

Minutes of the Nordic Leader Forum 2026 – Youth Work in Focus

Date: 3–4 June 2026

Place: Aalborg, Denmark

Minutes: Lasse Winther Wehner

Participants:

Riinette Askgaard	Anna Hjaltadóttir	Trine Seljeseth
Estella Björnsson	Risto Hoikkanen	Trine Skov Uldall
Cathrine Ellefsrød	Hege Høgmo	Hanna Tenhunen
Helene Engh	Trine Mette Johansen	Tommy Tindahl
Gøran A. G. C. Forsgren	Kai Koivumäki	Moa Wahlqvist
Linda Gavelin	Kirstine Højme Lambert	Ole Wøssner
Jackie Lehmann Hansen	Håkon Lie	Thomas Øverby
Louise Hassing	Roar Meland	
Elfa Hermannsdóttir	Gro-Anita Nummedal	

Wednesday 3 June

9:00 – 9:15 Welcome and introduction

Tommy Tindahl, CCSN and Gøran Forsgren, Nordic Welfare Centre welcomed the participants and provided practical information.

9:15 – 9:45 Opening of Nordic Leader Forum of Deafblindness

Carsten Lindgaard Johansen, CEO of CCSN, delivered the opening speech.

Carsten spoke about the newly formed Danish government. He noted that the government's political foundation includes five lines on the social welfare system, which could be seen as positive news.

Other key points from the speech included:

- Many people with deafblindness live in the neighbourhood around the premises where NLF is being held. They need to navigate an increasingly complex world.
- Nordic cooperation is vital. Individually, the professional fields of deafblindness in each country are small, but together they are larger and stronger.
- Many of the current professionals are approaching retirement. What does the new generation expect from the labour market – and from us?
- Many groups are competing for political attention and funding.
- What is the future of specialised expertise? Politicians want the greatest possible value for money, and we need to demonstrate the value of what we do. We need to show those who pay us what they receive in return. Results cannot be invisible; we must make them visible.

- If specialised services are weakened, people with deafblindness stand to lose a great deal – including opportunities for participation and quality of life in general.
- We need to learn from each other across the Nordic countries!



9:45 – 10:25 Presentations from the Nordic countries: Youth work

Norway 09:45 – 10:05

Trine Seljeseth:

In Norway, young people with deafblindness are not treated as a separate group. Instead, the work is based on a Life-span perspective. This may partly be due to Norway's geography, where services are often provided through local centres. In general, it is difficult to arrange youth meet-ups and similar activities, with Eikholt being an exception.

The presentation also raised the question of how “young people” should be defined. Does it mean people under the age of 35, or under 40? One possible indicator is how young people communicate, for example through Snapchat, Instagram, Facebook and other digital platforms.

Thomas Øverby from Eikholt then presented examples of Eikholt's work with young people.

Eikholt experiences a challenge in reaching users earlier than is currently possible. This can lead to what was described as “*late intervention*”.

Eikholt offers rehabilitation courses for children, young people, adults, relatives, and people with both acquired and congenital deafblindness. Examples of courses and activities include:

- Parents and children: A course focusing on early identification. Eikholt has governmental funding for this work.
- Preparing for adult life: For young adults, typically aged 20–30.

- Creative workshop: Exploring how AI can support storytelling and other forms of expression.
- The Snapchat group is a forum for young people, with Eikholt involved, making it easier for young people to get in touch with one another.
- Skills for safe travel and independence: A course focusing on mobility, safety and independent living.
- Communication and music: A course for people with congenital deafblindness and other disabilities.

A key point from the presentation was that the best services are created in partnership between professionals, users and families.

Update from the Norwegian school system

Hege Høgmo from Diamanten School gave an update from the Norwegian school system.

Diamanten School is both a primary and secondary school. In 2025, the school moved into new, adapted premises. It has capacity for approximately 12 students and currently receives funding for 10 students with complex needs.

The school's work is based on a holistic approach to development, with a knowledge-based, interdisciplinary focus and a multi-sensory approach.

Hege also issued a call for partners to collaborate on the topic of sexuality. She emphasised that this topic must be addressed. The national programme is not designed for students with special needs, and in the past, the school has often addressed the issue too late, only responding when challenges arose. The aim now is to work proactively and to begin slowly already in kindergarten.

Diamanten School is too small to develop and implement such a programme on its own. The school is therefore seeking Nordic cooperation on this topic.

Finland 10:05 – 10:25

Risto Hoikkanen from the Finnish Deafblind Association and Hanna Tenhunen, Social Manager in Rehabilitation Services, presented the update from Finland.

