



## At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deafblindness An overview

Representing between 0.2% to 2% of the population, persons with deafblindness are a very diverse yet hidden group and are, overall, more likely to be poor and unemployed, and with lower educational outcomes. Because deafblindness is less well-known and often misunderstood, people struggle to obtain the right support, and are often excluded from both development and disability programmes.

This document seeks to start a dialogue between international disability rights and development stakeholders, and is based on research undertaken by the World Federation of the Deafblind (WFDB). It is the organisation's aim to produce the first global report on the situation of persons with deafblindness.

The findings will be presented at the 2018 Helen Keller World Conference to women and men with deafblindness from across the world. They will contribute to the production of the global report with their lived experiences and will decide the recommendations going forward.

### Table of Contents

Introduction.....	2
The diversity of persons with deafblindness .....	3
Overview of international obligations under the CRPD.....	5
Focus: participation in political and public life .....	8
Persons with deafblindness and inequality: what does the data say? .....	9
Methodology.....	9
<i>Review of literature</i> .....	9
<i>Country data analyses</i> .....	9
<i>WFDB and Sense International member and partner surveys</i> .....	10
The challenges of 'counting' persons with deafblindness .....	10
Persons with deafblindness and poverty.....	12
Persons with deafblindness and work .....	13
<i>In our own words: Edgar Reyes (Dominican Republic)</i> .....	15
Persons with deafblindness and education .....	16
Persons with deafblindness and health .....	17
Persons with deafblindness and social life .....	18
<i>In our own words: Carlos and Sofia (Brazil)</i> .....	20
References.....	21
Acknowledgement and disclaimers.....	23

## Introduction

Echoing the changes triggered by the UN Convention on the Rights of Persons with Disabilities (CRPD), the adoption of **Agenda 2030 and the Sustainable Development Goals (SDGs) emphasised the importance of inclusive development and leaving no one behind**. Worldwide, there is a growing momentum for change based on inclusion, which marks a significant shift from the invisibility and exclusion of persons with disabilities from the Millennium Development Goals (MDGs). However, it is vital to recognise that **persons with disabilities are not a homogenous group, and some constituencies, such as persons with deafblindness, remain marginalised and, in many ways, invisible**.

**Persons with deafblindness represent between 0.2% and 2% of the global population and are more likely to live in poverty and be unemployed, with lower educational outcomes than other persons with disabilities**. They face multiple barriers, such as a lack of access to support services and accessible information, which ultimately makes it extremely difficult to voice their issues.

**In many countries, persons with deafblindness are not recognised as a distinct disability group. This has contributed to a persistent statistical invisibility even when efforts are made by governments to collect disability-related data**. This is reflected at international level, with only seven references to persons with deafblindness in the 2011 landmark World Report on Disability (WHO-World Bank, 2011) [1].

The experiences of the World Federation of the Deafblind (WFDB), Sense International (SI) and the International Disability Alliance (IDA) in the last 10 years indicate that the issues faced by persons with deafblindness have largely been ignored.

Evidence confirms a disability and development gap [2], and there is a **significant risk that efforts to implement the CRPD and inclusive SDGs will exclude persons with deafblindness, among other marginalised groups**.

WFDB and SI agree that the **relative invisibility of persons with deafblindness is both a cause and a consequence of a lack of understanding across disability rights and development stakeholders, both in terms of the extent and diversity of their issues, as well as their specific inclusion requirements**.

**A literature review conducted for this report found that there is a lack of good quality, comparable data on persons with deafblindness**. The majority of studies documented were small in scale and focused only on people in specific circumstances, such as members of deafblind organisations, people in assisted living, and those who attend rehabilitation centres. The review also found that most research focused on adults who acquired deafblindness later in life or was undertaken in the United States or European countries. There were almost no studies from low or middle-income countries.

This global report has, therefore, been conceived as an evidence-based awareness raising tool, as well as to contribute to the global monitoring of both CRPD and the SDGs. It will feed into the 2020 SDG baseline and a follow-up report is planned for 2025.

Combining **the largest population-based analysis of persons with deafblindness conducted to date** (disaggregation of 11 population-based surveys from low, middle and high-income countries), an academic literature review, two surveys conducted among members and partners of WFDB and Sense International, and case studies, the report covers the diversity of persons with deafblindness, their lived experiences, and the barriers and inequalities they face. It also seeks to develop concrete recommendations for member states, development agencies and civil society organisations.

**The findings of this report will be presented at the 2018 Helen Keller World Conference to women and men with deafblindness from across the world. They will contribute to the production of the global report that reflects lived experiences and will also decide on the recommendations going forward.**

## The diversity of persons with deafblindness

Deafblindness is often underestimated and misunderstood, and this contributes significantly to the many barriers faced by persons with deafblindness. Some persons with deafblindness are completely deaf and blind, but many have a little sight and/or hearing they can use.

Based on the Nordic definition [3], the WFDB defines deafblindness as ***a distinct disability arising from a dual sensory impairment of a severity that makes it hard for the impaired senses to compensate for each other. In interaction with barriers in the environment, it affects social life, communication, access to information, orientation and mobility. Enabling inclusion and participation requires accessibility measures and access to specific support services, such as guide interpreters, among others.***

The age of onset of a person's vision and hearing impairment has a profound impact on the consequences of deafblindness, particularly in relation to communicative development and language acquisition. It is therefore important to differentiate.

- ***Pre-lingual deafblindness***, which describes a vision and hearing impairment acquired at birth or at an early stage in life before the development of language. This may be due to infections during pregnancy, premature birth, birth trauma or genetic conditions (e.g. Down's syndrome, Usher syndrome, and CHARGE).
- ***Post-lingual deafblindness***, which describes vision and hearing loss acquired following the development of language (spoken or sign language). Deafblindness can be caused by illness, accident or as a result of age-related conditions associated with the loss of vision and hearing (e.g. cataracts, glaucoma and macular degeneration for vision loss, and presbycusis for hearing loss) [4, 5]. While Usher syndrome is an inherited genetic condition, it typically manifests itself (visual and/or hearing loss) in later childhood or adolescence, following the development of language [6].

Deafblindness is more prevalent among older age groups. However, among children and young adults, deafblindness presents additional implications, impacting on learning and gaining employment.

### ***A diversity of barriers and a diversity of support requirements***

*"For me personally, in some optimal times when the light is perfect and the noise level low, I can manage pretty good myself. But when for example I go into the centre of our city and the sun shines strongly then I can't see at all and, as it is often very noisy all around, I can't hear what is being said to me and it is very difficult to manage myself. But I'm not deafblind because in other situations I can see and hear better. It is therefore much easier to identify myself with the term 'person with deafblindness'." C. Nilsson*

***Each person with deafblindness connects, communicates and experiences the world differently.*** Each individual may face ***restrictions of participation that are affected by the level of support and barriers in their environment, the severity of the vision and hearing impairment and the age of onset, among other elements.*** Persons with deafblindness constitute a diversified group with a broad experience of disability and may have different support and inclusion requirements.

***It is vital, therefore, that persons with deafblindness access services that meet each individual's needs and not a combination of services designed for blind or deaf people.***

While persons with deafblindness may require support to access information, communicate, interact and move freely on an equal basis with others, the type and level of support varies from individual to individual. ***Some persons with deafblindness may experience other functional difficulties and therefore may have additional support needs.***

*Persons with deafblindness frequently require support for:*

- ***Communication***

There is a variety of techniques and methods of communication support, and there is no standard way of communicating. Communication approaches are likely to vary based on whether a person has pre-lingual

or post-lingual deafblindness, which impairment developed first, and the level of residual hearing or sight [7]. For example, people with profound hearing impairments who later develop a visual impairment may still be able to communicate with sign language, with some adaptations. Similarly, people with profound vision impairments who develop hearing impairments may have benefited from braille instruction, but may now require clear speech interpreting. People with pre-lingual deafblindness will use different approaches to acquire language.

A wide range of communication methods [8] exist, including:

- *Tactile interpreting (i.e. tactile sign language to one person with deafblindness) or finger spelling of the manual alphabet.*
- *Close vision interpreting (i.e. visual sign language within close proximity to a person with deafblindness) or visual frame interpreting (i.e. visual sign language to more than one person with deafblindness).*
- *Clear speech interpreting (with or without hearing aids) or speech-to-text interpreting (with certain adaptations and with or without technical equipment, such as a computers, large screens and braille displays).*

Depending on the person and the situation, any one and/or combination of methods may be required. Furthermore, communication strategies may change over time, particularly if the individual experiences changes in the severity of their hearing and/or visual impairments [9].

Persons with deafblindness may also use assistive technology to support communication. Examples of assistive products include braille displays and writers, hearing aids and loops, and glasses and/or magnifiers. However, it is important to remember that such assistive products will not meet every individual's needs in all circumstances, and that support may be required in other areas, such as that provided by an interpreter-guide.

- **Mobility**

The ability to get around fully and freely is essential to full and effective inclusion and equal participation. For some persons with deafblindness, qualified guiding to support mobility and orientation may be necessary. Guiding is also considered an integral part of interpreter-guide services, as it is not possible to guide and describe for a person with deafblindness without being able to communicate.

- **Description**

In order to fully understand and connect with the environment, some persons with deafblindness choose to use description. This not only encompasses physical surroundings, such as walls and windows, but also occurrences, people and physical objects, including books, posters, and both digital and printed brochures.

The WFDB considers description an integral part of any interpreter-guide service. It should be offered at the same time as guiding and interpreting of speech, according to the situation [8].

