

Sweden's report to the Nordic Leadership Forum 2025

The Deafblind Council – a structured co-operation around deafblindness in Sweden

The National Deafblind Council is committed to ensuring that individuals with deafblindness receive high-quality and equitable support, regardless of where they live in Sweden. By bringing together a range of expertise, the Council facilitates the exchange of knowledge and the dissemination of information to relevant authorities, services, and organizations.

The Council's work is grounded in several key objectives. It aims to foster national collaboration in order to develop a shared understanding and cohesive approach to issues concerning deafblindness. Through active information sharing, the Council promotes mutual awareness of the various roles and responsibilities involved, which contributes to a broader and more informed perspective on the needs and challenges in the field. Continuous monitoring of national and international developments ensures that the Council remains up to date with current trends and best practices. Furthermore, the Council seeks to influence decision-making processes by advocating for effective support systems that meet the needs of children, young people, and adults with deafblindness throughout the country. The Swedish Deafblind Council includes the following organizations:

- The Association of the Swedish Deafblind (FSDB) including Deafblind Children and Youth (DBU in Swedish) and the Parent Council
- The National Resource Center for Deafblindness (Nkcdb)
- The National Agency for Special Needs Education and Schools (SPSM) - Resource Center deafblind activities (Rcdb)
- Swedish National Upper Secondary School for the Deaf and the Hard of Hearing
- Deafblind teams/networks from two of Sweden's 21 regions that offer services within habilitation/rehabilitation.
- The Swedish Public Employment Service (Arbetsförmedlingen) Units of Sight, Deaf and Hard of hearing under the Rehabilitation Department
- The Audiological Research Center in Örebro

Below follows a summary of the different activities regarding projects and resources on a national level.



Nationellt kunskapscenter
för dövblindfrågor

The National Resource Center for Deafblindness (Nkcdb)

Since 2013, the National Resource Centre for Deafblindness (Nkcdb) has been part of the Swedish National Board of Health and Welfare. From 2003 to 2013, it was run by the Mo Gård foundation.

Nkcdb provides information, training, and support to professionals and organizations working with individuals who have deafblindness. Our mission is to help ensure that children and adults with deafblindness receive the right support to live active, inclusive lives. We share knowledge through courses, consultations, written materials, and our website. We also collaborate with government agencies, researchers, and organizations led by or representing people with deafblindness. Listening to the voices of those with lived experience is key to creating effective support.

Nkcdb's team includes 10 staff members and about 20 consultants, most of whom are linked to regional teams across Sweden. This national network allows for fast knowledge sharing and better local insight. We also work closely with researchers in Örebro to strengthen and expand deafblindness knowledge in Sweden.

Current Work and Priorities:

Professional Support and Website Development

We continue to support professionals such as psychologists, social workers, audiologists, and vision specialists with expert guidance. A new website, launched in May 2025, will make it easier to find resources and contact us. Accessibility is a top priority—webinars include sign language interpretation and captions if needed, and all materials are offered in accessible formats. The new site also host a model called "[Vägledningshjul](#)," which provides guidance in five key areas: detection, identification, assessment, intervention, and collaboration.

Courses and Publications

Nkcdb offers yearly [hybrid courses](#) on both congenital and acquired deafblindness. We also provide [on-demand online courses](#) that are free and open to everyone. Statistics show that these are widely used. A well-attended, [online-based course for professionals working with children](#) will return in spring 2025. This spring, a webinar series for psychologists and social workers was offered for the first time, focusing on therapeutic conversations and the life adjustment model, which addresses the high mental health risks in this group. To mark 200 years of braille in 2025, Nkcdb will organize awareness activities throughout the year.

Recent publications include:

- [*Socialhaptiska signaler som AKK*](#)
- [*Visuellt anpassat teckenspråk*](#)
- [*Vårdbesök för barn med medfödd dövblindhet*](#)
- [*Viktigt med egna erfarenheter*](#)

A new book on the role of siblings of people with deafblindness will also be released in 2025.

Digital Accessibility

In response to the EU Accessibility Directive taking effect in summer 2025, Nkcdb is working to clarify its impact for people with deafblindness. We're testing systems and defining how regional rehabilitation services should meet new digital accessibility standards.

