

## Minutes from the Nordic Leadership Forum of Deafblindness 2023

“Political influence and leadership within the disability field”

**June 14<sup>th</sup> and 15<sup>th</sup>, 202**

Blindrafélagið, Reykjavík, Island

### 1. Welcome and introduction

*Gøran Andreas Gregor Caspian Forsgren, Nordic Welfare Centre.*

### 2. Welcome from the Icelandic Ministry

Anna Klara Georgsdóttir, Ministry of Social Affairs and Welfare

### 3. Workshop part 1: Cross-sectorial understanding of lifelong learning

Within health and education and the borderline in between

*Gro-Anita Nummedal, NKDB, and Hege Kristine Høgmo, Diamanten skole, Statped.*

### 4. Workshop part 2: Cross-sectorial understanding of lifelong learning

Questions for the group discussion and some comments from the discussion:

- What measures can be taken to prevent interruptions in services and ensure lifelong learning?
  - Coordination and knowledge about the system. Ensure that the knowledge about the individual is maintained despite constantly shift in staff. Cross-sectorial collaboration to see the client with “different glasses”.
  
- How can we ensure that the skills acquired by individuals with deafblindness not only persist, but also develop further?
  - Lifelong documentation of skills, and staff with knowledge about the individual. Clients should not just receive care, but also education and personal development.
  
- How can you, as a leader, influence both your staff and sector to make a meaningful impact and contribute to cross-sectional lifelong learning?
  - Be able to explain and support your staff to spread knowledge in a simple way. Educate your staff to achieve sufficient knowledge. Inspire your staff to coordinate.

## 5. Status on working groups and networks, part 1

### Applications

#### *Nordic network Usher syndrome*

The network application for the Nordic network on Usher syndrome was approved.

### Network reports

All the Nordic networks have submitted their reports. There were no comments or questions in the meeting, and all the reports were approved. The networks continue.

In 2024, all the networks will come together in a meeting in Denmark. Invitations will follow.

### Working group reports

#### *Nordic master*

Status for the working group on the Nordic master is presented in the report. The group will continue the collaboration with the Groningen University on a master with a Nordic perspective, and will give a report to the Nordic Leadership forum in 2025.

#### *Nordic study plan*

The group working on the curriculum will submit a report to the Leadership Forum in 2024.

#### *Nordic definition and need for revision*

The Nordic definition should be reviewed every four year. To do this, we need a group consisting of one person from each of the Nordic countries and a representative for one of the user organizations. The assignment is to review the definition and suggest whether it should be revised or not. Suggestions should be presented at the leadership forum in 2024, possible changes will be decided by the forum.

You will all receive an e-mail from NWC asking for members to the group. NWC will contact The Nordic Committee on Deafblindness for a user representative.

### Items to discuss

#### *Elderly people with age related deafblindness*

Do we need a Nordic study group/working group on elderly people with age related deafblindness? An invitation to initiate a study group will be sent out from NWC. This may start as a study group, to a possible working group from the next leadership forum.

Norway has a network already. The network was established in 2020 and it's a small network. The network focuses on both acquired and congenital deafblindness.

#### *Research network*

So far, the research network is an informal network, as it has not been through the application process. The network already has 24 members, a group that can discuss and do research. All the Nordic countries, except Iceland, are represented. If this will result in a formal network, the criteria for membership will be formalized.

## 6. Part 1 How can we use the political system for our greater good?

*Eva Franzén, NWC.*

## 7. Part 2 Discussion, how can we be influencers towards the political system on behalf of the population we represent?

What do we want to focus on? Some thoughts and ideas submitted in the meeting:

- The history and impact of the Nordic definition
- How can we make knowledge from the deafblind field beneficial for other groups in the society? It's small area, but we do great work.
- More political awareness: money in the right places for the right service.
- Political commitment: Deafblindness is a small area. It is crucial to be in touch with and work towards the political establishment.
- We need to work on awareness – deafblindness is unique. If deafblindness is not addressed, it becomes invisible. How about a PR-strategy to obtain more awareness, to be stronger and more visible? Should we initiate a working group on this subject? NWC will contact the Nordic leaders in order to establish such a group.
- Focus on the group of elderly people with age related sensory losses. What are the consequences if they do not get proper support? And how can we document how many from this group who needs support?
- Haptic communication and the blind community; haptic communication comes from the Nordic countries.
- Should deafblindness be a diagnosis? Do we need to address this?
- The target group is small, we need to look into data. We need to prove that the services we give are effective.
- The systems in the Nordic countries when it comes to identification are very different.
- Genetic screening is the future, and several different syndromes will be discovered.
- Welfare technology for our group.
- The Nordic countries have all possibilities to learn from each other. We have the same kind of welfare system.
- The data base in Sweden has been updated. The data base contains many articles are about genes, but not so much about communication. Much experienced base knowledge is silent, could this be a subject to write about?

Some information from NWC

*Tactile working memory scale*

In 2024 the last session on tactile working memory scale will be held, [remember to apply on the website](#).

*Digital calendar*

How can we share information on courses, seminar, conferences? NWC suggests a digital calendar, where links to courses, seminars etc. may be submitted and published. It's not up and running yet, NWC will announce it as soon as it is available.

8. "Art and deafblindness"

*Julius Birgir Johansson*

The first day ended with a meeting with the Icelandic artist *Julius Birgir Johansson*.

## 8. Pandemic and its effect on deafblindness

*Mattias Ehn. Ehn participated online.*

## 9. Continuing status on working groups and networks, part 2

*Rasmus Hougaard Pedersen.*

### Assessment tool and education

Presentation of the working group's revision of the existing material and discussion concerning future work.

Questions for the group discussion:

- Thoughts on the education – can the Nordic Leadership Forum support this idea?
- Who should be the owner of such course or education, and what will be the role of other Nordic organization be?
- Which proposal for financing provides the most optimal solution?

Several of the groups questioned the number of students; in the beginning several persons will need the education, but after a few years the number will shrink. One answer is to offer the education over a limited period of time, and continue with internal education.

The material has a congenital deafblindness approach, is it even possible to make acquired deafblindness more visible? When pilots are completed, we need to evaluate to see if the material is useful for acquired deafblindness.

Is the purpose of use of the material to establish whether a person is deafblind or not, or do we need the material to map a person and find out what kind of services/interventions are needed?

Is the term 'identification' covering? The term is used in the Nordic definition, but is used in different ways in the Nordic countries.

The discussion still left many questions around the material and the education. Is it even possible with a common education? The identification material will be a starting point. There are also economical and financial issues to look into.

## 10. Evaluation and planning of 2024

The next Nordic leader forum next year: 12<sup>th</sup> and 13<sup>th</sup> of June and the meeting will be in Sweden.

### Evaluation

NWC has sent out a questionnaire to all participants.