### ***The critical importance of an interpreter-guide***

While some persons with deafblindness may use communication or basic mobility support in a familiar environment, most will require support from an interpreter-guide in other situations, depending on the circumstances.

Interpreter-guide services are truly responsive to the compounded support requirements of persons with deafblindness, both in terms of communication and mobility. The service offers support in line with article 19 of the CRPD, allowing persons with deafblindness to live autonomously and be included in the community. A professional interpreter-guide service can be the key to accessing other services and fundamental rights, such as education, employment, healthcare, culture and recreation.

<b>A diversity of support services (non-exhaustive list)</b>
--------------------------------------------------------------

<b>Mobility and communication</b>	
Interpreter-guide	A professional who provides communication and mobility support, including guiding and description, which is adapted to the needs of the person. Proper and appropriate communication methods are used at any given time and occasion.
<b>Communication</b>	
Tactile communication	<b>Tactile sign language:</b> a common means of communication used by persons with deafblindness. Signs are primarily indicated in the palm of the hand.
	<b>Tactile fingerspelling:</b> a variation of tactile sign language using finger-based signs that follow a specific pattern. 
	<b>Tactile alphabet:</b> communication based on spelling words, letter by letter, and indicating block letters in the palm of the hand of the individual. 
Tadoma	Communication through jaw movements, vibrations and the facial expressions of the speaker, achieved by placing a thumb on the speaker's lips and the remaining fingers along the face and neck.
Visual frame interpreting	Sign language that is adapted to fit a limited field of vision with a person who has some degree of residual sight.
Clear speech	An effective and commonly used method of communication for people who have some degree of residual hearing.
Braille/moon	<b>Braille</b> is a system that uses a series of raised dots (six in two columns of three) to represent letters or groups of letters.
	<b>Moon</b> is similar to braille but uses raised, adapted capital letters that are simpler to feel.
<b>Assistive devices</b>	
Hearing	<b>Hearing aid:</b> a small electronic device that is placed behind or inside the ear to amplify sound and speech. Essential in combination with clear speech interpretation.
	<b>Cochlear implant (CI):</b> a surgically implanted electronic device that provides a sense of sound, bypassing the hearing process that has been impaired.
	<b>Loop:</b> a unique sound system used by people with hearing aids. The hearing loop provides a magnetic, wireless signal that is picked up by the hearing aid and/or cochlear implants.
Reading/writing	<b>Braille reader/display:</b> a device enabling one and/or two-way communication through computers, smartphones and similar devices using braille.
Mobility	<b>Red and white striped cane:</b> identifies a person as having a combined sight and hearing impairment.

## Overview of international obligations under the CRPD

The CRPD applies to all persons with disabilities without distinction and all human rights standards apply to all persons with disabilities. The diversity of persons with disabilities (and their diverse inclusion requirements) is recognised and serves as a core principle. The **CRPD also acknowledges the imperative to promote and protect the rights of persons with disabilities who require more intensive support,**

**which is likely to apply to persons with deafblindness.** Persons with disabilities should not be excluded or discriminated against because of the nature of their disability.

Deafblindness is specifically mentioned in the CRPD under article 24 (Education) and has been recognised by the Committee in several General Comments and Concluding Observations. Based on this recognition in international law, as well as the recognition of deafblindness as a distinct disability in the legislation of many countries, states have an obligation to acknowledge and respond to the requirements of persons with deafblindness across legislation, policy, programmes and budgets.

The CRPD recognises a wide range of communication methods, such as tactile communication and braille, and languages, including sign languages and non-spoken languages, which may be used by persons with deafblindness.

The General Comment No. 2 on Article 9: Accessibility of the Committee on Rights of Persons with Disabilities (CRPD/C/GC/2) provides further clarity on **states' obligations to enable persons with deafblindness to access information, communication and other services in order to live independently** and to effectively participate in society. States, therefore, must address key issues, such as a lack of adequate communication training among service providers. In addition, they must provide live assistance and intermediaries, such as guides and interpreters, to remove barriers to communication, information and other services. States must also ensure a minimum quality of communication-related services, such as interpretation and personal assistance, and aim for standardisation across the board.

Accessibility is not limited to communication and information. Persons with deafblindness experience many barriers to orientation and mobility in public spaces. Therefore, states should provide access to signage in braille or live assistance and intermediaries, such as interpreter-guides, to facilitate accessibility and mobility. Crucially, states must establish minimum standards in terms of the accessibility of services provided by public and private entities. This will improve general access for persons with deafblindness across different sectors, such as work, education and health.

Reasonable accommodations may also improve access for persons with deafblindness, particularly where accessibility standards are not implemented or if a person's requirements fall outside the scope of such guidelines. For persons with deafblindness, reasonable accommodations often include communication, orientation and mobility support, either through the use of aids, assistive devices and/or live assistance, such as interpreter-guides. Importantly, reasonable accommodation is not limited to accessibility, and may also include the adaptation of work schedules or procedures, among other changes.

For the purpose of this report, two key proxy indicators were identified to assess whether states have taken the appropriate steps to implement the CRPD provisions for persons with deafblindness. These indicators are: the official recognition of persons with deafblindness as a distinct disability group and the provision of interpreter-guide services.

### ***Official recognition of persons with deafblindness***

One of the fundamental asks of WFDB and its members is the recognition of deafblindness by states as well as other international, national and sub-national actors as a distinct disability. In many countries, the absence of such recognition leads to invisibility in statistics, policies, programmes and services, both for the general population and for persons with disabilities. In addition, it contributes to the lack of attention paid to the specific support required by persons with deafblindness across all sectors, perpetuating their exclusion.

In 2017, WFDB and SI surveyed their members about the official recognition of deafblindness and available support in their country. From the 50 countries for which data was available, 19 (37%) officially recognise deafblindness as a distinct disability. The survey also indicated that **countries that do officially recognise deafblindness as a distinct disability and/or have a definition of deafblindness are more likely to provide specific support services.** This is particularly the case in low and middle-income countries.

0-24%; 25-49% 50-74%; 75-100%	High-income countries (N=19)	Upper-middle income countries (N=13)	Lower-middle and low-income countries (N=18)	ALL (N=50)
Is 'deafblindness' recognised as a unique disability in your country?	32%	38%	44%	37%
Is there an official definition of deafblindness in your country?	37%	62%	44%	46%

### ***Access to specific support services***

The survey identified a scarcity of services for persons with deafblindness. It is important to note that, even when a service is said to be available, it does not mean that this service is actually available in all areas of the country and in adequate quantity. Services may be provided in some states and/or provinces but not in others, e.g. in urban rather than rural areas.

As expected, support services are far more widely available in high-income countries. However, it is to be noted that guide interpreters are available in only 58% of high-income countries and 42% provide government-funded interpreter-guide services. The situation is more challenging in low and middle-income countries. Interpreter-guide services are only provided in 10% of countries (N=31; low and upper-middle income countries), with only one country providing government funding. There is, however, higher availability of regular communication and mobility-only services.

0-24%; 25-49% 50-74%; 75-100%	High-income countries (N=19)	Upper-middle income countries (N=13)	Lower-middle and low-income countries (N=18)	ALL (N=50)
Availability of professional guide interpreters	58%	15%	0%	30%
Does the government pay for guide interpreter services?	42%	8%	6%	20%
Availability of professional mobility support	74%	15%	22%	40%
Availability of professional support for accessing information	63%	31%	33%	22%

## Focus: participation in political and public life

Country: Kenya

The enjoyment of political rights, including the right to vote and to be elected, is an important aspect of participation in political and public life. Persons with deafblindness are often excluded from decision-making processes and positions of authority, in government, the workplace and public life more generally. It is extremely rare for persons with deafblindness to stand for elections, hold office or perform public functions at any level of government.

However, Emma Mbugua, a woman with deafblindness, served as a member of the county assembly for Nakuru County from 2013 to 2017. In Kenya, persons with disabilities are increasingly represented in both local and national public offices. This is in part thanks to legislation which prescribes that persons with disabilities should fill 5% of all public positions.

Ms Mbugua has long been an active advocate for disability rights in Kenya, working on a range of issues, including education and voting rights, for many years prior to taking office. It was through this work that she first came into contact with the Jubilee Party, which nominated her to serve as a member for the county assembly.

At first, Emma covered the costs of employing a personal assistant to support her inclusion in processes related to her duties. However, the county eventually agreed to pay for assistive devices and an assistant to support mobility, access to documents, and participation in assembly debates. County officials were also sensitised to increase their understanding of how they could support her.



Image 1. Emma Mbugua



Image 2. Emma presents an award to a group of young people at a local football tournament

With the support of Sense International, Emma successfully sponsored the 2014 Nakuru County Persons with Disabilities Bill. The Bill was made into an Act and Emma has since worked on its implementation. Emma has demonstrated that persons with deafblindness can engage effectively in public life and has helped to break the stigma that prevents many persons with disabilities from participating in government.

Case study and contact details: Sense International Kenya, Edwin Osundwa, [edwin@senseint-ke.org](mailto:edwin@senseint-ke.org)

## Persons with deafblindness and inequality: what does the data say?

The data collection undertaken for this report combines a review of academic literature and two surveys undertaken among members and partners of WFDB and Sense International, as well as case studies. Additionally, a quantitative analysis of census and other large survey data was undertaken, representing the largest and most internationally representative analysis of the situation of deafblindness conducted to date.

