keen interpersonal awareness, robust working memory, and capacity for temporal referencing.

Humour provides a very naturalistic observation approach, whereas the Tactile Working Memory Scale (TWMS) is, in contrast, a highly structured approach. From both perspectives, the network asked the same three questions during the analysis: What do we see? What could this mean? What could we do?

The focus was further narrowed to social cognition, as cognition is an extensive and broad field. Social cognition refers to understanding others' emotions, intentions, and actions and interacting with them in social settings.

Humour as a subject was chosen because humour often reveals complex levels of cognitive processing. Humour, through the lens of social cognition, involves understanding the playful frame and others' intentions, engaging in clowning, teasing, and elaboration to foster connection and interaction. The "playful frame" is an intersubjective and imaginative space where individuals observe and adapt to one another, engaging in improvisation, emotional expression, and

sensory exploration, fostering creativity and connection.

– There was an instance when Olle was biting his thumb. This could have been a reaction to something else, but it could also have been him teasing, doing something he knows he shouldn't do. We thought this was the case because of a reaction from the partner, says network member Joe Gibson.

The network was particularly looking for teasing and clowning behaviour from the humour perspective. Clowning involves repeating actions to evoke laughter while teasing provokes reactions by playfully disrupting shared understandings or ongoing activities.

– Another example we observed was Olle initiating fast nose tapping. We wondered whether this could be teasing or clowning, him doing something he knew was wrong in the situation.

The network noted that Olle also changed the game at one point from nose tapping to hand clapping, which might have been him teasing as well.

– He certainly seems to understand the partner's intentions. For that to be funny, he has to understand that his partner had a plan, and he also has to understand that it would be amusing to deviate from that plan to get a reaction, says Joe Gibson.

Following a moment of tension, Olle's joke appears to be an attempt to reset the interaction, demonstrating bravery, self-confidence, and contextual awareness. The network concluded that he displays complex social cognition.

To support Olle, the network suggests that the partner could develop tactile ways to acknowledge his jokes, such as ensuring he can feel her laughter.

– If we see him as someone who makes jokes and acknowledge him as a funny person, adding that to his list of character traits, we can start to look for more instances where he might be trying to be funny or making a joke. This expands our understanding of him and his potential

repertoire. We could then respond in a bodily tactile way to reaffirm the joke.

The second part of the video analysis by the Nordic Network on Cognition in Relation to Congenital Deafblindness focused on the Tactile Working Memory Scale (TWMS), a behavioural observation tool for identifying bodily-tactile working memory in everyday situations and social interactions.

The scale consists of twenty items that can be identified as present, emerging, or absent in the situation being analysed. Four of these items focus on social relationships, three of which the network found to be present in the clip, with one emerging.

The present items on the TWMS were as follows:

Item 8: Uses active touch and motion to intentionally explore and interact with the interaction partner during close bodily contact.

Item 10: Uses active touch and motion to explore an object together with the interaction partner while displaying behaviours of social attention.

Item 11: Uses active touch and motion in a purposeful manner to recognise (the intentions of) the partner during the interaction.

The emerging item was **Item 9:** Uses active touch and motion to capture the emotionally triggered bodily signals or reactions of the partner.

– We marked this as *emerging* since we weren't sure if he was reading her emotions, even though there was a lot of emotion generally present in the clip, Joe Gibson says.

The network concluded that, from a tactile memory perspective, Olle has effectively developed his tactile working memory in relation to social cognition. He engages well during close bodily contact, maintaining focus for extended periods and drawing attention to his actions. He demonstrates the ability to use past information, such as routines, and has built

a strong foundation for utilising touch and motion.

– Additionally, we concluded that he was able to give emotional expressions, but we weren't absolutely sure if he was able to respond to emotional expressions as well, Joe Gibson says.

To further support Olle, the network recommends encouraging his awareness of emotions and feelings by helping him identify and recognise facial and bodily cues in himself and his interaction partner, possibly incorporating humour.

The network also noted that Olle seems to enjoy the interaction, so one further intervention could be to provide lots of opportunities for close bodily contact through routines and structured activities that align with his interests and are playful or humorous.

