

COMPREHENSIVE ICF CORE SET FOR DEAFBLINDNESS

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Abstract Deafblindness is a condition combining little or non-useful hearing and little or non-useful sight. Although causing an enormous physical and emotional impact during daily activities, it is one of the most infra-diagnosed conditions. Deafblind people often rely on social care evaluations made by following non-standard indicators. Not having a neutral certified evaluation scale allows a vast range of discriminatory practices affecting the deafblind worldwide.

Introduction

There are three overarching types of Deafblindness: congenital, acquired and ageing.

At least **80 medical conditions may cause Deafblindness**¹. A person might be born deaf and become blind at a later stage in life, or the other way round. While the medical cause-effect relations for Blindness and Deafness have been clearly established, this is not the case for Deafblindness.

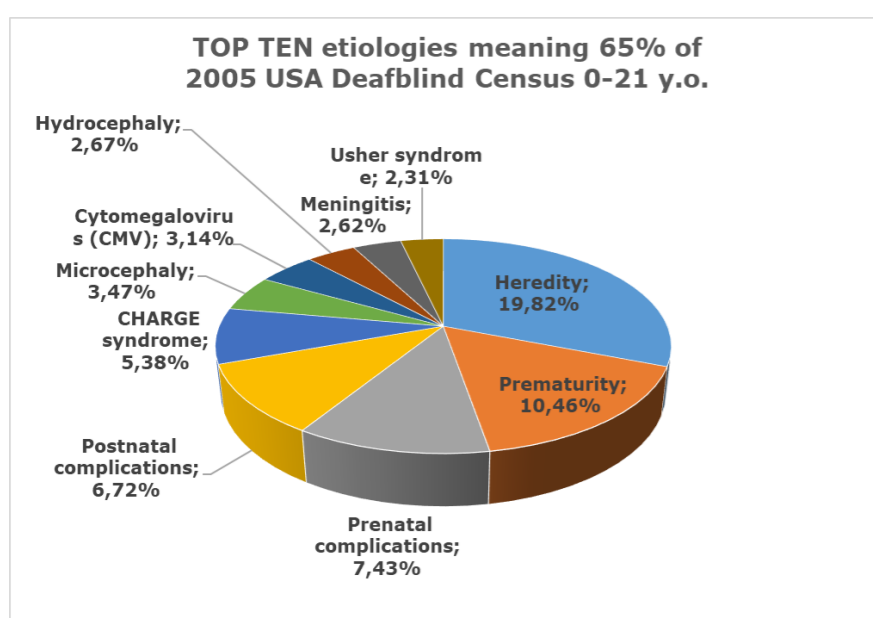


Chart 1: Top ten etiologies meaning 65% of 2005 USA Deafblind Census 0-21 y.o. Graphic is authors own creation on the data provided by the census².

Moreover, even being highly incapacitating **Deafblindness is one of the most infra-diagnosed conditions** in the medical practice. Normally, a person who is potentially deaf & blind goes through a long process of clinical evaluation commonly executed in two separate processes: one for the sight loss and one for the hearing loss, not having any medical scale intended to put together both inputs.

As a consequence, Deafblind people have to be evaluated following non-standard indicators generating subjective or incomplete results with a huge impact on the further intervention and assistive plan.

There is **no reliable available data** on the global **Deafblind Population** as every authority would report based on their own criteria. This creates a risk of leaving out some of the most complex cases.

In this context, the development of an international standard following the International Classification of Functioning, Disability and Health (ICF), the framework of WHO to measure **health and disability on an individual level and population**³ seems necessary and convenient.

Methods & Materials

The planned procedure is called, "**ICF Core Set for specific conditions**". WHO requires 4 studies (working groups) at the preparatory stage:

- **Empirical Multicenter Study (EMS)**. Identification of the most common problems experienced by the target group of individuals by applying the ICF checklist.
- **Systematic Literature Review (SLR)**. Summarizing the international scientific literature on the particular health condition, health condition group or healthcare context.
- **Qualitative Study (QS)**. Reflects the view of individuals living with Deafblindness. The acquired ones by themselves, the congenital by their parents.
- **Experts Survey (ES)**. An internet-based study addressed to gather opinions of experts on aspects of functioning and environmental factors that are relevant for persons with Deafblindness. A Delphi study may also be conducted.

Deafblind International (DbI) has made an international call for Deafblindness experts interested in a long-term commitment to this project. A team of **20 experts** from different continents has been already confirmed.

Identical methods will be used for the **QS focus groups**, seeking a wider variety of etiologies as possible.

During these **focus groups**, the deafblind should be under the full supervision of professional **interveners in Deafblindness** (one for each deafblind) in order to ensure plenty of access to information and communication through the process.

Expert organisations from the same **cultural and linguistic backgrounds** of the participants will be selected through DbI as well.

Next steps:

- Train project moderators, assistants and interveners for the focus groups.
- Run the 4 studies of the preparatory stage.
- Organize an international consensus conference in parallel with a global DbI conference.
- Dissemination of the ICF Core Set worldwide.

Expected Results

The aim of this proposal is to **develop a specific ICF Core Set (ICF-CS) for Deafblindness** that could provide a standardized description for the wide range of combinations of hearing and sight loss causing Deafblindness independently of the medical cause or level of individual autonomy of the Deafblind.

This project **would help millions of Deafblind** people in the world as it will establish the basis for a standardized process of evaluation, certification and intervention that could promote the maximum physical, cognitive and emotional development and autonomy of the individual.

Conclusions

International organizations working in the **Deafblind field**, consider it a priority to develop a **comprehensive ICF Core Set** that would provide a scientific basis for the assessment of functional status, goal setting, treatment planning and monitoring of the evolutions, as well as a measurement of the outcome.

Having a **well-structured ICF Core Set** could clearly benefit Deafblind people by allowing a more accurate detection and improved intervention standards.

The whole project would also contribute to **raise awareness** on Deafblindness inside the medical community worldwide.

Notes

- The total population in **Europe** (2014) is about 490M and the **estimated deafblind people** is 2,5M (0,8M under 65 and 1,7M over 65)⁴.
- From the group of sensory impairments, only **Hearing loss has a specific ICF-CS** already developed.
- **DbI is an international** non-profit membership organization focused on the needs of the deafblind, their families and professionals. It is managed by volunteers from around the world.

References

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