The majority of the available literature came from the United States and European countries, and almost no studies were identified from low and middle-income nations. As such, a specific focus has been placed on quantitative data analysis and fact-finding from the global South.

### Methodology

#### Review of literature

PubMed, Google Scholar, Web of Science and Education Resources Information Centre (ERIC) were searched between August and November 2017. Search terms included 'deafblindness', 'dual sensory impairment' and combinations of 'deaf' and 'blind', 'visual impairment' and 'hearing impairment'. References made to relevant articles were also checked to obtain additional sources.

Studies were included in the review if they were written in English or French, focused on measurements of deafblindness (definitions, estimates of prevalence and causes), or the impact of deafblindness. There were no restrictions by study location or setting.

#### Country data analyses

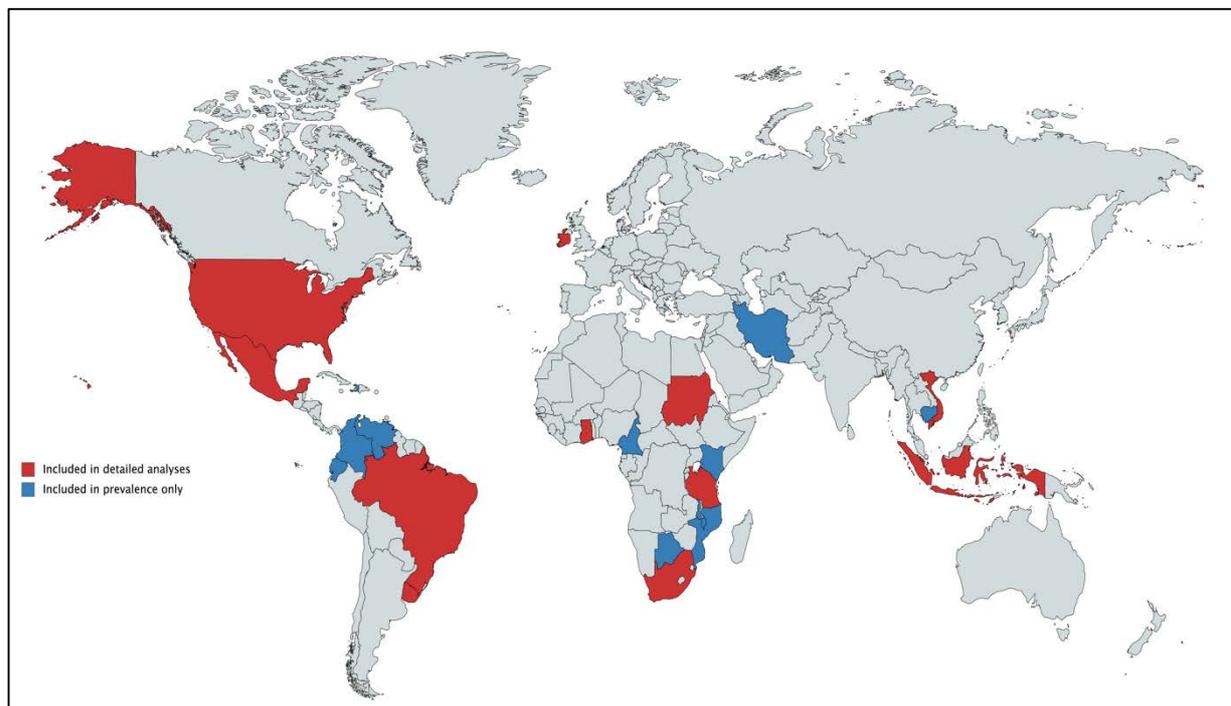


Figure 1. Countries included in the data analysis

Nationally representative population-based surveys from 22 countries were used to measure the prevalence of deafblindness (see Figure 1). Eleven of these countries were selected for further detailed analysis based on their relevance, particularly in relation to how they measured deafblindness and whether they provided a large enough sample size to complete an analysis. Consideration was given to ensuring representation by region and country income group. ***In total, over 97.6 million people were included across the 22 datasets. This is the largest population-based analysis on***

***deafblindness conducted to date and includes evidence from a variety of regions and country income groups.***

*WFDB and Sense International member and partner surveys*

To fully identify the issues and remove the barriers experienced by persons with deafblindness, it is essential to harness the perspectives of support organisations. A survey was conducted among all member organisations of the WFDB. The WFDB survey was distributed to 76 associations of persons with deafblindness with a response rate of 56% (43 answers). The same approach was used to undertake a survey among professionals working with or for persons with deafblindness on a global scale. Sense International and WFDB disseminated the questionnaire to Sense International country programmes, International Disability and Development Consortium (IDDC) members and Dbl (Deafblind International) members. A total of 20 questionnaires were returned. In combination, the two surveys allowed the collection and collation of information from organisations of persons with deafblindness and their allies from 50 countries, as follows:

- *High-income countries:* Australia, Chile, Canada, Sweden, Spain, Switzerland, Japan, Macau (China), Austria, Belgium, USA, Uruguay, Hungary, Italy, Czech Republic, Norway, Denmark, and Germany.
- *Upper middle-income countries:* South Africa, Malaysia, Dominican Republic, Romania, Croatia, Russia, Peru, Brazil, Colombia, Ecuador, Mexico, Venezuela, and Thailand.
- *Lower middle-income and low-income countries:* India, Ghana, Bangladesh, Guatemala, Salvador, Kenya, Uganda, Tanzania, Ethiopia, Malawi, Nepal, Philippines, Bolivia, Honduras, Nicaragua, Ivory Coast, Nigeria, and Zambia.

## The challenges of 'counting' persons with deafblindness

The literature reviewed provided contrasting definitions and measurements of deafblindness, with no agreement on 'best practice' [7, 10, 11]. In broad terms, definitions of deafblindness fell into two major categories [10]: definitions (clinical assessments of the level of hearing and visual impairment); or functioning-based definitions (self-report or observations of a person's ability to hear and see, and its impact on the individual's participation in everyday activities). Even within these categories, significant variations in criteria were used to determine deafblindness. For example, different thresholds of hearing and visual loss in clinical assessments were identified across the studies. The lack of a clear, consistently used definition of deafblindness makes it difficult to gather data that is comparable between studies, settings and over time [7, 9-11]. However, across the range of definitions, some commonalities were identified. For example, almost all definitions acknowledged that deafblindness does not only refer to people who are both deaf and blind, but include people with some vision and/or hearing [12]. A key characteristic of deafblindness is the combined effect of hearing and vision loss on a person's ability to communicate, so that the severity of each impairment is such that one sense cannot compensate for the other [10, 12].

No large, population-based studies were identified that measured the all-age prevalence of deafblindness. The analysis of country-level census data, therefore, provides a unique opportunity to estimate the prevalence of deafblindness across a range of contexts. Figure 2 shows the prevalence of deafblindness in each of the 22 country datasets initially explored. The measurement of deafblindness varied across the datasets. For example, in Iran, Indonesia, Ecuador, Venezuela and Haiti, definitions included people who are completely deaf and blind, while the remaining countries also included people with some residual vision and hearing. A sub-set of censuses used the Washington Group Questions, which is an internationally comparable module on reported difficulties with six functional domains, including vision and hearing.

The prevalence of severe deafblindness (in individuals aged five years and older) across the 22 surveys ranged between 0.01% in Cambodia, Haiti, Iran and Venezuela, to 0.85% in the United States. ***The weighted prevalence across all datasets was 0.21%.***

### On average, 0.2% of the population lives with deafblindness

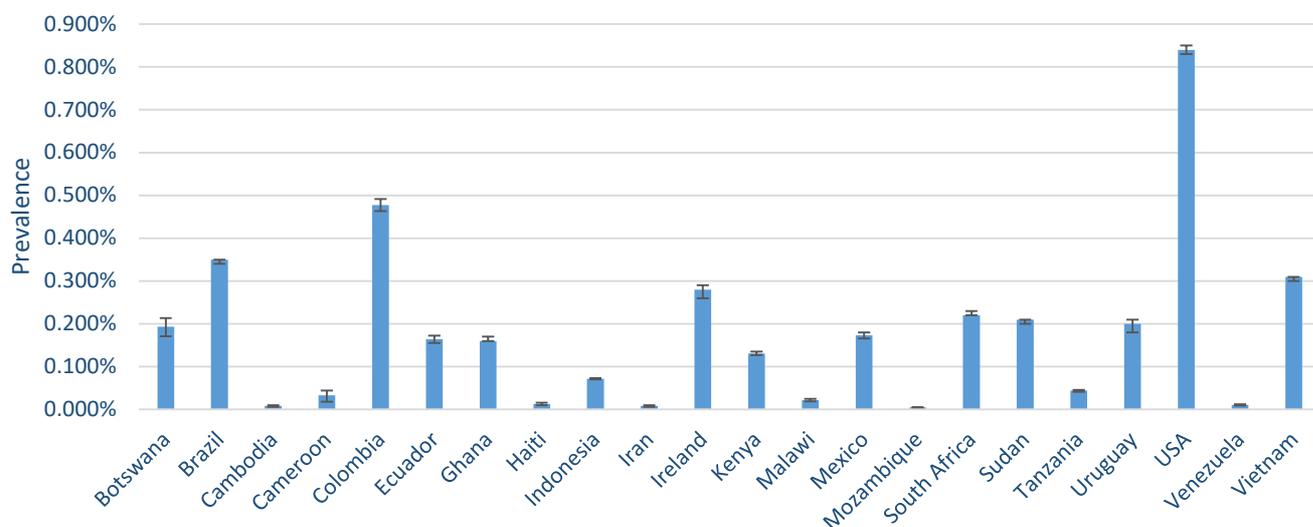


Figure 2. Prevalence of deafblindness among people aged 5 years and over across 22 countries

In datasets that used the Washington Group Questions, it was possible to explore the prevalence and different levels of deafblindness. Figure 3 illustrates the prevalence of deafblindness using a lower threshold, whereby ‘some’ or a ‘greater difficulty’ in seeing and hearing was reported. The prevalence of this ‘less severe’ level of deafblindness is much higher than severe deafblindness, and ranges from between 0.4% in Tanzania and 3.1% in Brazil.