– By using two distinct approaches—one highly qualitative and the other more structured—we arrived at remarkably similar results. Emotion emerged as a key overlapping theme and a central focus for intervention, Joe Gibson concludes.

4.6 The Nordic network on Usher syndrome

The Nordic Network on Usher Syndrome initially found the video analysis challenging. The subject of the video, Olle, has CHARGE syndrome and congenital deafblindness. His situation is, therefore, very different from Usher syndrome, which may result in acquired deafblindness.

The network decided to take a holistic perspective and focus on deafblindness in general in their video analysis, basing it on the main implications in the Nordic definition of deafblindness: "To varying degrees, deafblindness limits activities and restricts full participation in society. It affects social life, communication, access to information, orientation, and the ability to move around freely and safely."

The network based their analysis questions on the definition, asking how Olle can be active and participate in his daily life in

a way that allows him to have agency based on his prerequisites. What can be enhanced? What are the barriers and facilitators for Olle? How can his needs be mapped?

[The International Classification of Functioning, Disability and Health \(ICF\)](#) is a framework created by the World Health Organisation for describing and organising information on functioning and disability. It provides a standard language and conceptual basis for defining and measuring health and disability. The model consists of nine life domains, of which the network decided to look at three: Learning and applying knowledge, communication and Interpersonal relations.

The network found two instances in the video where they interpreted learning and applying knowledge taking place. One of them is the gesture that Olle makes with his hand to his forehead.

– It might be that Olle wants to make himself more sensorily prepared to learn by making the gesture. It might be something he is doing to address to himself that he is prepared, network member Rasmus Hougaard Pedersen says.

The other sequence where learning and applying knowledge might take place is where the partner is giving the tactile sign for "slow".

– We see in the interplay after that there are some changes in the pace. We take it as a sign that Olle is learning and applying what he has just learned: Learning how to understand a new sign and knowing how he can use it.

The network agreed with the other networks' analysis regarding communication, as all had addressed it. The Usher Network added some additional comments, specifically considering the ICF Model.

– There is a lot of complex communication going on, with lots of tactile language terms. We noted gestures, sounds, smiling, and, of course, clapping. In every second of the video, there is complex communication going on, network coordinator Bettina Kastrup Pedersen says.

Regarding the barriers and facilitators in this communication situation, the network noted that the facilitators are both Olle and the partner, as they assist each other with the communication. The barrier might be that Olle's communication is not seen or felt. The positioning is what makes this possible.

– If they were not positioned like this—for instance, if they were sitting or standing next to each other—they might not have the same opportunities, Bettina Kastrup Pedersen adds.

Regarding the third part of the analysis, interpersonal relations and relationships, the network notes that Olle seems to have a good relationship with his communication partner. They are playing, and he is laughing. Possible barriers from this perspective might be that other people in his life lack the appropriate communication competence. The network proposes a goal to ensure that Olle has the same opportunities to communicate with others he encounters in his life, such as family members, friends, and even strangers.

In summary, the network suggests that all nine life domains in the ICF Model should be mapped from the perspective of Olle's life situation on a regular basis.

– This means finding out what the current situation is, what the facilitators and barriers are, what goals need to be set so we know what kind of support to provide, and what interventions need to be made to help Olle become an actively participating individual in his own life in a way that aligns with his wishes, agency, and prerequisites, network member Moa Wahlqvist explains.



Photo: Mostphotos

Chapter 5

Dr Paul Hart: Analysis and comments

The network seminar continued with a summary by Dr Paul Hart, former Head of Operational Support, Practice Development and Quality at Sense Scotland, highlighting the key points from the presentations and video analyses provided by the networks. He noted that the Nordic countries have played an enormous role in his own learning and knowledge development within the deafblind field.

Paul Hart emphasised the importance of understanding the individual who is the focus of the analysis, as well as their way of being within the context of deafblindness. He also underscored the advances made in the deafblind field in recent years, which have contributed to standard literature on human development and aided in attaining a fundamental understanding of what it means to be human.

Paul Hart centred his summary of each of the network's video analyses on Olle, particularly considering what we can admire about him.

