



ORIGINAL ARTICLE

# Development of core sets for deafblindness using the International Classification of Functioning, Disability, and Health: the perspectives of individuals with lived experience

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## ABSTRACT

**BACKGROUND:** The needs of people with deafblindness remain poorly understood and addressed globally. This study is part of a larger body of work to develop Core Sets for deafblindness using the International Classification of Functioning, Disability, and Health (ICF).

**AIM:** To determine the perspectives on functioning of individuals with lived experience of deafblindness as they relate to the ICF.

**DESIGN:** Cross-sectional interview study.

**SETTING:** Global, representing all six regions of the World Health Organization.

**POPULATION:** A diverse cohort of 72 individuals living with deafblindness or as close family members, ranging across the spectrum of severity.

**METHODS:** Qualitative interviews and focus groups were used to explore six open-ended questions about perceived barriers and facilitators to functioning of body functions and structures, activities and participation, and environmental and personal factors. Data were synthesized using content analysis, and the resulting topics were linked to the ICF codes using established linking methodology prescribed by the World Health Organization's ICF Research Branch. Descriptive statistics summarized all demographic data.

**RESULTS:** The analyses of the transcripts uncovered 2534 meaning units, leading to the identification of 492 corresponding distinct codes from the ICF framework, and spanning across 93.33% of coding categories available. Sensory (b2) and Mental Functions (b1) emerged as the most frequent Body Functions (b) codes. Most categories referred to Activities & Participation, with Mobility (d4) being the most frequently mentioned topic. Services, Systems and Policies (e5) was the most frequently used Environmental factor.

**CONCLUSIONS:** Over 93% of the ICF classification categories were accessed to code the data provided by participants, demonstrating the complexity of functioning with deafblindness. This study provides valuable information to shape policy and research by providing representation of lived experience towards the consensus conference for the comprehensive and abbreviated Core Sets for deafblindness.

**CLINICAL REHABILITATION IMPACT:** The inclusion of lived experience provides a holistic understanding of the daily challenges faced by individuals living with deafblindness. By being part of this process, they have a voice in shaping the classification system that will be used to describe their experiences, fostering a sense of ownership and empowerment.

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**KEY WORDS:** Deafness; Blindness; International Classification of Functioning, Disability and Health; Qualitative research.

Deafblindness is functionally defined by the limitations that the combined vision and hearing difficulties place on the ability to participate in society; these limitations can only be addressed through support services and strategies, adaptations to the environment, and the introduction of assistive devices and technologies.<sup>1</sup> Definitions based on variables used in the medical field (*e.g.*, visual acuity, visual field diameter and pure-tone audiogram thresholds) can vary widely, depending on location and context.<sup>2</sup> Additional variability is created by using self-report measures, creating prevalence estimates ranging from as low as 0.003% at the population level,<sup>3</sup> to as high as 58.6% among older adults.<sup>4</sup> Many of these definitions have been criticized for underestimating the complexity of the impairment and the experience of disability because they are considering vision and hearing separately, thereby ignoring the potential interaction of the combined impairment and its unique nature.<sup>5</sup>

A key approach to advancing the definition and the recognition of deafblindness as a unique disability, and to harmonize a global terminology and comprehension of its functional effects, is the development of World Health Organization, International Classification of Functioning, Disability and Health (ICF) Core Sets.<sup>6</sup> Using the ICF coding system, Core Sets provide a condensed, usable, and relevant approach to implementing the ICF codes for clinical assessment, research, and policy development in relation to specific health conditions. More importantly, Core Sets are mandated to be finalized based on the perspectives of all interested parties, including professional experts (*e.g.*, in the case of deafblindness: tactile sign language interpreters or intervenors), health and social service providers, as well as the individuals with lived experience themselves.<sup>7</sup> Work has been undertaken towards the development of Core Sets for deafblindness,<sup>8</sup> whereby the perspectives of researchers<sup>9, 10</sup> and expert professionals or health and social service providers in the field<sup>11</sup> have previously been published. The next step in this process is the exploration of the viewpoint on functional aspects related to living with deafblindness.

The perspectives of individuals living with deafblindness are generally underrepresented within the research literature.<sup>12</sup> In part, this underrepresentation is rooted in methodological difficulties that arise when working with persons that have difficulty accessing traditional research modalities, such as paper-format consent forms, or questionnaires.<sup>13, 14</sup> However, there are several examples where such access and inclusion barriers were overcome successfully, providing insight into the concerns of in-

dividuals with deafblindness. For example, a scoping review of studies exploring reasons for device abandonment summarized qualitative and quantitative data collected with participants with deafblindness.<sup>15</sup> A recent eBook presented a collection of studies on deafblindness that included individuals across all ages, exploring their perspectives on topics such as wellbeing and health, communication and information access, assistive technology and devices, and general methodological and support topics.<sup>16</sup> Individuals with deafblindness have been involved in best practice development.<sup>17</sup> Their perspectives include those of individuals ageing with congenital deafblindness<sup>18</sup> as well as those that age into acquired deafblindness.<sup>19</sup> Finally, and most importantly, the leadership of researchers and topic experts that live with deafblindness themselves guides the way towards equity and inclusion in the determination of priorities and the development of solutions.<sup>20-24</sup> Given the diversity of the population of individuals with deafblindness, and that the degree of impairment prevents some individuals from sharing their experiences in a formal way, the perspectives of parents and other family members are critical. There are important examples of parents who have engaged as researchers and experienced experts themselves, on behalf of their own children living with deafblindness.<sup>25-27</sup> Participatory action research examples include the experience of parents and siblings,<sup>28</sup> and those of the children of parents living with deafblindness.<sup>29</sup>

