

Report from Sweden to the Nordic Leadership Forum 2026

The Swedish National Resource Center for Deafblindness

This report will in parts relate to the questions posed, what is new during the last year, which challenges you are facing and positive examples from your practice.

The Swedish National Resource Center for Deafblindness (Nkcdb) has the assignment from the Swedish National Board of Health and Welfare to provide support to professionals in the field of deafblindness. This means that Nkcdb are to gather and spread information and knowledge on deafblindness regardless of age or cause to professionals as well as the public with regards to deafblindness. The assignment also entails that Nkcdb, in all aspects of its work, shall collaborate with people living with deafblindness.

What is new during the last year

In the last year we have been doing this in different ways such as webinars, courses, publications and more. For example, Nkcdb have developed a new web-based education on tactile language, and a course on deafblindness aimed at professionals who meet adults with congenital deafblindness in re/habilitation or in group homes. Nkcdb has also published several new publications, for example a guide for orientation and mobility, material for assessment of hearing impairments when also having vision impairments as well as material for providing augmentative alternative communication including social haptic communication to people with deafblindness. Further, the Nkcdb is currently working on an update of a previous material on young adults with deafblindness. We have also on the behalf of the Authority on Participation (Myndigheten för delaktighet, MFD) conducted a mapping of deafblind interpreting services in Sweden, which included information provided from the Nordic countries and a review of research. You can find our courses, publications and more on our website www.nkcdb.se.

From the 1st of January the Nkcdb has a new deputy manager, Moa Wahlqvist, who combines this with her assignment as a research and development coordinator. During the last year Nkcdb has had a focus on vision specialists and their role as supporting individuals with deafblindness in re/habilitation.

Challenges

In terms of challenges that we are facing, Nkcdb receive more questions addressing individual consultations of people with deafblindness. There are also requests with regard to Nkcdb's possibilities to provide group interventions to people with deafblindness directly, groups that have been especially addressed are youth with deafblindness and parents with deafblindness. A dialogue is therefore ongoing with the regions, which are responsible for providing habilitation and rehabilitation services, regarding how Nkcdb could support the regions by offering group interventions on their behalf, while the regions retain responsibility for needs assessments and follow-up.

In a broader context, in Sweden today we identify that there is a gap between interventions and support asked for from the target group and what is provided from health care and social services. This is more prominent within the support that is the responsibility of the municipalities and regarding guidance, personal assistance and transport services.

In the work with the report to the MFD it was identified that people with deafblindness do not have access to deafblind interpreters to the extent that they would like and that guidance is not always offered to such an extent that is needed. The individuals with deafblindness reported that they to a larger extent wanted to have a possibility to impact when to get a deafblind interpreter to certain activities. Social activities have a lower priority for the units that provides interpreter services than for instance health care, which is reasonable, however, to be able to participate in a social activity can have great importance in order to decrease the risk of isolation and loneliness.

A challenge that we are facing is to identify competence in the field of vision. Professionals with a specialization in vision and visual impairments and who provide rehabilitation within the field of vision are lacking. For the last one and a half year we have had an occupational therapist working part-time at Nkcdb, responsible for issues related to rehabilitation/habilitation within vision and deafblindness. From the autumn of 2026, this person will not be working with us any longer as she is going to start doctoral studies. We are currently discussing what needs that are within this area and how to fill the gap when she finishes.

The Swedish Public Employment Service has over the years gone through several reorganizations of operations. The employment service has specialized units with a responsibility to provide services to people who are deaf, have visual impairments or deafblindness. Those units have so far been relatively spared from reorganization, but this has now changed. This has led to a need to educate the staff working at specialized units. This is an assignment that Nkcdb has taken on and will together with the management at the specialized units, develop a course in deafblindness targeting the staff.

Positive examples from our practice

Nkcdb's ambition is to serve as a national hub for knowledge on deafblindness in Sweden. We see that our webinars are well attended, our courses and training programs attract many participants, our publications are widely requested and used, and Nkcdb is receiving an increasing number of requests for support in various forms.

In particular, we have seen that in recent years Nkcdb has improved its outreach to professionals working with both children and adults with congenital deafblindness. Awareness of the importance of early detection and identification has also increased, and Nkcdb is receiving a growing number of inquiries related to how this can be achieved. The new section on our website, "Guidance Wheel (Vägledningshjulet)", has likely contributed to this development. We receive very positive feedback on this resource, along with requests to further develop the sections related to adults and older people, something we intend to address.

Serving as a hub for deafblindness also involves collaboration with others. Nkcdb leads a national deafblindness council with representatives from services working with providing support to people with deafblindness, as well as user organizations, including their youth organization. This is a key success factor, as it provides a platform for exchanging information, creating a shared understanding of current developments, and identifying needs for action. One example is that changes and emerging needs within the Public Employment Service were highlighted in this forum.

Lund, 2026-05-03

Helene Engh and Moa Wahlqvist

Manager and Deputy Manager/Research and development coordinator

The Swedish Association for the Deafblind

Organization

Over the past year, the Swedish National Association of the Deafblind (FSDB) has continued to develop both its organization and its ways of working.

