

Deafblindness, population, definition and identification

Current practices and challenges

The National Interdisciplinary Team for Identification
and Diagnosis of Deafblindness (NTT)

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The National competence service for the deafblind – NKDB

NKDB consists of:

- National Advisory Unit on Deafblindness, University Hospital of North Norway, UNN, Tromsø
- Four regional centres; Oslo (Statped), Bergen (Statped), Tromsø (UNN), and Andebu (south of Oslo)
- Eikholt – a National Resource Centre for People with Deafblindness. Drammen (south of Oslo)
- The Interdisciplinary team for identifying and diagnosis of deafblindness, University Hospital of North Norway, Tromsø

The Nordic definition

- **Deafblindness is a combined vision and hearing impairment of such severity that it is difficult for the impaired senses to compensate for each other. Thus deafblindness is a distinct disability.**

- Ass. Prof. em. Bertil Bjerkan, Tromsø University hospital:

Deafblindness can also be regarded as an illness or condition with a progressive development towards the combination of impairments described in the Nordic definition.

Most likely social contact, communication, orientation and information acquisition will increase with use of tactile intervention and interpreter/guide

The Norwegian method for identification of deafblindness

- The regional centre is contacted when the local system or the user/parents report/suspect a dual impairment
- At the centre there are extensive guidelines for observations and assessments. One guideline for congenital deafblindness and one for acquired deafblindness.
- If the centre suspects that the person could have a deafblindness, the case is submitted to The National Interdisciplinary team for identification and diagnosis (NTT)
- The guidelines make the foundation for the reports to NTT

Members of NTT 2021 – An interdisciplinary team

- Arvid Heiberg, Senior consultant in clinical genetics, Professor em.
- Ketil Heimdal, MD, PhD, Consultant in clinical genetics
- Randi Skarpaas Tranheim, Ophthalmologist (vision physician)
- Geir Siem, Othorinolaryngologist (ear,nose,throat psysician)
- Anne Nafstad, PsyD, Special psychologist in deafblindness
- Jude Nicholas, PsyD, Clinical neuropsychologist and researcher
- Gunilla Henningsen Rønneblom, Senior advisor, Gestalt therapist
- Sissel Torgersen, Low vision specialist, Mobility instructor
- Charlotte Caspari, Auditory educator, Auditory verbal therapist
- Britta Nilsson, Leader, Psychologist, MHD

NTT – The purpose

NTT shall ensure the quality of medical and functional assessments and diagnostics in the ordinary service system, as well as ensure diagnosis and identification of deafblindness in people with rare conditions and syndromes

- **Confirm identification of deafblindness**
- **Uncertainty - suggest further tests, observations**
- **Deny/refute deafblindness**

NTT cont.

- Two meetings a year - approximately 18 - 25 cases in a year (total 156)
- Approximately 75% considered to have deafblindness
 - congenital (ca 20%)
 - acquired (ca 80%)
- No medical diagnosis in the ICD 10 for deafblindness.
- Of the remaining 25% approximately 1/2 is considered not to have a functional deafblindness.
- For the remaining group NTT often asks for
 - a) additional functional observations
 - b) recent vision- and hearingtests
 - c) description of compensatory use of the tactile modality
 - d) genetic test
- Age-related deafblindness not included in our population.

The Norwegian practice

A solid «safety net», but still substantial challenges

- The population heterogenous
- Different causes, trajectories, prognosis
- Sometimes known genetic causes
- Sometimes an enhanced risk for deafblindness
- Sometimes unknown causes
- How to differentiate deafblindness from visual and/or hearing impairment in conditions effecting functionality in all modalities
- Are we missing persons with a deafblind impairment
- Are we missing persons at risk of developing deafblindness
- How to study/detect/evaluate CVI and APD
- Tactile modality
- The elderly population (blind and progressive hearing impairment, deaf and progressive visual impairment) – not obvious agerelated

Webinar Day two, 9.06.2021 (Britta)

The lack of a National register

- Used to have a national register - inclusion problems – terminated
- Approximately 350 persons with deafblindness i Norway
- Norway has the opportunity to register persons with deafblindness through the contact the regional centres and NTT have with the persons with deafblindness
- Today we have 156 cases in NTT's database

Webinar Day two, 9.06.2021 (Britta)

The purpose of a National register

- Describe the population and the subgroups
- The nature, degree, prognoses, trajectories of the vision- and hearing impairments
- Congenital, acquired, genetic with a late onset, elderly «not agerelated»
- Syndromes, cases at risk for deafblindness
- Time of on-set (before/after language acquisition)
- Diagnostic delay
- Combination with other impairments and illnesses
- Stable or progressive
- Treatment and intervention
- Same criteria and intervention all over the country
- Collaboration with other registers (RP and Hearing and Mental Health)
- Research
- Use for health policy

Webinar Day two, 9.06.2021

Just a thought (Britta)

- Using the Nordic definition
- Using the same criteria and guidelines for identification
- Identify and agree upon similar methods of coping with «grey zones» and cases at risk
- Develop similar registers in the Nordic countries and The Netherlands - or one Nordic register (if possible in terms of privacy and data security)
- We will have a larger data base which will give us greater, better knowledge, earlier identification and intervention and greater political influence