Previous studies on deafblindness have considered the ICF as its framework or analysis guide; for example, when exploring activity limitations and participation barriers,<sup>19, 30</sup> or environmental and contextual obstacles to assistive device use.<sup>15</sup> Crowe and colleagues<sup>31</sup> framed their interpretation of communication strategies used by older individuals with deafblindness within the ICF. Finally, Möller<sup>32</sup> critically examined the ICF as an assessment tool when working with participants with deafblindness. Möller's study laid some of the groundwork for the need to consider the development of Core Sets for deafblindness, as the author specifically points towards potential benefits (*e.g.*, common language), shortcomings (*e.g.*, personal factors and quality of life), and solutions (*e.g.*, development and inclusion of more complex social variables in the coding system) of applying the ICF to deafblindness. The development of ICF Core Sets is an important step in achieving such solutions. Here, we focus on the perspectives of individuals living with deafblindness themselves in relation to functioning to contribute to this process.

## Materials and methods

### Ethical considerations

This multi-site study was approved by the institutional review boards of the Centre de recherche interdisciplinaire en réadaptation du Montréal métropolitain (MP-50-2023-1749), and the Université de Montréal (CERC 2023-4150) in Canada, the Instituto del Salud Carlos III (#CEI PI 44\_2021-v3) in Spain, and the University of Melbourne (#2023-25708-42888-3) in Australia. The findings are presented here following the recommendations laid out in the CONSolidated criteria for REporting Qualitative research (COREQ) checklist.<sup>33</sup>

### Study design

We utilized a qualitative methodology with focus groups and individual interviews as primary means of data collection as recommended by Selb *et al.*<sup>7</sup> for this stage of developing Core Sets for deafblindness. More specifically, 26 interviews and 9 focus groups were conducted, online or in person, with participants from the six WHO regions. The modality depended on the context and feasibility of local circumstances for interacting with participants (*e.g.*, the availability of interpreters/intervenors/parents, and/or assistive devices), with the goal of enhancing the participation of individuals with deafblindness across as many regions as possible. For example, individuals who required tactile communication support were recruited for individual interviews instead of participation in a focus group, given the logistics barriers for group communication among individuals living with deafblindness.

### Recruitment procedure

We employed convenience sampling with a maximum variation strategy,<sup>34</sup> which was ensured by considering factors such as age, sex, severity, and etiology of deafblindness. Recruitment procedures varied according to local context, ranging from identification through client databases of rehabilitation or health and social services centers, snowball sampling, or referral through professionals or service providers. Based on a local grant, participants recruited and/or interviewed through the Canadian sites received \$50 CAD as acknowledgement of the time and effort provided by participating.

### Study population

We included individuals living with deafblindness and/or informal caregivers as the target population. Individuals

with deafblindness were considered eligible for participation if they 1) self-identified as deafblind, regardless of clinical confirmation; 2) were at least 18 years of age; 3) were willing to openly discuss various aspects related to functioning, disability, and contextual factors concerning their personal experience with deafblindness; and 4) demonstrated comprehension of the study's objectives. This was determined through the recruitment process and obtaining consent to participate. Informal caregivers (*e.g.*, parents of children with deafblindness or other family members) were included to provide a perspective on deafblindness relevant to children under 18 with deafblindness, and those with children (in some cases adult children) with congenital deafblindness who were unable to self-report. Caregivers were eligible if they 1) were at least 18 years of age; and 2) cared for an individual with deafblindness of any age. Each recruitment site was provided with instructions to approach potential participants that vary on the following criteria: age, age of onset of either impairment, sex, severity of either impairment, communication modality, and diagnostic information (if available). As recruitment was progressing, the research team monitored the distribution of participant characteristics as much as possible, and the encouraged sites where recruitment was still ongoing to identify under-represented individuals (*e.g.*, we specifically aimed to include individuals who live with one congenital and one age-related sensory impairment, as this group is rarely represented in deafblindness research).

### Materials

To conduct the interviews and focus groups, a standard interview guide was available to local moderators, which included items to collect demographic information. It was followed by a section asking six open-ended questions, aligned with various ICF components such as Body functions, Body structures, Activities & participations, Environmental factors, and Personal factors (Supplementary Digital Material 1: Supplementary Tables I-V) Each moderator also incorporated probing questions to provide clarification as needed. These questions were adapted from previous core-set projects<sup>7</sup> and tailored to suit the specific communication needs of the children and adult participants with deafblindness.

