

Developing a New Nordic Definition of Deafblindness

Background information

The first Nordic Definition of Deafblindness was developed in 1980, and accepted by the Nordic Board for Disability Issues, an expert team, answering to the Nordic Council of Ministers. Based upon function, it was an advanced definition at the time. For 25 years, it was accepted and used in many countries by professionals as well as by persons with deafblindness. This definition took an individual perspective as follows: **Deafblindness** is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, **deafblindness** is a distinct disability.

In the following years, some important actions undertaken by the international community made it clear that it was time for some changes. The United Nations accepted the adaptation of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities¹ in 1993. The standard rules designate persons with disabilities as citizens who have the same rights and duties as other members of society. The UN declared that there were still barriers that restrain persons with disabilities to fulfil their rights and freedom.

During the 1990's, the Nordic Staff Training Centre (NUD)² took several initiatives to revise the definition, but eventually it all came to a standstill when the parties involved were not able to agree.

In 2001, WHO³ endorsed The International Classification of Functioning, Disability and Health (ICF)⁴. It offers a four-dimensional framework for describing and organizing the main components of a disability. In addition to the impairment, assessment of the individuals functioning and participation within their environment are taken into account.

When the Nordic countries, initiated by NUD, started to revise the definition of deafblindness in 2004, everybody agreed that the definition had been very important up until that time, and had fulfilled its role. With the UN standard rules and the ICF we tried to revise the definition in order to keep it in line with a more modern view of people and disability policy.

With influence from both practice and the documents mentioned above, a committee created a definition consisting of two sentences, which paid attention to those concepts from ICF concerning activities and participation. The initial suggestions for a revised definition was put out for a field trial. Feedback from the field trial resulted in

¹ www.un.org/esa/socdev/enable/dissre00.htm

² NUD was created in 1981 by the Nordic Council of Ministers. It ceased to exist after it merged with several Nordic organization to become on January 01, 2009, the Nordic Centre for Welfare and Social Issues (NVC- www.nordicwelfare.org)

³ www.who.int

⁴ www.who.int/classifications/icf

a revised definition accepted by the Nordic Leaders' Forum in 2007 as the revised Nordic definition.

At the same time, there was voiced after some years there should be an evaluation of the functionality nature of the definition. The Leaders Forum decided in 2013 that it was time for an evaluation of the definition and recommended that a working group be established to undertake this project. The working group was made up of experts in the field of deafblindness representing the Nordic Countries as follows: Estella Björnsson⁵ (Iceland), Ritva Rouvinen⁶ (Finland), Marianne Disch⁷ (Denmark) and replaced by Henriette Hermann Olesen⁸ (Denmark), Trine Seljeseth⁹ (Norway) and Helene Engh¹⁰ (Sweden). Maria Creutz¹¹ (Sweden), later became an associated member of the working group. Knut Johansen¹² (Norway) was asked to lead this work.

The Leaders' Forum accepted the initial working groups' recommendation that the definition should be revised. It advised the working group to continue this work, with the addition of Linda Eriksson representing the Deafblind Nordic Cooperation Committee¹³.

The task then was to propose a revised definition that should be simpler and easier to read. The group undertook a field trial to examine different options to present the definition's text. After deciding on the best option, numerous English-speaking colleagues from USA, Great Britain and Australia were consulted along the way to ensure a fluent English language. A final meeting took place in September 2015 to finalize the new definition.

The new Nordic Definition of Deafblindness - approved June 2016

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

Main implications

⁵ Icelandic National Institute for the Blind, Visually Impaired (www.midstod.is) is small corporate member of Dbl.

⁶ The Finnish Deafblind Association (www.kuurosokeat.fi) is a small corporate member of Dbl.

⁷ Formerly with the Denmark National Board of Social Services
www.socialstyrelsen.dk/handicap/dovblindhed

⁸ The Center for Deafblindness and Hearing Loss, Denmark www.cdh.m.dk is a small corporate member of Dbl.

⁹ Norwegian National Advisory Unit on Deafblindness (www.dovblindhet.no)

¹⁰ The Swedish Resource Centre for Matters Regarding Deafblindness (www.nkcdb.se) is a small corporate member of Dbl.

¹¹ Nordic Centre for Welfare and Social Issues(www.nordicwelfare.org) is a small corporate member of Dbl.

¹² Signo Dovblindesenter (www.signodovblindesenter.no) is a small corporate member of Dbl.

¹³ www.fsdb.org

To varying degrees, deafblindness limits activities and restricts full participation in society. It affects social life, communication, access to information, orientation and the ability to move around freely and safely. To help compensate for the combined vision and hearing impairment, the tactile sense becomes especially important.

On the combined vision and hearing impairment

The severity of the combined vision and hearing impairment depends on:

- the time of onset, especially in relation to communication development and language acquisition
- the degree and nature of the vision and hearing impairments
- whether it is congenital or acquired
- whether it is combined with other impairments
- whether it is stable or progressive

On the distinct disability

The fact that it is hard for the impaired senses to compensate for each other means that:

- Attempting to use one impaired sense to compensate for the other one is time consuming, energy draining and most often fragmented.
- A decrease in the function of vision and hearing increases the need for making use of other sensory stimuli (i.e. tactile, kinaesthetic, haptic, smell and taste).
 - It limits the access to distance information.
 - It creates a need to rely on information within the near surroundings.
 - To create meaning, it becomes necessary to rely on memory and to draw conclusions from fragmented information.

On activities and participation

Deafblindness limits activities and restricts full participation in society. In order to enable the individual to use their potential capacity and resources, society is required to facilitate specialized services:

- The individual and their environment should be equally involved, but the responsibility for granting access to activities lies on society. An accessible society should at least include:
 - available competent communication partners
 - available specialized deafblind interpreting, including interpreting of speech, environmental description and guiding
 - available information for everyone
 - human support to ease everyday life
 - adapted physical environment
 - accessible technology and technological aids

- A person with deafblindness may be more disabled in one activity and less disabled in another activity. Variation in functioning might be the consequence of both environmental and personal factors.
- Specialized competence related to deafblindness, including an interdisciplinary approach, is vital for proper service provision.

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