### Many more people (2.1% of the population) may experience milder forms of deafblindness

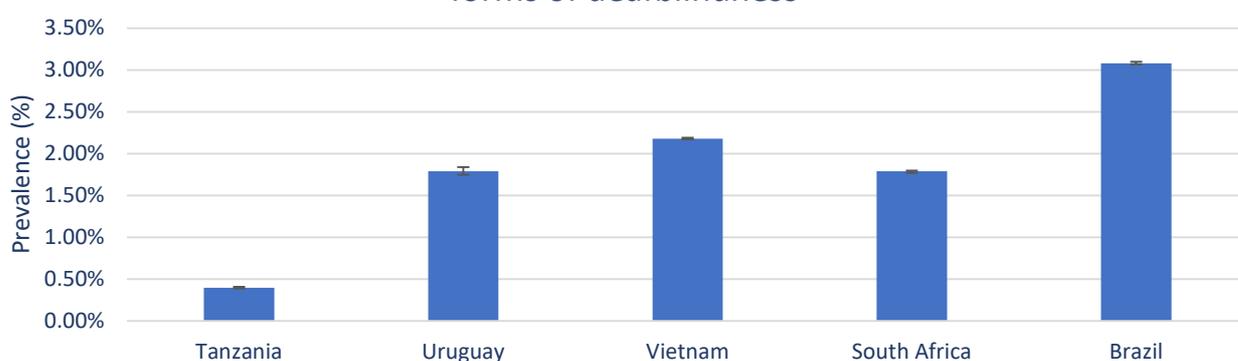


Figure 3. All-age prevalence of moderate deafblindness using the WG Questions

Figure 4 details the prevalence of deafblindness in the 11 countries chosen for subsequent analyses throughout the report, stratified by age group. The graph illustrates a strong association between the prevalence of deafblindness and age. **In almost all study countries, less than 0.1% of the population aged 40 years and under has deafblindness, and this rises to 6% of the population aged 75 and over.** An increased prevalence of deafblindness linked to age is also reflected in the literature review [11, 13-18]. For example, a large, general population study of sensory impairments in adults aged 50 years and older in 11 European countries identified a prevalence of 5.9% [18]. **While deafblindness is more common among older age groups, deafblindness among children and young adults presents additional implications, for example in terms of education and employment.**

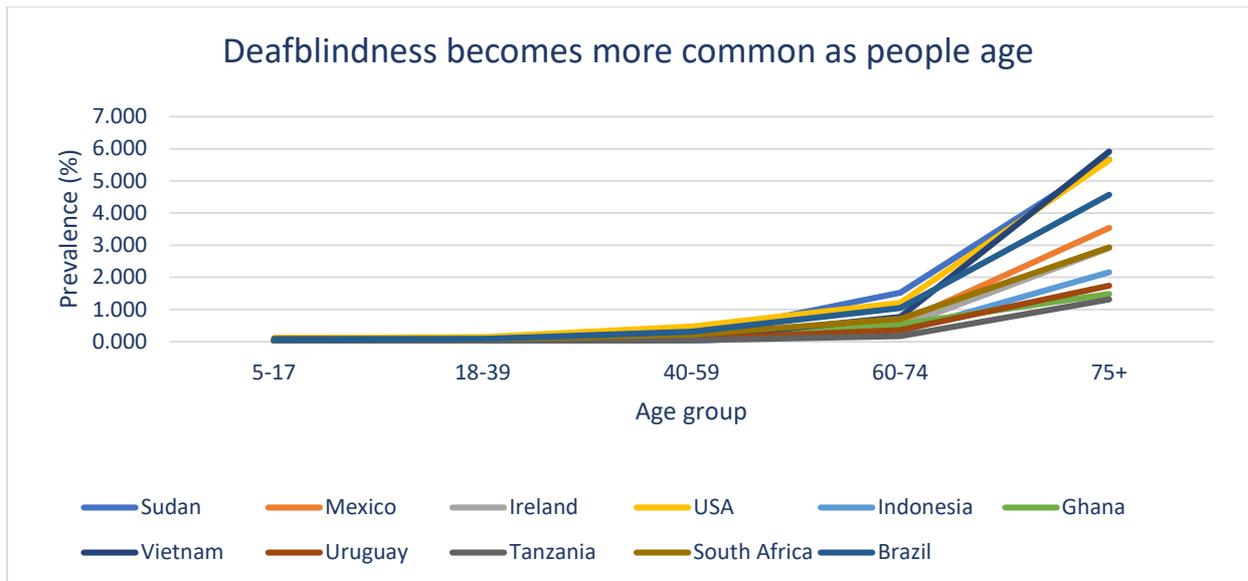


Figure 4. Prevalence of deafblindness by age

The prevalence of deafblindness was also found to be slightly higher in women than men in each of the study countries (Figure 5). After accounting for age (given that women generally live longer than men), this finding was statistically significant in all datasets, except Ireland and Uruguay.

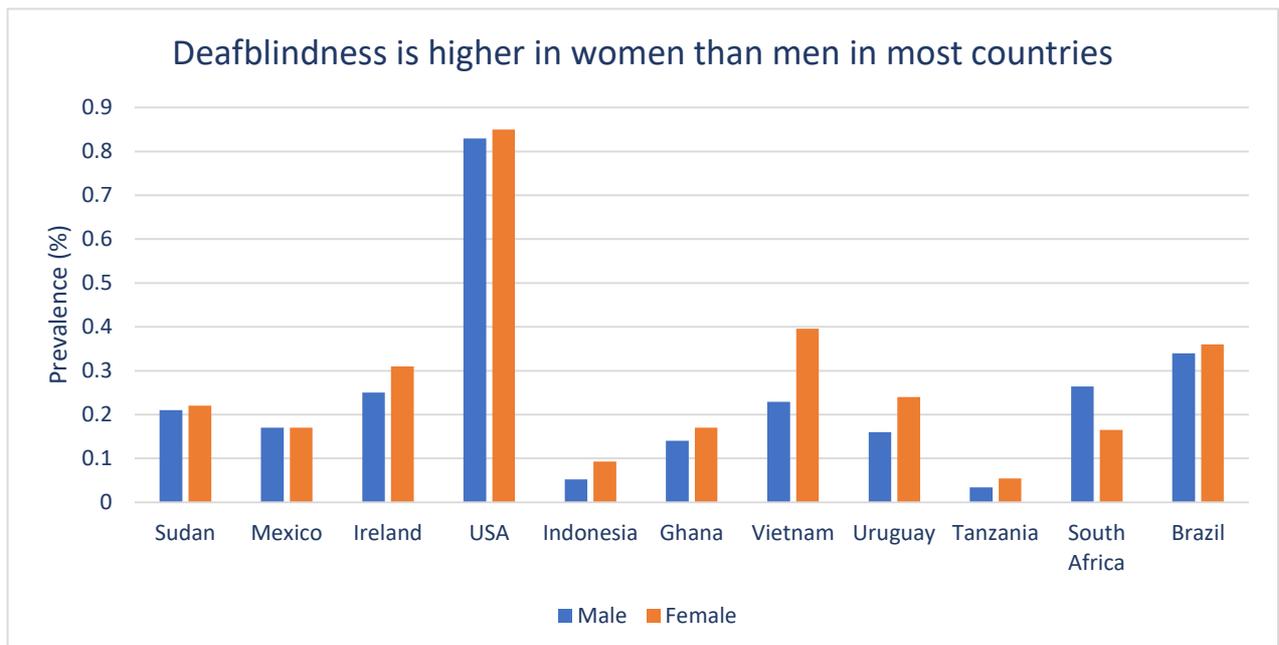


Figure 5. Prevalence of severe deafblindness by sex

## Persons with deafblindness and poverty

The majority of the studies included in the literature review did not provide evidence on the socio-economic status of people living with deafblindness. In all 11 countries covered by the data analysis, **households that included persons with deafblindness were more likely to be in the bottom 40% in terms of socio-economic status compared to households with no members with disabilities**<sup>1</sup> (Figure 6). The

<sup>1</sup> Derived from a principal component analysis of household assets and dwelling characteristics.

gap in poverty was most pronounced in Ireland (25.9%), the United States (18.9%), Ghana (16.9%) and Tanzania (17.6%). Differences were statistically significant after adjusting for household characteristics (e.g. size, age structure and location) in all countries, with the exception of Vietnam. **Compared to people with other disabilities, persons with deafblindness were statistically more likely to be in the bottom 40% in all countries except Vietnam, Sudan and Tanzania.** Households containing younger adults with deafblindness (aged 50 years and under) were more likely to be living in poverty in five countries (Brazil, South Africa, Vietnam, the United States and Indonesia). This indicates that persons of working age with deafblindness may be more greatly affected by poverty.