### Data collection procedure

Depending on the communication capacities or preferences, informed consent or assent was obtained verbally, through signed or tactile communication methods, or through a communication facilitator (*e.g.*, family mem-

ber), in line with previously described guidelines and recommendations.<sup>13, 35</sup> Each focus group or interview was overseen by a local moderator with extensive training and experience in leading discussions and conducting interviews with individuals living with deafblindness. These moderators included project research assistants, interpreters/intervenors, or individuals affiliated with organizations providing deafblind-specific services. In situations where it was feasible and suitable, an assistant accompanied the moderator to facilitate the interactions. Focus group session or interviews lasted up to 3 hours, were recorded, and later transcribed *verbatim*. When necessary and possible, the transcripts of interactions conducted in a language other than English were translated using DeepL Translator software (Cologne, Germany), and then proofread by a bilingual native speaker.

### Data linking methodology

The key research team members (AJ, SG, WW) received training from the WHO's ICF Research Branch on developing ICF Core sets, including the linking procedure.<sup>8</sup> Subsequently, these authors trained other team members (SD, TOO, CG). The training on the linking process involved identifying underlying concepts related to functioning in the data and linking them to ICF categories using established ICF linking rules.<sup>36, 37</sup> The methodology for data linking in this qualitative study followed the same steps as in our previous ICF systematic literature review and the expert survey<sup>9, 11</sup> and was conducted by the same team members (TOO, SD, CG) to benefit from their experience, ensure consistency, and reduce inter-rater variability. Drawing on the expertise of a senior author (SG), a linking template was created, guiding the process across seven sections: Meaning Unit; Meaningful Concept; Interpretation of Underlying Meaning; Linking Unit; ICF Code; ICF Description; and Final Codes.<sup>38</sup> All the qualitative responses from the participants were coded and linked using this template. Adhering to updated rules for ICF linking,<sup>36</sup> codes such as "other specified" [code 8] and "unspecified" [code 9] were selectively applied when the available information could not be accommodated within existing codes. Whenever relevant, personal factors were identified and coded as PF.

## Results

### Participant characteristics

Qualitative interviews and focus groups engaged a diverse cohort of 72 participants, strategically recruited to ensure

TABLE I.—Study characteristics of participants (N.=72).

Sex %	
Female	41.67 (N.=30)
Male	31.94 (N.=23)
Unknown	26.39 (N.=19)
Age: mean (SD) [range]	41.69 (19.56) [1-83]
<18	6.94 (N.=5)
18-40	25 (N.=18)
41-60	22.22 (N.=16)
>61	9.72 (N.=7)
Unknown	36.11 (N.=26)
Participant %	
Person living with deafblindness	45.83 (N.=33)
Caregiver	41.66 (N.=30)
Not specified	12.5 (N.=9)
WHO Region (%)	
Region of the Americas	27.78 (N.=20)
Canada	N.=10
Mexico	N.=10
Western Pacific Region	18.06 (N.=13)
Australia	N.=13
European Region	13.89 (N.=10)
Spain	N.=7
United Kingdom	N.=2
France	N.=1
African Region	12.50 (N.=9)
Zambia	N.=9
Eastern Mediterranean	12.50 (N.=9)
Egypt	N.=9
South-East Asia	15.28 (N.=11)
India	N.=7
Nepal	N.=4
Deafblindness onset (%)	
Congenital	47.22 (N.=34)
Acquired	11.11 (N.=8)
Not specified	41.67 (N.=30)
Deafblindness diagnosis (%)	
Usher Syndrome	16.67 (N.=12)
Rubella	5.56 (N.=4)
CHARGE syndrome	5.56 (N.=4)
Complication of prematurity	2.78 (N.=2)
Glaucoma, nature of hearing loss unknown	2.78 (N.=2)
Glaucoma and middle ear/eardrum damage	1.39 (N.=1)
CAGSSS syndrome	1.39 (N.=1)
NORRIE disease	1.39 (N.=1)
Chromosome 10q translocation	1.39 (N.=1)
Quadriplegic Cerebral Palsy	1.39 (N.=1)
Cerebral Palsy, Klinefelter's Syndrome	1.39 (N.=1)
Smith-Magenis Syndrome	1.39 (N.=1)
Viral infection	1.39 (N.=1)
Cataracts, nature of hearing loss unknown	1.39 (N.=1)
Cataracts and hearing infections	1.39 (N.=1)
Coloboma, nature of hearing loss unknown	1.39 (N.=1)
Congenital deafness with bilateral cataracts	1.39 (N.=1)
Multiple congenital anomalies with deafblindness	1.39 (N.=1)
Direct Trauma to the eye and/or ear	1.39 (N.=1)
Retinal detachment and age-related hearing loss	1.39 (N.=1)
Hydrocephaly	1.39 (N.=1)
Maternal drug use	1.39 (N.=1)
Other	2.78 (N.=2)
Unknown	38.89 (N.=28)
Value rounded to two decimal places.	

equitable representation across the six WHO regions. The recruitment target of at least seven participants from each region was met, fostering a globally inclusive perspective. The Americas and the Western Pacific regions emerged as significant contributors, yielding 20 and 13 participants, respectively. Table I provides detailed information on the profiles of the study sample.