Ongoing Projects:

Identifying Deafblindness

We're developing tools and routines for [early detection](#) and [identification](#), including a national routine created with the four northern regions. A pediatric audiology project launched in 2024 will result in a book on hearing assessment for children with vision loss. We're also contributing to Nordic work on new materials and education for assessing functional deafblindness.

Communication

Demand for support in tactile sign language and social haptic signals is high. Short educational videos recorded in 2024 will be released in 2025 as an on-demand online course. A project on communication needs in acquired deafblindness will also publish findings and methods this year.

Cochlear Implants (CI)

Our project about CI highlights that CI rehabilitation often relies too much on vision. We've published [new guidance](#) to support professionals working with CI users who have vision loss.

Life Adjustment Model

Nkcdb is participating in a pilot project exploring the life adjustment model as a group rehabilitation method. Two staff members are involved and will revise the evaluated manual during 2025.

ICF Core Set for Deafblindness

Following WHO's adoption of the ICF core set for deafblindness in 2024, Nkcdb will explore how it can be applied in Sweden. Work in 2025 will involve collaboration with professionals and researchers to adapt and implement the tool. Nkcdb has updated the [information about ICF](#) on the new website based on the new core sets.

Lund 2025-05-05

Caroline Lindström, vice head of operation, Nkcdb
Helene Engh, Head of operation, Nkcdb

The National Agency for Special Needs Education and Schools (SPSM) – Resource Center deafblind activities (Rcdb)

At the Resource Center, we continue to carry out special needs assessments for individuals with deafblindness. We receive a steady number of new cases and work as a team across different professions. This way of working helps us provide better support. We are always working to improve what we do. Recently, we updated how we carry out our assessments to ensure better quality information and training for preschools, schools, and parents. Below, we will report of some specific ongoing projects.

Concept Development

SPSM is now creating a shared set of terms and definitions, called "the Thesaurus." This is to help everyone at SPSM—and those we work with—use the same language when we describe, analyze, or compare information. A common language helps avoid misunderstandings. The Deafblind Competence Group at SPSM has helped review the terms related to deafblindness.

Braille Support

We are finishing our development work on how to best support preschools, schools, and families with Braille. A new plan for how to help children who read or will read Braille has recently been approved. This includes children and students who are blind or have severe vision loss, with or without other disabilities.

Students who use Braille are supported through a process based on their individual needs. In some cases, we do not need to carry out a full assessment if a child cannot use visual reading materials. Still, we provide support through our method-based process.

Training

We have created a series of webinars that are free and open to all. Part 1 introduces both congenital and acquired deafblindness. Part 2 is divided into two tracks—one for congenital and one for acquired deafblindness. People can take one or both tracks. Part 1 will stay available online for a long time so more people can watch it when it suits them. We are also recording short, simple videos to show how to support communication and interaction.

Collaboration and Networks

We work closely with other organizations and networks. For example, we meet regularly with Nkcdb to strengthen our work and learn from each other. We also join several networks through NVC to share knowledge and develop new ideas. Within SPSM, we collaborate through different expert groups. In the Deafblind Competence Group, we do things like follow new research, provide training, and plan support materials and study packages.

Every year, we offer professional development for individuals and our team. This past year, we focused on training in vision-related areas. Three of our staff members have taken university courses in vision. One staff member will begin a master's program in Groningen, Netherlands, in fall 2025. Two others have received training in the Tactile Working Memory Scale (TWMS).

Stockholm 2025-04-16

Linda Gavelin, Unit Manager RC Deafblind, SPSM



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The Swedish Public Employment Service (Arbetsförmedlingen)

Units for Sight, Deaf, and Hard of Hearing (SDH) – Rehabilitation Department

The SDH units operate across all regions of Sweden and currently have approximately 110 employees working actively with individuals from the target groups registered with the Swedish Public Employment Service. These employees include specialists in vision, hearing, and deafness, as well as staff dedicated exclusively to supported employment.

For those working with supported employment within SDH, it has long been a challenge to guide individuals through the often complex regulations—particularly when errors can lead to financial penalties. For example, submitting activity reports is frequently cited by the target groups as a difficult task.

To address this, the Swedish Public Employment Service has added two additional videos in sign language to its website this year, aiming to improve understanding of key procedures and regulations. The most recent video is an 11-minute guide focused on activity reports.

