

From Research to Impact in Vision Science: Outcomes of the MAB–University Collaboration



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The Nordic definition of deafblindness:

Nordic Leadership Forum on Deafblindness. (2024). *The Nordic definition on deafblindness*. <https://doi.org/10.52746/SIMH2921>

Deafblindness is a distinct disability.

Deafblindness is a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree that society is required to facilitate specific services, environmental alterations and/or technology.



Cited on webpage of WFDB

What is deafblindness?



<https://wfdb.eu/what-is-deafblindness/>

In line with text on Dbl webpage

What is Deafblindness?

The term deafblindness describes a condition that combines in varying degrees both hearing and visual impairment. Two sensory impairments multiply and intensify the impact of each other creating a severe disability which is different and unique.

All people who are deafblind experience problems with communication, access to information and mobility. However, their specific needs vary enormously according to age, onset and type of deafblindness.

People who are deafblind are unable to use one sense to fully compensate for the impairment of the other. Thus they will require services which are different from those designed exclusively for either people who are blind or people who are deaf.



Deafblind
International Dbl

<https://www.deafblindinternational.org/encyclopedia-of-deafblindness/>

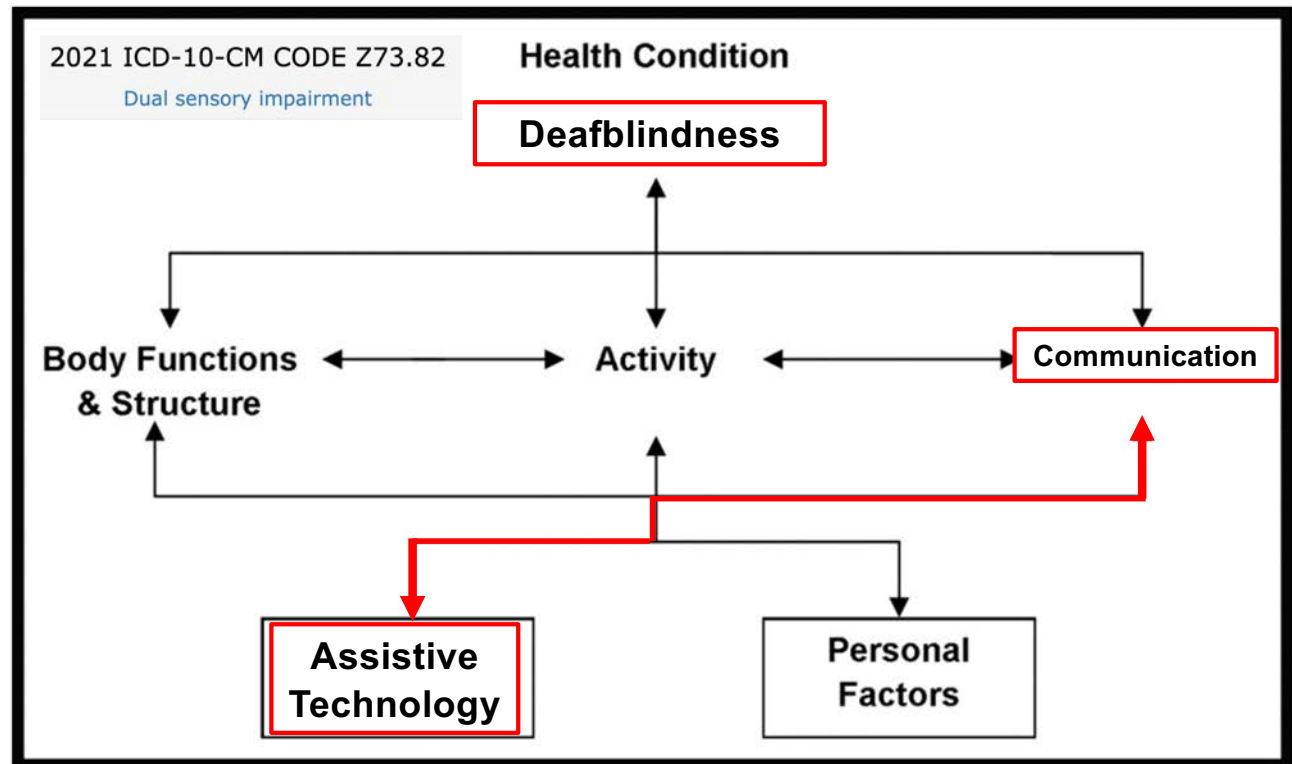
The ICF

Health Condition:
Disorder or Disease

Body Functions & Structure:
Impairment

Activity:
Limitations

Participation:
Restrictions



The ICF Framework

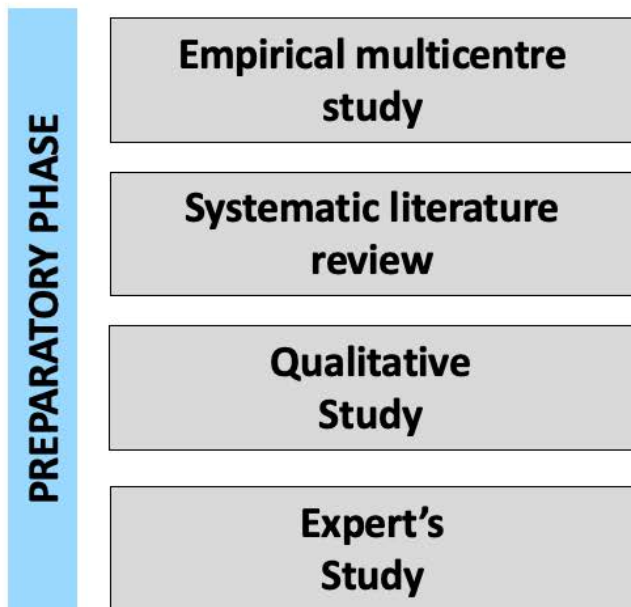
Interaction among the ICF components (WHO, 2001, page 19)

What is a Core Set?

- ICF Core Set = **reduced number** of categories, **specific to a disorder or disease**
- Clear and **specific terminology**
- Regulated process of how to develop a Core Set

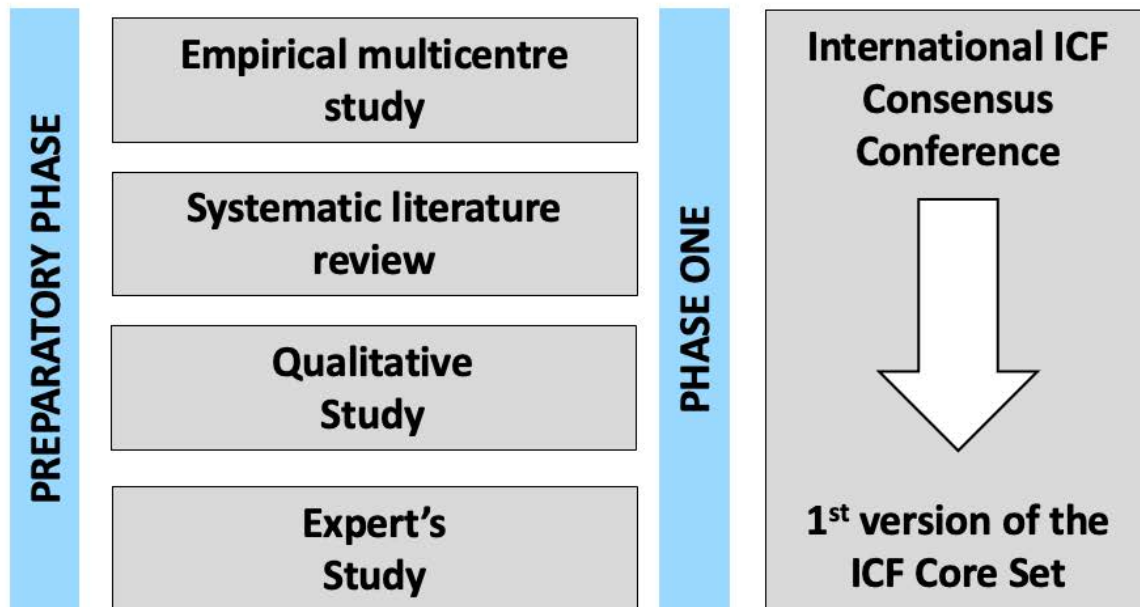
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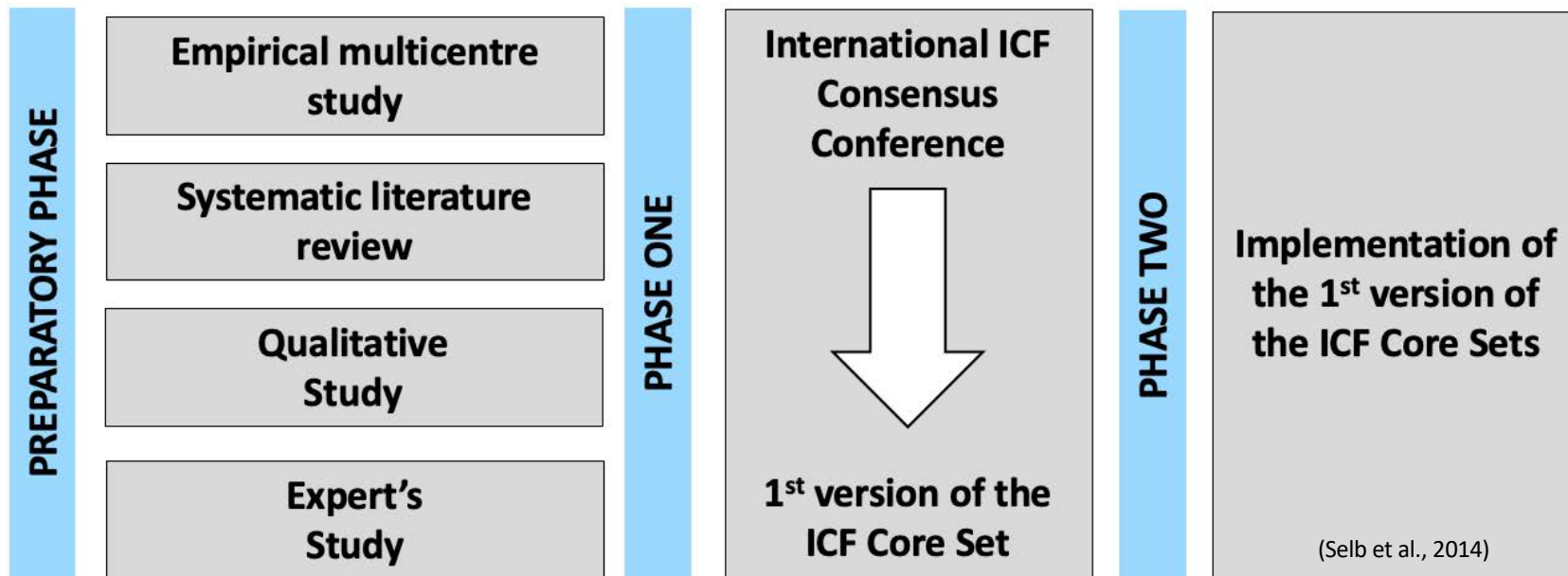
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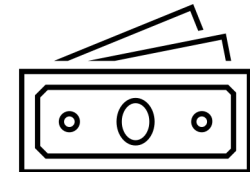
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Who would use this terminology?

- Insurance Companies
- Ministry for Health and Social Services
- Ministry for Education
- Funding agencies
- Non-for-profit organizations
- Government organizations
- Health and Social Services providers
- Researchers: identifying **priority areas of functioning (!)** that are not yet being studied





PREPATORY PHASE

Study 1: Systematic literature study

(Paramasivam et al. 2023, Jaiswal et al. 2024)

Study 2: Qualitative study

(Wittich, Dumassais, Prain, et al., 2024)

Study 3: Expert survey

(Wittich, Dumassais, Jaiswal, Paramasivam, et al., 2024)

Study 4: Multi-centered clinical evaluation

(Ogedengbe et al., 2025; Aminparvin et al. in press)

PHASE 1

International Consensus Conference

Cala Font, Spain on October 7 & 8, 2024

1st Version of the Comprehensive Core Set for deafblindness

(Wittich, Dumassais, Jaiswal, Ogedengbe, et al., 2024)

PHASE 2

Finalization of the Intermediate and the Brief Core Sets

Implementation of the 1st Version of the Core Sets
February 2025 onwards

Recruitment of **service providers** through

- dual-sensory program at MAB and
- programme surdicecité at INLB


Recruitment of **deafblind participants** through

- dual-sensory program at MAB and
- programme surdicecité at INLB


The Consensus Team






 **Comprehensive
Core Sets**



 **Intermediate
Core Sets**



 **Brief Core
Sets**

The Comprehensive Core Set (218 codes) provides a detailed list of all key factors to assess or manage deafblindness, supporting thorough care and policy planning.

The Intermediate Core Set (137 codes) summarizes the Comprehensive Core Set by grouping all its items into a more concise list, facilitating interprofessional communication.

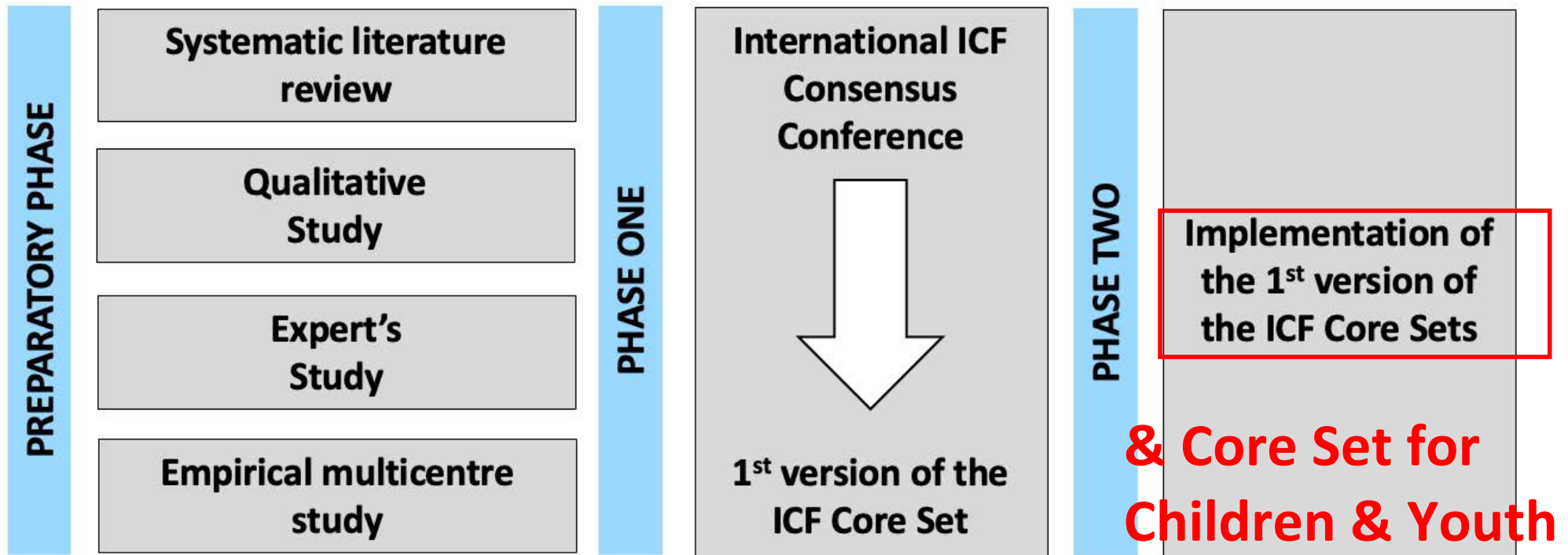
The Brief Core Set (33 codes) is a concise version that highlight only the most essential areas for quick and efficient individual clinical evaluation.

Early signs of implementation

- Summary videos in American Sign Language and Quebec Sign Language available on YouTube
- Spain organised interdisciplinary presentations for government and policy representatives in Barcelona
- Sweden has translated and published the CoreSets to facilitate local dissemination and implementation in local assessments
- Poland is using them in collaboration with the government to improve access to services



Next Steps



(Selb et al., 2014)

Thank you to all of you who helped
and to our
Research Funding bodies



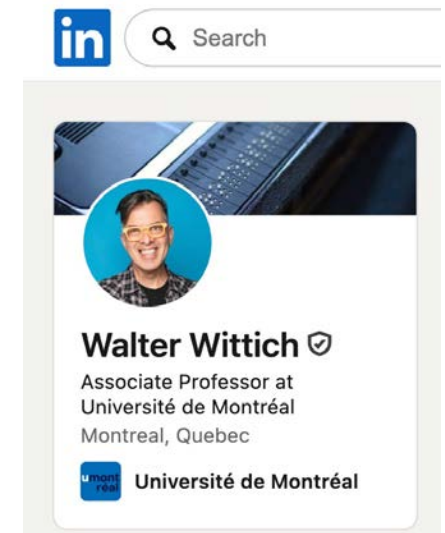
Partnership Funding

Institut Nazareth et Louis-Braille du CISSS de la Montérégie-Centre
Centre de réadaptation Lethbridge-Layton-Mackay du CIUSSS du CODIM



Merci / Thank you

<https://whoisdeafblind.org/>



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