**ICF categories**

The analyses of the transcripts uncovered 2534 meaning units, leading to the identification of 492 distinct codes from the ICF framework. The management of this large number of codes was facilitated by systematic tracking and sorting within a central Microsoft Excel file in which codes and their associated information could be sorted and counted as needed. A proportional overview of their distribution is provided in Figure 1, and a breakdown of the identified code for each chapter of each category is provided in Table II. Of the 30 chapters comprising the ICF, 28 were included in the coding process, corresponding to 93.33% of coding categories available.

*Body functions (B)*

A total of 707 meaning units regarding body functions were raised by participants (27.90%). Seven of the eight chapters of this category were identified as relevant to deafblindness. Of these:

- 44.59% belonged to Chapter 1, Mental functions;

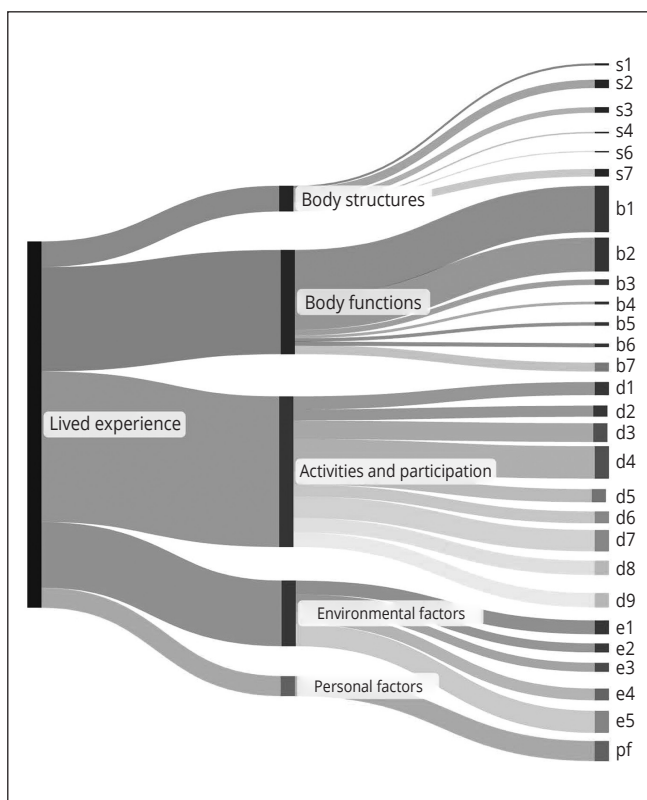


Figure 1.—Proportional frequency distribution of ICF chapters utilized during the linking process of responses from 72 individuals with lived experience of deafblindness. The width of each branch represents the proportional frequency use of unique ICF codes.

TABLE II.—Frequency of distinct codes identified within each chapter of the ICF framework categories concerning deafblindness.

Category	Chapters									
Body structures	s1 Structures of the nervous system N.=3	s2 The eye, ear, and related structures N.=12	s3 Structures involved in voice and speech N.=8	s4 Structures of the cardiovascular, immunological and respiratory systems N.=2	s5 Structures related to the digestive, metabolic, and endocrine systems N.=0	s6 Structures related to the genitourinary and reproductive systems N.=1	s7 Structures related to movement N.=11	s8 Skin and related structures N.=0		
Activities and participation	d1 Learning and applying knowledge N.=19	d2 General tasks and demands N.=16	d3 Communication N.=27	d4 Mobility N.=47	d5 Self-care N.=19	d6 Domestic life N.=17	d7 Interpersonal interactions and relationship N.=31	d8 Major life areas N.=21	d9 Community, social and civic life N.=21	
Environmental factors	e1 Products and technology N.=20	e2 Natural environment and human-made changes to environment N.=13	e3 Support and relationships N.=13	e4 Attitudes N.=17	e5 Services, systems, and policies N.=33					
Body functions	b1 Mental functions N.=67	b2 Sensory functions and pain N.=49	b3 Voice and speech functions N.=8	b4 Functions of the cardiovascular, haematological, immunological, and respiratory systems N.=4	b5 Functions of the digestive, metabolic and endocrine systems N.=5	b6 Genitourinary and reproductive functions N.=5	b7 Neuromusculoskeletal and movement-related functions N.=13	b8 Functions of the skin and related structures N.=0		

- 32.43% belonged to Chapter 2, Sensory functions and pain;
- 8.78% belonged to Chapter 7, Neuromusculoskeletal and movement-related functions;
- 5.41% belonged to Chapter 3, Voice and speech functions;
- 3.38% belonged to Chapter 5, Functions of the digestive, metabolic and endocrine systems;
- 3.38% belonged to Chapter 6, Genitourinary and reproductive functions;
- 2.03% belonged to Chapter 4, Functions of the cardiovascular, hematological, immunological, and respiratory systems;
- no meaningful concepts were identified in relation to Chapter 8, Functions of the skin and related structures.