The Finnish Deafblind Association provides rehabilitation services and is managed by people with deafblindness. The association has around 75 employees, and there are now more young people represented on its board.

A key principle in Finland is inclusion for as long as possible, beginning in local schools. The association provides interpretation and other support services from the outset. As students grow older, they generally become more independent. There is no dedicated school for people with deafblindness in Finland, although the school in Jyväskylä was mentioned as an exception.

Rehabilitation services are provided nationwide from Tampere.

A family-centred approach is important to the association. Family involvement helps transfer newly learned skills to everyday life.

There are 43 known deafblind pupils and students in the Finnish education system. Almost all of them have cochlear implants or hearing aids, and very few use sign language.

Among children and young people with congenital deafblindness and multiple needs, 22 are aged 7–16. Of these, three have cochlear implants and one is a sign language user.

Stipends have made it possible to organise meet-ups, including a highly successful event in Malta. In the Finnish field of deafblindness, the term “young people” now may include people up to the age of 45.

There are also WhatsApp discussion groups and activities including chess, bowling and hiking groups. These activities may take place only once a year, but they show that initiatives are happening, mainly on a self-organised basis.

The Comenius five-year project was also mentioned as a project supporting marginalised people in getting back on track.

10:25 – 10:45 Coffee break

10:45 – 12:00 Presentation from the Nordic countries: Youth work

Iceland 10:45 – 11:05

Estella Björnsson from Sjónstöðin presented the update from Iceland.

There are approximately 100 people with deafblindness in Iceland. Around 40% have acquired deafblindness, while 60% have congenital deafblindness.

In the age group 13–30, there are 35 people with deafblindness. Of these, approximately 17% have acquired deafblindness, while around 80% have multiple disabilities.

Sjónstöðin cooperates with rehabilitation centres and schools at all levels. Individual programmes are provided for orientation and mobility, as well as activities of daily living (ADL).

There is no specific focus on young people with deafblindness.

Gló Training Centre works to increase the social participation of children and young people. Reykjadalur offers leisure activities for young people with special needs.

There are camp activities for blind, visually impaired and deafblind participants. Focus is on building confidence through adapted sports and games. The camp also includes skills assessment for further physical education.

In 2025, a survey was carried out among adults with late-onset combined vision and hearing loss. Contact Estella for the full survey.

Fjóla, the deafblind association in Iceland, was also mentioned. Around half of its members are young people. The association is slightly less formally organised than Sjónstöðin, but the two organisations work together.

Sweden 11:05 – 11:25

Linda Gavelin from SPSM and Moa Wahlquist, Deputy Head of the National Centre for Deafblindness in Sweden, presented the update from Sweden.

SPSM provides education and support. Recent developments include a new screening tool, TWMS, braille-related initiatives, quality assurance work, and a new educational platform.

The braille training process begins with mapping the child's tactile abilities using TP MDVI and TWMS. The material is then adapted to the individual child.

The team features six special educators and two psychologists, who assess a child from different perspectives. An ophthalmologist will also be joining the team.

Quality assurance is an important focus area, and the work is both research-based and evidence-based. A new learning platform has also been developed.

One of the challenges mentioned was that the support available from SPSM is not sufficiently well known.

A legal review has also affected the organisation's work. SPSM is not authorised to provide services that qualify as healthcare. This is a new issue, as SPSM has been providing such support since 1986. As it was phrased in the presentation, "we have done more than what we should be doing." The organisation is therefore considering whether its formal mission should be expanded, which would allow it to continue this work, or whether changes are needed.

Positive examples included a well-attended webinar series, renewed applications, and being featured in a magazine.

NKCDB

The National Knowledge Centre for Deafblindness, Nkcdb, provides support for professionals working in the field of deafblindness across all age groups.

Nkcdb develops and provides materials and courses, including resources on social-haptic communication as augmentative and alternative communication.

A digital parenting course is currently on pause.

FSDB

FSDB, the Swedish Association of the Deafblind, has a section for young people. Its activities include youth camps, excursions, hiking trips and meet-ups. FSDB will also host next year's youth conference on deafblindness.

One challenge mentioned was low recruitment numbers.

Denmark 11:25 – 12:30 included presentation of the youth project MUUS

Louise Hassing, Head of the Specialist Consultancy for the Deafblind, presented the work with children and young people with deafblindness from birth to the age of 18. The consultancy is government-funded.

Assessment and counselling processes typically last around eight months and involve professionals, families and others around the child or young person. The consultancy has followed many of the young people from birth, but identifying and reaching them can be a challenge and often happens by coincidence.

