

Annual report from the Nordic Network on Usher Syndrom 2025

Coordinators:

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Members:

Sweden: Emma Varga (NKCDB), Maria Olander Nilsson (SPSM)

Denmark: Bettina Kastrup Pedersen (Coordinator, Specialist Consultancy for the Deafblind), Rasmus Hougaard Pedersen (Specialist Consultancy for the Deafblind), Jackie Lehmann Hansen (chairman of Deafblind Denmark) representing DBNSK

Iceland: Steinunn Sævarsdottir (Sjónstöðin), Estella Björnsson (Sjónstöðin)

Norway: Bodil Ballovara Olufsen (UNN), Linn Solli (Statped)

Aim and purpose for the network

The Nordic Network on Usher Syndrome aims to provide a platform for knowledge and experience sharing among professionals in the Nordic countries regarding the living conditions and support for individuals with Usher Syndrome, as well as for parents of children with the syndrome. The network focuses on both practical aspects, supporting professionals, families, and individuals with Usher Syndrome, and on research.

Status of the network

In 2024, the network hosted its first webinar on technology and digital accessibility for individuals with Usher Syndrome. In 2025, the network held its first seminar, bringing together participants from across the Nordic region and Canada, with a focus on life adjustment.

Feedback from the seminar highlighted the network's value, demonstrating its potential to contribute to the fields of Usher Syndrome and acquired deafblindness, and potentially to other related areas. This is an ongoing discussion in the network – both being one of the only networks focusing specifically on acquired deafblindness in the Nordic collaboration, but also how we can bring our knowledge into play in other areas. The webinar in 2024 was also applicable for other groups and at the seminar, we also focused on how to apply the knowledge from the life adjustment model to other areas – for instance on congenital deafblindness.

The network welcomed a new member from Norway, Linn Solli from Statped. Currently, we consist of members from Sweden, Norway, Iceland and Denmark. Participation in the Nordic conference in Copenhagen in 2026 may facilitate the inclusion of members from Finland.

Meetings

In 2025, we had 6 meetings in the Nordic network on Usher syndrome. Using a rotating chair for each of our meetings, we try to create a shared responsibility for the network. This was discussed at the meetings:

Online meeting – 13th of February 2025

- Welcome and minutes
- Evaluation from the network days in Malmö
- Evaluation from the webinar
- Seminar on life adjustment perspective
- Structure of future meetings

Online meeting – 3rd of April 2025

- Welcome and minutes
- Venues and rules for payment
- Suggestion for schedule of the seminar
- Plan B if no attendees
- Other remarks

Online meeting – 15th of May 2025

- Welcome and minutes from last time
- Schedule for the seminar in November
- Attendance in the core group
- Responsibility of the programme
- Distribute tasks
- Other remarks

Online meeting – 24th of June 2025

- Welcome and minutes from last time
- Finalize details for the seminar in November
- Other remarks

Online meeting – 29th of August 2025

- Welcome and minutes from last time
- Finalize details for the seminar in November
- AI for minute taking
- Other remarks

Online meeting – 31st of October 2025

- Welcome and Introductions
- Participant List and Group Formation
- Seminar Programme Review
- Evening Meeting – Logistics
- Action Items & Next Steps

Activities

In 2025, the primary focus has been on the seminar:

- Seminar 12th and 13th of November on the Life Adjustment Model at Folkets Hus in Hallunda, Stockholm.

The seminar, attended by 24 people including network members and two attendees from Canada (Roxanne and Karen), was deemed successful. The seminar covered implementation of the model across countries, research perspectives, and lived experience. Participants highlighted good lectures, networking opportunities, and the well-organized structure. Göran Forsgren reported a participant satisfaction score of 88 %, which is above the average in the organization of 82 %. Key feedback included the desire for more in-depth discussion and the importance of considering the linear vs. non-linear application of the model. These perspectives could also be discussed further in this network. Jackie Lehmann Hansen emphasized the importance of including people with deafblindness in the planning process in workshops based on or related to the life adjustment model.

This was the programme for the seminar:

12th of November – Presenting the life adjustment model

09:00-09:30	Welcome to this seminar
09:30-09:50	The history of the life adjustment model
09:50-10:20	Break (coffee break)
10:20-10:30	Overview of the life adjustment model
10:30-10:50	Introduction to “Phase 1: Holding on” and “Phase 2: Processing and Exploring”
10:50-11:20	Reflections in groups of first and second phase
11:20-11:35	Summarizing the reflections
11:35-12:35	Lunch
12:35-12:55	Introduction to “Phase 3: Rooted in oneself” and “Phase 4: Living with and Maintaining”
12:55-13:25	Reflections in groups of third and fourth phase
13:25-13:40	Summarizing the reflections
13:40-13:50	Break (communication break)
13:50-14:35	Experiences of working with Life adjustment model in Sweden
14:35-14:50	Break (coffee break)
14:50-16:00	Cont. experiences of working with Life adjustment model in Sweden

13th of November – Experience and implementation

08:30-08:45	Welcome and reflections on yesterday
08:45-09:45	Experiences from Iceland on using the life adjustment model
09:45-10:15	Break (coffee break)
10:15-11:00	Experiences of living with Usher syndrome related to the life adjustment model
11:00-11:15	Break (communication break)
11:15-12:00	Group work – Implementing the model in my work/life
12:00-12:30	Summarizing the group work in a plenary session
12:30-13:00	Reflecting on the seminar
13:00-14:00	Lunch

Plans and activities for the future

Building on the experiences from the seminar in Stockholm, the network is planning to have a course on the life adjustment model at the Nordic conference in 2026 in Copenhagen. The course will cover the core aspects of the model, including its phases and ten themes, and will encourage participants to reflect on its applicability and ethical considerations.

At the first meeting in 2026 the network discussed future ideas (focus on children, role models, ICF (International Classification of Functioning), violence in close relationships and publication of lived experience). Prior to the conference, the primary focus will be on developing the course. Following the conference, the network will explore the potential future ideas discussed.