The top five identified codes in this category, all levels combined were emotional functions (b152; N.=57), temperament and personality functions (b126; N.=43), hearing functions (b230; N.=40), seeing functions (b210; N.=39), and confidence (b1266; N.=32). The extensive list of meaning units for this ICF category is provided in Supplementary Table I.

#### *Body structures (S)*

A total of 74 meaning units in relation to body structures were raised by participants. Six of the eight chapters of this category were identified as relevant to deafblindness. Of these:

- 32.43% belonged to Chapter 2, The eye, ear, and related structures;
- 29.73% belonged to Chapter 7, Structures related to movement;
- 21.62% belonged to Chapter 3, Structures involved in voice and speech;
- 8.11% belonged to Chapter 1, Structures of the nervous system;
- 5.41% belonged to Chapter 4, Structures of the cardiovascular, immunological and respiratory systems;
- 2.70% belonged to Chapter 6, Structures related to the genitourinary and reproductive systems;
- no meaningful concepts were identified in relation to Chapter 5, Structures related to the digestive, metabolic, and endocrine systems as well as Chapter 8, Skin and related structures.

The top five identified codes in this category, all levels combined were eye, ear and related structures, unspecified (s299; N.=10), retina (s2203; N.=7), lens of eyeball (s2204; N.=5), structure of external ear (s240; N.=4), teeth (s3200; N.=4). The extensive list of meaning units

for this ICF category is provided in Supplementary Table II.

#### *Activities and participation (D)*

This ICF category elicited the greatest number of meaning units (n=894, 35.28%). All nine of the chapters were identified as relevant to deafblindness. Of these:

- 21.40% belonged to Chapter 4, Mobility;
- 14.22% belonged to Chapter 7, Interpersonal interactions and relationships;
- 12.56% belonged to Chapter 3, Communication;
- 9.77% belonged to Chapter 9, Community, social and civic life;
- 8.84% belonged to Chapter 8, Major life areas;
- 8.84% belonged to Chapter 1, Learning and applying knowledge;
- 8.84% belonged to Chapter 5, Self-care;
- 7.91% belonged to Chapter 6, Domestic life;
- 7.44% belonged to Chapter 2, General tasks and demands.

The top five identified codes in this category, all levels combined were communication, unspecified (d399; N.=34), socializing (d9205; N.=31), walking around obstacles (d4503; N.=26), interpersonal interactions and relationships, unspecified (d799; N.=20), and work and employment, other specified and unspecified (d859; N.=19). The extensive list of meaning units for this ICF category is provided in Supplementary Table III.

#### *Environmental factors (E)*

Environmental factors comprised the second category to elicit a great number of meaning units (N.=785, 30.98%). All five chapters of this category were identified as relevant to deafblindness. Of these:

- 34.78% belonged to Chapter 5, Services, systems, and policies;
- 21.74% belonged to Chapter 1, Products and technology;
- 15.22% belonged to Chapter 4, Attitudes;
- 14.13% belonged to Chapter 2, Natural environment and human-made changes to environment;
- 14.13% belonged to Chapter 3, Support and relationships.

The top five identified codes in this category, all levels combined were societal attitudes (e460; N.=72), immediate family (e310; N.=58), personal care providers and personal assistants (e340; N.=52), assistive products and technology for communication (e1251; N.=45), and

individual attitudes of immediate family members (e410; N.=36). The extensive list of meaning units for this ICF category is provided in Supplementary Table IV.

### *Personal factors*

Meaningful concepts that could not be coded using the ICF framework were identified as nc. Twenty-nine personal factors were identified. The most prominent ones included the experience of the COVID-19 pandemic (N.=9), health status (N.=8), age (N.=5) as well as housing/living situation (N.=5). The complete list of personal factors is provided in Supplementary Table V.

## Discussion

An overview of the perspectives of persons with lived experience of deafblindness reveals a remarkable 93.3% of available ICF chapters that were accessed during coding the data, emphasizing the complexity of their experiences. This proportion stands out in comparison to the 73.3% of chapters involved in the coding of the data in the deafblindness experts survey,<sup>11</sup> 60% of chapters accessed for coding the qualitative interviews conducted with individuals living with hearing loss,<sup>38</sup> and 53.3% used when coding the vision loss systematic literature review.<sup>39</sup> It is not surprising that the largest proportion of codes relevant to the participants referred to Activities and Participation (e.g., aspects related to communication). This finding is in line with the results of previous research<sup>9</sup> but in comparison with the results of the expert survey<sup>11</sup> was higher. The proportional presentation of Activities and Participation was somewhat under-represented among the responses of experts. Unlike experts, both individuals with lived experience and the systematic literature review placed proportionally less emphasis on environmental variables, such as assistive devices and human support. Somewhat unexpectedly, individuals with lived experience provided detailed information on the affected body structures, much in line with the data that emerged from the research literature.

