# News from Norway 2025

In our newsletter, we present status of some of our projects and working groups. At the end, we will present a list of articles published in 2024.

#### Work with New Website Provider

Since December, we have been working on switching our website provider. We have chosen the same publishing platform used by all health trusts in Norway. The advantage of this system is that many contributors are continuously working to ensure the solution functions optimally. It also provides good opportunities to suggest improvements, and changes are usually implemented quickly. Our goal is to launch the new website in autumn 2025. The web address dovblindhet.no will remain the same.



#### One-Year Project on Professional Content at dovblindhet.no

In October 2024, Irene Bondahl began a one-year project position to review the professional content on dovblindhet.no. She is updating existing material and identifying any missing content. New content is being produced in collaboration with staff from the NKDB units. The work is well underway, and both revised and new material will be published on the new website.

#### Sign Language Videos in the Acquired Deafblindness E-learning Course

The e-learning course on acquired deafblindness now includes sign language interpretation on all videos, in addition to audio description. The course is easily accessible on the front page of dovblindhet.no for anyone interested in seeing how it's structured.

#### Department Combined Sensory Loss and Deafblindness, Statped

Statped is a service provider within deafblindness in charge of two regional centres in Norway located in Oslo and Bergen. Our department working with congenital deafblindness has the last year worked particularly on the following projects.

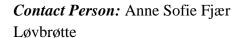
#### **E-Learning: Communicative Relations**

Statped is in the process of developing an e-learning course based on the book "Communicative Relations" by Anne Nafstad and Inger Rødbroe. This course aims to make the important content of the book more accessible through short video lectures and animations. That course will now be expanded to include a new module on video analysis, providing participants with the opportunity to learn how to use video as a tool to analyse and enhance communicative relations. The launch of the course is planned for this fall, and it will be available in both Norwegian and English versions.

Contact Persons: Håkon Lie and Anne Nafstad

### TAKOM - Expanding Our Resources

We are starting work to expand TAKOM with more signs and learning videos. This initiative aims to enhance the resources available for those interested in teaching and learning tactile signs. By adding new content, we hope to provide a richer and more comprehensive experience for all users.





#### **Project Pling**

Project Pling involves the development of an adaptation of an observation test designed to assess the sound attention of pre-linguistic children and young people with congenital combined visual and hearing impairments, as well as multiple disabilities. This innovative test aims to provide insights into how these children engage with and respond to various sounds in their environment. The Pling observation test is based on the framework of the Distraction Test developed by the British Society of Audiology (BSA). However, it has been modified to better suit our target group. Unlike traditional hearing tests, the Pling test does not measure hearing thresholds. Instead, it maps the child's responses to different sounds while they are filmed during the assessment. The recorded footage is analysed to evaluate the child's listening behaviour and ensure the quality of their responses. Currently, we are working on finalizing the test manual and preparing for field testing. This test will also be assessed



through master's study, and we are excited about the potential it has to enhance understanding and support for hearing and sound attention for children with combined visual and hearing impairments.

Contact persons: Lene Skaget and Guri Engernes Nielsen

### Our department working with acquired deafblindness has the last year worked on various subjects such as:

- Producing a review on elderly people with dual sensory loss together with Signo
- Strengthening our assessment process on deafblindness when it comes to content and multidisciplinarity. Our assessment team works on a coordinated process in assessment and observation
- Testing new assessment procedures on functional hearing loss through a cooperation
  with the Department of Special Needs Education, University of Oslo where they have
  a learning and research lab where they receive users with various special educational
  needs. Statped is now in the initial phase of a collaboration with the University of Oslo
  to utilize their assessment services for users referred to us. The collaboration will also
  include practical guidance for students in educational audiology who need to learn
  more about combined sensory loss and deafblindness
- Emphasis on tactility through teaching students in interpretation and guiding including

user experience in tactile sign language and haptic communication

- The Norwegian report from the Tactile Transition project is now published and we are working on how to implement the results in our service provision in addition to our courses in haptic signals
- Statped has been involved in the process of developing the ICF core set for deafblindness. It remains to find a way to implement the core set in our practise.



#### News from Signo Resource Centre

#### Voicing with deafblindness

Ragnhild Dalheim, a senior advisor at Signo Kompetansesenter, commenced her PhD at the University of Innlandet in October 2024. Her research focuses on the role of "voicing"—encompassing both the role of the physical voice and the right to express oneself—among individuals with congenital deafblindness and their communication partners. Dalheim aims to explore voice as a multisensory and multimodal phenomenon, integrating aspects of physical, social, artistic, musical, and communicative actions.



