



CONFERENCE REPORT

Deafblindness, Definition, Population, and Identification

June 18-19, 2021 & November 17-18, 2021

Statped, Unit for combined vision and hearing
loss and deafblindness, Norway

Nasjonal kompetansetjeneste for døvblinde /
NKDB Norway

Reviewed by Anne Varran Nafstad

The conference was arranged as two webinars and streamed internationally. Video recordings from the first webinar are available on Statped homepage (www.statped.no) or if you google 'Deafblindness: Population, definition and identification'. Recordings from Webinar 2 are expected to come up with the same search words in January.

The invited speakers were specialists in the conference topic from the deafblind field or neighboring fields; practitioners, researchers, or both. They came from the Nordic and The Netherlands, from medicine, pedagogy, psychology and health science and colleagues from 15 different countries around the world followed the conference. The invited speakers were Arvid Heiberg (N), Claes Moeller (S), Jesper Dammeyer (DK), Saskia Damen (NL), Marleen Janssen (NL), Henriette Olesen (DK) Kolbein Lyng (N) Else Marie Svingen (N), Knut Slåtta (N), Terje Nærland (N) and Maria Creutz (S) From the hosts: Marianne Disch, Jude Nicholas, Britta Nilsson, Anne Nafstad (all N).

The conference was dedicated to address how professionals work with deafblindness as a unique disability in the clinical practical field and in research. The point of departure was the widespread reference to the Nordic functional definition of deafblindness. One question was if and how the definition is used to survey and overview the population and its needs. Another issue was how the definition is used to identify deafblindness in individuals for both clinical and research purposes. Particular attention was given to the issue of the vulnerability of the

fast-growing sub-group of elderly with combined sensory loss and deafblindness, to the increasing number of referrals of individuals with brain related functional deafblindness in both sides of the spectrum of onset, to early genetic diagnosis of risk of deafblindness in rare syndromes. Increasing variation and complexity in the conditions in the targeted population implies overlaps and grey zones and the need for better differential diagnostic practices.

One important issue in the conference is how the professional fields could engage more collaboratively in the future, not only in the Nordic but also internationally. So far, to start with the participants in this conference were Nordic- Dutch. That might be just a beginning of more extended and planned international collaboration about comparable professional practices and a more solid and shared knowledge base.

The following issues were raised and discussed by the speakers and panelists

- The conference established that The Nordic functional definition of deafblindness described by the Nordic Welfare Centre is widespread and used as conceptual reference to the label 'deafblindness' by professionals from different disciplines within the Nordic and many other countries. However, it is a current and future challenge to work out how to apply this definition in our professional practices. It was agreed that the definition is good for social awareness purposes, but it is demanding to use it in professional practice to identify deafblindness /differentiate deafblindness from conditions with overlapping functional features. One task for the future could be to develop shared guidelines and use shared variables that enable us to compare populations for survey purpose to obtain a better overview of the population and subpopulations and their needs. Another purpose would be to use the definition as a background for developing more sensitive and specified criteria for individual referrals in clinical practice. A third purpose would be to be able to use the definition as inclusion criteria for research purposes. This would enable comparable data as a basis for more solid knowledge development. The conference presented ongoing projects towards more precise guidelines for functional assessment practices, as well as new alternative updated ways of thinking about inclusion criteria, differential diagnostics, overlaps and grey zones.
- The conference established that the population of deafblind in the statistical sense is not well known in any of the participating countries, and estimated prevalence varies even across countries in Scandinavia that are culturally very similar and share the historical and social political reference to the Nordic definition., The conference discussed some of the underlying factors for these differences. The purpose of this discussion was to work towards similar and comparable criteria of inclusion, aiming to collaborate on better estimates of prevalence. The conference established that the

best route ahead is through a long term one; through collaborating across the Nordic and internationally on the contents of deafblind-specific expertise required by professional experts in the field.

- The conference established that the elderly with deafblindness is the most extensive subgroup in the population, and numbers are increasing in welfare societies as people live longer. This subgroup was surveyed systematically some years ago by Else Marie Svingen and Kolbein Lyng who also developed validated criteria of inclusion, based on the Nordic functional definition. Their research found the subgroup of elderly much more numerous than previously known. The conference raised awareness about the need to continue to discuss how this most extensive and fast growing sub-population may be reached, and also how the result of the mentioned research can be used more efficiently in practice.
- The conference established that there are all the time better opportunities for diagnosing rare genetic syndromes early, which in turn raises the question of early intervention targeted to reach children at risk of developing deafblindness with the aim of preventing it or reducing its negative developmental consequences. The field of early intervention is likely to profit from deafblind specific knowledge about multimodal support to communicative development which in turn is likely to have a positive transactional effect on emotional, cognitive, and social development and thereby reduce negative transactional effects of biological congenital risk factors. The obvious relevance of early identification of risk and early preventive intervention raised the issue of specificity and onset of involvement by expertise in deafblindness, and pointed at the contemporary and future need for research-based knowledge about long term effects of early detection of risk and early intervention.
- The conference established that the population of deafblind is characterized by diversity and variation even within one and the same diagnostic group and by increasing complexity. Better medical services available in welfare societies are one of many reasons for the increasing complexity in both ends of the age spectrum, as observed in both congenitally deafblind and among the elderly with deafblindness. Increasing complexity means more co-morbidity which raises the issues of grey zones and differential diagnostics. The conference raised and discussed several issues of complexity, diversity and variation more concretely, including the issue of recognizing that deafblindness as disability may be present in some situations but not in others and that deafblindness among the sub group of the congenitally deafblind more and more often is brain-related.

- The Conference established that deafblindness is a socially or culturally/social politically constructed concept, updated to reflect not only disability but also ability, focusing on the compensatory use of the bodily tactile modality in the core areas communication, access to information and mobility. The conference pointed at ongoing work to develop guidelines for identification that capture compensatory cognitive use of the bodily tactile modality which can and should be used to identify functional deafblindness in complex cases. The importance of this approach considers the mentioned growing number of cases with brain related visual and hearing loss that professionals encounter, in other words there are more and more combined visual and auditory processing disorders (APD and CVI) among referred cases.
- The conference established a great need and motivation among the participants for Nordic and international collaboration about guidelines for identification of deafblindness in clinical practice and about research that aims to develop a better shared knowledge base for the field. As mentioned, the best route to a more knowledge based and shared professional field was assumed to go through collaboration across national borders about the content of education in deafblind-specific issues for professional experts

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