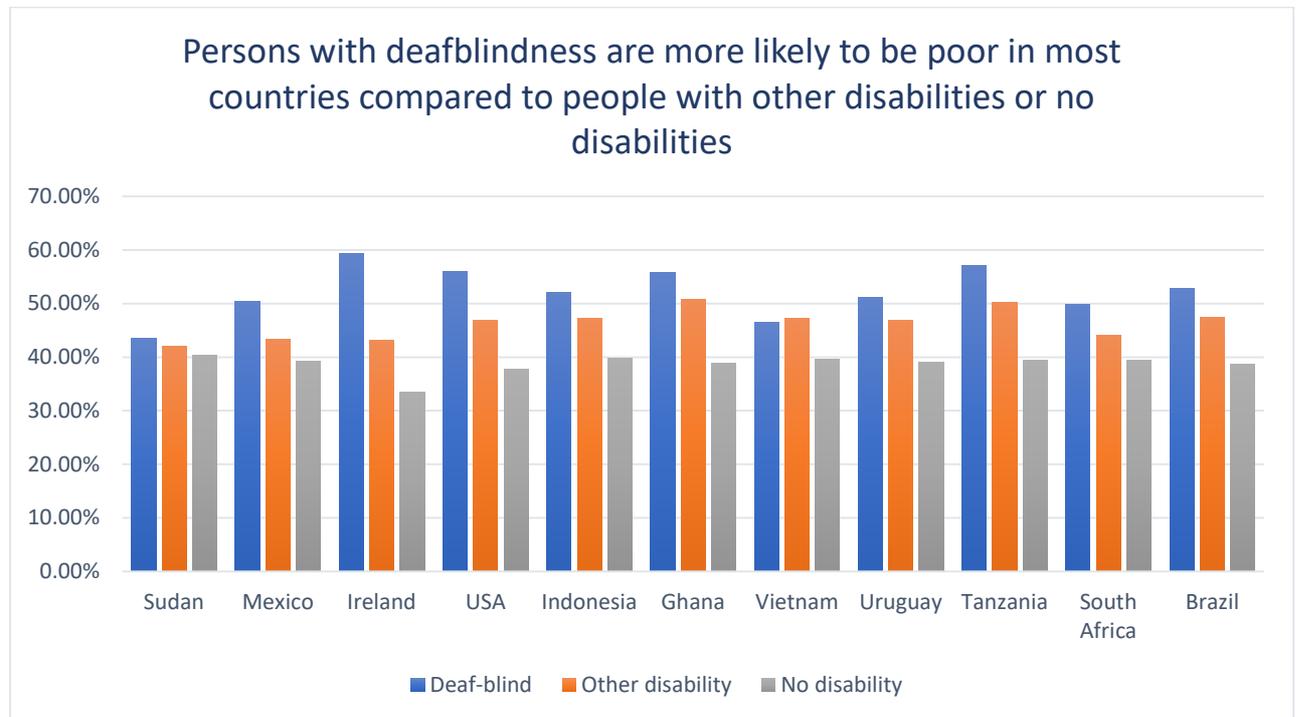


Figure 6. Proportion of households with persons with deafblindness that are in the bottom 40% in terms of socio-economic status compared to households with people who have other disabilities and households with no members who have disabilities

## Persons with deafblindness and work

Only three studies included in the literature review, two from the United States and one from Denmark, examined access to work among persons with deafblindness [4, 19, 20]. All found barriers to engaging in employment, although sample sizes were small and not representative of the broader population. Some challenges highlighted included difficulties transitioning from school to work, the need for vocational training [20], and early retirement following the onset of deafblindness in older age [19].

Figure 7 compares the working status of persons with deafblindness, people with other disabilities, and people with no disabilities across the datasets. Specifically, the survey reports on whether or not the respondent has undertaken any work for cash or in-kind payment over the last 12 months. The findings are restricted to persons of working age (15 to 64), excluding those currently in education.

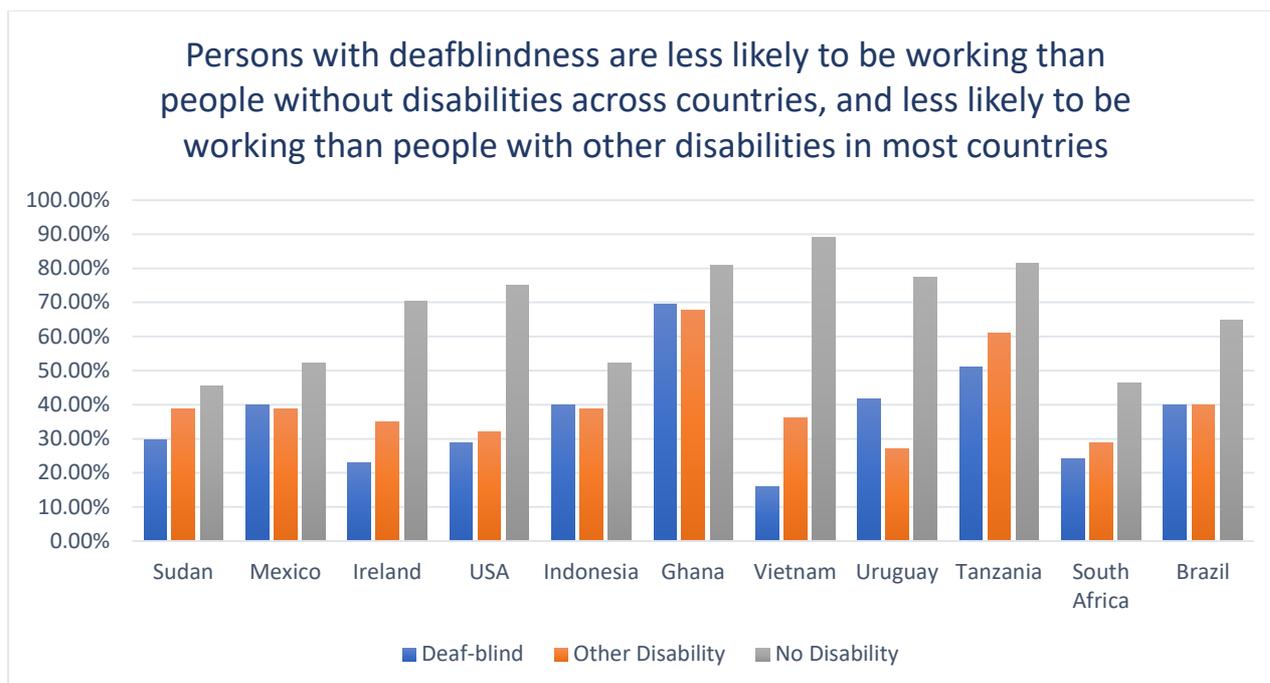


Figure 7. Working status of adults (18 years and over) with deafblindness, other disabilities and no disabilities (has worked in the last 12 months, excluding people currently studying)

***In comparison with people with no disabilities, persons with deafblindness were statistically less likely to be working across all 11 datasets.*** Participation rates among persons with deafblindness tended to be higher in low-income settings compared with high-income settings. For example, only 23% of adults with deafblindness in Ireland and 29% in the United States were working, compared with 70% and 75% of people without deafblindness respectively. In comparison, gaps in participation rates in Sudan (a gap of 15%<sup>2</sup>) and Ghana (11%) were lower. This trend was inconsistent, however, as high gaps in participation were also evident in Indonesia (55%) and Vietnam (73%).

Compared to people with other disabilities, ***persons with deafblindness were statistically less likely to be working in seven of the eleven datasets*** (Sudan, Ireland, United States, Vietnam, Indonesia, Tanzania and South Africa), after controlling for age and gender. There were no consistent trends between men with deafblindness and men with other disabilities, but ***women with deafblindness were less likely to be working than women with other disabilities in seven of the eleven datasets*** (Sudan, Ireland, United States, Tanzania, South Africa, Indonesia and Brazil).

It is important to note that ***this data does not account for work security or type of work***. For example, in many low and middle-income countries, the informal economy is the main source of employment. While it is easier to find informal work, employment is typically less stable, lower paid and does not offer protections for workers (e.g. sickness/accident insurance, pensions or representation) [21]. There is evidence that people with disabilities are overall more likely to work in the informal sector [21], which is therefore likely to be similar for persons with deafblindness. Additionally, ***persons with deafblindness may be less likely to work if they have access to social welfare and benefits. For example, in the study conducted in Denmark, while only 8 of the 163 (5%) people with acquired deafblindness between the ages of 18 and 64 years were employed, 63% were receiving the country's disability living allowance*** [4].

<sup>2</sup> Gap in crude percentage points, not a proportion.

## In our own words: Edgar Reyes (Dominican Republic)

“After working for 20 years as director of services of the unit for blind people at the National Library of the Dominican Republic, I applied alongside other professionals without disabilities to become a teacher for secondary level students. It was the first time that a person with deafblindness participated in such an application process. I got 85 points out of 100 as a result.



“In October 2015, I started my work as a Spanish and literature teacher with students of 1, 2, and 3 grade at a school named Dr Julio Abreu Cuello in my city (Monte Plata). It was a surprise and bewildering for the staff when I started; however, my interaction with the students and good relationship with the staff led to my fast inclusion within the teachers group.

“When I got to know that I successfully passed the application process and got a teaching position, I felt a mix of satisfaction and uncertainty. I asked myself: How will I have good communication with students without disabilities? What will be the attitude of my colleagues? Which strategies will I use so that my disability does not interfere with education, work and the relationship with the students?