Dalheim's study emphasizes the significance of voicing as a form of tactile communication, for children with congenital deafblindness. She seeks to challenge traditional perceptions of voice by considering vibrations and body movements as integral components of voicing practices in communication. The research also aims to influence service providers and give practical applications in the field, advocating for individualized and inclusive methods.

Throughout her PhD-project, Dalheim will share her process and reflections, promoting knowledge exchange and inspiring others in the deafblindness field. Through funding by NKDB she will post articles online, podcast episodes and other posts on social media giving insight into how her PhD-project progresses. She encourages engagement through her Instagram account @veien\_til\_doktorgraden

#### Podcast "Sanser og Samspill"

The 2024 season of the universally designed podcast "Sanser og Samspill" marked the podcasts third year of running. In 2024 eight episodes were released, as usual available in both audio and video format, and with pdf-transcript available. This season of the podcast has aimed to highlight the voices of deaf and deafblind individuals, and their own lived experiences. Episode 22 was released on Norwegian sign language, and a voice transcribed audio version was released on podcast platforms. The podcast continues to grow and reach new viewers and listeners, reaching 3000 downloads on podcast platforms in the spring of 2025.

#### Spor 2 development

This project aimed to revisit and update the work presented in the 2004 educational film Spor, which demonstrated tactile communication with individuals with congenital deafblindness exemplified through the communication between a deafblind student and her teacher. The project initially intended to recreate scenes from the original film, but over time the project's focus shifted toward identifying and documenting the principles behind successful tactile communication, rather than merely replicating past situations.

The projects follow a guided process involving a primary caregiver and the woman from the original "Spor" film who lives in a residential facility. The caregiver is mentored the former special education teacher from the original film. Six video recordings were produced over ten months. These videos explore shared bodily-tactile attention during a routine activity: a haircut. This activity was chosen for its regularity and structure, helping to highlight key communication principles in everyday interactions. The project identified several essential principles for tactile communication, such as pacing, repetition, shared attention, context, and narrative structure. It concluded that understanding these principles is more beneficial than copying specific scenarios from Spor (2004).

The team plans to create an e-learning course to train parents, educators, and professionals working with individuals with congenital deafblindness. Additional steps include completing detailed analysis of the recorded material, defining course objectives, writing content, and publishing an academic article. Discussions are ongoing about collaboration, funding, and resource allocation for the e-learning development.



#### Advisory Centre for The Deafblind, University Hospital Nothern Norway, Tromsø

- Tactile Working Memory Scale (TWMS) supervisor training program is now finished and now we are planning for a TWMS symposium in Tromsø May 20 – 22 2026. This symposium is planned to be open for other professionals, and as a gathering of supervisors. We look forward to hosting this symposium.
- The group working with the identification of deafblind form are now planning and starting a course in how to use it. The lectures will be from the group the first year, and the Advisory Centre for The Deafblind in Tromsø has one lecturer present.
- This year Advisory centre for the deafblind has had several courses regarding bodilytactile communication to municipalities in the Northern Norway.
- Advisory centre for the deafblind have three advisors in involved in their professional specialization. Our psychologist is pursuing her specialization in habilitation psychology, whilst one of our social workers is specializing in vision pedagogic. The third advisor is current a student at the University of Groningen pursuing a master's in communication and deafblindness.
- Advisory centre for the deafblind is contributing in several university courses, teaching
  about the consequences of living with deafblindness. Also involved in the understanding
  of combined visual and hearing impairment for students of psychology and clinical
  psychologists. We also have students in practice at our organization and we supervise
  students in their bachelor- and master degrees.
- Our neuropsychologist Jude Nicolas is in collaboration with John Ravencroft (Edinburgh University), Christine Sauvé Guindon (University Ottawa) and Anne Schoone (Kentalis, Netherlands) regarding Brain related Auditory and Vision Impairment (BAVI). Jude Nicholas has introduced BAVI to all of the habilitation units in the hospital this year.
- Jude Nicholas and Annika Maria Johannessen have contributed a chapter to the Handbook on deafblindness, "Considering tactile cognition: Assessment of learning
  - strategies through working memory", published by Oxford University Press. This book is now in the final stage before publishing.
- Advisory centre for the deafblind is a
   part of an internal project that has the
   aim to secure that all our advisors have
   the same understanding of
   deafblindness. There has been a lot of
   turn over in our field during the passed
   years, and we have to assure our
   quality of service towards our clients.