Many young people are highly dependent on their parents or families. An important aim of the counselling process is to help them find their own voice and become better able to communicate what life is like with a syndrome such as CHARGE, or with other conditions. After the eight-month counselling process, the consultancy is not allowed to contact them again; the young people or their families must initiate further contact themselves.

Trine Skov Uldall from CFD then presented the work with adults with acquired deafblindness. CFD has 15 deafblind consultants working with people aged 18 and above, and some users transition from Louise's area of responsibility into CFD's services. However, some young people are lost in the system during this transition.

CFD does work with young people over the age of 18. At this stage, the young person decides to what extent parents or family members should be involved.

Counselling may include topics such as education, personal capabilities, dreams and ambitions, access to technical aids, and how to plan a youth life while studying with combined vision and hearing loss. Other themes include identity, employment, communication with employers, energy loss, moving out, and becoming an adult. Many young people experience considerable uncertainty about the future.

CFD previously created a meet-up group for young people. Three meetings were held, but different people attended each time, and the initiative eventually faded out. It was suggested that perhaps the young people wanted to spend their own time doing something other than talking about deafblindness.

MUUS – Meaningful youth with Usher Syndrome

The MUUS project, *Meaningful Youth with Usher Syndrome*, was presented by Rasmus Hougaard Pedersen from the Specialist Consultancy for the Deafblind, working with children and young people under the age of 18, and Eva Juul Toldam from CFD, working with adults aged 18 and above.

MUUS is a joint venture between the two organisations. It is an action research project, allowing the target groups to be actively involved in the development of knowledge and practice.

The project focuses on the rehabilitation of young people with Usher syndrome. One of the central questions is how professionals can strike the right balance between being too helpful and being genuinely helpful.

An interview study carried out as part of the project showed that young people expressed more interest in counselling than in assistive devices.

Key themes in the project include empowerment, developing new knowledge, and improving counselling. The young people expressed a need for advice, support and access to knowledge.

The presentation emphasised that collaboration between organisations leads to better advice and support. Supporting autonomy is also seen as an important way to create meaningfulness for young people with Usher syndrome.

12:30 – 13:30 Lunch break

13:30 – 14:45 Group work on strategies for working with young people and plenary summaries

Group work with participants split into four groups.

Grp. 1	Grp. 2	Grp. 3	Grp. 4
Louise	Gro-Anita	Hege	Trine U
Trine S	Elfa	Linda	Anna
Helene	Ole	Roar	Hakon
Elisabeth	Tommy	Dackie	Estella
Risto	Cathrine	Trine M	Moa
Thomas		Hanna	
CANTEEN	MEETING ROOM 1	IN HERE	OFFICE

GROUP WORK: 13.30-14.20
PLENARY DISCUSSION: 14.20-14.50

Group 1

Group 1 focused on how to reach young people. The group emphasised the need to think outside the box when it comes to communication. Traditional channels such as Facebook and websites are no longer sufficient for reaching this target group. Instead, platforms such as TikTok, Snapchat and Instagram may be more relevant, and the possible role of AI was also mentioned.

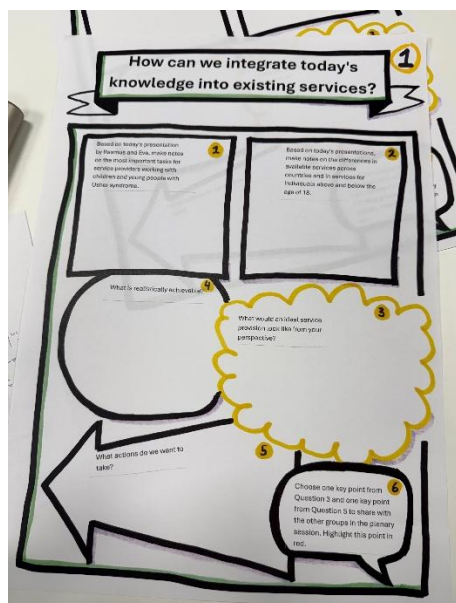
There is a need for a communication strategy aimed specifically at young people.

Group 2

Group 2 discussed the fragmented nature of services across all the Nordic countries. This was identified as a common challenge.

The group suggested that each country should have one national service responsible for coordinating services in the field. The group also emphasised the need for stronger collaboration between services across national borders.

Other important focus areas mentioned were documentation, research and information.



Group 3

There is a need to simplify everyday life for individuals with deafblindness through tailored services.

The group also raised the question of whether a shared platform could be developed for research and exchange of experience across the Nordic countries.