“In an initial meeting with the director and teachers in the school, I explained the nature and characteristics of deafblindness and said that the disability did not stop me from being a cultural manager, radio, television and written newspaper journalist. I felt that I had the capacity and motivation to take on the challenge of starting as a teacher of teenage students without disabilities, to whom I could also become a concrete example of overcoming barriers and negative attitudes faced by persons with disabilities.

“At the beginning of the school year I explained to the students in a clear and simple way that I am a person with deafblindness, asking them to participate in class by speaking clearly and at a high volume. I also asked them to commit to being collaborative with me in the activities that are visual, such as checklists, supervision and discipline, management of non-accessible technology, and the use of the board. As a result, I got their active collaboration in a natural and spontaneous way.

“The main barriers were actually managing a group of 30 students, planning work in didactic units, managing class resources and mobility around the school. I agreed with the director and coordinator about working with groups of 15 students at a time, even if I had to duplicate my work. For planning, resource management and mobility, I got the support of my colleagues, my students and the administrative staff, who all contributed to my accommodation.

“To become a teacher required me to learn a lot, additional effort, creativity and imagination to achieve better communication, which in turn increased my capacities, self-esteem, autonomy, social relationships and security.

“The year after, I was assigned to another school named Secundario Madre Ascensión Nicol, and there, inclusion was even faster and easier, and became deeper and deeper.

“I think that working in the wider community environment, with the students, families and colleagues, allowed me to show them all the contribution that persons with deafblindness can make. Showing our capacities in daily action means more than presentations and speeches at conferences and media.”

## Persons with deafblindness and education

Excluding Uruguay and Ireland due to the small sample sizes, nine datasets provided evidence on school enrolment among children with deafblindness aged 5 to 17 years. **Children with deafblindness were statistically less likely to be in school than children without disabilities across each of the datasets, with the biggest gaps in enrolment in Mexico (12 times less likely), Indonesia (23 times less likely) and Vietnam (nine times less likely).**

In eight of the nine datasets considered (excluding Brazil), **children with deafblindness were also statistically less likely to be in school than children with other disabilities.** The gap in enrolment between children with deafblindness and children with other disabilities was largest in Mexico (15%), Indonesia (15%) and Vietnam (16%). There was no difference in the proportion of girls and boys with deafblindness attending school.

It is important to note that **evidence from the country analyses does not provide an indication of the quality of education children with deafblindness receive.** Findings from the literature review, which primarily features studies from the United States, raises concerns regarding the quality of education for children with deafblindness. **As deafblindness in children and young adults is rare, most educational professionals receive little, if any, training or support to work with students with deafblindness** [22, 23]. Learners with deafblindness are also a very heterogeneous group, so **teaching and learning strategies may vary greatly between individuals.** For example, strategies can depend on whether deafblindness is pre-lingual or post-lingual, and the level of hearing and visual impairment [10]. Furthermore, many children and young adults with deafblindness have additional disabilities, which require extra learning support [24, 25]. Early identification and referral to programmes for infants and young children with deafblindness is essential for improving educational, as well as cognitive and social, outcomes [24, 26]. However, delays in accessing services are common. For example, across different states in the United States, only 0-26% of children with deafblindness were referred to appropriate services before the age of three [26]. These issues are likely to be even more pronounced in low and middle-income settings where there has been less investment in inclusive education.

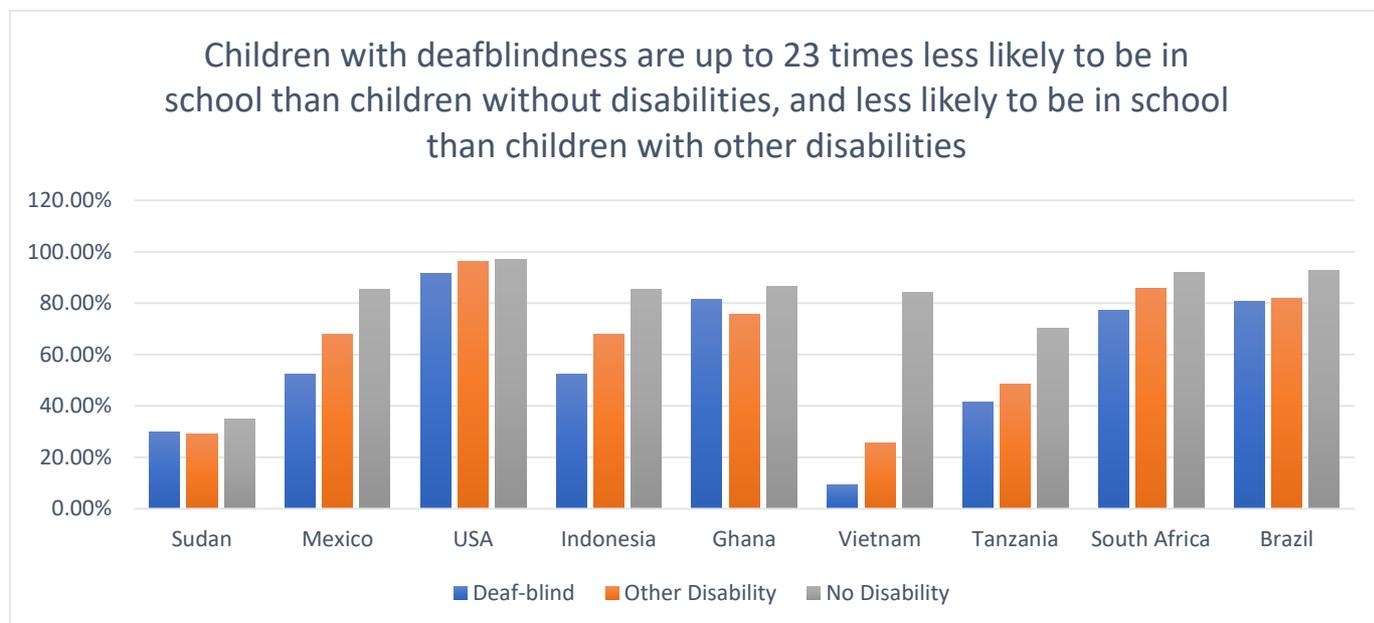


Figure 8. Educational status of children (aged 5 to 17 years of age) with deafblindness, children with other disabilities, and children without disabilities

### Spotlight on access to education: Gift's story

Gift\* is a 15-year-old boy from rural Malawi. He was born with a severe visual impairment. When he was a toddler, Gift experienced hearing difficulties that were caused by recurrent and unresolved ear infections. Even now, his ears regularly produce pus and cause him pain. Access to medicine is difficult due to issues with stock, and going to the hospital involves significant travel. He was also referred for spectacles, but his family cannot afford to buy them.

Gift is currently attending school, and is in grade 5. He has repeated grades four times. "I have difficulties understanding what the teachers are teaching," Gift explains. "I was mostly absent from school because I was going to the hospital to get treatment for my eyes." He also experiences frequent pain in his eyes and ears, which disrupts his learning. During the dry season in particular, when there is a lot of sun, his eyes become red, painful and teary. In addition to missing school, Gift has also experienced bullying: "My friends are teasing me that I have red eyes... it hurts me because I am not happy with my condition."

Gift and his parents have, however, seen some positive changes at school, and these have helped him to learn. For example, he sits at the front of the class so he can hear his teachers and see the blackboard more clearly. The teachers also write in a larger font so that he is better able to read the text. While he still faces difficulties, Gift is motivated to continue his education. He says he "admires his friends in upper classes" and wants to get a good job after finishing school.

\*Name changed to protect identity

Source: International Centre for Evidence in Disability, a project funded by the Norwegian Association of Disabled

## Persons with deafblindness and health

The country analyses provided little data on health status and access to healthcare. The only indicator of health status was the presence of additional disabilities. Figure 9 shows the proportion of persons with deafblindness with other functional difficulties in each dataset. Between 20% and 75% of persons with deafblindness reported functional difficulties, such as mobility and cognition, and the presence of other functional difficulties remained high across all age groups, including children. Multi-morbidity among children and adults with deafblindness was also reflected in the literature review. For example, among children with deafblindness in Montreal, Canada, 86% had additional disabilities [25].

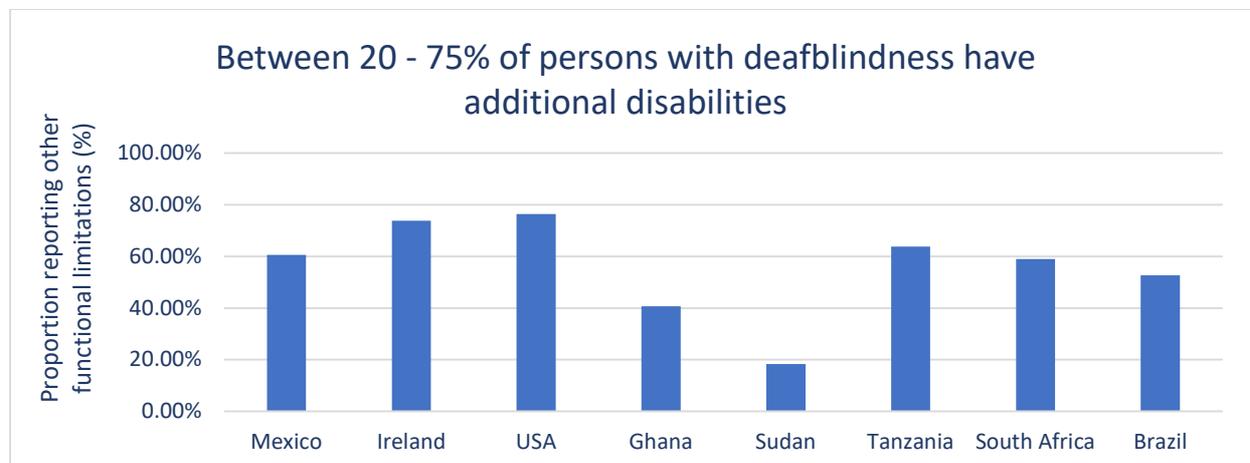


Figure 9. Proportion of persons with deafblindness reporting other functional limitations

**The literature review also found evidence that persons with deafblindness may experience poorer levels of health and barriers to accessing health services. These studies are, however, mostly restricted to high-income settings.** For example, persons with deafblindness reported poorer self-rated health in the United States and Japan [14, 27, 28], as well as increased mortality rates [29-31]. Common challenges to accessing both general health and rehabilitation services included: a lack of accommodations in health facilities, particularly in terms of accessible information and alternative forms of communication; costs of accessing care, as insurance often does not always cover all expenses; concentration of services in cities, with little available in rural areas; and a lack of knowledge of and training on deafblindness among health professionals [12, 32].