The Communicative Relations network underscored the dialogical nature of communication, emphasising the importance of viewing it as a partnership. The Cue Model, Diamond Model, and related concepts illustrate how

communication and meaning emerge through interaction.

– It is impossible to consider communicative relations as involving only one partner in that connection; they must involve both individuals. In the video analysis, I believe the Communicative Relations network helped us to recognise the speaking and listening positions that both Olle and his partner adopt.

Paul Hart noted that the network directed their analysis towards the joint attention between Olle and his partner, the agency Olle demonstrated, and the elements of trust between them, alongside the emotional components, authenticity, and rhythm of their interaction.

Paul Hart stated that we can admire several aspects of Olle through the lens of the video analysis provided by the Communicative Relations network.

– Olle is a boy with something to say; he can listen to your story, has agency, knows what he wants, and trusts others while being trustworthy as a communication partner himself. He is a budding musician, dancer, storyteller, or, in one way or another, a creator. And he remains authentic to himself.

The Tactile Language network demonstrated increasing confidence in recognising tactile communication as a genuine language, tracing its evolution from iconic gestures to more conventionalised signs. This has sparked reflections on the typical development of new languages.

– I think the development of tactile language is one of the most exciting things happening within the field of deafblindness.

Paul Hart noted that a discussion is taking place in the deafblind field regarding whether to teach conventional signs in tactile modality to a deafblind individual or to adopt the natural signs that the individual is developing.

– In the video analysis, the network centred on the utterances, tactile language elements, and tactile categorisation and how these were linked back to the Diamond and Cue model. The breaks and flow in the relationship were also mentioned, along

with tactile pointing and joint attention.

From the Tactile Language network's video analysis, Paul Hart identified several qualities of Olle that are commendable.

– He can solve problems and find solutions; he is able to learn about the world; he keeps his partners engaged and challenges them further; he is a communicator and a user of language. If we acknowledge that new tactile languages are emerging globally, Olle and many other deafblind individuals around the world are pioneers in the development of this language. Therefore, Olle is both a pioneer and a fellow traveller.

The CHARGE Syndrome network concentrated on sensory integration, emotional regulation, and the significance of scaffolding development. They observed how individuals demonstrated strong narrative skills, categorisation abilities, and the capacity to introduce surprise and novelty, and time and tempo as key to the interaction.

– We might admire Olle for his way of being in tune with his existence in the world; he learns from others and has learned how to categorise the world around him.

Paul Hart also focused on the fact that Olle is a storyteller who knows how to build tension and introduce surprises in his communication.

– He allows his character to shine through, and he is happy to be understood.

The Self-Regulation network emphasised the need to move beyond outdated views of "random, purposeless movements" and instead recognise the purposeful strategies individuals employ to optimise information intake and engagement.

– We no longer think of movements as random or purposeless because they wouldn't be random for the person, and they are not without purpose. Again, I believe our field develops considerably through these kinds of networks.

In the video analysis of the Self-Regulation network, Paul Hart

noted that the network spoke about the change of attention and how that is often linked to sensory integration, such as biting a finger or grinding teeth. The network also discussed arousal intensity and how it was linked to the rhythm of the conversation, as well as pace, intensity, sensory availability, bodily contact availability, turn-taking, imitation, confirmation, recognition, sensory stimuli and appropriately challenging.

The network also noted that Olle stays focused on his goals and contributes initiatives with known patterns from previous interactions with the same partner.

– We can admire Olle for being able to recognise you from previous encounters and know what you like to do. He keeps focused on his goals, uses his body to communicate what he is thinking, uses vocalisations to let you know what he is thinking or feeling, and can easily switch from one topic to another. He's got a great sense of humour.

The Cognition network took an asset-based approach, highlighting individuals' astute understanding of others, effective working memory, and ability to reference the past and anticipate the future. Paul Hart particularly praised the network's 2020 publication 'Revealing Hidden Potentials – Assessing Cognition in Individuals with Congenital Deafblindness'.

– I use it frequently. It is a superb publication that is ultimately optimistic and takes an asset-based approach; it is not interested in finding out what a person can't do but rather in discovering what a person can do.

Paul Hart emphasised that this approach is vital.

– If we expect someone to be a good communication partner, for instance, that is what they will become. If we expect someone to be able to connect, that is what they'll do.

In the network's video analysis, Paul Hart pointed out the network's focus on Olle's teasing and clowning, which is related to language development and how each of us

becomes who we are. Tapping the nose and changing the game, which the network noted that Olle does, is also related to this.

The network also noted that Olle takes initiative and introduces new ideas and topics, feels the energy and emotion of the other person, recognises the intention of the partner, directs and shares attention, and anticipates the next steps.

– We can admire that Olle is bright and understands other people, has a great sense of comedic timing, and possesses many I-positions. He has an effective working memory, can stay focused for a long time. He can refer to the past, and can anticipate what is going to happen.

The Usher network adopted a life perspective with the individual at the forefront. They used the ICF model, which takes a bio-psycho-social approach, allowing for a more holistic understanding of a person's medical aspects, personality, outlook, and life experiences, and how these shape their condition. Crucially, the ICF model also stresses society's responsibility to provide adequate support and accommodations.

In the video analysis, the network focused on three areas: learning and applying knowledge, communication and interpersonal relations.

– Through the lens of the ICF model and throughout all the analyses and discussions, I believe we can all conclude that Olle is simply a young boy and a fellow human being. He knows how to apply learning and knowledge, and he is good with other people. Ultimately, after being our focus, he has become our teacher. Paul Hart concluded.



Photo: Mostphotos

Chapter 6

Conclusions, suggestions, and plans for the future

Summing up the takeaways from the video analyses and the commentary by Dr Paul Hart, Gøran Forsgren, senior adviser at the Nordic Welfare Centre, said Olle almost became a new individual when all his competencies and potential were brought to light.

Gøran Forsgren underscored the need to apply this wisdom in each and every encounter we have when meeting people with deafblindness, their relatives, and society at large.

– This is the first time I have seen so many levels of interpretation and so much potential regarding one person being shown. If we can use this technique and show the parents of people with deafblindness and show society that those we work with actually do have this potential and these competencies, then we would have a win-win situation for everybody.

By combining medical, psychological and social perspectives, the networks have shown that individuals with deafblindness can develop advanced narrative abilities, categorisation skills and a strong understanding of others when given the right support.

This paradigm shifts from a deficit-focused to a strengths-based approach marks a revolution in the field, which will influence the future of support services.

Gøran Forsgren also appreciated Paul Hart's approach of looking at the person from the perspective of what we can admire about them.

– By asking what we can admire about a person, we can help ourselves see that person's potential.

6.2 Comments and suggestions from DBNSK

Jackie Lehmann Hansen is chairperson of the Danish Deafblind Association and the DBNSK (Deafblind Nordic Committee on Collaboration). The DBNSK addresses issues related to people with deafblindness in Denmark, Finland, Iceland, Norway, and Sweden. DBNSK is a network for the chairpersons and vice-chairpersons of deafblind associations in the Nordic countries.

Grounded in the principle of the equal worth of all individuals, DBNSK advocates for the rights of people with deafblindness to fully participate, enjoy equality, exercise autonomy, and achieve self-determination in all aspects of life across the Nordic countries.

During the network seminar's final session, Jackie Lehmann Hansen advocated for closer collaboration between the Nordic networks and the DBNSK. He said the Nordic countries are considered leading in the deafblind field worldwide, but at the same time, some of the rights of deafblind people within the Nordic countries are threatened.

– We realise that the Nordic countries are considered role models, so it is very important for us to strengthen our work in this area. At the same time, we, the people living with deafblindness, are seeing our rights being decreased at the moment, and we would like to do something about that.

Lehmann Hansen noted that the Nordic networks on deafblindness within the Nordic Welfare Centre work very well. Regrettably, the DBNSK has observed that it does not

function as effectively due to resource constraints, both financial and human resources. Lehmann Hansen asked the representatives of the Nordic networks at the conference if they would be interested in a deeper collaboration with the DNBSK.

The question was met with an overwhelming 'yes'. Several network representatives took the opportunity to emphasise how a deeper collaboration could benefit both DNBSK and the Nordic networks on deafblindness.

– Your answer makes me very happy. We are the ones who live with deafblindness. We want to be involved in professional seminars, and we want to and can contribute, Lehmann Hansen said.