All three data sources confirmed that among Body Functions (b) codes, Mental functions (b1) and Sensory functions (b2) were of most prominent concern, followed by Neuromusculoskeletal and movement-related functions (b7). It is likely that the importance of this last chapter indicates that deafblindness is often part of a complex health profile that includes many other impairments beyond the sensory, such as in the most common genetic cause of congenital deafblindness – CHARGE syndrome,<sup>40</sup> or age-related comorbidities such as rheumatoid arthritis.<sup>41</sup> The

distribution of code priorities within Activities and Participation (d) as reported by individuals with lived experience highlighted Mobility (d4), Interpersonal interactions and relationships (d7) and Communication (d3). Interestingly, while d4 was also among the four most frequently expressed perspectives of experts,<sup>11</sup> very little research focused on aspects of mobility<sup>9</sup> – a clear gap that needs addressing. Both Interpersonal interactions and relationships (d7) and Communication (d3) were core components in all data three sources. It is of note that mobility and communication are prerequisites for interactions and relationships with others. Communication has been recognized as a key issue for this population. The development and maintenance of expressive and receptive communication abilities of individuals living with any form and severity of deafblindness is key to the development of cognition as well as literacy.<sup>42</sup> Its importance is recognized for all aspects of activities and participation across the lifespan.<sup>43, 44</sup> Similarly, Interpersonal interactions and relationships (d7) are agreed upon as important for individuals living with deafblindness, reflecting the role of family, friends, and members of the immediate environment as part of their interactions with their social network. The perceptions of these interactions (or lack thereof) may include the experience of how living with such a profound disability affects social relationships in general. Interpersonal interactions likely play an even larger role in low- or middle-income regions of the world where neither policies and services, nor extensive support through technology or other environmental variables are available.

Individuals with lived experience emphasized the importance (and/or absence) of Services, systems, and policies (e5) and Products and technology (e1) for achieving independence and quality of life. Interestingly, the research literature reflected this emphasis on Products and technology,<sup>9</sup> whereas the expert survey aligned with the need for Services, systems, and policies.<sup>11</sup> However, while research has otherwise focused on the Natural environment and human-made changes to environment (e2) in the context of accessibility adaptation, experts also emphasized Supports and Relationships (e3), neither of whom were frequently mentioned among the perspective of individuals with lived experience. As previously alluded to,<sup>11</sup> it is possible that research topics according to published literature are influenced by funding priorities, more so than the needs of the target population. It may simply be easier to obtain technology research and development funds than find support for psycho-social research. Similarly, experts may be more concerned about services they

offer and the availability of policies and services that can support their professions, given that their income and careers depend on them. Either way, it was remarkable to observe how many personal factors emerged according to the participants with lived experience. The detailed descriptions of needs, barriers and facilitators provided more refined information about the specific variables of interest to our target population than any other methodological approach (Supplementary Table V).

### Research and policy implications

The comparison of ICF categories used across the preparatory studies so far has clearly indicated gaps that will become research priorities in coming years, especially now that the main concerns of individuals living with deafblindness are clearly indicated. Aside from the glaring lack of research in mobility for individuals with deafblindness, there are additional priority areas that become apparent on more detailed examination of the data. For example, factors related to self-care (d5) or domestic life (d6) are proportionally mentioned much more often by individuals with lived experience than they are acknowledged by the research literature or experts. It is possible that this observation is an indicator for individuals with deafblindness of a wish for increased independence, with a focus on self-care at home, that is not well communicated or understood by the individuals in their immediate environment. Such discrepancies can assist in determining research priorities to improve the lives of individuals with deafblindness by placing effort in line with need. Such an approach will likely increase community engagement in promoting research priorities and is an important step for forming critical mass on a global scale to bring together collaborative teams. Collaborations among the team members and their community partners have already extended into work on the Global Sustainable Development Goals in the specific context of deafblindness.<sup>45</sup> Finalizing the Core Sets will further focus these efforts.

### Limitations of the study

The limitations of this study need to be viewed within the context of conducting research with individuals living with deafblindness across the globe. It is remarkable that this international collaboration was able to facilitate recruitment and data collection across all six regions of the World Health Organization; however, not all data collection sites were equipped with comparable resources. Therefore, some of the demographic data are incomplete

or were not obtainable. In addition, there is likely recruitment bias present, given the resources necessary to identify and recruit individuals with deafblindness, as they need to be known to the local partners, be reachable and have the resources to become part of the project. Even though the team took all possible steps to support participation, equal access to identify and include all potential participants across the entire spectrum of recruitment criteria may not have been realizable within the constraints of the project in all of the WHO regions.

A methodological limitation of the process when developing Core Sets is the cross-sectional approach to each of the preparatory studies, including the present qualitative interviews. This approach does not allow for an in-depth understanding of how functional abilities vary or develop over time. Therefore, future studies on the implementation and acceptance of the Core Sets, and their refinement over time will depend on longitudinal approaches to using them in research and service delivery.

The analysis and synthesis presented here provide a merged view across all regions, yet it is likely that barriers and facilitators differ as a function of financial resources and vary for different sub-populations of individuals living with deafblindness. Therefore, the next step in the analysis is to explore coding differences as a function of the WHO region and compare variations according to the income level of participants and/or the represented countries. Furthermore, we are planning to separate data that refer to children and youth, supplement these data through additional data collection, and then develop additional Core Sets specific to Children and Youth. This final step is particularly important in the context of deafblindness, given the large number of congenital and early onset diagnostic categories that cause deafblindness.<sup>3, 46</sup>

### Conclusions

The present study provides a clear voice for individuals living with deafblindness and their family members and carers to contribute to the development of ICF Core Sets for deafblindness. The inclusion of their perspective allows the resulting Core Sets to reflect their level of functioning and can guide the development of content that points toward important facilitators and barriers towards participation. The representation of participants from across all six regions of the World Health Organization and across the range of ages, severities, diagnostics, and communication modalities makes this synthesis especially valuable, given that recruitment and data collection with this population



was successful despite logistic and infrastructure limitations. The representation of health and social care needs from the perspective of persons with lived experience is a challenge in general but becomes an even more pressing topic when the population of interest is, by its very nature, marginalized because of communication barriers, as in the case here. The next step in the process of Core Set development is the integration and synthesis of the data from the preparatory studies to assemble the preliminary Core Sets, currently scheduled to be discussed at a consensus conference in October 2024. We anticipate the presentation and publication of the finalized version of the comprehensive and abbreviated Core Sets for deafblindness before the end of 2024, allowing us to begin the process of implementation and refinement.<sup>7</sup>

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#### *Conflicts of interest*

The authors certify that there is no conflict of interest with any financial organization regarding the material discussed in the manuscript.

#### *Authors' contributions*

Walter Wittich, Atul Jaiswal, Ricard Lopez and Sarah Granberg have given substantial contributions to the conception and the design of the manuscript, Shirley Dumassais, Atul Jaiswal, Meredith Prain, Tosin Omony Ogedengbe and Renu Minhas contributed substantially to acquisition, analysis and interpretation of the data. All authors have participated in drafting the manuscript, Walter Wittich revised it critically. All authors read and approved the final version of the manuscript.

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SUPPLEMENTARY DIGITAL MATERIAL 1

Supplementary Table I.—Identified ICF codes from the Body Functions (b) category mentioned by the participants per sub-level.

Sub-level	b1 Mental functions n=67	b2 Sensory functions and pain n=49	b3 Voice and speech functions n=8	b4 Functions of the cardiovascular, haematological, immunological, and respiratory systems n=4	b5 Functions of the digestive, metabolic and endocrine systems n=5	b6 Genitourinary and reproductive functions n=5	b7 Neuromusculoskeletal and movement-related functions n=13	b8 Functions of the skin and related structures n=0
Codes	b114	b210	b3100	b440	b510	b6202	b7151	
	b1140	b2100	b3101	b4550	b515	b6400	b730	
	b1141	b21000	b320	b4552	b520	b6500	b7306	
	b1142	b21008	b3302	b4553	b530	b6502	b7508	
	b1149	b21009	b3303		b555	b6508	b755	
	b117	b2101	b3308				b7600	
	b122	b2102	b3400				b7601	
	b126	b21020	b349				b7603	
	b1260	b21021					b7652	
	b1261	b21022					b7653	
	b1262	b2108					b770	
	b1263	b2109					b7800	
	b1264	b220					b799	
	b1265	b229						
	b1266	b230						
	b1267	b2300						
	b1268	b2301						
	b127	b2302						
	b130	b2303						
	b1300	b2304						
	b1301	b2308						
	b1304	b2309						
	b134	b235						
	b1340	b2350						
	b1349	b2351						
	b140	b2352						
	b1400	b236						
	b1401	b2400						
	b1402	b2401						

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b1403	b2402
b144	b2408
b1441	b249
b1442	b255
b1448	b260
b147	b265
b1470	b270
b152	b2701
b1520	b2702
b1521	b2703
b1522	b279
b1528	b280
b156	b2800
b1560	b28010
b1561	b28013
b1562	b28014
b1564	b28015
b1565	b28016
b160	b28018
b1600	b289
b1601	
b1602	
b1603	
b164	
b1640	
b1641	
b1642	
b1644	
b1649	
b167	
b16702	
b1671	
b16710	
b16712	
b1679	
b180	
b1800	
b1802	

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To view the complete description of each code, visit: <https://apps.who.int/classifications/icfbrowser/>

Supplementary Table II.—Identified ICF codes from the Body Structures (s) category mentioned by the participants per sub-level.

Sub-level	s1 Structures of the nervous system n=3	s2 The eye, ear, and related structures n=12	s3 Structures involved in voice and speech n=8	s4 Structures of the cardiovascular, immunological and respiratory systems n=2	s5 Structures related to the digestive, metabolic, and endocrine systems n=0	s6 Structures related to the genitourinary and reproductive systems n=1	s7 Structures related to movement n=11	s8 Skin and related structures n=0
Codes	s110 s1106 s120	s220 s2201 s2203 s2204 s2205 s230 s2301 s240 s250 s2600 s298 s299	s310 s320 s3200 s3201 s3202 s32041 s3208 s330	s41008 s4101		s6303	s7 s710 s7102 s7103 s7108 s730 s7300 s750 s75001 s75011 s7600	

To view the complete description of each code, visit: <https://apps.who.int/classifications/icfbrowser/>.