- The work has been based on the operational plan for 2025–2027, with a focus on long-term development and clearer governance.
- The association has held a national meeting, dialogue forums (communication between regional and national levels), and competence development initiatives to strengthen collaboration between the national level and regional associations.
- Membership development has been prioritized, with a focus on structure, follow-up, and recruitment.
- FSDB has continued to develop its internal communication, digital working methods, and support for regional associations.
- The association is engaged in international cooperation, including work within the Nordic region, Europe, and globally.

Overall, the year has been characterized by an increased focus on structure, follow-up, and strengthening the organization's long-term capacity.

Advocacy work

Interpreting services

Interpreting services and deafblind interpreting have been among the highest priority areas.

- The government has decided to establish a national function for interpreting services, which is the result of long-term advocacy efforts.
- The shortage of interpreters and the need to strengthen education and skills provision have been highlighted as key future issues.

Summary:

The issue has moved from political discussion to concrete implementation, but major challenges remain.

Guided Assistance (LSS and SoL)

Work on guided assistance and the right to personal support has remained a priority.

- FSDB has advocated for the right to guided assistance under LSS and has worked to ensure that people with deafblindness are included in the appropriate eligibility group that grants access to LSS.
- Several legal cases have resulted in positive rulings for people with deafblindness, which may indicate a cautious shift in trend.
- At the same time, significant shortcomings remain:
 - restrictive assessments
 - unequal access between municipalities

- insufficient understanding of communication as a fundamental need
- FSDB has maintained dialogue with authorities and participated in consultation processes, including those related to the National Audit Office's review of LSS.

Summary:

Some legal progress has been made, but major structural problems remain in implementation.

Brief Conclusion

The past year has been characterized by:

- strengthened internal organization and structure
- clear progress in interpreting services at the national level
- continued challenges in guided assistance and personal support

FSDB continues to work long-term to ensure equal living conditions, access to support, and full participation for people with deafblindness.

Stockholm 2026-05-04

Klas Nelfelt

Chair of the Swedish National Association of the Deafblind

Research on deafblindness in Sweden

Overview

The research group at Örebro University consists of senior and junior researchers, clinical professionals with master's degrees, and a PhD student within the field of deafblindness. Another member of the group will hopefully be accepted as a PhD student in May. The members of the research group are from around the country, and from Denmark. We hold various professional, as well as academic backgrounds. The research group leader, Moa Wahlqvist works part time at Region Örebro County as a researcher and part time at the Swedish National Resource Centre for Deafblindness (Nkcdb) in Lund, which is regarded as beneficial for both parts. It 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 as well as a two-day seminar where strategic plans for future work were discussed. A follow-up meeting is planned to take place in June.

The research collaboration with researchers from the Netherlands and Denmark is ongoing. We met in Denmark in the autumn of 2025, and the next meeting is planned to take place in Sweden late this autumn. 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. Recently, we have also initiated a discussion to apply for Horizon Europe 2027 financing for a collaboration research project regarding deafblindness, independence and inclusion. This is a quite complicated process so the planning for such an application has already begun.

Researchers from the Örebro research group assisted in an investigation about every-day interpretation for adults with deafblindness, which Nkcdb conducted on behalf of the Swedish Agency for Participation. It was officially completed in January this year.

Several of the researchers have presented their research at relevant conferences during the year and will participate at the Nordic Conference on deafblindness in Copenhagen in September 2027. The leader of the research group has been the chair of the Scientific committee and one member in the group has been representing from Sweden.

Below, we will report of some specific ongoing projects run by researchers belonging to the Örebro research group.

Adults with congenital deafblindness

Some articles have been published, and others are still in preparation phase. Emil Holmer in Linköping is the principal investigator for these studies.

Covid-19

The first manuscript in Mattias Ehn's project focusing on experiences about health and supportive interventions for people with deafblindness during the Covid-19 pandemic is just about to be submitted. It focuses on professionals working in deafblind rehabilitation. The findings reveal that professionals were "bending, but not breaking" during the pandemic. The second study is under analysis.

Digital inclusion

Jenny Widmark, PhD student, is just about to finalize the analysis in her first study, and her second study, which is an intervention study has started. For now, 6 participants (of 35) have been enrolled.

Health and family climate in families where a parent has deafblindness

Two book-chapters reporting from the project has recently been published and we currently have written a commentary for a special issue in the journal Language, Speech, and Hearing Services in Schools under review. There, we argue for children's right to a shared language with parents having deafblindness.

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 in her final phase of developing her master thesis into a scientific article together with her previous supervisors. She will be presenting the findings at the Nordic Conference on Deafblindness in Copenhagen. The findings indicate that the rejection of companion service negatively affected the participants' psychological basic needs and that their health and well-being were at risk.

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

This project is in the phase of summarizing the results and report them to the funder, as well as to a broader audience. In parallel, we are discussing how to proceed with national implementation of the model and if the manual, which the intervention is based on should be published and translated into English for professionals from other countries to adapt it to local settings. We are also discussing if professionals who want to use the manual should be offered education beforehand and perhaps supervision during implementation phase. The research group have postponed the idea to continue with an application for a full-scale study right now.

Örebro 2026-04-24

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And

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