Among the suggestions for further collaboration between the DNBSK and the Nordic Networks was to conduct a video analysis in the same way as at the network seminar, where a person living with functioning deafblindness could add another perspective to the analysis. Another concrete proposal was to start sharing meeting notes, reports and decisions with each other.

Jackie Lehmann Hansen praised the good work being done by the Nordic networks.

– Your work makes a significant difference for us. And you do it for us. At the same time, I would like to reiterate our motto: nothing about us without us.

6.2 Towards the future: Plans, comments and suggestions

The conference concluded with a forward-looking perspective. Gøran Forsgren, the event organiser and senior adviser at the Nordic Welfare Center, shared his vision for network collaboration in the coming years.

Nordic conferences are to be held every four years, with the next scheduled for September 2026 in Denmark.

– One of the themes at the conference will be called "New Nordic Voices", which reflects the new knowledge that gets

developed through collaboration within the networks. This represents new researchers in the field as well, Gøran Forsgren explained.

In the interim, network seminars, courses, and publications of new material by the networks will take place.

New ideas for future research

A significant portion of the concluding session of the network seminar in Malmö comprised an open discussion, during which all participants could express their vision for the network's future and discuss how to develop the knowledge gathered at this particular network seminar.

Many network representatives expressed a desire for increased collaboration across networks. The suggestion of conducting more cross-network video analyses similar to the one at this network seminar was put forward.

Numerous attendees highlighted the benefits of performing video analysis collaboratively with other networks. The need for creating a practical guide for video analysis from a cross-network perspective was also raised.

Another practical method for networks to collaborate put forward during the final discussion is as consultants on specific cases involving deafblind individuals. One network's perspective could illuminate aspects that might otherwise remain unnoticed. During the discussion, several instances were identified where one network could function as a consultant for another network or for practitioners working directly with deafblind people.

The need to bring the networks' work closer to practitioners and individuals living with deafblindness was recognised. Many networks also emphasised the need for collaboration with the DBNSK, as suggested by Jackie Lehman Hansen, and for building stronger connections between the networks to produce new research material, webinars, courses, and guides.

One proposal for collaboration with the DBNSK at the next

network seminar was that representatives from different countries within the DBNSK should prepare questions to be discussed with each of the networks. This would allow the DBNSK to gain the networks' perspective on their work, and the networks themselves could analyse the questions to gather new knowledge.

The networks were also requested to identify common themes for collaboration at the next conference or network seminar.

Two themes were suggested: ageing and accessibility. These themes were seen as suitable since they are relevant to the perspectives and expertise of all the networks within the deafblind field. Each network could contribute input to generate new knowledge regarding ageing and accessibility and how they uniquely affect deafblind people.

The importance of demystifying the networks' work was also mentioned, as well as the general need to provide better guidance on how to read and interpret scientific reports and literature.



Photo: Sigve Nedredal

Collaboration and generosity

– The possibilities of future collaborations and the networks getting together to share ideas were the real power of collaboration within research, Paul Hart summed up his main takeaway from the network seminar.

Gøran Forsgren underscored the generosity within the field and the willingness to look at the potential of the individual

being the focus of video analysis, as clearly reflected in Paul Hart's approach to summing up the different network analyses (see Chapter 5), as one main takeaway from the meeting.

– The asset-based approach really did come through. We did not look at the individual in terms of what he could not and did not do, but rather what he can do. This is the type of generosity we have in the field, all of us who are working with deafblind people, both those with congenital and acquired deafblindness. We try to see the best: what are your competencies and assets, and how can you contribute?

In his closing statement, Gøran Forsgren underscored the need for more collaboration, as new knowledge is generated when people with different perspectives work together. At the same time, he identified the need for Nordic experts within the deafblind field to strengthen their standing as experts in society, as the general trend is one of diminishing resources.

– We need to solidify our position in society by becoming a beacon of knowledge. Our knowledge can help not only those living with deafblindness but also those in the bordering areas who are not diagnosed but might still have a combined vision and hearing loss or deafblindness, such as individuals with cerebral palsy, stroke survivors, or older people in general.

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