**There is also a growing body of research demonstrating that persons with deafblindness are more likely to experience depression and other mental health conditions compared to both people without sensory impairments or with visual or hearing impairment alone** [13, 33-39]. Persons with deafblindness often experience barriers to accessing mental health services. For example, in the UK, 60% of persons with deafblindness surveyed reported experiencing psychological distress, while only 5% said that they had access to mental health services [33]. Similarly, in the United States, only 16% of mental health service providers had procedures in place to accommodate persons with deafblindness [40].

## Persons with deafblindness and social life

The country-level analyses provided minimal information on social life, with the exception of marital status and the presence of biological parents in the household for children. Women with deafblindness were much less likely to be married than men with deafblindness in each dataset, even after accounting for age (see Figure 10). **Women with deafblindness were also statistically less likely to be married than women with other disabilities across the five datasets, and less likely to be married than women without disabilities in all datasets.**

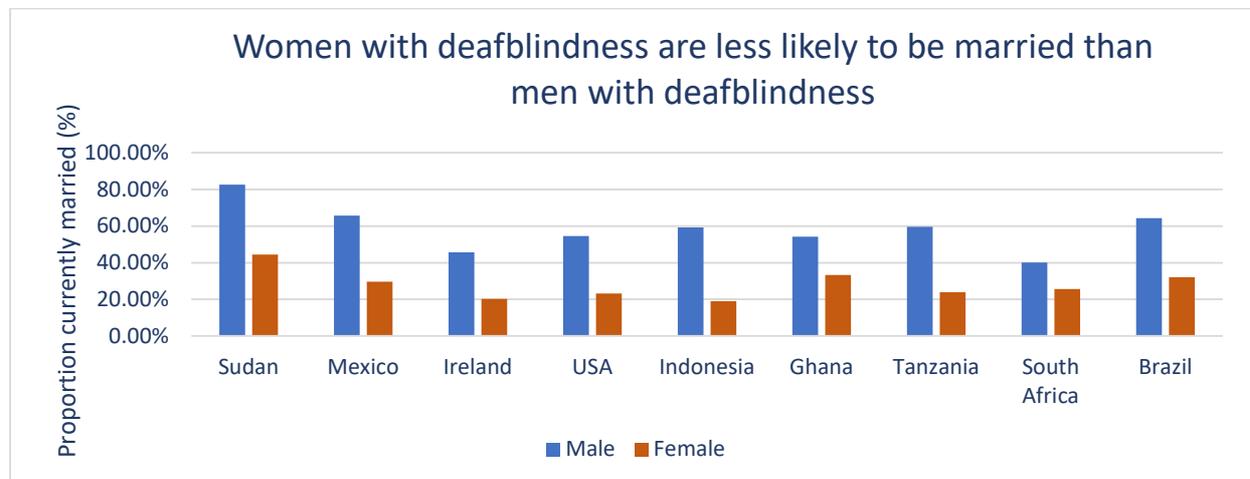


Figure 10. Marital status among women and men with deafblindness

Among those aged under 18 years, **children with deafblindness were statistically more likely to have at least one biological parent absent from their household in five of nine datasets** (South Africa, Sudan, United States, Mexico and Indonesia) (see Figure 11). Compared to children with other disabilities, most datasets did not show any statistically significant differences, with the exception of Sudan and Indonesia, where children with deafblindness were more likely to be living without at least one parent.

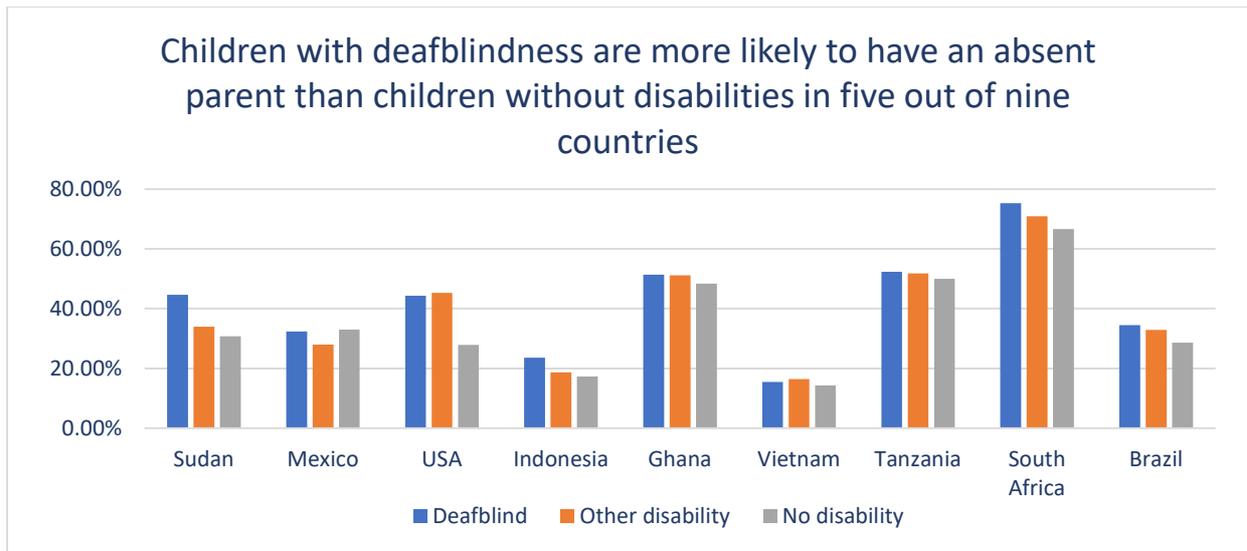


Figure 11. Proportion of children aged 5 to 17 years with one or both biological parents absent from the household

The literature review included several studies that explored other indicators related to social life among persons with deafblindness. These were mostly from high-income countries and among older adults. For example, several studies among older adults with deafblindness found that many experienced decreased participation in everyday activities [14, 41-43]. A study of older adults with deafblindness in Sweden found some chose not to participate in physical activity due to stigma, low self-esteem or other responsibilities, such as contacting health and welfare agencies [43].

**Social isolation among persons with deafblindness was also a common theme in the literature.** Across the 11 European countries, adults aged over 50 with deafblindness were twice as likely to be socially inactive compared to people without sensory difficulties [18]. Challenges to understanding and being understood by others were major barriers to social inclusion, which also contributed to fatigue, frustration and stress. Several studies reported a lower quality of life and wellbeing among older adults with acquired deafblindness [13, 44, 45].

## In our own words: Carlos and Sofia (Brazil)

“We are a couple of two deafblind persons who have Usher syndrome. We've been married for 12 years, living in Sao Paulo, Brazil. I (Sofia) use a hearing aid that helps me recognise sounds and noises. Carlos Jorge is totally deafblind.

“In the first building we lived in, other residents didn't know how to communicate with us. Carlos uses tactile signing. I use Tadoma and tactile signing.

“When we fell in love, Carlos's family in Rio de Janeiro city were worried and scared because they considered that it could be very difficult for two persons with deafblindness to live together. My teacher explained to them that couples can live independently together and then they accepted.

“My family was also worried and wanted me to forget that I was in love. A teacher in Sao Paulo convinced them otherwise. I went to Rio de Janeiro and met the family and they were more relaxed with the idea.

“We had a lot of support from friends to book the church, talk to the priest and explain why we needed to be with interpreter-guides during the ceremony.

“To become more independent and have autonomy, we had training and adapted the home appliances and devices so they were more accessible for us, we know how to cook, clean, etc.

“We have the support of the doorman, neighbourhood, friends and relatives that bring us to the church, the supermarket, the bank and we take a known taxi to go to work. If there are conferences or government meetings, we use the government transportation service for persons with disabilities. When we need to go to the doctor or have a medical test, we go with an interpreter-guide.

“One of the most important things when we got married was getting a little puppy. She found out that we were deafblind and helped us to notice noises such as the phone ringing, someone knocking on the door or ringing the doorbell.

“We knew it wasn't easy to live by ourselves, but we needed to adapt ourselves, especially in urgent and dangerous situations.”