## Projects at Eikholt National Centre on Combined Visual and Hearing Impairment/Deafblindness

#### 3D printed sign language alphabet

The idea of a 3D-printed sign language alphabet has been in the mind of Cathrine Timm Sundin, Senior Communications Advisor at Eikholt, for some time. She recognised a need for three-dimensional tactile models (3D models) of the various letters in the sign language alphabet for use in training. In collaboration with colleague Rolf Mjønes, Cathrine's hands have been scanned and models of her hands are printed on a 3D printer. Models of different sizes and materials are tested by visitors to Eikholt. Their feedback provides valuable correction and input for developing good 3D models of the letters. Read more about the project here: 3D printed sign language alphabet - a learning resource for everyone



Contact person: Cathrine Timm Sundin, Senior advisor – Communication

#### **Architecture for all senses**

Eikholt is now launching the groundbreaking project "Architecture for all senses" - which will develop a guide for the universal design of public buildings with a special focus on people with combined visual and hearing impairments. The project starts now in April and is supported through Bufdir with Grant for universal design 2025, and aims to develop a practical and user-friendly guide for municipal planners, architects and designers. The aim is to ensure that public buildings not only fulfil legal requirements for universal design but also become inclusive and functional for everyone - regardless of sensory impairment.

The project is carried out in close co-operation with national and international experts, including Severin Kas, architect and experience consultant with combined sensory loss, Arne Kjeldstad, visual educator, mobility instructor and experience consultant and Richard Cooper,

architect and expert on accessibility for people with visual impairments. Read more about the project here: Eikholt - Architecture for all senses - inclusive for all

Contact person: Rolf Lund, Researcher

#### User involvement in the development of new technology

This is an exciting project on user involvement for people with combined visual and hearing impairments in the development of new technology. The project started in 2023 and will conclude in the fall of 2025.

The project is carried out with user involvement in all phases, also known as collaborative research. Joint competence development on research and project work has therefore been part of each meeting. Furthermore, the project group has planned the testing of assistive devices and conducted data collection. In January 2025, the project completed the analysis of the collected data.

New insights and knowledge are constantly being uncovered, both about collaboration between developers and users of technological aids and about interaction within a project group. In the spring of 2025, the project group is in the writing phase, and we look forward to sharing the results and experiences from the project in the fall of 2025.

In parallel, we are planning the content of the group course to be held at Eikholt in August User involvement in the development of new technology - Eikholt

Contact person: Kari Jokstad, Research leader

#### Optimising visual functions for people with RP

The aim of the Retinitis Pigmentosa project, was to identify which measures are used to optimise visual function in people with RP. During the project period, we developed

knowledge by testing some of these measures in collaboration with project participants with RP at different stages.

This project is now finished. You can read about the project and find 9 videopresentation here:

Optimising visual functions for people with RP – Eikholt

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Contact person: Rolf Lund, Researcher

#### List of articles published in 2024.

<u>Preliminary validation of the Norwegian version of the Berlin Misophonia Questionnaire</u> Revised (BMQ-R-NOR).

Krog E, Falck A, Nielsen GE

Scand J Psychol. 2024 Oct;65(5):901-910

PMID: 38824419

The assessment and diagnosis of intellectual disability when development is atypical. A

Norwegian population study of individuals with CHARGE syndrome.

Skei L, Skei S, von Tetzchner S, Hartshorne T, Landrø NI

Int J Neurosci. 2024 Oct;134(10):1120-1133

PMID: 37675478

Cognitive potential of children and adolescents with CHARGE syndrome and deafblindness.

Skei L, Skei S, Hartshorne T, Landrø NI

Orphanet J Rare Dis. 2024 Jun 11;19(1):230

PMID: 38863011

In addition, Eikholt has published three articles in his Eikholt Reports. A project report on Grenseløs idrettsglede (ISBN 978-82-93653-31-8) and two articles on haptic communication (ISBN 978-82-93653-34-9 and ISBN 978-82-93653-33-2).

## Contact information for the National Advisory Unit on Deafblindness

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Our Instagram profile: <a href="https://www.instagram.com/dovblindhet/">https://www.instagram.com/dovblindhet/</a>