Group 4

Multidisciplinary teams working from a holistic approach are important. The group also underlined the need to listen closely to the wishes and needs of each individual.

In addition, the group pointed out that the system itself needs to be addressed, including politicians and decision-makers. Support for youth organisations was also highlighted as an important priority.

14:30 – 15:00 Plenary based on the group discussions

Jackie Lehmann Hansen noted that, when hosting Nordic and European summer camps, the “young” participants attending seem to be getting older and older. This raises the question of when a person is considered young. In the light of this, it was also suggested that acceptance of one’s deafblindness may happen later in life than before.

Gro-Anita Nummedal reflected that when children are small, professionals mainly work with the parents. Then, for a long period, the young people themselves are often not seen directly. In some cases, contact is not re-established until they are around 30 years old. She also pointed out that talking to professionals may remind young people of things they do not like or do not want to be confronted with. She supported the idea of establishing a working group but emphasised that such a group should include young people themselves.

Gøran Forsgren highlighted the strong Nordic opportunities for cooperation on the topic of youth and raised the question of whether a working group could be established.

Jackie also commented that even extraordinary services should not fully shield young people with deafblindness from challenges. The aim should not be to create a “curling culture”.

Overprotectiveness can make it more difficult for young people to develop their own identity. Good guidance and counselling include allowing people to make mistakes.

Kai Koivumäki added that a great deal of Nordic work is currently taking place, including work related to sexuality.

Lasse Wehner from Materialecentret spoke about available publications in English. The new publication *Døvblindepædagogik – en grundbog* has currently not received funding for translation into English. However, one chapter may be made available for download in 2027. This is subject to change.

15:30 Tour of the facilities

After this, the day's programme concluded with a tour of the premises surrounding the venue, including Materialecentret, Aalborgskolen, C-Huset and Ungdomshjemmet, guided by Tommy Tindahl and Lasse Wehner.

Thursday, 4 June

09:00 – 09:15 Reflections from yesterday

No feedback from the participants.

09:15 – 09:45 Long-term plans for the Nordic Welfare Centre and the Support Programme

Kai Koivumäki, Operations Manager at the Nordic Welfare Centre, presented the long-term plans for the Nordic Welfare Centre and the Support Programme.

Disability cooperation is the Nordic Welfare Centre's largest area of work. This year marks 50 years of Nordic cooperation on disability.

Kai informed the forum that Göran Forsgren will leave the Nordic Welfare Centre at the end of September. The recruitment process for his replacement is ongoing. Four candidates have been selected for the first round, and two candidates will continue to the second round. It is hoped that the selected candidate will be able to participate in the Nordic Conference on Deafblindness in Copenhagen in September.

The Nordic Welfare Centre's current framework runs until the end of 2027. An evaluation will take place in 2026, and a new revised programme will be developed for the period 2028–2030.

Current and upcoming projects include working life and new technology/AI, implementation of the CRPD, and inclusive education for children and youth with disabilities.

Kai mentioned several upcoming meetings and seminars:

- Meeting of the Nordic Disability Council, Trondheim, Norway, 11–15 May 2027.
- Annual cooperation meeting with representatives from organisations for young people with disabilities, also referred to as the Nordic Youth Disability Summit 2027, including a meeting of the Nordic Disability Council, Valdres, Norway, 23–26 August 2029.

The project *Inclusive education for children and youth with disabilities* will run from 2025 to 2027. It was suggested that a deafblind perspective could potentially be included in this work.

Regarding the Nordic Welfare Centre's funding scheme for disability and chronic disease organisations, the next call will be open from 24 September to 29 October 2026, with a total of SEK 1.5 million available.

Kai also noted that it would be beneficial for the Nordic Leader Forum of Deafblindness to work more closely with the Nordic Disability Council, in order to strengthen mutual learning.

He concluded by emphasising that the forum exists for a reason: the field is small. However, it is therefore important to stand out and make the field visible, including to the Nordic Disability Council.

09:45 – 10:00 Coffee break

10:00 – 10:30 The Nordic Education on Assessing Functional Deafblindness

Helle Buelund Selling and Rasmus Hougaard Pedersen from the Specialist Consultancy for the Deafblind presented the new Nordic education programme on assessing functional deafblindness.

The first group of students will complete the programme next week in Lillestrøm, and the feedback from participants has been very positive.

The presentation included an overview of the education programme, including its timeline, content and structure.

A central feature of the programme is co-creation. Many of the participants are already carrying out assessments, and their experiences therefore contribute actively to the development of the education.

The aim has been to create a more shared understanding of assessment across the Nordic countries, and the presenters noted that this aim appears to be succeeding.

