

GLOBAL NORTH-SOUTH REPRESENTATION IN ACTION: THE ICF CORE SETS FOR DEAFBLINDNESS AS A MODEL FOR INTERNATIONAL COLLABORATIVE RESEARCH

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We present the approach used in developing the International Classification of Functioning, Disability and Health (ICF) Core Sets for deafblindness (combined hearing and vision impairment) that enabled broad global representation by recruiting across the six regions of the World Health Organization and examine differences in ICF code distributions between high- and low-resourced regions (i.e., Global North; GN and Global South; GS).

METHODOLOGY

1. Qualitative study

Perspective of individuals with lived experience of deafblindness

Online and in-person focus groups and interviews

- How does your deafblindness affect the way your body and your mind work?
- In which parts of your body does your deafblindness give you problems?
- How does your deafblindness affect the things you can and cannot do in your everyday life?
- What and/or who in the environment where you live and work/go to school is helpful and supportive in your everyday life with deafblindness?
- What and/or who in the environment where you live and work/go to school make everyday life with deafblindness difficult for you?

26 interviews and 9 focus groups

72 individuals with lived experience of deafblindness (GN n = 33, GS n = 39)

2. Expert survey

Perspective of individuals providing services to or working with individuals with deafblindness

• Online survey

- From your experience working with individuals with deafblindness, how does deafblindness affect the way their body and mind works?
- From your experience working with individuals with deafblindness, which parts of their body does deafblindness affect the most?
- From your experience working with individuals with deafblindness, how does deafblindness affect the things they can and cannot do in their everyday life?
- From your experience working with individuals with deafblindness, what and/or who in the environment is helpful and supportive in their everyday life with deafblindness?
- From your experience working with individuals with deafblindness, what and/or who in the environment is difficult in their everyday life with deafblindness?

• 105 professionals across 13+ professions

(GN n = 65, GS n = 40)

FOUR ICF DOMAINS

- Body functions
- Body structures
- Activities and participations
- Environmental factors

RESULTS

When comparing the Global North and the Global South, no significant differences were observed in the distribution of codes between the qualitative study and the expert survey.

However, within the qualitative study data, differences were observed between GN and GN in one of the four ICF domains: Environmental Factors.



CONCLUSION

Global collaboration is essential when developing universal tools like ICF Core Sets. Variations in environmental factors between the Global North and South reveal how context shapes the experience of disability worldwide. Crucially, participatory research involving individuals with lived experience provided unique, nuanced insights, underscoring its essential role in creating relevant, person-centered tools.

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