Additionally, Nkcdb has granted SDH employees free access to its course on deafblindness. A selected number of staff members attend this course each year.

Växjö 2024-04-21

Linda Dahlén, Section Manager, Swedish Public Employment Service

Research on deafblindness in Sweden

The research group at Örebro University consists of senior and junior researchers, clinical professionals with master's degrees, master students and a PhD student within the field of deafblindness. The members are from around the country, and from Denmark. The research group leader, Moa Wahlqvist works part time at Region Örebro County as a researcher and part time at the Swedish National Resource Center for Deafblindness (Nkcdb) in Lund, which is regarded as beneficial for both parts. Over the years, more members of the research group are becoming employed with the Nkcdb, which facilitates collaboration between research and strategic work on national level for people with deafblindness. Many of the members of the research group participate in several national and international networks, which is valuable in terms of keeping updated, sharing information and is a base for future research collaboration.

The research group has during the last year had several virtual meetings. At these meetings, we have discussed ongoing and planned research projects, upcoming conferences and newly published literature. We have also discussed strategic plans for our future work and shared results from research and developmental work that has been conducted by members of the research group.

The research collaboration with researchers from the Netherlands and Denmark is ongoing. We met in the Netherlands in the autumn of 2024, and the next meeting is planned to take place in Denmark in October. We discuss collaboration on general basis, and specifically within the field of working life for people with acquired deafblindness, communication for people with congenital deafblindness and educative interventions for families where a family member has deafblindness. The Swedish research group has repeatedly applied for funding related to working life, to conduct similar studies that are ongoing in the Netherlands and Denmark. Unfortunately, we have not yet received any funding. However, Moa Wahlqvist received a network grant from the Swedish Research Council for Health, Working life and Welfare (FORTE) which is to be used to further develop the research group and its networks.

Several of the researchers from Örebro will present study results at conferences within the next months; NNDR I Finland, Usher Coalition in the Netherlands, European Federation of Audiology Societies in Austria and at Vision 2025 in Italy.

Below, we will report of some specific ongoing projects in Örebro.

Health and family climate in families where a parent has deafblindness

The last article within the project has been published, see:

<https://doi.org/10.1080/09638288.2024.2443566>

The two book-chapters reporting from the project will be published during this year and after that, the project will be closed.

Covid-19

There have been two projects about deafblindness and Covid- 19 running. Moa Wahlqvist finished her project about information and access to information for people with deafblindness in times of crises in 2023. However, the project will also result in a publication on recommendations for guidelines, which is still to be finalized.

Mattias Ehn's project focusing on experiences about health and supportive interventions for people with deafblindness during the Covid-19 pandemic is still running but is a bit behind schedule. We hope to submit the first article during this year.

Validation of the Life adjustment model - A psycho- educative intervention for persons living with deafblindness.

The data-collection is finalized in this project. The intervention was offered to adults with deafblindness at two regional deafblind rehabilitation units. Four of the patients volunteered to participate in the evaluation of the intervention, where the content as well as the evaluation itself was evaluated. The analysis is ongoing, and the plan is to report the small-scale study results this year. Based on the results, the research group will continue with an application for a full-scale study in the coming years.

A Swedish audio-visual speech perception test

The work with the Swedish audio-visual speech perception test, by Erik Witte and colleagues from the research group Interdisciplinary Research in Clinical Audiology (IRCA) at Örebro University, and Rolf Mjølnes from Eikholt in Norway has been paused this year. The reason for this pause is that other research activities had to be prioritized.

Adults with congenital deafblindness

The researchers working together with Emil Holmer from Linköping University in the project focusing on communication between persons having deafblindness and their caregivers held a closing conference of the project in January. The process of the project, as well as results were shared. Some articles have been published and others are in preparation phase.

Life without access to municipal companion service applied for: focus on experiences of adults with Usher syndrome

Emma Varga, who is employed by the Nkcdb is developing her master thesis into a scientific article together with her previous supervisors. Hopefully this work will be finalized during the beginning of the autumn. The topic is highly relevant as official statistics has shown that people with certain disabilities recently have been denied companion service in Sweden to a higher degree than before.

Örebro 2025-04-08

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