Participant feedback has shown that the programme helps assessors become more aware of their own role and position in the assessment process. This was described as a form of “researching yourself”.

Although the Nordic countries share a common definition of deafblindness, there are still differences in how deafblindness is identified, particularly in relation to congenital deafblindness.

The presenters also raised the question of how much time participants need for the course, and where the boundary lies between course work and professional work. Since many participants are already carrying out assessments, some of the assignments may overlap with reports they would need to write as part of their regular work.

A survey is being prepared.

Finally, the presenters issued a call for teachers for future editions of the education programme. Ideally, some of the teachers would be participants from the first round of the course.

10:55 – 11:00 Network applications and reports

There were no new network applications.

Reports from the existing networks had been submitted and were all approved without comments. Ongoing networks will need to be renewed in three years.

The countries were invited to comment on the reports, but no comments were made. It was noted that the reports were clear and that they will be made available on the Nordic Welfare Centre website.

It was also noted that the Nordic definition of deafblindness is revised every eight years, with the next revision scheduled for 2032.

11:00 – 11:10 Nordic Conference

Göran Forsgren gave an update on the upcoming Nordic Conference.

The registration deadline is 13 August. At present, 157 participants have registered, out of a total capacity of 220.

The programme has been set and slightly revised. One of the keynote presentations will focus on the reconciliation process in Finland and will be given by two sign language users.

The conference will deviate from the standard conference format. It will be more interactive, with a strong focus on discussions, including roundtable discussions. This was presented as a new concept to be tested at the conference.

The conference will also include “New Nordic Voices”, with the aim of promoting the field of deafblindness and welcoming new people into the field. Göran emphasised that professionals should not have to have worked in the field for more than 20 years before being invited to give a speech.

It was also noted that a Nordic research seminar is held every four years, and that the same applies to all the networks. Upcoming seminars are planned for 2027 and 2028, one of them in Trondheim.

The next Nordic Conference will take place in 2030.

11:10 – 12:00 Evaluation and next Nordic Leader Forum

The final item on the agenda was the evaluation of this year’s Nordic Leader Forum and information about the next forum.

It was noted that the Nordic Leader Forum is always held in week 23. The next forum will take place in Norway. But due to scheduling conflicts the next meeting will be held week 22 on the 2nd and 3rd of June.

Trine Seljeseth informed the participants about the location, while the theme had not yet been discussed in detail. The coordination unit has booked a hotel in Sommarøy, near Tromsø — a place described as “where time does not exist” due to the midnight sun. A video of the location was shown.

Participants are expected to arrive on the 2nd of June and leave on the 10th of June.

Discussion on sexuality

The topic of sexuality was also discussed as part of the evaluation.

It was noted that *Uge Sex*, the Danish sex education campaign, will be represented at the Nordic Conference in September.

The question was raised whether the Nordic Leader Forum should establish a working group on sexuality. The group could focus on youth services, but the topic could also be developed in several different directions.

Norway expressed interest in participating. Denmark is already working on the topic, with Morten Axelgaard Christiansen mentioned as a relevant contact.

Jackie Lehmann Hansen noted that Nordic youth leaders also have their own conference. SUMH was mentioned in relation to *Uge Sex*. He suggested reaching out to Nordic youth leaders or DBNSK, while also pointing out that user organisations are under pressure, both financially and in terms of time.

Kai Koivumäki suggested inviting some of the deafblind organisations working with youth.

One possibility discussed was to establish a working group under the Nordic Welfare Centre, potentially with subgroups.

Lasse Wehner added that Materialecentret is starting work on a publication in summer 2026, which will hopefully be published in autumn 2027.

The last comments

It was noted that there is currently one working group on age-related dual sensory loss. The working groups on study plans and the Nordic definition of deafblindness have recently concluded their work. There are currently seven networks.

Hege Høgmo suggested including email addresses in the participant list in the future, to make it easier for participants to contact one another.

She also raised the idea of creating a shared resource page for the Nordic Leader Forum, which could make it easier to find relevant colleagues and partners across the Nordic countries. The Nordic Welfare Centre is not able to host such a page. Göran Forsgren instead suggested sharing links to the websites of the participating organisations, which could also help increase web traffic to those sites. Göran also suggested creating a Microsoft Teams group for the Nordic Leader Forum.

Finally, Göran gave an overview of the Nordic Welfare Centre's communication channels, including Facebook and the newsletter. Participants and organisations were encouraged to contribute content for the newsletter or suggest posts for Facebook, which generates a lot of traffic. As he put it: "Please send things to us, and we will share it."