Supplementary Table III.—Identified ICF codes from the Activities & Participation (d) category mentioned by the participants per sub-level.

Sub-level	d1 Learning and applying knowledge n=19	d2 General tasks and demands n=16	d3 Communication n=27	d4 Mobility n=47	d5 Self-care n=19	d6 Domestic life n=17	d7 Interpersonal interactions and relationship n=31	d8 Major life areas n=21	d9 Community, social and civic life n=21
Codes	d115	d210	d310	d400	d5	d6100	d710	d810	d9
	d120	d2100	d3108	d410	d510	d620	d7100	d820	d902
	d129	d2102	d3150	d4103	d5109	d630	d7101	d825	d910
	d130	d220	d3151	d4104	d520	d6300	d7102	d826	d9100
	d133	d2202	d320	d415	d5201	d6309	d7104	d830	d9101
	d135	d230	d325	d4151	d530	d640	d7105	d838	d9109
	d140	d2301	d329	d4152	d5300	d6400	d720	d839	d920
	d145	d2302	d330	d4153	d5301	d6402	d7200	d845	d9200
	d155	d2303	d335	d4154	d5302	d6409	d7201	d8450	d9201
	d1550	d240	d3350	d4200	d5308	d649	d7202	d8451	d9202
	d1551	d2400	d3351	d4301	d540	d6506	d7209	d8452	d9203
	d1558	d2401	d340	d4302	d550	d660	d729	d8458	d9204
	d159	d2402	d349	d4303	d560	d6600	d730	d850	d9205
	d160	d2409	d350	d4304	d570	d6601	d7400	d8502	d9208
	d163	d298	d3500	d4305	d5700	d6602	d7402	d8508	d9209
	d166	d299	d3503	d440	d5701	d6608	d7408	d8509	d930
	d170		d3504	d445	d5702	d6609	d7409	d855	d9300
	d198		d3509	d4452	d598		d750	d856	d940
	d199		d360	d4453	d599		d7500	d859	d950
			d3600	d4458			d7501	d860	d998
			d3601	d4459			d7504	d8700	d999
			d3602	d449			d7509		
			d3608	d450			d760		
			d3609	d4502			d7600		
			d369	d4503			d7601		
			d398	d4508			d7602		
			d399	d4509			d7603		
				d455			d7609		

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d4550	d7701
d4551	d798
d4552	d799
d4558	
d4559	
d460	
d4600	
d4601	
d4602	
d4609	
d469	
d470	
d4701	
d4702	
d4708	
d475	
d489	
d498	
d499	

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To view the complete description of each code, visit: <https://apps.who.int/classifications/icfbrowser/>

Supplementary Table IV.—Identified ICF codes from the Environmental Factors (e) category mentioned by the participants per sub-level.

Sub-level	e1 Products and technology n=20	e2 Natural environment and human-made changes to environment n=13	e3 Support and relationships n=13	e4 Attitudes n=17	e5 Services, systems, and policies n=32
Codes	e1101	e210	e3	e410	e515
	e115	e2151	e310	e415	e5151
	e1151	e2201	e315	e420	e535
	e120	e225	e320	e425	e5350
	e1201	e2254	e325	e430	e5358
	e125	e2400	e330	e435	e540
	e1250	e2401	e335	e440	e5401
	e1251	e250	e340	e445	e555
	e130	e2500	e350	e450	e5550
	e1300	e2501	e355	e455	e560
	e1301	e255	e360	e460	e5600
	e1308	e298	e398	e461	e5700
	e1351	e299	e399	e462	e575
	e150			e463	e5750
	e1501			e465	e5751
	e155			e498	e580
	e1551			e499	e5800
	e165				e5801
	e1650				e5802
	e198				e5808
				e585	
				e5850	
				e5851	
				e5858	
				e5859	
				e590	
				e5900	
				e595	
				e599	
				e520	
				e5408	
				e570	

To view the complete description of each code, visit: <https://apps.who.int/classifications/icfbrowser/>



Supplementary Table V.—Identified personal factors relevant to deafblindness and their frequency.

Factor	Frequency
Experience of COVID-19 Pandemic	9
Health status	8
Age	5
Housing/Living situation	5
Faith	4
Education status	3
Appearance	2
Genetic factors	2
Height	2
Nature of diagnosis	2
Relaxation habits	2
Sexual habits	2
Using “amplified voice technique”	2
Access to healthcare	1
Adapting the way of communication/communication strategies	1
Communication strategies (sitting in front of the interpreter, asking questions)	1
Early onset	1
Employment status	1
Hand spelling	1
Hearing strategies	1
history of functional vision	1
precautionary measures	1
Satisfaction with life	1
World view	1