## References

1. World Health Organization & World Bank, *World report on disability*. 2011: World Health Organization.
2. Groce, N. and M. Kett, *The Disability and Development Gap*, in *Leonard Cheshire Working Paper Series*. 2013, Leonard Cheshire Disability and Inclusive Development Centre: London.
3. The Deafblind Nordic Cooperation Committee. *The Nordic definition of deafblindness*. n.d. [cited 2018 June 2]; Available from: [http://www.fsdb.org/Filer/DBNSK English.pdf](http://www.fsdb.org/Filer/DBNSK%20English.pdf).
4. Dammeyer, J., *Characteristics of a Danish population of adults with acquired deafblindness receiving rehabilitation services*. *British Journal of Visual Impairment*, 2013. **31**(3): p. 189-197.
5. Klaver, C.C., et al., *Age-specific prevalence and causes of blindness and visual impairment in an older population: the Rotterdam Study*. *Archives of ophthalmology*, 1998. **116**(5): p. 653-658.
6. Wolsey, J.-L.A., *Perspectives and Experiences of DeafBlind College Students*. *The Qualitative Report*, 2017. **22**(8): p. 2066.
7. Simcock, P., *One of society's most vulnerable groups? A systematically conducted literature review exploring the vulnerability of deafblind people*. *Health & social care in the community*, 2017. **25**(3): p. 813-839.
8. World Federation of the Deafblind. *Deafblind Interpretation*. 2018 [cited 2018 June 2]; Available from: <http://www.wfdb.eu/interpretation/>.
9. Simcock, P., *Ageing with a unique impairment: a systematically conducted review of older deafblind people's experiences*. *Ageing & Society*, 2017. **37**(8): p. 1703-1742.
10. Dammeyer, J., *Deafblindness: a review of the literature*. *Scandinavian journal of public health*, 2014. **42**(7): p. 554-562.
11. Schneider, J.M., et al., *Dual sensory impairment in older age*. *Journal of Aging and Health*, 2011. **23**(8): p. 1309-1324.
12. Saunders, G.H. and K.V. Echt, *An overview of dual sensory impairment in older adults: perspectives for rehabilitation*. *Trends in amplification*, 2007. **11**(4): p. 243-258.
13. Chia, E.-M., et al., *Association between vision and hearing impairments and their combined effects on quality of life*. *Archives of Ophthalmology*, 2006. **124**(10): p. 1465-1470.
14. Harada, S., et al., *Gender difference in the relationships between vision and hearing impairments and negative well-being*. *Preventive medicine*, 2008. **47**(4): p. 433-437.
15. Schneider, J., et al., *Prevalence and 5-year incidence of dual sensory impairment in an older Australian population*. *Annals of epidemiology*, 2012. **22**(4): p. 295-301.
16. Caban, A.J., et al., *Prevalence of concurrent hearing and visual impairment in US adults: The National Health Interview Survey, 1997–2002*. *American Journal of Public Health*, 2005. **95**(11): p. 1940-1942.
17. Kasthuri, A., *Visual and hearing impairment among rural elderly of south India: A community-based study*. *Geriatrics & gerontology international*, 2012. **12**(1): p. 116-122.
18. Viljanen, A., et al., *Dual sensory loss and social participation in older Europeans*. *European Journal of Ageing*, 2014. **11**(2): p. 155-167.
19. Brennan, M., *Impairment of both vision and hearing among older adults: Prevalence and impact on quality of life*. *Generations*, 2003. **27**(1): p. 52-56.
20. Cmar, J.L., M.C. McDonnall, and K.M. Markoski, *In-School Predictors of Postschool Employment for Youth Who Are Deaf-Blind*. *Career Development and Transition for Exceptional Individuals*, 2017: p. 2165143417736057.
21. International Labour Organisation, *Women and Men in the Informal Economy: A Statistical Picture*. 2002, International Labour Office: Geneva.
22. Bruce, S., K. Ferrell, and J.L. Luckner, *Guidelines for the Administration of Educational Programs for Students Who Are Deaf/Hard of Hearing, Visually Impaired, or Deafblind*. *Journal of the American Academy of Special Education Professionals*, 2016. **47**: p. 59.
23. Nelson, C. and S.M. Bruce, *Critical Issues in the Lives of Children and Youth Who Are Deafblind*. *American annals of the deaf*, 2016. **161**(4): p. 406-411.
24. National Centre on Deaf-Blindness, *The 2013 National Child Count of Children and Youth who are Deaf-Blind*. 2014.

25. Wittich, W., D.H. Watanabe, and J.P. Gagne, *Sensory and demographic characteristics of deafblindness rehabilitation clients in Montreal, Canada*. *Ophthalmic Physiol Opt*, 2012. **32**(3): p. 242-51.
26. Purvis, B., et al., *Early Identification and Referral of Infants Who Are Deaf-Blind*. 2014, National Center on Deaf-Blindness.
27. Crews, J.E. and V.A. Campbell, *Vision impairment and hearing loss among community-dwelling older Americans: implications for health and functioning*. *American journal of public health*, 2004. **94**(5): p. 823-829.
28. McDonnall, M.C., et al., *Needs and Challenges of Seniors with Combined Hearing and Vision Loss*. *Journal of Visual Impairment & Blindness (Online)*, 2016. **110**(6): p. 399.
29. Laforge, R.G., W.D. Spector, and J. Sternberg, *The relationship of vision and hearing impairment to one-year mortality and functional decline*. *Journal of Aging and Health*, 1992. **4**(1): p. 126-148.
30. Lam, B.L., et al., *Concurrent visual and hearing impairment and risk of mortality: the National Health Interview Survey*. *Archives of ophthalmology*, 2006. **124**(1): p. 95-101.
31. Liljas, A., et al., *OP07 Sensory impairments and mortality in older british community-dwelling men: a 10-year follow-up study*. 2015, BMJ Publishing Group Ltd.
32. Guthrie, D.M., et al., *The health and well-being of older adults with Dual Sensory Impairment (DSI) in four countries*. *PloS one*, 2016. **11**(5): p. e0155073.
33. Bodsworth, S.M., et al., *Deafblindness and mental health: Psychological distress and unmet need among adults with dual sensory impairment*. *British Journal of Visual Impairment*, 2011. **29**(1): p. 6-26.
34. Chou, K.L. and I. Chi, *Combined effect of vision and hearing impairment on depression in elderly Chinese*. *International journal of geriatric psychiatry*, 2004. **19**(9): p. 825-832.
35. Capella-McDonnall, M.E., *The effects of single and dual sensory loss on symptoms of depression in the elderly*. *International journal of geriatric psychiatry*, 2005. **20**(9): p. 855-861.
36. Lupsakko, T., et al., *Combined hearing and visual impairment and depression in a population aged 75 years and older*. *International journal of geriatric psychiatry*, 2002. **17**(9): p. 808-813.
37. Heine, C. and C.J. Browning, *Mental health and dual sensory loss in older adults: a systematic review*. *Frontiers in aging neuroscience*, 2014. **6**: p. 83.
38. Cosh, S., et al., *The association amongst visual, hearing, and dual sensory loss with depression and anxiety over 6 years: The Tromsø Study*. *International Journal of Geriatric Psychiatry*, 2017.
39. Davidson, J.G. and D.M. Guthrie, *Older adults with a combination of vision and hearing impairment experience higher rates of cognitive impairment, functional dependence, and worse outcomes across a set of quality indicators*. *Journal of aging and health*, 2017: p. 0898264317723407.
40. Wiley, S., et al., *Outcomes for children with deaf-blindness with cochlear implants: a multisite observational study*. *Otology & Neurotology*, 2013. **34**(3): p. 507-515.
41. Tiwana, R., S.M. Benbow, and P. Kingston, *Late life acquired dual-sensory impairment: A systematic review of its impact on everyday competence*. *British Journal of Visual Impairment*, 2016. **34**(3): p. 203-213.
42. Brennan, M., Y.-p. Su, and A. Horowitz, *Longitudinal associations between dual sensory impairment and everyday competence among older adults*. *Journal of rehabilitation research and development*, 2006. **43**(6): p. 777.
43. Moller, C., *Deafblindness: living with sensory deprivation*. *The Lancet*, 2003. **362**: p. s46-s47.
44. Lehane, C.M., et al., *Sexuality and well-being among couples living with acquired deafblindness*. *Sexuality and Disability*, 2017. **35**(2): p. 135-146.
45. Lehane, C.M., et al., *A relationship-focused investigation of spousal psychological adjustment to dual-sensory loss*. *Aging & mental health*, 2016: p. 1-8.

## Acknowledgement and disclaimers

The project is coordinated by Rune Jensen and Ximena Serpa under the supervision of Geir Jensen with technical support from Alexandre Cote (IDA-CIP), Bailey Grey (Sense International), Morgon Banks and Islay MacTaggart of International Centre for Evidence in Disability (ICED). The WFDB and SI surveys were developed with the support of Akiko Fukuda, WFDB General Secretary from Japan.

The team would like to thank all the persons that contributed to the report, in particular the WFDB board members and UN agencies personnel that took part in the September 2017 Geneva technical meeting.

The report was made possible thanks to the overall organisational and technical support of the International Disability Alliance and the financial support from the UK Department for International Development (DFID) and Norwegian Ministry of Foreign Affairs (NMFA).

*The information and views set out in this background document are those of the author(s) and do not necessarily reflect the official opinion of the International Disability Alliance, the International Centre for Evidence in Disability (ICED) at the London School of Hygiene and Tropical Medicine (LSHTM), the UK Department for International Development (DFID) and Norwegian Ministry of Foreign Affairs (NMFA).*

In cooperation with:



With the support of:

