# Report on Consensus work on Deafblindness using the International Classification of Functioning, Disability and Health (a WHO Initiative for Standardisation)

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## Executive Summary

Deafblindness, or dual sensory impairment (DSI), significantly impacts an individual's ability to navigate and participate in everyday life due to the compounded effects of vision and hearing loss. This report critically examines the fragmented classification systems in New Zealand, contrasts them with international practices, and draws lessons from the 2024 Consensus Conference on Deafblindness. Using the International Classification of Functioning, Disability, and Health (ICF) framework as a foundation, the conference highlighted the importance of integrating medical, functional, and societal perspectives.

New Zealand's reliance on separate classification systems for vision and hearing impairments limits recognition of the complexities associated with Deafblindness. These gaps hinder diagnosis, resource allocation, and policy-making while perpetuating social barriers. Incorporating insights from international contexts and lived experiences, this report recommends aligning New Zealand's practices with global best practices, ensuring holistic support for individuals with Deafblindness.

## Introduction

Deafblindness is a distinct disability caused by the combined loss of vision and hearing. While definitions vary globally, the Nordic definition, widely adopted internationally, describes Deafblindness as a condition where one impairment cannot compensate for the other, creating challenges that exceed the sum of their individual effects (World Federation of Deafblindness, 2024) . However, definitions based solely on functional limitations often fail to account for societal and environmental factors, which play a critical role in shaping the lived experience of individuals with Deafblindness (Jaiswal, 2019) .

In New Zealand, fragmented classification systems and limited data collection hinder accurately identifying individuals with Deafblindness. Without a unified framework, diagnosing the condition, allocating resources, or designing inclusive policies is challenging.

## Background

### Definitions of Deafblindness

Definitions of Deafblindness vary widely across regions, reflecting local healthcare priorities and social contexts. The Nordic definition, adopted by the World Federation of the Deafblind, emphasises the interaction of impairments, describing Deafblindness as a distinct condition where vision and hearing loss are so severe that neither sense can compensate for the other (World Federation of Deafblindness, 2024) . This definition has been instrumental in highlighting the functional impacts of dual sensory impairment and advocating for tailored support. However, critics like Bacchini and Simcock (2019) argue that the narrow focus on severe impairments may exclude individuals with moderate impairments who face substantial daily life barriers.

International definitions further illustrate the diversity of approaches. The European Deafblind Network (EDbN) emphasises the inability of corrective aids, such as glasses or hearing devices, to restore full functionality, framing Deafblindness as a condition that significantly restricts daily life (European Deafblind Network, 2024). The United States National Centre on Deafblindness prioritises challenges in communication and mobility, focusing on the need for tailored systems to support community participation (National Center on Deafblindness, 2024). Meanwhile, Canada adopts an individualised perspective, focusing on fostering independence and community inclusion by addressing the specific needs of each person (Canadian Deafblind Association, 2024a, 2024b).

Deafblind International (DBI) combines functional, social, and developmental perspectives, defining Deafblindness as a combination of vision and hearing impairments that create challenges with communication, information access, and mobility across life stages (Deafblind International, 2024). This definition aligns with research by Larsen and Damen (2014), which identifies several common elements in global definitions: severity of sensory impairments (based on the best ear and eye), onset relative to communication development or age, and functional impacts on mobility, information access, and communication.

The Consensus Conference on Deafblindness held in Tarragona, Spain, in October 2024 proposed adopting the International Classification of Functioning, Disability, and Health (ICF) framework to enhance these definitions by integrating medical, functional, and societal factors (*Comprehensive ICF Core Set for Deafblindness Project - Who Is Deafblind ?*, 2024). This holistic approach accounts for the environmental and societal barriers that exacerbate the challenges of Deafblindness, such as inaccessible communication tools, public spaces, and discriminatory attitudes (Jaiswal et al., 2019, 2022). It also underscores the importance of recognising societal stigma and systemic constraints as barriers to accurate diagnosis and support.

In New Zealand, the absence of a unified national definition limits efforts to identify and support individuals with Deafblindness. This gap not only hinders visibility but also perpetuates inequities in service provision, particularly for individuals with intersecting challenges like ageing or additional disabilities (Bacchini & Simcock, 2019; Jaiswal, 2019). Without a standard framework, the identification and diagnosis of Deafblindness depend heavily on fragmented systems that focus on single impairments.

### Medical, Social, and Functional Models

The medical model of disability focuses on diagnosing impairments based on clinical thresholds. In New Zealand, classification systems for vision and hearing impairments adhere to this approach, emphasising thresholds for eligibility. For example, Blind Low Vision NZ determines eligibility for services based on corrected visual acuity (≤6/24) and visual field (≤20 degrees). At the same time, the New Zealand Audiological Society categorises hearing loss by decibel thresholds - mild to profound (New Zealand Audiological Society, 2022). Although these criteria provide diagnostic clarity, they often fail to account for the cumulative impact of dual impairments (Dammeyer, 2014)

The social model shifts attention to societal barriers restricting participation, such as inaccessible infrastructure or negative attitudes towards the disabled. This perspective is particularly relevant to Deafblindness, where challenges often stem from external factors rather than the impairments themselves (Bacchini & Simcock, 2019; Simcock & Wittich, 2019)  . However, the social model's limited emphasis on medical needs risks neglecting necessary healthcare interventions.

Functional models, such as those embedded in the ICF framework, provide a balanced approach. By addressing both impairments and contextual barriers, they comprehensively represent how Deafblindness affects individuals (Paramasivam et al., 2021; WITTICH et al., 2024). The Consensus Conference's emphasis on the ICF reflects its potential to guide diagnostic processes, resource allocation and policy development.

### Classification Systems in New Zealand

New Zealand's classification systems for sensory impairments operate in silos, focusing on single impairments rather than the compounded effects of Deafblindness. Key frameworks include:

| **Organisation** | **Vision Criteria** | **Hearing Criteria** |
| --- | --- | --- |
| Blind Low Vision NZ (Blind Low Vision NZ, 2024) | ≤6/24 acuity or ≤20° visual field | Not addressed |
| Work and Income NZ (Work and Income NZ, 2024) | ≤3/60 acuity or ≤5° either side of fixation visual field | No formal hearing criteria |
| New Zealand Audiological Society (New Zealand Audiological Society, 2022) | Not addressed | Mild (26–40 dB) to Profound (>90 dB) |

These systems fail to integrate functional assessments or address societal factors. For example, individuals with moderate impairments in both senses may face significant challenges in mobility and communication but may not qualify for support under existing frameworks (Alfaro et al., 2020, 2021).

The reliance on fragmented frameworks impedes accurate diagnosis and equitable resource distribution. Without functional assessments, individuals with significant barriers may be excluded from support. Jaiswal et al. (2019) highlight that integrating societal and environmental factors into classification systems improves their relevance and inclusivity. New Zealand's current approach also limits the ability to collect meaningful data on Deafblindness, further hindering efforts to address policy and service provision gaps.

### New Zealand Data

#### Limitations of the Washington Short Set

The 2023 New Zealand Census included the Washington Short Set (WSS) questions on disability, independently assessing vision and hearing impairments. However, the failure to link these impairments prevents identifying individuals with Deafblindness and the unique context these bring.

As with Deafblindness, it is challenging to determine the prevalence of vision and hearing impairment alone as no national register or tracking exists. In 2023, the New Zealand Census, the Washington Short Set, was introduced to track self-identified impairment (Washington Group on Disability Statistics, 2024) . However, the questions related to difficulty seeing and hearing could be interpreted as corrected or uncorrected. In health It is expected to consider a hearing or vision impairment as the best-corrected measurement. Statistics in the 2023 Census for difficulty seeing or hearing are shown in Table 1:

Table 1 - 2023 Census in NZ data for difficulty seeing and difficulty hearing using the Washington Short Set questions (Statistics New Zealand, 2024)

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Difficulty Seeing | | |  | Difficulty Hearing | | |
| Classification | N | % |  | Classification | N | % |
| Total Responses | 4,705,533 |  |  | Total Responses | **4,705,533** |  |
| No difficulty | 3,209,862 | 68.2% |  | No difficulty | **3,408,114** | 72.4% |
| Some difficulty | 695,493 | 14.8% |  | Some difficulty | **494,232** | 10.5% |
| A lot of difficulty | 64,797 | 1.4% |  | A lot of difficulty | **62,640** | 1.3% |
| I cannot do it at all | 7,119 | 0.2% |  | I cannot do it at all | **5,736** | 0.1% |
| Total stated - difficulty seeing | 3,977,277 | 84.5% |  | Total stated - difficulty hearing | **3,970,722** | 84.4% |
| Not elsewhere included | 728,256 | 15.5% |  | Not elsewhere included | **734,814** | 15.6% |

Without integrated data, policymakers cannot accurately estimate the prevalence of Deafblindness or design targeted interventions and support systems. Prescott et al. (2020)  emphasise that reliable and fit for purpose data is essential for advocacy and resource allocation. With this in mind a standardised functional and measured definition and criteria could improve this.

## The Consensus Conference on Deafblindness

In October 2024, the Consensus Conference on Deafblindness brought together over 30 leading experts representing more than 24 countries, spanning the United Nations' regions. This pivotal event aimed to develop a core set of guidelines for Deafblindness, grounded in the International Classification of Functioning, Disability and Health (ICF). The collaborative effort sought to ensure that definitions and frameworks for Deafblindness reflect the interplay of medical, social, and environmental factors that uniquely shape the lives of those affected by dual sensory loss.

### Preparation and Contributions

The lead-up to the conference involved substantial preparatory work. Participants were required to complete approximately 30 hours of activities to shape a shared understanding of Deafblindness as a multifaceted condition. This preparation included submitting opinions and evidence-based perspectives on the unique factors that define Deafblindness. These included:

* **Medical factors**, such as severity thresholds for vision and hearing impairments and their interactions.
* **Social factors**, including barriers to participation, communication challenges, and societal attitudes.
* **Environmental factors**, such as the accessibility of public spaces, availability of assistive technologies, and community support structures.

This comprehensive approach ensured that the framework developed would not only address the functional challenges of Deafblindness but also account for the societal and contextual barriers that impact individuals’ quality of life.

### New Zealand’s Representation and Key Outcomes

Dr Sally Brinell, a Senior Lecturer and Senior Research Fellow at Auckland University of Technology (Figure 1), attended the conference as New Zealand’s representative. Supported by Kevin Prince, President of the Deafblind Association New Zealand, Dr Britnell contributed her expertise as a Nurse, Researcher and Board Member of Deafblind Association of NZ along lived experience while Prince provided knowledge around Deafblindness from the perspective of an Accessibility Advisor and President of the Deafblind Association NZ. Together, they brought insights from New Zealand’s unique context, highlighting the fragmented systems currently in place and advocating for a more integrated and culturally responsive approach.



Figure 1 - Dr Sally Britnell voting no on behalf of NZ to one of the proposed classifications. To her left (out of photo) is Kevin Prince, however you can see he is also voting no to the same proposal.

The conference took place in Tarragona, Spain, where the proposed ICF core set for Deafblindness was finalised and presented to the Spanish government. The framework aims to serve as a global benchmark for recognising and addressing Deafblindness, ensuring that it is incorporated into national and international healthcare systems. The core set will next be submitted to the World Health Organisation (WHO) for inclusion in the ICF, marking a critical step in standardising the understanding and support of Deafblindness worldwide.

**Lessons Learned from the Conference**

* **Global Collaboration Strengthens Frameworks:** The diversity of perspectives from over 24 countries underscored the importance of addressing Deafblindness as a global issue. Shared experiences revealed common challenges, such as stigma, underreporting and gaps in data collection, which require international cooperation to address effectively.
* **Holistic Definitions Are Essential:** The inclusion of social and environmental factors alongside medical criteria ensures that the framework developed is inclusive and reflects the lived experiences of individuals with Deafblindness. This aligns with the World Federation of the Deafblind’s advocacy for definitions that go beyond impairments to address societal barriers and support needs.
* **New Zealand’s Role in Shaping International Standards:** New Zealand’s participation highlighted its commitment to aligning national practices with global standards. Dr Britnell and Prince’s contributions reinforced the need for New Zealand to adopt a unified framework that integrates functional, medical, and societal dimensions, as advocated by the ICF.

This comprehensive approach ensured that the framework developed would not only address the functional challenges of Deafblindness but also account for the societal and contextual barriers that impact individuals’ quality of life.

A group of people posing for a photo

A group photo of three rows of people represening the 30 countries who participated.

Figure 2 - Consensus Conference Participants representing a mixture of those with clinical, academic and lived experience of Deafblindness. The group represents over 30 countries and the 6 World Health Organisation regions.

## Future Implications for New Zealand

The outcomes of the 2024 Consensus Conference on Deafblindness offer a transformative opportunity for New Zealand to enhance its approach to identifying, supporting, and advocating for individuals with Deafblindness. Adopting the International Classification of Functioning, Disability, and Health (ICF) core set for Deafblindness presents a pathway to address longstanding gaps in classification systems, data collection, and societal inclusion. These changes have far-reaching implications for policy, healthcare, and community engagement.

#### Enhancing Classification Systems

New Zealand's current classification systems for sensory impairments operate independently, using strict medical thresholds for vision or hearing loss without considering the compounded effects of dual impairments. This fragmented approach risks excluding individuals whose impairments, while moderate, create significant functional challenges when combined (Bacchini & Simcock, 2019). By adopting the ICF core set, New Zealand can:

* **Integrate Functional and Societal Dimensions:** The ICF framework incorporates medical, functional, and societal factors, ensuring a comprehensive understanding of Deafblindness. This shift would improve the inclusivity of classification systems by recognising barriers such as communication challenges, mobility restrictions, and environmental inaccessibility (Wittich et al., 2024).
* **Standardise Definitions Across Sectors:** Implementing the ICF core set would align New Zealand’s practices with international standards, facilitating consistency in diagnosis (medical model) and service provision (social model). This alignment is essential for improving cross-sector collaboration and ensuring equitable access to support services.

#### Improving Data Collection

Accurate data on the prevalence and impact of Deafblindness is critical for evidence-based policy-making and resource allocation. However, the 2023 New Zealand Census, which relied on the Washington Short Set (WSS), failed to capture the intersection of vision and hearing impairments, leaving individuals with dual sensory loss uncounted. Adopting the ICF framework provides an opportunity to:

* **Capture Comprehensive Data:** The ICF’s holistic approach would enable the development of integrated survey tools that link vision and hearing impairments, providing a clearer picture of the prevalence of Deafblindness in New Zealand (Prescott et al., 2020).
* **Inform Policy and Resource Allocation:** Improved data collection would allow policymakers to identify gaps in service provision, allocate resources more effectively and advocate for targeted interventions to address the needs of individuals with Deafblindness.

#### Addressing Societal Barriers

Deafblindness is not only a medical condition but also a social and environmental challenge. Individuals with dual sensory impairments face significant barriers to participation, including inaccessible public spaces, inadequate communication tools, and discriminatory attitudes. By adopting the ICF core set, New Zealand can:

* **Promote Inclusive Policies:** The ICF framework emphasises the importance of addressing societal barriers, providing a foundation for policies that prioritise accessibility and inclusion. This could include funding for assistive technologies, improving public transportation, and ensuring access to interpreters and tactile communication tools (Dyzel et al., 2020).
* **Raise Public Awareness:** Integrating the ICF framework would support national campaigns to educate the public about Deafblindness, reducing stigma and fostering greater understanding of the challenges faced by individuals with dual sensory impairments (Wittich et al., 2016).

#### Leading Global Change

As the ICF core set moves toward approval by the World Health Organization (WHO), New Zealand has the opportunity to position itself as a leader in its adoption and implementation. By committing to this framework, New Zealand can:

* **Demonstrate Global Leadership:** Implementing the ICF core set would place New Zealand at the forefront of international efforts to standardise definitions and practices for Deafblindness. This leadership could inspire other countries to adopt similar approaches, contributing to a global shift toward more inclusive policies.
* **Strengthen Regional Collaboration:** Aligning with international standards would facilitate collaboration with other countries in the Pacific region, enabling shared learning and resource development to address common challenges.

### Conclusion

The adoption of the ICF core set represents a significant step toward creating a society where Deafblindness is not only recognised but also supported through evidence-based, inclusive policies. For individuals with Deafblindness, this shift would mean greater access to the resources and support needed to participate fully in their communities, fostering independence and improving quality of life.

New Zealand’s commitment to this framework would signal a broader commitment to equity, inclusion, and the rights of all individuals, regardless of their sensory abilities. By embracing the lessons of the Consensus Conference and integrating the ICF core set into its policies, New Zealand can lead the way in creating a future where no one is left behind.

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